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A PSYCHOSOCIAL EDUCATIONAL PROGRAMME FOR CAREGIVERS OF PEOPLE DIAGNOSED WITH BIPOLAR DISORDER

by

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PROMOTER: DR CL CARBONATTO
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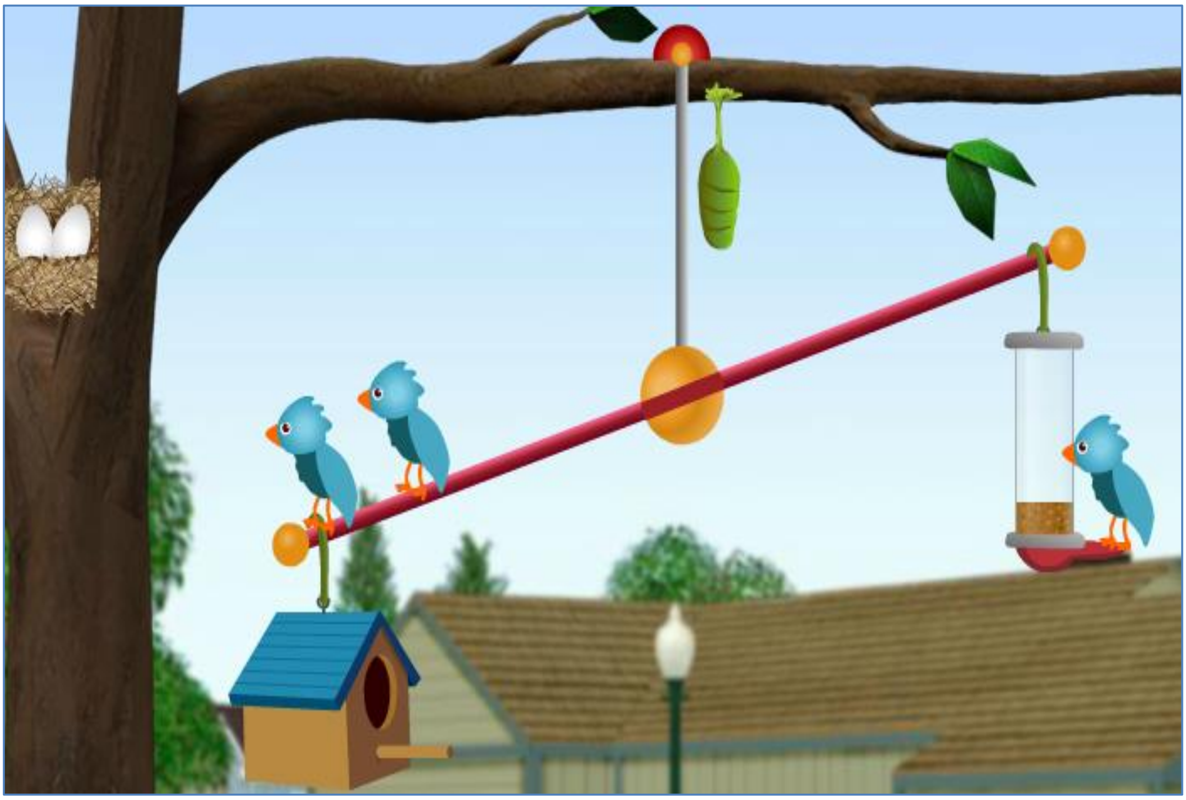

“If only, after diagnosing bipolar disorder and condemning both parents and patient thus, the therapists would communicate with the parents during or after the treatment, so much torment and tragedy could be avoided or averted. After all is said and done, we, the parents, lived with the patient before they were ‘couched’ and must again when they are discharged - more often than not without any after-care or future consideration.

We were essential for their conception. We introduce them to life, raised them and will probably bear witness alone to their progress, regression or annihilation. Why exclude us from the consultation or treatment? Yes, we were unfortunately responsible for their hereditary genes but nevertheless we should not be condemned by ignoring our existence once they have been diagnosed “(mother of patient).

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Acknowledgements

“eucharistia”

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OPSOMMING

‘N PSIGO-MAATSKAPLIKE OPVOEDKUNDIGE PROGRAM VIR VERSORGERS VAN INDIVIDUE WAT GEDIAGNOSEER IS MET BIPOLëRE VERSTEURING

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Bipolêre versteuring is ‘n kroniese, herhalende en ernstige siekte met ‘n voorkoms van 1 % wêreldwyd. Pasiënte kan psigoties word, selfmoordideasie hê en ook soms aggressief raak. Dikwels moet hulle gehospitaliseer word - ook teen hulle wil, want hulle mag soms geen insig toon nie. Pasiënte mag presenteer met ‘n ko-morbiede toestand, byvoorbeeld substansmisbruik of ‘n persoonlikheidsversteuring. Dit gebeur dikwels dat hulle nie hulle toegewysde rolle, byvoorbeeld dié van gade, broodwinner, ouer of volwasse kind, kan vervul nie.

Versorgers van pasiënte gediagnoseer met bipolêre versteuring, word eweneens beïnvloed deur die siekte en die gepaardgaande stigma daarvan. Dit kan vir hulle baie moeilik wees wanneer hulle die verantwoordelikhede en rolle van die pasiënt moet oorneem. Beskou vanuit die oogpunt van ‘n ekologiese sisteemperspektief is die aard van hierdie impak op die maatskaplike funksionering van die versorgers relevant vir maatskaplike werk in die geestesgesondheidsveld. Die verkenning van hierdie impak en die ontwikkeling van ‘n intervensie om die impak aan te spreek het dus die rasionaal van hierdie studie gevorm.

Die geïntegreerde biopsigososiale model, binne ‘n ekologiese sisteem perspektief, word aangewend by die psigiatriese instelling waar die navorser werk. Hierdie benadering het dus ook gedien as die vertrekpunt vir die betrokke studie.

Die gemengde-metode navorsingsbenadering is tydens hierdie studie benut ten einde ‘n uitgebreide analise van die navorsingsprobleem te verskaf.

Die voorgenome studie het binne die kategorie van toegepaste navorsing geval, want die doel daarvan was om ‘n program te ontwikkel om hulp te verleen aan versorgers van individue gediagnoseer met bipolêre versteuring. Die navorser het haar navorsing gerig aan die hand van Rothman en Thomas (1994) se intervensie ontwerp en ontwikkelingsmodel (D&D) deur gebruik te maak van kwalitatiewe en kwantitatiewe metodes.

Na afloop van die analise van die kwalitatiewe data, is ‘n unieke psigo-maatskaplike opvoedkundige program, die SEE-SAW program, ontwikkel en toe geïmplementeer. Die konsep van balans versus wanbalans binne die sisteem is essensieel; die navorser se program het ten doel gehad om beter balans binne die sisteem van die pasiënt en versorger te bewerkstellig.

Die gevolgtrekkings het duidelik getoon dat die versorger van die bipolêre pasiënt blootgestel is aan ‘n wye spektrum van behoeftes en uitdagings, maar dat intervensies soos die SEE-SAW program van groot waarde mag wees.

Sleutelwoorde: bipolêre versteuring, versorger, behoeftes van versorgers, biopsigososiale model, psigo-opvoeding, ekologiese sisteem perspektief, intervensie navorsing, gemengde-metode verkennende navorsing, psigo-opvoedkundige programme, multidissiplinêre span.

ABSTRACT

A PSYCHOSOCIAL EDUCATIONAL PROGRAMME FOR CAREGIVERS OF PEOPLE DIAGNOSED WITH BIPOLAR DISORDER

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Bipolar disorder (BD) is a chronic, recurrent, serious illness that occurs in 1 % of people globally. Patients might become psychotic, suicidal and sometimes violent. They often need to be hospitalised, even against their will because they may have no insight. Patients may have a comorbid condition such as substance abuse or a personality disorder. They are frequently unable to fulfil their assigned roles of spouse, breadwinner, parent or adult child.

Caregivers of patients diagnosed with BD are also affected by the illness and the associated stigma. It becomes very difficult for them when they have to take over the responsibilities and roles of the patient. The nature of this impact on the social functioning of the caregivers, understood from an ecological systems perspective, is relevant for social work in the mental health care field. Discovering more about this impact and developing an intervention to curb it therefore formed the rationale for this study.

The integrated biopsychosocial model, within an ecological systems perspective, is being used at the psychiatric institution where the researcher works. This approach therefore also served as the point of departure from which this research was conducted.

A mixed methods research approach was utilised to provide a comprehensive analysis of the research problem.

The proposed study fell into the category of applied research, due to its aim of designing a programme to assist caregivers of people diagnosed with BD. The researcher directed the study according to Rothman and Thomas's (1994) intervention design and development model (D&D), using qualitative and quantitative methods.

After the analysis of the qualitative data a unique psychosocial educational programme, the SEE-SAW programme, was developed and then implemented. The concept of equilibrium versus disequilibrium in the system is central; the researcher’s programme therefore strove towards better equilibrium within the system of patient and caregiver.

From the conclusions it is apparent that the caregiver of the BD patient is exposed to a wide spectrum of needs and challenges, but that interventions such as the SEE-SAW programme may be very helpful.

Keywords: bipolar disorder, caregiver, needs of caregivers, biopsychosocial model, psychoeducation, ecological systems perspective, intervention research, mixed method exploratory research, psychoeducational programmes, multidisciplinary team.

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1. CHAPTER ONE: GENERAL INTRODUCTION

1.1 INTRODUCTION

Just like acrobats, people with a bipolar disorder (BD) are often precariously **balanced** on the high wire - with or without a safety net - and ideally they learn to 'balance in formation' with the support of family members and friends (Parker & Ketter, 2010:349). BD is one of biological psychiatry's greatest success stories. Pharmacotherapy is the first-line offence against episodes of mania and depression, as well as in maintaining long-term stability. Nonetheless, clinicians and researchers are increasingly recognizing the value of **psychosocial interventions** as adjunctive to pharmacotherapy (Miklowitz, 2010a:575).

In this chapter the definition of key concepts will be given, followed by a literature review, theoretical framework, the rationale of the study and problem formulation, research goals and objectives, research question/hypothesis, overview of research methodology, limitations and strengths of the study and, finally, the contents of the research report.

Subsequently the key concepts in this study are defined.

1.2 DEFINITION OF KEY CONCEPTS

1.2.1 Bipolar Disorder (BD)

There are currently two main diagnostic schemes for classifying BD: the *International Classification of Disease* (ICD), produced by the World Health Organization and the *Diagnostic and Statistical Manual of Mental Disorders* (DSM 5), produced by the American Psychiatric Association. At the hospital where the researcher is employed, the DSM 5 is used. Therefore, this classification system was chosen and used for the study.

According to DSM 5 (APA, 2013:123-154) the different diagnoses are:

- **Bipolar I Disorder**: It is necessary to meet criteria for a **manic episode**. The manic episode may have been preceded by and may be followed by hypomanic or major depressive episodes.
- **Bipolar II Disorder**: It is necessary to meet criteria for a current or past **hypomanic episode** and criteria for a current or past major depressive episode.
- **Cyclothymic Disorder**: The essential feature is a chronic, fluctuating mood disturbance involving numerous periods of hypomanic symptoms and periods of depressive symptoms that are distinct from each other. During the initial 2-year period, the

symptoms must be persistent and any symptom-free intervals last no longer than 2 months.

- **Substance/Medication-Induced Bipolar and Related Disorder**: The diagnostic features are essentially the same as those for mania, hypomania, or depression.
- **Bipolar and Related Disorder due to Another Medical Condition**: The essential features are the presence of a prominent and persistent period of abnormally elevated, expansive, or irritable mood and abnormally increased activity or energy predominating in the clinical picture that is attributable to another medical condition.
- **Other Specified Bipolar and Related Disorder**: It applies to presentations in which symptoms characteristic of a bipolar and related disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the bipolar and related disorder diagnostic class.
- **Unspecified Bipolar and Related Disorder**: This category is the same as above, but is used in situations in which the clinician chooses **not** to specify the reason that the criteria are not met, and includes presentations in which there is insufficient information to make a more specific diagnosis (e.g. in emergency room settings).

DSM 5 **specifiers** for bipolar and related disorders include: with anxious distress, with mixed features, with rapid cycling, with melancholic features, with atypical features, with psychotic features, with catatonia, with peripartum onset and with seasonal pattern. It should also be specified if the illness is in partial or full remission and whether the current severity thereof is mild, moderate or severe.

From experience in this field the researcher is well aware that the diagnosis for BD is very complex. Thus, for purposes of this study, the diagnosis of this illness had to be made by a psychiatrist.

1.2.2 Caregiver

The Older Persons Act 13 of 2006 defines a caregiver as any person who provides care. The Training Manual on Older Persons' Legislation from the Department of Social Development, South Africa ([sa]:5) adds that persons providing care may be professional or voluntary. The manual states that most caregivers in South Africa are family members who accept the responsibility of caregiving.

Ostacher, Nierenberg, Losifescu, Eidelman, Lund, Ametrano, Kaczynski, Calabrese, Miklowitz, Sachs and Perlick (2008:50) suggest the following **criteria** for identifying the primary caregiver (the caregiver must meet at least three of these criteria):

- be a spouse, parent or spouse equivalent;
- have the most frequent contact with the patient;
- help to support the patient financially;
- have most frequently been a collateral in the patient's treatment; and/or
- be contacted by treatment staff in case of an emergency.

The researcher agrees with the definition given by Ostacher et al. (2008:50), but would like to add that a caregiver may also be a child of the person diagnosed with BD. In short, for the purpose of this study a caregiver was considered as any lay person who cares about, and is in frequent contact with, the person diagnosed with BD.

1.2.3 Psychosocial rehabilitation

Bachrach (1992:1456) defines psychosocial rehabilitation as a therapeutic approach to the care of mentally ill individuals that encourages each patient to develop his or her fullest capacities through learning procedures and environmental supports. For this study, the researcher would have liked **caregivers** to develop to their full capacity given the context of being a caregiver. Although there has been a great deal of research on the psychological factors that may cause depression, there is a lack of research on these factors as possible causes for BD. However, psychological factors are an important part of the treatment programme in terms of dealing with the sequelae (consequences) of BD (Burke, 2013:177). The researcher considered **psychological aspects** that are important emotions such as anger, resentment, guilt and fear. Pertinent **social aspects** may include relationships (sometimes rejection), networking, stigma attached to mental illness, losses, as well as certain practical issues, for example financial constraints and accommodation problems. A psychosocial model must therefore be prepared to consider and respond to the interaction of a multiplicity of factors. This is the way in which the researcher would have liked to approach the caregivers because by doing so the complexity of the context would be recognised.

1.2.4 Psychoeducation

Psychoeducation is education about an illness combined with information on helpful management strategies (Berk, Berk, Castle & Lauder, 2008:283). Psychoeducation does not aim to modify beliefs but rather to impart information to patients and families in order to help them cope more effectively with the illness (Baumann, 2007a:477). It may however happen that caregivers change their beliefs once they have received additional information. The researcher views psychoeducation as the process of providing information about an illness, its implications, and how to manage it successfully within the patient system. The importance of adherence to prescribed medication and the identification of the early signs of relapse are also important aspects thereof.

1.3 LITERATURE REVIEW

Miklowitz (2010b:443) points to the importance of considering the **family** or **marital context** when understanding the symptomatic fluctuations and functional consequences of BD. If nothing else, BD creates havoc and emotional pain for family members, to the point where they develop health and mood problems themselves. The compromised emotional state of some caregivers can have a negative influence on the patient’s course of illness. On the other hand, a spouse or parent who develops an understanding of the nature, course, triggers and treatment of the disorder may help create a milieu which helps protect the patient against recurrences.

According to the American Psychiatric Association, BD is a severe, chronic, almost invariably recurrent, mood (affective) disorder (2000:383-401). It is a relapsing and remitting illness and is characterised by episodes of mania or hypomania alternating with episodes of depression. BD may also be referred to as ‘manic depression’, ‘bipolar affective disorder’ or ‘bipolar spectrum disorder’ (Vieta, 2009:1). In the DSM 5 (2013:123) bipolar and related disorders are separated from the depressive disorders and placed between the chapters on the schizophrenia spectrum and other psychotic disorders and depressive disorders in recognition of their place as a bridge between the two diagnostic classes in terms of symptomatology, family history, and genetics.

This disorder occurs in **1 % of people**; this seems to be true around the **world** in any population investigated (Hunt, 2005:23). Gradidge (2009:15) agrees, saying that BD affects up to 1 % of the population in **South Africa**. The South African National Mental Health Policy Framework and Strategic Plan (2013-2020:12) reflects that the first nationally representative psychiatric epidemiological study, the South African Stress and Health (SASH) survey found that 16,5 % of adults have experienced a mood, anxiety or substance use disorder in the previous 12 months. This study concurred with a 1 % for BD. In South Africa this is therefore a very real problem. One merely has to watch the media to become aware of the prevalence of BD. Van der Westhuizen (2011), a reader of the **Beeld** newspaper asks the pertinent question in the letter column: “Is everybody suddenly bipolar?”

The researcher has been working for more than 24 years as a social worker in a government psychiatric hospital in Gauteng, South Africa. She started contemplating whether caregivers are influenced by this disease. If so, then in what way are they influenced? Are their **needs** being recognised? Would a **psychosocial educational programme** that equips them with skills and knowledge help them to cope better? With these pertinent questions in mind, the research topic was chosen.

One important psychosocial area to investigate is the patient's **interpersonal** environment (Lam, Donaldson, Brown & Malliaris, 2005:431). The South African Mental Health Care Act (Act 17 of 2002), uses the term ‘mental health care user’ (MHCU) for patients. The researcher will however use the term ‘patient’ in this study, as it is still the well-known term. The patient must be seen within the context of his or her interpersonal environment and the stressors within this environment. The caregiver is part and parcel of the patient’s environment.

Olivenstein points out that what most people don’t think of, is that a BD diagnosis rocks more than one world (in Berk et al., 2008:266). Caring for a relative with BD poses both **objective** burdens (such as increased expenditure of time and money) and **emotional** burdens (such as worry, tension and grief). Family members must contend with multiple and qualitatively different sources of stress, including stress relating to their relative's illness, symptoms and problem behaviours, as well as stress relating to societal stigmatisation of people with mental illnesses and their families (Perlick, Rosenheck, Miklowitz, Kaczynski, Link, Ketter, Wisniewski, Wolff & Sachs, 2008:484-485). Hunt (2005:74) mentions that family members need to take care of themselves. Their difficulties must be acknowledged and the range of emotions that they are likely to be experiencing. This can help to reduce the guilt they usually feel. They must be encouraged to find time for themselves away from caring.

Mabunda (2004:70, 71, 74, and 76) indicates the fact that families’ lack of understanding of the mental illness and how to deal with it, affects the **rehabilitation** outcome negatively. She also states that there are weaknesses in the health care provider system that hinder the rehabilitation process. Relatives are not equipped with the knowledge and skills to deal with the patient’s mental illness. They live in constant fear, because they do not know how to manage the patient in a relapsed state. Families should be assisted in taking an **active**

role in dealing with their mentally ill relative, how to deal effectively with their roles in the family unit, and how to respond to the patient being ill. From her practical point of view, the researcher agrees with this author and it is another reason why she believes this research is worth conducting.

BD is usually treated with mood-stabilising medication during acute periods of illness and for long-term maintenance. More recently, however, various forms of **psychosocial treatment** have emerged as adjuncts to standard pharmacotherapy. Psychosocial treatment is considered part of the prophylactic maintenance treatment of the disorder rather than part of the acute treatment (Miklowitz, 2004:159, 162). Current trends in psychiatric literature point to the routine implementation of psychosocial interventions for persons with BD. This trend is in line with traditional social work theories and values, presenting an opportunity for social workers in the field of mental health to utilise this evidence in their practice (Buila, 2009:572). The researcher agrees that social workers can play key roles in improving outcomes for persons who have BD, but wants to add the **important role** that the **social worker** plays in regard with the patients' **significant others**.

Once a patient stabilises from an acute episode, **relapse prevention** becomes the central objective of treatment. Bipolar patients have a host of psychosocial impairments that persist even when they take medication. Combining pharmacotherapy and psychosocial intervention has the potential to alleviate the psychosocial impairments not addressed by medication alone (Miklowitz, 2004:160).

Other experts in the field **substantiate** the importance of psychosocial treatment. Swartz and Frank (2001:11) mention that since the introduction of lithium in 1949, clinicians and researchers have focused on somatic approaches for the treatment of BD. It has become increasingly clear, however, that treatment with pharmacotherapy alone fails both to prevent recurrence in a substantial proportion of individuals with BD, and to address the significant residual functional deficits associated with its long-term course. Huxley, Parikh and Baldessarini (2000:126) agree that there is a need for adjunctive methods to optimise the considerable benefits of pharmacological treatments and to better manage the psychological and social contributors to, and consequences of, bipolar illness. It can be stated that more than perhaps for virtually any other mental illness, there is a need for a **comprehensive and integrated approach** to the management of BD (Colom & Vieta, 2006:xi).

Lam et al. (2005:431, 439) also mention the limitations of pharmacotherapy pertaining to BD, and point out that these were acknowledged in the 1996 report by the National Institute of Mental Health which emphasised the need for psychosocial intervention as an adjunct to medication. They are of the opinion that psychoeducational materials are often a valuable resource. The researcher's intention to have developed a **psychosocial educational programme** for caregivers was therefore motivated by her own experience and support from relevant literature.

It is clear that BD is a debilitating psychiatric condition, which not only affects the patient but also has a profound effect on his or her significant others. It is an international problem, but it is the researcher's opinion that it might even have a more profound effect on a third-world country like South Africa, which lacks the necessary resources to manage it correctly. At the start of this research it was envisaged that the researcher would assess the **needs** of caregivers and would then develop a psychosocial educational **programme** as an adjunctive form of treatment.

1.4 THEORETICAL FRAMEWORK: An integrated biopsychosocial model, within an ecological systems perspective

The ecological systems perspective, based on systems theory, is an approach to human behaviour. An ecosystem is a system of systems, including the individual, family, sociocultural environment and the therapeutic systems (Surdut, 1998:440). It can even be said that the mental health of the individual is interdependent with the ecological health of the larger nationwide system (Smith, 2007:654).

From an ecological perspective, the **context** within which the individual functions is crucial and helps the clinician to identify the sources of stress and contributing events (Surdut, 1998:440). The researcher is of the opinion that it is crucial to see the patient as part of a complex ecological system and not as an isolated entity. This perspective is helpful in both the assessment of social needs and in planning intervention.

Social intervention is aligned to **systems theory**, specifically ecological systems models, which are consistent with biopsychosocial approaches. The 'life model' of ecological systems theory provides an account of how people impact on and in turn are impacted upon by their environment, and of the resultant **stresses** when there is a **disequilibrium** in the system. As was already mentioned, the smallest system is the individual, who functions within a larger system, being the **family** or small group system within a larger community system. That system might be a caring, supportive, adequately resourced family.

Alternatively, the system may comprise multiple family pathologies, physical illnesses, substance abuse, domestic violence and crime (Smith, 2007:639-640).

Persons, not minds or bodies, develop illnesses, and when they do so, both psyche and soma, or mind and body, are involved (Baumann, 2007b:10). The fact that all health problems are multi-factorial and interrelated, is recognised. It has been the researcher's experience that the integrated **biopsychosocial model**, within an **ecological systems perspective**, is being used at the psychiatric institution where she is employed. This approach therefore also served as the point of departure from which this research was conducted. In the researcher's workplace the term "**biopsychosocial-psychoeducation**" is used when discussing the treatment plan.

The researcher is of the opinion that it is important to understand the **difference** between the **biomedical** and **biopsychosocial** approaches (**Table 1.1**).

Table 1.1: Biomedical and biopsychosocial approaches to the problem of pain (Baumann, 2007:14)

	Biomedical	**Biopsychosocial**
Paradigm	Pain as illness	Pain as experience
Determinant	Disease process	Interaction of biological, psychological, and social factors
Role of clinician	Expert/technician	Educator/facilitator/mediator
Role of patient	Passive	Active
Interaction	Directive	Collaborative (team approach)
Goal of treatment	Elimination of symptoms	Improved function/quality of life
Methods	Pharmacological/technical	Educational/pharmacological
Focus of attention	Symptoms	Interactive, cyclical, and biopsychosocial interactions, impact of pain on life, patient's belief regarding pain
Management	Confined to biological interventions	Involves psychological and social levels of care

Theoretical models, or ways of looking at problems, shape the way in which medicine is practised. Much of the success of modern medicine is based on the use of a **biomedical** model. According to this model, the symptom signals an underlying disturbance of structure or function. By treating the underlying cause, it is expected that the disease may be cured. The person affected by the disease and the social context are incidental to the process.

This model has several limitations, particularly with regard to chronic disorders. The great majority of illnesses, whether of a psychological or a physical nature are not amenable to cure, and are shaped by psychological and social factors.

A **biopsychosocial** framework addresses biological and psychosocial **predisposing, precipitating, perpetuating and protective** factors. The emphasis is more on prevention and rehabilitation than cure. The focus is less on the pathogen or the pathology than on the affected individual in a particular social and cultural context. The framework is less reductive and mechanistic than enabling and holistic, and it is considered the appropriate way of understanding and treating the majority of psychiatric disorders (Baumann, 2007b:10). According to the perspective of the biopsychosocial model behaviour is too complex to be understood from one perspective only. It takes the view that psychological disorders are caused by **multiple** biological, psychological, and social factors in interaction with each other (Botha & Moletsane, 2013:80).

The **biopsychosocial** model combines generic and specialist healthcare with assessment and therapeutic interventions in respect of the psychological and social underpinnings of mental health. This is consistent with the primary health-care approach, in that it moves away from a compartmentalised, fragmented, traditionally medically dominated model to more comprehensive care, which focuses on the person as a whole, viewing many health problems as being rooted in social conditions and poverty.

The **management plan** is developed within a biopsychosocial framework, depending on the findings of the assessment. As the aetiology of mental illness is invariably multi-factorial, this more comprehensive, integrated approach is appropriate. On the basis of the assessment, treatment strategies may usefully be divided into biological, psychological, social, community or cultural components (Chetty, 2007:69). Both **assessment** and **treatment** require an integrated biopsychosocial approach to prevent the entrenchment of the symptoms and the associated disabilities (Baumann, 2007c:320).

In the opinion of the researcher, aspects mentioned in **Table 1.1**, as well as elements of the ecological systems model, can also be extended to the diagnosis of **BD** and the way it should be approached. The concept of **equilibrium versus disequilibrium** in the system is very important and the researcher's programme strived toward achieving an enhanced equilibrium within the system of patient and caregiver. Most models of psychosocial intervention draw from the assumption that certain stressors interact to produce episodes of BD. These stressors and associated processes operate against the background of biological and genetic vulnerabilities (Miklowitz, 2010a:578).

In conclusion, it is also important to take note of the **recovery model**. This is an approach to mental health care and rehabilitation which holds that hope and restoration of a meaningful life is possible, despite serious mental illness. Instead of focusing primarily on symptom relief, as the medical model dictates, recovery casts a much wider spotlight on restoration of self-esteem and identity and on attaining meaningful roles in society (National Mental Health Policy Framework and Strategic Plan, 2013-2020:9).

1.5 RATIONALE OF THE STUDY AND PROBLEM FORMULATION

While working in a psychiatric hospital as a social worker, it became clear to the researcher that the multi-disciplinary team (MDT) focuses mainly on the patient, whereas the partners, families or **caregivers** are often **neglected**. An important role of the social worker in a psychiatric hospital is to reach out specifically to the significant others, because they are the secondary sufferers of the mental illness. If their needs could be addressed, the patient would also benefit.

There were various reasons for the researcher to thought this research worth conducting. Dore and Romans (2001:48) state that **studies** on how family factors influence the outcome in BD are **scarce**. Ogilvie, Morant and Goodwin (2005:25) concur that despite the extent of the impact of BD, very little work has been done to define more precisely the **caregiver's burden** associated with this illness. This fact indicated to the researcher that there might be a knowledge gap pertaining to caregivers in this regard. The researcher has sufficient clinical experience to realise that caregivers often refuse to take patients back into their care after discharge. They verbalise that they are **afraid of the patient** (sometimes they even obtain a protection order) or that they can no longer tolerate the stress the patient puts on the family system. It is possible that they will be more willing to take a patient home, were they to feel more empowered to do so and had they been equipped with relevant knowledge.

Psychiatric care and especially inpatient care is very **expensive**, because it can be of a chronic nature. Private psychiatric care is a challenge because the medical aid benefits for admissions are quickly exhausted. A psychosocial educational programme that equips significant others can reduce the treatment costs of an illness episode and can even prevent admission. It can help caregivers to become less dependent on the health-care system.

South Africa is a **multicultural** country and all cultural groups are affected by this illness. From practical experience the researcher knows that there are families who perceive mental illness as ‘bewitchment’ and they might seek traditional consultation. The illness is then treated with ‘muti’ (traditional medicine) or, in some instances, by taking with very harsh measures. This indigenous alternative treatment can also be costly to and very taxing on the family system. Different cultures and their belief systems must be respected and considered in that all cultural groups may be provided with valuable information on BD.

The researcher contacted a number of social work colleagues at other psychiatric hospitals in South Africa to find out whether they thought that psychoeducation was important for caregivers and whether their institutions had any formal psychoeducation programmes aimed at this target group. They were also asked whether they or their colleagues were involved in such programmes. Based on this, it appears that psychoeducation forms part of social workers’ intervention on an ongoing basis. It was considered as an important aspect that should be addressed. However, none of the institutions contacted had a formal programme for psychoeducation for caregivers in place, and it was drawn up if and when there was a need. The researcher was asked to give feedback when her research was done.

As was mentioned, it was thus expected that this study would give an indication of the possible **needs** of the caregivers of patients diagnosed with BD, and that a **programme** would be specifically developed to address the needs of caregivers. Such a needs assessment and programme could provide general guidelines, also in terms of other mental illnesses. It could make a significant **contribution** locally, as well as nationally. The researcher would be able to make **recommendations** for practice, and develop a programme that can be internationally applied and thereby increase the value of the study.

BD affects multiple neurological and bodily systems, creating disabilities, pain, and grief that cannot be explained in simple descriptive terms about a person’s moods and emotions. This illness has biological, social, and economic repercussions. Periods of frightening manic and depressive episodes can lead to divorce, loss of jobs, decreased opportunities, homelessness, alcohol and substance abuse, and hardships for family members (Taylor, 2006:12).

In terms of the present **mental health policy** in South Africa and the Mental Health Care Act (Act 17 of 2002), MHCUs (patients) are discharged as soon as possible to prevent institutionalisation and costs. Since 1994, mental health policy in South Africa has aimed to develop appropriate and accessible mental health services for all people in South Africa. The primary objective of South Africa’s mental health policy is the development of comprehensive **community-based** mental health services. This means that the majority of people with mental illnesses should be treated in the community for most of the time during the period of their illness (Thom, 2007:3).

In her work sphere, comprising a psychiatric hospital admitting patients of different cultures, it is the researcher’s experience that the support system is mostly **not ready** and often unwilling, to take the patient in again following hospitalisation. This results in the patient **relapsing** and needing **readmission**. It has also been her experience that the community service system is not able to accommodate the needs of the psychiatric patients and their caregivers. As **hospitalisation** of psychiatric patients has become **shorter and shorter** (nationally and internationally) and as patients are discharged in quite unstable clinical states, the burden on the caregivers has become quite considerable. In this environment, caregivers need support, education and advice in coping with the patient’s ups and downs (Miklowitz & Goldstein, 1997:5). To elaborate, this burden may consist of illness symptoms like insensitivity, shifting responsibility for their own actions to others, violent behaviours, withdrawal and dependence (Lam et al., 2005:432).

Caregiver burden has been defined as the impact of the mental illness of one family member on the emotional well-being of other family members, and on the family members’ use of time, finances and general living conditions. In addition to the adverse effects of caregiving on the caregivers themselves, caregiver burden has been correlated with poorer clinical outcomes for patients (Colom & Vieta, 2006:20; Ostacher et al., 2008:50). In this study, the researcher considered the **caregivers**’ possible **needs** and their burdens as the primary problem to be addressed. During her literature search, it became clear to the researcher that psychological and social problems associated with BD are universal. The difference may only be that first-world countries have more resources (including mental health practitioners and community resources). South Africa has a severe **shortage** of skilled mental health-care professionals (Thom, 2007:5).

The specific focus of this study is thus that BD usually presents challenges to the caregivers of affected individuals. Caregivers could experience such challenges as a possible burden. They may need support, which could be given by means of a structured **programme**. Such a programme must be user friendly, needs-appropriate, and applicable to lay people and different cultures, since a lack of understanding may result in a lack of insight and the necessary support needed by the patient.

1.6 RESEARCH GOALS AND OBJECTIVES

The **first goal** of this research was to do an **exploratory descriptive study** of the **needs** of the caregivers of individuals diagnosed with BD (phase one). A descriptive study that aims to develop an initial understanding of a phenomenon is more likely to be exploratory (Fouché & De Vos, 2005a:107).

A **second goal** was to develop, implement and evaluate a **psychosocial educational programme** based on the needs of the caregivers of individuals diagnosed with BD (phase two). Such a programme may be considered as an adjunctive form of treatment. The **purpose** of the psychosocial educational programme was for caregivers of bipolar patients to become better informed and more able to accept the diagnosis and the need for sustained treatment to be better prepared to recognise and cope with re-emerging symptoms, stressors or other ‘warning signs’, and to become more adept at acquiring skills aimed at minimising the risk of major recurrences of the illness. It was aimed at striving to improve knowledge and skills, and, in doing so, prevent a relapse of the patient.

In order to realise these goals, the more specific **objectives** of the proposed study included:

- describing the BD spectrum and the specific appropriate patient profile;
- describing the treatment and intervention options available;
- identifying and exploring the needs and psychosocial challenges of caregivers of individuals diagnosed with BD;
- describing and exploring any relevant psychosocial educational programmes for caregivers on a national and international level;
- developing a psychosocial educational programme, relevant to South Africa, based on the possible needs and challenges of caregivers of individuals diagnosed with BD;
- implementing a psychosocial educational programme for caregivers;
- evaluating the programme that was developed and implemented, and
- formulating recommendations regarding a psychosocial educational programme for caregivers of individuals diagnosed with BD in order to empower caregivers, as well as mental health-care providers.

1.7 RESEARCH QUESTION/HYPOTHESIS

Research questions guide investigations and are concerned with unknown aspects of a phenomenon of interest (Teddlie & Tashakkori, 2009:5). The **research question** for **phase one** of this study was: What are the needs and challenges of the caregivers of individuals diagnosed with BD? This was assessed during the first phase of the study. Jansen (2007:2) states that any research stands or falls by the quality of the research question.

A research hypothesis is a specialised QUAN (quantitative) research question in which investigators make predictions, based on theory, previous research, or some other rationale about the relationships among social phenomena before conducting a research study (Teddlie & Tashakkori, 2009:5). The **hypothesis** for **phase two** of this study was as follows: If caregivers of individuals diagnosed with BD participate in an unique psychosocial educational programme that has been specifically developed based on their unique needs, then their level of knowledge about the illness and skills to approach it, will improve.

1.8 OVERVIEW OF RESEARCH METHODOLOGY (For detail refer to chapter 5)

The researcher used the **qualitative** approach for phase one and the **quantitative** approach for phase two, thus conducting **mixed methods** research. Mixed methods investigations involve integrating quantitative and qualitative data collection and analysis into a single study or a programme of inquiry. This form of research is more than simply collecting both quantitative and qualitative data. It indicates that data will be integrated, related or mixed at some stage during the research process (Delport & Fouche, 2011:433). The researcher used the **exploratory mixed method design**. This design is used when a researcher first needs to explore a phenomenon using qualitative data before attempting to measure or test it quantitatively. As a two-phase design, the results of the first phase (**qualitative data**) can help develop or inform the second phase (**quantitative data**) (Delport & Fouche, 2011:441).

Studies that aim primarily to solve a particular problem confronting a group of people are often referred to as **applied social research** (Bless, Higson-Smith & Kagee, 2006:43). The proposed study fell into the category of applied research, because its aim was to design a programme to solve the problem of possible lack of knowledge and skills of caregivers of individuals diagnosed with BD. A type of applied research in the social sciences targeted at addressing the application of research in practice is '**intervention research**'. It has been conceptualised by Rothman and Thomas (Rothman & Thomas, 1994; De Vos & Strydom, 2011:473-475). The researcher conducted the study according to their **intervention design and development model** (D&D). It consists of research directed towards developing innovative interventions. The researcher developed a programme with the aim of enhancing the functioning and well-being of a given population in practice.

Non-probability purposive sampling was used to select caregivers of individuals with the diagnosis of BD, which caregivers were to meet certain selection criteria. The samples in both phase one and phase two were selected by means of non-probability sampling, with 11 participants in phase one and 27 participants in phase two. Five of the caregivers took part in both phase one and phase two, and a total of 33 participants took part in the study.

In **phase one** a collective case study design was used, interviewing 11 caregivers of persons with BD, in order to explore and describe their needs and challenges. From these findings a programme was developed that was implemented using 27 participants (**phase two**). A pre-test was conducted before the programme commenced and a post-test was performed upon completion of the programme. The methods of data collection and data analysis are discussed in detail in chapter five, together with trustworthiness, reliability and validity. The ethical considerations are also discussed in detail.

1.9 LIMITATIONS AND STRENGTHS OF THE STUDY

The following table (**Table 1.2**) provides an overview of the limitations and strengths of the study:

Table 1.2: Limitations and strengths of the study

Limitations	Strengths
The extensive **ethical permission** process and the fact that the researcher had to obtain such permission from both the Faculty of Health Sciences and that of Humanities made the research process more challenging.	
Making use of the **mixed method** methodology, which is time consuming, prolonged the research process.	The **mixed method** methodology allowed the researcher to provide a more comprehensive perspective on the research question and hypothesis.
	The researcher started the research process by interviewing caregivers of BD patients in order to establish their needs. The SEE-SAW programme was developed in a **needs appropriate** way.
The researcher, although being employed at a government hospital, decided to also approach caregivers of BD patients in the **private sector**. This proved to be taxing, since referrals from both	The fact that caregivers in the **private sector** had also been approached made the sample more representative.

Limitations	**Strengths**
a private psychiatrist and a bipolar support group had to be relied on.	
This study was **not fully representative** of the cultures of South Africa, since the referrals received (see above) had to be relied on.	The study can be generalised to apply to caregivers of patients of varying mental disorders. The SEE-SAW programme can be developed to expand on **diverse cultures**' perception of BD and the treatment thereof.
	Caregivers of psychiatric patients do not always receive the recognition they deserve, nor the necessary psychoeducation that can lead to empowerment. The SEE-SAW programme made a difference in this regard by making caregivers aware of the fact that they have rights too.
BD is a **complex** psychiatric diagnosis. The researcher therefore had to familiarise herself with aspects like medication for BD in order to be able to convey such information to the participants in the study.	The fact that the researcher is not a medical doctor had the advantage that she could understand the caregivers' need for greater medical knowledge. The SEE-SAW programme could be presented at the "**level**" of the caregivers.
	The researcher contacted a number of social workers at psychiatric hospitals, other than her workplace, throughout South Africa to establish whether **psychoeducation** for caregivers in South Africa occurs in accordance with any specific programme, and it was found that there was not.
Within the researcher's **workplace** research is not considered a priority and thus the focus falls more on working with individuals, groups and the community. The researcher therefore had to conduct the major part of this study in her spare time whilst **concurrently** being employed on a full-time basis.	Working with **experts** in the field of psychiatry - specifically the "bipolar" MDT - on a daily basis, and having access to their expertise, contributed to the researcher's experience and knowledge. Support from members of the MDT and social work colleagues was beneficial.
The researcher was not given permission to personally ask caregivers to **participate** in the study. Caregivers from her caseload were not allowed to participate.	Since the actual **participants** were not part of the researcher's caseload, it made the study more trustworthy.

Limitations	Strengths
	Needs of participants (caregivers of patients with BD), are more than likely universal and thus the SEE-SAW programme can be **generalised** to apply to caregivers of patients with other psychiatric conditions.
	Results of the needs assessment of phase one of this study can be communicated to caregivers as well as to other professionals to better equip them. The researcher has already **given lectures** to caregivers in this regard, as well as to undergraduate and postgraduate students and members of the MDT.
The researcher is aware that caregivers had a definite **need to be able to voice their frustrations** during the course of the SEE-SAW programme, but it was beyond the scope of this particular programme. There could have been more time allocated to interaction with the respondents.	The SEE-SAW programme is **easy to understand** and caregivers as well as other mental health care practitioners will be able to use it.
	The SEE-SAW programme provides **flexibility** within a certain framework. It may be presented as a one-day programme, while certain aspects can be elaborated on over a longer period of time. The programme can evolve, be re-evaluated and improved as it runs its course.
In retrospect the researcher would like to **critically evaluate** the **questionnaire**, in that it may have been too extensive with some questions having been found difficult to understand (especially among elderly respondents). Questions being put in the negative (like question 11.3) were found difficult to answer. The questionnaire did perhaps not take into consideration that people's attitudes and beliefs might not change after having attended a one-day programme.	

Limitations	**Strengths**
An **experimental group and a control group** were to be put together, but due to the ethical issues in inviting the control group to the programme for the pre-test only and it not being able to attend the programme itself, the plan was reconsidered and decided against. The focus was then changed to one group per day. No respondents were willing to be in the control group, whilst having to travel to the venue for the pre-test questionnaire **and** then return seven hours later to fill in the post-test. It is the researcher's opinion that it would not have been ethical to expect such efforts from respondents and that many may not have come back, since participation was on a voluntary basis. This challenge was discussed with a number of experienced colleagues in psychiatry, psychology, occupational therapy and social work, who agreed that it would be unethical.	
	The implementation of the programme was run on a **pilot** basis and limitations observed during this period can be improved on with each successive run.
The researcher did not repeat the **questionnaire** a few months later to test the respondents' level of acquired knowledge over a longer term, since it was beyond the scope of this particular study, and because it would also have been unethical to expect the respondents who did not reside in Pretoria to come again for a post-test three months later.	E-mails and SMSs were sent by respondents at their own discretion up to the timespan of three months after the programme, which allowed them to express appreciation and show their growth in knowledge and benefits since attending programme.
	The researcher's **experience** (32 years in social work in health care) and education (Honours and Masters of Social Work in Health Care degrees) contributed to her level of insight and knowledge.

1.10 CONTENTS OF THE RESEARCH REPORT

The research report (**Table 1.3**) was structured in accordance with the recommendations of Strydom (2005d:251-254) and Maree (2007:299-300).

Table 1.3: Contents of the research report

CHAPTER 1: GENERAL INTRODUCTION	A general overview of the study, including an introduction and rationale for the study are given as well as a literature review and theoretical framework. This chapter also contains definitions of key concepts, the research goals and objectives, research question and hypothesis and limitations and strengths of the study.
CHAPTER 2: BIPOLAR DISORDER SPECTRUM AND THE SPECIFIC PATIENT PROFILE	A literature exploration with regard to information on BD and patients being diagnosed with this illness is provided.
CHAPTER 3: LIVING WITH BIPOLAR DISORDER - TREATMENT AND INTERVENTION	A literature overview of different treatment modalities (biological and psychotherapeutic) is presented. The role of the social worker in the psychiatric hospital, novel treatment, psychiatry in the Southern African context, and prognostic features are other areas that are highlighted.
CHAPTER 4: NEEDS AND PSYCHOSOCIAL CHALLENGES OF CAREGIVERS IN RELATION TO THE INDIVIDUAL WITH BIPOLAR DISORDER	Literature is explored to ascertain the needs and psychosocial challenges for caregivers.
CHAPTER 5: RESEARCH METHODOLOGY	The research approach, including the type of research, and the research design and methodology that were followed in the study are discussed. Trustworthiness, pilot study and ethical considerations are also highlighted.
CHAPTER 6: EMPIRICAL RESEARCH FINDINGS OF THE QUALITATIVE PHASE OF THE STUDY	Empirical findings of the qualitative research study are discussed.
CHAPTER 7: PSYCHOSOCIAL EDUCATIONAL PROGRAMMES FOR CAREGIVERS AND THE SEE-SAW PROGRAMME	Available psychosocial educational programmes in psychiatric settings are addressed in this chapter, as well as the researcher's own SEE-SAW programme.

CHAPTER 8: EMPIRICAL RESEARCH FINDINGS OF THE QUANTITATIVE PHASE OF THE STUDY	Empirical findings of the quantitative research study are discussed.
CHAPTER 9: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS	The researcher gives a summary of the goals and objectives, and presents conclusions drawn from the study. Recommendations for future research are discussed.

Subsequently, chapter two will discuss the BD spectrum and the patient profile.

2. CHAPTER 2: BIPOLAR DISORDER SPECTRUM AND THE SPECIFIC PATIENT PROFILE

2.1 INTRODUCTION

Bipolar disorder (BD) is a highly complex and heterogeneous psychiatric condition characterised by both a variety of symptoms and marked variability in course. For example, a patient with BD can experience episodes of depression, hypomania, mania, or psychosis, and even a mixture of emotional states, or cycle rapidly between them. Marked variability exists between patients in terms of the length, number and type of episodes, severity and type of symptoms, and the degree of inter-episode recovery experienced (Michalak, Murray, Young & Lam, 2010:254). The researcher has observed that patients, their families and society tend to **oversimplify** this psychiatric condition and people even want to diagnose themselves as having this illness. It has been the researcher's experience that every patient's and family's (caregiver's) reaction is unique when being confronted with BD.

It is thus clear that despite frequent descriptions in the popular media, BD remains one of psychiatry's most **misunderstood** diagnoses. Many who suffer from this illness believe they do not have it, and there are some who are certain they have it, but do not. While depressed people often know they have a problem, and are frequently willing to seek treatment; most manic individuals do not see a problem or the need for help. They often put themselves and their loved ones through a number of horrific episodes before they "get it". What makes this even more tragic is that good, effective treatments are available, and most people with this illness can live a "normal" life if they find, and keep to, appropriate treatment. Although not curable, BD can be controlled with treatment (Haycock, 2010:xiii, 1). Despite the great clinical and public health significance of BD, it is still under-referred, underdiagnosed and undertreated or mistreated (Rihmer & Fawcett, 2010:62).

According to Sadock and Sadock (2003:534), **mood disorders** encompass a large group of disorders in which pathological mood and related disturbances dominate the clinical picture. Mood disorders are best considered syndromes consisting of a cluster of signs and symptoms sustained over weeks to months, which represent a marked departure from a person's habitual functioning and tend to recur, often in periodic or cyclical fashion. These disorders virtually always result in impaired interpersonal, social, and occupational functioning. The field of psychiatry considers **major depression** and **BD** to be two separate disorders.

BD, classically known as “manic-depressive psychosis”, is a serious, chronic, and relapsing mental disorder (Colom & Vieta, 2006:3). The National Institute of Mental Health’s report (NIMH) (U.S. Government, 2010:2) adds that it is a **brain disorder** that causes unusual shifts in mood, energy, activity levels, and the ability to carry out day-to-day tasks and is a long-term illness that must be carefully managed throughout a person’s life. Miklowitz (2011:10) indicates that despite BD clearly being a disorder of the brain, and its genetic and biological underpinnings being well documented, it is still treated as a “**mental illness**”. Many people still erroneously believe it is related to their personal choices or morals. As a result, they may feel alienated from others when disclosing their disorder.

Despite the growing efficacy of available pharmacological tools, bipolar-affective disorders have continued to be a significant source of morbidity and mortality, doing serious harm to the quality of life of sufferers. They are the **sixth most major cause of disability worldwide** and being serious and chronic as they are, represent a heavy financial and social burden - both direct, for hospitalisations and consumption of medical resources and indirect, such as days missed from work and loss of productivity (Colom & Vieta, 2006:3). Relationships are another area which can be seriously affected, but NIMH (2010:2) also states: “Bipolar disorder **can be treated**, and people with this illness can lead full and productive lives”. It is important that patients and caregivers must never lose hope.

It needs to be indicated that some references use the term “bipolar mood disorder” (BMD) and the researcher cannot change the text, but according to the DSM 5 (2013:123) the term now is “bipolar disorder” (BD). The researcher did also use numerous references that were produced before the publication of the DSM 5 and it is her opinion that these references are still relevant. Aspects highlighting the DSM 5 will be included.

The great majority of illnesses, also BD, are not amenable to cure, and are influenced by psychological and social factors. A biopsychosocial model places emphasis on prevention and rehabilitation as opposed to cure. The focus is on the patient in a particular social and cultural context (Baumann, 2007b:11). Biological, psychological and social factors are in interaction with each other.

This chapter provides an overview of BD in adults, highlighting factors such as the history of the disorder, etiology, epidemiology, diagnostic considerations and clinical features, BD and crime and the genius-insanity debate.

2.2 HISTORY

Historically, the treatment and perception of the mentally ill have been influenced by religious and social norms. Treatment has varied from brutal, inhumane torture in asylums to community-based residential settings (Antai-Otong, 2003:21).

Taylor (2006:11) provides a good account of historical events and mentions that throughout recorded history there have been descriptions of people with symptoms resembling bipolar illness. Stories depicting manic and depressive episodes can be found in ancient Greek, Persian and biblical writings. Areteus, in the second century AD, recounted observing people who, for no known reason, danced throughout the night, appeared euphoric, were overly talkative and self-confident, and just as unexpectedly became sorrowful. Hippocrates was well aware of depression, and insisted that natural physical reasons, rather than spiritual or other forces, caused what we describe as mental illness. The Greeks also identified the brain as the organ responsible for emotional disorders and intelligence. Unfortunately, by the peak of the Roman Empire, scientific explanations for mental disorders gave way to mythology and religiously driven superstitions.

Colom and Vieta, 2006:4, 5 mention that in the late 1600s, attention was paid to more objective views of mental illness. Theophile Bonet is credited with describing patients who cycled between high and low moods. In the mid-1800s two French researchers, Jean Falret and Jules Baillarger, independently determined that a single form of illness could present both manic and depressive symptoms. Falret named the illness "**circular** insanity" and included symptoms much as those listed in today's diagnostic manuals. He considered the illness genetically caused, and hypothesised that research could find a medication for relieving symptoms. The introduction of **recurrence** and the notion of **cyclicity** to descriptions of the disorder is one of the breakthrough moments in the history of psychiatry. The German psychiatrist, Emil Kraepelin, built on the work of Falret and Baillarger. He was the one who truly defined the outlines of the disorder by introducing the longitudinal study as an essential diagnostic tool: his work *Manic-Depressive Insanity and Paranoia,* 1896 was a watershed in setting out the nosological aspects of bipolar disorders. Taylor (2006:11) states that his careful systematic observations documented that mania and depression can occur in a single form of mental illness.

The medical progress made in the late 1800s gave way to psychoanalytical philosophy as Europe and America entered into world War II. Major disorders such as manic depression and schizophrenia were largely framed as arising from unconscious conflicts caused by parents, environments and personal choice. It was hypothesised that bipolar symptoms would resolve once a patient gained insight, and chose to confront their unconscious fears, anger and incomplete parenting. The dominance of psychoanalytical talk therapy persisted in the United States for decades after World War II. This was also true throughout Europe. However, European doctors started using **lithium** shortly after John F.J. Cade discovered its therapeutic properties in the 1940s. The drug was not approved or widely available in the United States until the 1970s.

Haycock (2010:8) reports that three researchers, Carlo Perris, Jules Angst, and George Winoku, working independently from each other during the 1960s, have published works that influenced our present acceptance of the existence of bipolar disorders. They helped to unambiguously demonstrate the differences between unipolar and bipolar disorders. In 1979, Karl Leonhard separated BD from unipolar depression, which is the experience of depression with no mania or hypomania, and so the idea of "bipolar disorder" was conceptualised (Berk et al., 2008:2).

This and other research led to the 1980 decision by the American Psychiatric Association to refer to the body of symptoms, discussed above, as "bipolar disorder" in the third edition of its official *Diagnostic and Statistical Manual of Mental Disorders* (Haycock, 2010:8). The fifth edition, DSM 5, was released in 2013.

According to Antai-Otong (2003:21) the twenty-first century is placing greater emphasis on neuroscience, genetics, psychosocial rehabilitation, and the integration of client-centred mental health care. Currently, bipolar disorders are regarded as neurobiological diseases that are closely associated with specific and general abnormalities in the structures and metabolism of the brain (Taylor, 2006:11). The National Institute of Mental Health (2010:4) states that brain-imaging studies are helping scientists learn what happens in the brain of a person with BD. Newer brain-imaging tools, such as functional magnetic resonance imaging (fMRI) and position emission tomography (PET), allow researchers to study the brain's structure and activity.

2.3 ETIOLOGY/CAUSATIVE FACTORS: THEORIES AND PERSPECTIVES

> The **good news** is that although you can't control your biology and, therefore, can't control having BD, **you can control the course of the disorder itself** through medication, psychotherapy, and being aware of the environmental factors that play into your disorder (Berk et al., 2008:56).

Miklowitz (2011:75) argues that we need not think of BD as “only a brain disease” or “only a psychological problem”. It can be both of these things. Most professionals think of the cycling of BD as reflecting a complex interplay among the following factors:

- **Genetic** vulnerabilities: inheriting a propensity for the disorder from one or more blood relatives;
- **Biological** agents: abnormal functioning of brain circuits involving neurotransmitters such as dopamine;
- **Psychological** agents: such as one’s beliefs about relationships;
- **Stress** agents: either events that bring about positive or negative changes, such as transitions in a living situation or job or more chronic problems, for instance, severe family conflicts or taking care of someone who is seriously ill.

NIMH (2010:4) highlights the fact that most scientists agree there is **no single cause** for BD. Rather, many factors most likely act jointly to produce the illness or increase risk. Haycock (2010:57, 62) agrees and mentions that as scientists learn more about BD, it becomes clearer that **multiple** factors appear to cause and increase the risk of having this illness. A key tenet of biological psychiatry is that because the brain is a physiological organ, mental processes have a physiological basis. Therefore, the interplay of biology, emotions, and behaviour is important for understanding the origins and nature of mental illnesses. Unfortunately, at this time, scientists **cannot say exactly** what causes BD, nor can they explain exactly how different factors interact to produce the illness.

Berk et al. (2008:56, 57) are of the opinion that the underlying cause, as with any other illness, is biological. They explain the **interconnectedness** between **biological vulnerability** and **stress**. Biological vulnerability refers to a person’s **predisposition** to experience the symptoms of a particular illness. Stress can trigger biological vulnerability. According to Antai-Otong and Brackley (2003:67, 68) numerous research studies confirm the relationship between genetic and enzymatic defects and **genetic vulnerability** to **mental illness**. Genetic function is influenced by **prenatal** and **environmental factors** that activate intricate biochemical processes, which may in turn, affect behaviour and increase the likelihood of mental disorders. Some studies suggest that environmental factors are just as relevant as molecular-based genetic processes. Environmental factors may include parental treatment or caregiving patterns and family structures. These factors may buffer or **protect** genetically vulnerable clients so that people with a predisposition to a particular mental illness may not develop it because of exposure to protective environmental factors.

Major theories, such as **Psychodynamic, Existential, Cognitive-Behavioural and Developmental Theories**, of bipolar disorders are well documented and all these theories have speculated about the underlying cause of the illness. However, current research indicates that biological and genetic factors may be the most significant etiological factors. Psychosocial stressors can precipitate the onset of illness episodes, when **biologic** or **genetic** factors are present (Hines-Martin & Thomas, 2003:240). Berk et al. (2008:63) conclude: “Rather than a single pathway to illness, an interaction between biology as an underlying vulnerability, and a variety of **stressors** as triggers, may result in an episode of illness for a particular individual”. Bearing in mind that the etiology of BD is complex, the researcher will still discuss different possibilities.

2.3.1 Genetic vulnerabilities

As befitting an illness with such harmful sequelae, there is great interest in refining our understanding of the etiology of the disease. Research from twin and adoptive studies consistently indicates a strong and compelling influence of **genetics** on BD. Despite consistent evidence from twin, adoption, and family studies supporting the role of genes in BD, the precise molecular bases for the disorder appear complex and are poorly understood. Although some chromosomal regions have more consistent support than others, to date no specific gene has been identified that is known to contribute incontrovertibly to the etiology of BD (Hayden & Nurnberger, 2006:69, 70). Merikangas and Peters (2010:57) also mention in this regard that although there have been many studies designed to identify candidate genes underlying BD through either linkage (segregating within family) or association (differences between cases and controls), there are still no replicated genetic markers for BD. The researcher consulted the following resources and all the authors agreed that **genetic vulnerability** is very important:

- The evidence is overwhelming that BD has a strong genetic component. Of all the risk factors, family history is the strongest (Haycock, 2010:47).
- A family history of BD is one of the strongest and most consistent risk factors for the development of this disorder (Merikangas & Peters, 2010:57).
- Epidemiological and genetic evidence suggest that BD has a strong hereditary component and that prevalence is relatively insensitive to variations in personal or social adversity (Vieta, 2009:15).
- Studies of unipolar and BDs in families consistently show that these illnesses are strongly familial (Lewin, 2003:197).
- It is not unusual for BD to *co-segregate* or be associated in family trees with other kinds of mood disorders, particularly various forms of depression. Geneticists usually

establish that an illness is heritable through family studies and twin studies. The average rate of mood disorder among **first-degree** relatives of bipolar persons is about 25 %. The conclusion from various studies is that BD is 79-93 % heritable; meaning most of the variation in risk for the disorder is due to genes. The hypothesis that a person's genetic inheritance or biological vulnerabilities interact with specific environmental conditions to produce BD is just that - a hypothesis. Although a number of genes have been found to be associated with BD, no single gene provides an adequate explanation. Researchers suspect that many genes - each with a quite small effect - contribute to a genetic vulnerability for the illness. We know that BD involves changes in **circadian rhythms**: people with the disorder can have recurrences following a single night's sleep loss. Recent evidence suggests that genes that control our circadian rhythms ("clock genes") may be involved in the risk for BD and its recurrences (Miklowitz, 2011:77, 78, 79, 80 and 81).

- Adoption studies have also produced data supporting the genetic basis for the inheritance of mood disorders. The inheritability of BD I is also apparent in the fact that about 50 % of all bipolar I disorder patients have at least one parent with a mood disorder, most often major depressive disorder. If one parent has BD I, there is a 25 % chance that any child will have a mood disorder; if both parents have BD I, there is a 50 to 75 % chance that their child will have a mood disorder (Sadock & Sadock, 2003:540).
- The risk to relatives of those individuals with BD is significantly greater than the risk for those individuals without BD in the family history. The risk of developing BD is greatest when the disorder is present in first-degree family members; i.e. mother, father, or siblings (Hines-Martin & Thomas, 2003:242).
- As in the case of most neurobiological illnesses, science **does not** have a definitive **answer** for this question of etiology. Perhaps more so than for any other disorder, there is mounting evidence that most individuals **inherit** bipolar illness. Studies of twins, family histories, and adoptions support a genetic causation hypothesis. Genetics may explain causation in a large number of, but not all, cases; multiple neurological pathways may lead to developing bipolar disorders. The NIMH (2010:4) indicates that studies of identical twins have shown that the twin of a person with bipolar illness does not always develop the disorder (Taylor, 2006:13).

A dominant gene on chromosome 11 may predispose people to illnesses such as BD. Unfortunately, the data is still not strong enough to link BD with any specific genes. There is no bipolar gene; there are just groups of genes that appear to increase the chances of developing the mood disorder (Haycock, 2010:61).

In spite of the strong genetic component of this illness, Miklowitz (2011:85) argues that if one has BD, one's chances of passing it on to your children on average are about 9 %. So, in most cases, one's children will not develop anything. Taylor (2006:13) mentions that the important issue for patients and family members to know is that there is no scientifically accepted evidence that families or home environments cause BDs. The researcher is of the opinion that this is important; otherwise, families can feel very guilty for having contributed to the development of the illness.

2.3.2 Biological agents

An important theory of modern psychiatric therapy is **that all behaviours** are a reflection of brain function, and all thought processes represent a range of functions mediated by **neurons** in the brain. Just as the brain controls complex behaviours as normal feeling, learning, thinking, and speaking, it is the origin of disorders of affect, perception and cognition that characterises such diverse mental disorders (Antai-Otong & Sanford, 2003:43).

Miklowitz (2011:87) suggests that a biological **vulnerability** can be **dormant** and then become activated by a trigger, such as environmental stress or drug abuse. This, again, is according to the researcher, an indicator of the complexity of the etiology of BD. In practice it is often found that a patient may first become psychiatrically ill when abusing a substance, but then the illness will continue, even after termination of the substance use/abuse.

Taylor (2006:39) indicates that virtually all major universities and research programmes teach that bipolar disorders are illnesses stemming directly from structural and functional brain abnormalities. Studies illustrating that the brains of people with bipolar illnesses differ from those of individuals who have no psychiatric history are rapidly mounting. While the exact cause of this illness has yet to be identified, scientific findings indicate that bipolar symptoms are best understood as resulting from multiple interacting cellular structures and neurochemical systems that have been significantly altered. Vieta (2009:16) states that recent neuroimaging and post-mortem histopathology studies, using techniques such as positron emission tomography (PET), magnetic resonance imaging, single photon emission computed tomography, and magnetic resonance spectroscopy, have identified a range of **neurochemical** and **microstructural** differences between the brain tissue of bipolar patients and controls.

2.3.2.1 Neuroendocrinology, psychoneuroimmunology and neurochemical factors

- **Neuroendocrinology** - The neuroendocrine system contains the hypothalamus, pituitary gland, adrenal glands, gonads and pancreas. The hypothalamic-pituitary-adrenal (HPA) axis is particularly important in the response to threat or stress. Abnormalities in the HPA axis are known to contribute to, among others, BD (Antai-Otong & Brackley, 2003:67).

- **Psychoneuroimmunology** - The immune system plays a role in health and illness in the face of biological and psychosocial stress. Psychiatric illnesses, like affective disorders, have been linked to immune dysfunction (Antai-Otong & Brackley, 2003:67).

  Many studies have reported abnormalities in biogenic amine metabolites in the blood, urine and cerebrospinal fluid of patients with mood disorders. Of the biogenic amines, **norepinephrine** and **serotonin** are the two **neurotransmitters** most implicated in the pathophysiology of mood disorders. Data suggest that **dopamine** activity may be reduced in depression and increased in mania (Sadock & Sadock, 2003:536, 537). Haycock (2010:59) states that imbalances in the levels of these chemical messengers could account for mood swings if, for instance, they produce too little or too much stimulation on the cellular level. Miklowitz (2011:75) also mentions that a patient's brain may be over or under producing certain neurotransmitters, such as dopamine, serotonin, norepinephrine, or GABA, possibly resulting in the patient undergoing changes in the structure or function of his/her nerve cell receptors.

- **Neurochemical** processes underlying depression have been identified as the **Biogenic Amine Theory**, which implies that a deficiency exists in relation to certain neurotransmitters such as **norepinephrine** and **serotonin**. Deficiencies of these substances result in neurochemical imbalances. Psychopharmacologic treatment is based on the restoration of neurotransmitter systems. The mechanisms that underlie the development of mania are much less understood. Research to develop a more complete understanding of the neurochemical processes involved in mania is ongoing (Hines-Martin & Thomas, 2003:241). **Figure 2.1** portrays the interaction of different neurotransmitters.

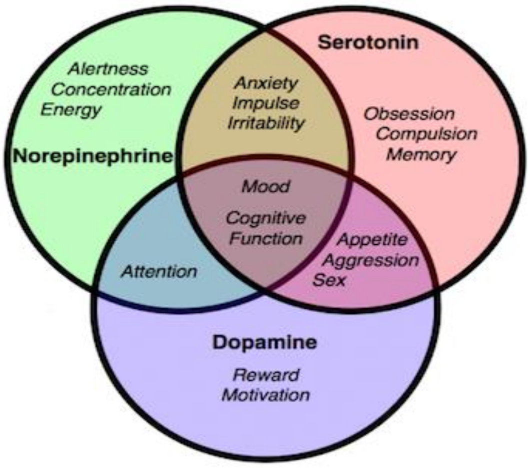


Figure 2.1: **The interaction of different neurotransmitters (http://www.google.co.za/Images for interaction of neurotransmitters)**

2.3.2.2 Neuroanatomical factors

According to Hines-Martin and Thomas (2003:241), the appearance of specific abnormalities or lesions in the white matter of the brain, in people with BD, has been reported.

Haycock (2010:57) mentions that **structural brain** imaging reveals differences in several parts of the brain in subjects who have BD. Those regions most affected are closely involved in processing emotions and in controlling emotional reactions. Many of these affected brain regions are part of what neuroscientists refer to collectively as the **limbic system**. Not all studies agree, but several have detected decreased volume in certain brain regions called the striatum and amygdala that lie below the outer cortex or surface of the brain. The amygdala is closely associated with fear responses, rage, and other strong emotions. Miklowitz (2011:75, 89) also indicates that a person might experience changes in the functioning or volume of certain brain structures, such as the subgenual prefrontal cortex or the amygdala. The neural circuits most associated with bipolar symptoms are being mapped through brain-imaging techniques such as functional or structural magnetic resonance imaging (MRI) or positron emission tomography (PET). These scans find evidence that the amygdala - a structure that is central to identifying emotional stimuli, both positive and negative - is both more active and larger in volume in people with BD, and areas of the prefrontal cortex may be correspondingly less active and smaller in volume.

In conclusion, **a patient's** biological predispositions affect his/her psychological and emotional reactions to stress. Recognising that the patient may be biologically and genetically vulnerable and that certain factors are stressful is the first step in learning skills for managing the disorder. Bipolar symptoms have a way of recurring when a person least expects them. This is because genetic and biological vulnerabilities are still present, even when medications and psychotherapy control a person's symptoms (Miklowitz, 2011:75, 76, 89).

2.3.3 Psychological agents

Sadock and Sadock (2003:541) discuss psychodynamic factors in mania and mention that most theories of mania view manic episodes as a defence against underlying depression. Karl Abraham, for example, believed that the manic episodes may reflect an inability to tolerate a developmental tragedy, such as the loss of a parent. Melanie Klein viewed mania as a defensive reaction to depression, using manic defences such as omnipotence, in which the person develops delusions of grandeur.

2.3.4 Stress agents

2.3.4.1 Life events and environmental factors

Environmental factors must play a role in the development of BD, since identical twins are frequently discordant for the condition. Indeed, a growing body of evidence suggests that environmental factors have an important impact on the onset, course, and expression of BD (Vieta, 2009:16). Miklowitz (2011:90) agrees, remarking that most scientists in the field doubt that environmental factors alone can *cause* BD without the contributing influences of genetics and biology. However, researchers are reasonably certain that stress and trauma affect the *course* of the illness.

Haycock (2010:63) mentions that although the underlying foundation for BD must have been present, some people report that their episodes began when they were under great stress. These stressful events can include childbirth, divorce or breakup of a relationship, loss of a job, death of a loved one, and serious financial difficulties. Medical researchers tend to agree that **stress**, in a variety of forms, is probably the most important **trigger** for BD. Stress can also result from other illnesses and injuries such as multiple sclerosis, epilepsy, and brain injury. Miklowitz (2011:96) mentions that another major type of stress has to do with ongoing relationships. There is no evidence that disturbances in family relationships are a primary cause of BD, but a high-intensity, **high-conflict family** can increase a person's likelihood of having a recurrence of BD once she or he has the said disorder. Conflict-ridden family environments seem to make bipolar people more recurrence prone. There is a possibility that the cycling of BD may also be affected by conflicts with other significant people, such as the person's employer, co-workers or friends.

Last (2009:39, 45), agrees that stress often contributes to recurrence; therefore, reducing stress and mitigating its impact (when it is unavoidable) are important to mood stability. Psychologically stressful events - like the death of someone close - can precipitate the development of a mood episode. Among experts in this field, the consensus is generally that events like these contribute more to the **timing** of mood disorders than to the underlying predisposition to have them.

As Sadock and Sadock (2003:540) point out, longstanding clinical observations indicate that stressful life events more often precede episodes of mood disorders rather than being subsequent to them. Taylor (2006:14) concurs, noting that there is some evidence that the first depressive or manic episode may be more influenced by stress, than those that follow. One theory proposed as an explanation for this observation is that the stress accompanying the first episode results in long-lasting changes in the brain's biology. As a result, a person has a high risk of undergoing subsequent episodes of a mood disorder, even **without** an external stressor (Sadock & Sadock, 2003:540) (the kindling theory, 2.3.4.2 below, also refers).

Taylor (2006:14) points to the fact that professionals, patients and families rightfully worry about the relationship between **stress** and bipolar symptoms. There are numerous assumptions and hypotheses relating to stress and illness onset, severity and cycling. The research supporting any of these concepts is minimal. Stress does not appear to be a major factor in explaining why people develop bipolar disorders, nor does it relate to the number of episodes and relapses that are experienced. Mental illness can develop in some people who have not been exposed to any events that others would consider traumatic. **Lack of social support** has also been connected to increased bipolar episodes. Having supportive friends and family nearby to lend encouragement between episodes tends to reduce stress (Haycock, 2010:64, 65).

2.3.4.2 Kindling theory

One theory of how BD begins and is ongoing is referred to as the kindling theory. This puts forward the notion that the condition develops as a result of the person's biologic and genetic predisposition in addition to environmental factors (Hines-Martin & Thomas, 2003:242). **Kindling** refers to a dynamic interaction where the brain learns, from repeated episodes, to automatically trigger future episodes. As in most physical illnesses, stress is most likely an additive interacting factor that plays a secondary role in symptom severity and quality-of-life issues (Taylor, 2006:14). Some experts believe that the reason episodes occur more frequently as one ages is that they are more easily triggered or require less of a trigger (or no trigger at all) as they increase in number. This explanation is consistent with “kindling theory”, which refers to the ability of a mental illness to take on a life of its own. It is hypothesised that while the first episode of illness may occur in response to a major stressor - like losing a job - subsequent episodes are triggered by increasingly less stressful events. Ultimately, the illness develops the ability to set itself off, so that new episodes of illness may be initiated by very minimal stressors or even when there are no stressors (Last, 2009:35).

According to Vieta (2009:13) the kindling model posits that regular and frequent periods of nervous system activation may predispose individuals to additional recurrences in an accelerated and automatic fashion. Initial bipolar mood episodes tend to arise in connection with interpersonal, chronobiological (see 2.3.4.3), or environmental factors, whereas later episodes, once “kindled”, may occur spontaneously and independently of external triggers.

2.3.4.3 Chronobiology/circadian rhythms

Circadian rhythm hypotheses have been prominent in the explanation of BD for more than 20 years and changes in sleep are part of the diagnostic criteria. There is consensus that biological rhythms play a critical role in the emotional dysregulation at the heart of BD (Murray & Harvey, 2010:263). Many scientists believe that stress can trigger bipolar episodes and may contribute to the onset of the disorder and sleep disruption resulting from stress is considered to be a factor (Haycock, 2010:24).

Researchers believe that people with BD are very sensitive to even minor changes in **sleep-wake rhythms**, such as when they go to bed, when they actually fall asleep, and when they wake up. If so, events that change their sleep-wake cycle will also affect their mood. Cindy Ehlers and her associates at the University of Pittsburgh (Ehlers et al., 1993 in Miklowitz, 2011:94, 95) formulated the social rhythm stability hypothesis that helps us to understand why life events might affect the mood cycles of people with BD. Ehlers’s theory states that the **core problem** in **BD** is one of **instability**. *Social rhythms,* i.e. regular patterns of daily activity and social stimulation, such as when you go to bed, are important in maintaining *circadian rhythms,* which are biologically driven cycles, such as when one actually falls asleep or the production of hormones such as melatonin. Social rhythms stay stable, in part, because of *social “zeitgebers”*, which are persons or events that function as an external time clock to regulate habits. In contrast, a *social “zeitstorer”* is a person or a social demand that throws everything off balance, such as when starting a new relationship and patterns of sleeping, waking and socializing change. It is thus important to remember that events that bring about changes in social rhythms alter circadian rhythms. A person with BD is particularly vulnerable to a manic episode after having had experienced a social-rhythm-disrupting life event.

Hines-Martin and Thomas (2003:242) agree with the above and say that another important factor playing a significant role in the development of BD is related to an area of study called **chronobiology** and focuses on the circadian rhythm or sleep-wake-cycle of the body. Several studies support the hypothesis that chronobiology mechanisms are involved in the pathogenesis of BD. **Seasonal variations** in circadian rhythms (internal clock mechanisms related to the seasons) may precipitate affective episodes. The strong association **between sleep deprivation** and the development of manic symptoms suggests that disruption of circadian rhythms may precipitate an affective relapse. Last (2009:42) states that while insufficient sleep has consistently been implicated as a trigger of mood episodes, research also shows that *any disruption or change* of the normal sleep-wake cycle is disturbing, even if a person ends up getting his or her usual amount of sleep. Changing **time zones** when travelling can also trigger mood episodes. It also appears that **social** routine patterns (sleeping, eating, exercise, daily activity) can cause disruption of circadian rhythms and thereby precipitate manic episodes (Last, 2009:43).

When thinking about the etiology of BD, Miklowitz (2011:11, 97) states that BD is not *just* about biology or *just* about environment but the **interaction** of the two. BD does not have clear-cut causes, but we know enough to say that it involves biological dysregulations that are partly under genetic control. These biological vulnerabilities may be set off by various kinds of stressors, conflicts, or life changes, whether positive or negative.

In **conclusion**, Haycock (2010:59) mentions that although it still lingers, the debate over nature versus nurture, or heredity versus environment, is an outdated concept. It is more accurate to discuss **nature *and* nurture**. The outside world, the environment, affects the function of the body, even going so far as to determine which genes are activated and how they function. From the above discussion, the importance of a genetic predisposition has become very clear. On the one hand, if a person's parents or siblings have this disorder, the chances of them having it are four to ten times greater than they would be if no one in that family had it. On the other hand, Haycock (2010:60) goes on to say that 60 % of children who have a parent with BMD, will never develop it.

2.4 EPIDEMIOLOGY (profile)

Over the past decade, the results of numerous international epidemiologic surveys using contemporary diagnostic criteria have strengthened the evidence base on the magnitude, correlates and consequences of BD in representative samples of the general population. This work has highlighted the dramatic personal and societal impact of bipolar disorders I and II (DSM 1V). The estimated disability-adjusted life years of BD outrank all cancers and primary neurologic disorders such as epilepsy and Alzheimer's disease, primarily because of its early onset and chronicity across the life span (Merikangas & Peters, 2010:52). There does not appear to be one, stand-alone reason that explains why one person has a mood disorder and another does not. It is much more likely that several factors function together to increase the risk (Haycock, 2010:45).

2.4.1 Incidence and prevalence

Worldwide, more than 250 million people may have BD, but no one knows exactly how many people in the U.S. have BD, since many are never diagnosed. However, if the estimate of the National Institute of Mental Health is correct and the number approaches 6 million, it has a significant impact on life in the US (Haycock, 2010:1, 45). Bipolar disorders occur worldwide. The WHO ranks BD as the 14th highest cause of disease burden within high-income countries, and the 19th within low-and middle-income countries. (Taylor, 2006:13).

Miklowitz (2011:4) indicates that BD is a mood disorder that affects at least one in every 50 people, and as many as one in 25 by some estimates, putting them at high risk for problems in their family, social, and work lives. Vieta (2009:6) mentions that the National Comorbidity Survey replication study found a lifetime prevalence of bipolar disorders in the USA of 4,4 %. According to Berk and Dodd (2005:12), the total bipolar spectrum may include more than 5 % of the population. Sadock and Sadock (2003:535) state that BD I is less common than major depressive disorder (MDD), with a lifetime prevalence of about 1 %. It is thus clear that different resources do not always report the same incidence.

Haycock (2010:48) expresses an interesting view on environmental factors: that although genes are powerful factors, they alone do not completely determine a person's fate (discussed in 2.3.1). Genes can, for instance, be influenced by diet, a key part of a healthy lifestyle. Consuming omega-3 fatty acid, for example, is associated with several benefits. Some studies indicate that consumption of seafood, which is rich in omega-3 fatty acid, lowers the risk of BD. This does not mean that eating fish, other foods rich in the nutrient, or taking supplements will cure the disorder, but it does suggest that environmental factors can influence its prevalence.

A special Sunday Times Newspaper investigation states that one-third of South Africa's population suffer from mental illness - "more than 17 million people in South Africa are dealing with depression, substance abuse, anxiety, bipolar disorder and schizophrenia" (Tromp, Dolley, Laganparsad & Govender, 2014:1). Considering that the minimum of people in a society suffering from BD is regarded as being 1 % and South Africa has a population of at least fifty million, it can be postulated that about 500 000 people in South Africa have this disease and that seems to be a conservative estimation.

2.4.2 Age of onset

The American Academy of Child and Adolescent Psychiatry (AACAP, 2007:107) reports that the number of **children and adolescents** receiving a diagnosis of BD has increased markedly during the past decade in the United States. BD was once thought to occur only rarely in youths, especially children. AACAP also states that the clinical bias, of mania not occurring in youths, persisted until large-scale studies of bipolar adults found that approximately one fifth of cases retrospectively had evidence of the illness before the age of 19 years. Although historically considered rare, childhood onset BD is now diagnosed much more commonly, including in preschool children. The typical age of onset is young adulthood (AACAP, 2007:109). Findings from short-term (2 year) follow-up studies show that young children with BD have a more severe form of BD, a continuous, very rapid cycling course with primarily mixed symptoms and no recovery between episodes (Last, 2009:50).

Berk and Dodd (2005:12) hold that the disorder tends to start in adolescence or occasionally preadolescence with a mean age of onset being 18 years. Miklowitz (2011:83, 17) indicates that BD can be diagnosed **at any age**, but many people develop it in the middle to late teens. New cases of BD have been recognised in young children and in the **elderly**, but the typical age at first onset is around 18. BD often develops in a person's late teens or early adult years. At least half of all cases start before age 25. Some people experience their first symptoms during childhood, while others may develop symptoms late in life (NIMH, 2010:1).

Vieta (2009:6, 7) concludes that the **first episode** of BD typically occurs in the second or third decade of life, with the peak age of onset between 15 and 25 years. However, there is often an **interval** of 5-10 years between the age of onset and first treatment or first hospitalisation. Being over age fifteen, but less than thirty, puts people in a high-risk category (Haycock, 2010:46). Sadock and Sadock (2003:536) state that the **onset** of BD I is earlier than that of **major depressive** disorder. The age of onset for BD I ranges from childhood (as early as age 5 or 6) to 50 years or even older in rare cases, with a mean age of 30. The mean age of onset for major depressive disorder is about 40 years. The **age** at which the disorder begins in bipolar depression sufferers is younger and the incidence of postpartum episodes is greater than in the case of unipolar depression (Colom & Vieta, 2006:11).

The onset of mania in individuals **over 60 years** of age is less likely to have a genetic basis; rather, it tends to be associated with underlying organic illness such as stroke or central nervous system lesions. As many as one in ten cases of BD first present after the age of 50 years. BD in elderly people, as in younger patients, may also be associated with general medical conditions, medications, or substance use. In particular, the onset of mania in later life is associated with high rates of medical comorbidity, especially neurological diseases, including right hemispherical cortical or subcortical lesions (Vieta, 2009:6, 7, 44). Singh, Kusumakar and Sajatovic (2009:204, 216, 217) also discuss the phenomena of bipolar in the elderly and state that *de nova* presentation of symptoms that meet DSM-IV criteria for BD is both challenging to diagnose and to treat. There is little data from controlled trials in BD in the elderly, specifically BD with onset late in life. Research in this population will undoubtedly help improve the care of elderly subjects with BD and will help inform treatment of BD across the life-cycle. Sajatovic and Kessing (2010:495) furthermore mention that data from mixed-age bipolar treatment trials cannot be readily extrapolated to geriatric populations, given the expected ageing-related biologic and social contexts. They agree that more research is critically needed to understand the expected illness trajectory's relationship to cognitive status and treatments that optimise all levels of health and functioning. The researcher agrees, from her clinical experience, that the elderly psychiatric patient forms part of a very vulnerable group.

An unfortunate reality of bipolar illness is that the length of time between episodes tends to decrease as people grow older (Last, 2009:34). This has also been observed by the researcher; with aging, the time between episodes/hospitalisation becomes shorter.

2.4.3 Gender

The researcher will provide a short summary of different authors on the gender aspect.

- Bipolar I disorder is **equally** distributed across genders (Haycock, 2010:46 & Taylor, 2006:13). AACAP (2007:109) states that although overall bipolar affects both sexes equally, early-onset cases are predominantly male, especially in cases with onset before age 13 years. Sadock and Sadock (2003:535) concur, pointing out that in contrast to major depressive disorder, BD I has an equal prevalence among men and women.

- Last (2009:53), El-Mallakh, Karippot and Ghaemi, (2006:167) and Sadock and Sadock (2003:535) agree that women may experience **depression** at two or three times the rate experienced by men.
- Hines-Martin and Thomas (2003:239) and Vieta (2009:6) concur that more **females** than males are affected by bipolar ll.
- Taylor (2006:13) states that **rapid cycling** occurs more frequently in women than in men. Last (2009:53), Haycock (2010:46) as well as Sadock and Sadock (2003:535) agree, saying that women are more likely to have the rapid-cycling form of BD, by a ratio of 3:1. Rapid cycling is defined as having four or more manic episodes in a 1-year period.
- The **onset episode** in women is most often depression, while the first episode for men tends to be mania (Last, 2009:52).
- For men **manic** episodes appear as frequently as or more often than depressive episodes (Taylor, 2006:13). According to Hines-Martin and Thomas (2003:239) males are more likely to be hospitalised with a manic episode, and are likely to have a comorbidity of substance abuse and dependence.

2.4.3.1 Women and BD

BD presents unique challenges for women. In particular, various stages and events in a woman’s reproductive life can affect and are affected by the disorder. Women are more likely to ruminate when depressed, whereas men are more likely to become aggressive or irritable. Women are also more likely than men to have anxiety, panic attacks, body image problems, and eating disorders (Miklowitz, 2011:257, 258). Mondimore (2006:172) points to the fact that although women are no more likely than men to suffer from BD, the hormonal changes that accompany menstruation and pregnancy affect the course of BD in women.

Michalak et al. *(*2010:254) report that a woman who develops BD at the age of 25 may lose 9 years in life expectancy (due to cardiovascular and other medical problems), 14 years of productivity, and 12 years of normal health. Taylor, Steiner and Soares (2009:154) state that the role of gender in BD has not been studied to the same extent as in other chronic mental illnesses, but there are some specific features of BD in women that set them apart from other patient populations:

- Women have a higher incidence of bipolar II disorder.
- Women present with a higher incidence of rapid cycling episodes, mixed states and antidepressant-induced mania.

- Women with BD have higher prevalence rates of alcoholism as compared to women without this disorder.
- The presence of medical comorbidities such as obesity, migraine and thyroid dysfunctions is also common in this population.

In addition to their own health, some **women** struggling with a mood disorder have an additional worry: the health of their **unborn children**. A mother's mental and physical health can affect her children as well as herself. If a woman with BD becomes **pregnant** or is thinking about it, she should obtain professional advice as soon as possible about how she should manage a mood disorder and pregnancy at the same time. The **decision** of whether or not to have children can be a heart-breaking one (Last, 2009:265). Miklowitz (2011:85) mentions important considerations, such as whether the person is clinically stable enough to take care of a child, physically healthy and in a satisfying relationship with his/her partner. The researcher has found that many patients already have children when they become ill and that it is consequently important to safeguard the children's security. It might be that the onus then falls more upon the other parent or even a grandparent.

Some BD medications can affect pregnancy - some cause birth defects. Pregnancy itself does not appear to increase the risk of having a bipolar episode, but the same is not true following birth, when the odds are in favour of a recurrence of symptoms including **postpartum** depression or psychosis (Haycock, 2010:53, 54). Last (2009:31, 53) agrees that women are at the highest risk for a mood episode after giving birth, that is, during the postpartum period. There is no clear relationship between the female monthly menstrual cycle and the timing of bipolar symptoms; it is different for individual women.

The researcher has experienced that becoming pregnant can be very stressful for a woman with a mood disorder. She might not know who the father is (falling pregnant while being manic) and it sometimes happens that such a mother therefore rather terminates the pregnancy. She might also not feel free to tell other family members that she is pregnant and it becomes a secret.

2.4.3.2 Male sex hormones and BD

Many men also go through a period later in life when their sex hormones decline, called andropause. Decreased levels of testosterone have been linked to depression, which, in turn, can exacerbate bipolar depression (Last, 2009:54). The researcher has sometimes had male patients whose libido was increased (usually during a manic episode) resulting in them behaving inappropriately towards their wives, children and even hospital staff, and they can become an embarrassment for the family within the community.

2.4.4 Marital Status

BD I is more common in divorced and single persons than among married persons, but this difference may reflect the early onset and the resulting marital discord characteristic of the disorder. The divorce rate among people with BDs is estimated to be 3-6 times higher than that found in the general population (Taylor, 2006:12, 13). Merikangas and Peters (2010:52) state that the rates of bipolar disorders are greater amongst those who were separated, divorced or widowed, compared to those who are married or never married in all of the recent US population surveys.

In the researcher's experience, she has observed a high divorce rate amongst bipolar patients (both male and female). Patients would also sometimes marry numerous times and after having known the new spouse for a very short time. The researcher has further observed that when two patients marry each other, it is a challenging situation but concedes that they might also offer support to each other.

2.4.5 Ethnicity, geography and socioeconomic status

BD affects people in different countries, from different socioeconomic levels (Berk et al., 2008:xiv). Haycock (2010:46) states that there are not statistically significant differences in the rates of BD globally or among different racial groups, and mentions that a 2007 survey of 9,000 randomly sampled people representing the population of the US discovered no differences based on ethnic background, race, or family income. Sadock and Sadock (2003:536) however state that a higher than average incidence of BD I is found among the upper socioeconomic groups. BD I is more common in persons who did not graduate from college than in college graduates, which also reflects the relatively early age of onset for the disorder. The prevalence of mood disorder does not differ among races. AACAP (2007:115) presents the view that **cross-cultural** issues may influence the expression or interpretation of symptoms and/or treatment response, and must therefore be assessed.

Hines-Martin and Thomas (2003:240) state that there are few cross-cultural studies of BD. In 1999, the *Mental Health: A Report of the Surgeon General* cited several studies that provided **comparative analysis** of disorder prevalence between various **racial or ethnic groups**, concluding that there was little difference in prevalence based on race or ethnicity alone but significant difference in mental health service access and use between the majority population and minority population. In South Africa, this also seems to be the case;

the minority can afford private psychiatric services, which also entails the more expensive medications which have fewer side effects. The same authors do however make it clear that there have been disparities in diagnosis of disorders based on race and argue that research has shown that clinicians are prone to misdiagnose mania as schizophrenia in African Americans. Colom and Vieta (2006:7) comment that more attention needs to be paid to the role of ethno-cultural variables in the presentation of manic symptomatology, which often mask it and make diagnosis difficult, especially when referring to hypomania. In conclusion, it is clear to the researcher that given certain life circumstances, many people are vulnerable to developing BD and one must then ask the important question that if a person has a predisposition to this illness, can it then really be prevented?

2.5 DIAGNOSTIC CONSIDERATIONS AND CLINICAL FEATURES

"Being diagnosed with BD meant that finally not only did my moods have a name but there was also something I could do to get them more under control" (Berk et al., 2008:1).

2.5.1 Mood disorders

BD is one of four major mood disorders recognised by psychiatrists. The others are unipolar depression and mood disorders induced by substances or due to a general medical condition (Haycock, 2010:1).

2.5.2 Diagnostic evaluation/assessment

The researcher is of the opinion that diagnosis should commence with a comprehensive **evaluation/assessment** (also refer to 2.5.11.1 where the challenge of under diagnosis, miss-diagnosis and over diagnosis is discussed). Kowatch, Fristad, Birmaher, Wahner, Findling, Hellander and the Child Psychiatric Workgroup on bipolar disorders (2005:2) emphasise such aspects assessing of symptoms and signs, psychosocial-stressors, family functioning, coping abilities and risk for suicide. Exclusion of GMC (general medical condition) that may mimic mania (for example, hyperthyroidism or SLE) or an increase in mood cycling (for example tricyclic antidepressants) must be excluded. Substance use/abuse must also be excluded.

NIMH (2010:4) states that the mental health professional should conduct a complete diagnostic evaluation. He or she should discuss any family history of BD or other mental illnesses and take a complete history of symptoms.

Please refer to **Appendix 2.1 Bipolar Symptoms: A Self-Administered Checklist** (Miklowitz, 2011:38, 39). This checklist is a tool that might be given to the patient to fill in; or the therapist could also fill it in with the patient.

The mental health professional should also talk to the person's **close relatives** or spouse and note how they describe the person's symptoms and family medical history. People with BD are more likely to seek help when they are depressed than when experiencing mania or hypomania. Therefore, a careful medical history is needed to assure that BD is not mistakenly diagnosed as major depressive disorder. Whenever possible, **previous records** and input from family and friends should also be included in the medical history. Kowatch et al. (2005:2) agree that information supplied by families is essential to make the diagnosis of BD. Families need to become educated about BD and its effects on the family. The researcher is therefore of the opinion that the **history** taken from the patient and his/her relatives is of great importance. The clinician cannot compare the patient's current mental state with their usual self; only relatives can do this. Some patients may not appear overly distressed, but the relatives may describe a marked change.

AACAP (2007:115), Berk et al. (2008:2) and NIMH (2010:4) highlight the fact that unlike **physical illnesses** such as diabetes and stroke, BD cannot be diagnosed by biological tests such as a blood test or brain scan (these tests can help rule out other contributing factors, such as a stroke or brain tumour). Instead, diagnosis relies on identifying current and past symptoms. The *Diagnostic and Statistical Manual of Mental Disorders (*DSM-IV) (American Psychiatric Association, 2000) and the *International Classification of Diseases* (ICD-10) (World Health Organisation, 2006) stipulate certain criteria as a guide for diagnosis. Fawcett (2010:44) mentions that it is customary to periodically revise the diagnostic system in the field of psychiatry. This is justified on the assumption that over a period of time there are new developments and findings that comes to light. The effort to revise the present DSM-IV classification for the planned DSM-5 classification published in 2013 was undertaken in 2007 by the American Psychiatric Association. A Mood Disorders Work Group was formed, reviewing the DSM-5 classification and relevant scientific-clinical literature.

Colom and Vieta (2006:6) refer to the fact that the diagnosis of BD and its episodes is purely based on clinical criteria, which are thus subject to controversy and interpretation. In 2009 Vieta (2009:29) wrote that the diagnosis of BD relies on clinical assessment, augmented by the use of screening tools and diagnostic scales. Fast and Preston (2004:3) mention that it is important that evaluation be done by a mental health professional who specialises in treating severe mental illness; the diagnosis must be clear and correct. The researcher agrees with Haycock's (2010:xiv) statement that there are many **complicating** factors in the diagnosis and treatment of BD. This includes the effect on the family, misdiagnoses and alternative diagnoses, substance abuse, creativity, medications, and alternative treatments. It is very important to acquire a solid grasp of the **multifaceted nature** of this disorder so as not to be surprised by the various and sometimes confusing symptoms of the illness. BD is complex and can be very confusing. There are so many different symptoms within symptoms that it may at first seem impossible to be able to grasp on all that is going on, but it is possible (Fast & Preston, 2004:21, 24).

It is helpful to organise the clinical information using a **life chart** to characterise the course of illness, patterns of episodes, severity, and treatment response. Using such a longitudinal perspective to conceptualise the disorder helps with diagnostic accuracy because the presenting symptoms, during the acute phases, are frequently confused with other disorders (AACAP, 2007:115). In conclusion, the researcher agrees with Miklowitz (2011:28) who emphasises that the first step in obtaining optimal treatment is to obtain a proper diagnosis.

2.5.3 Course of illness

According to Last (2009:31), the **course** of BD is extremely variable. Some people have mood episodes like clockwork; for example, according to seasons or following certain types of stressful life events, while for others episodes seem to appear "out of the blue". BD is however a very predictable and often very treatable illness (Fast & Preston, 2004:9). Vieta (2009:24) refers to **early warning signs**; episodes of both mania and depression may be preceded by a **prodromal period**. These early signs; events, and stressors (sometimes known as the "**relapse signature**") can vary from person to person, but typically include a marked increase in the number and magnitude of symptoms compared with remission.

2.5.4 Time frame

Various authors agree that it may take years before the diagnosis of BD is made and that it is a difficult diagnosis to make:

- "There may be a long delay, lasting years in many cases, between the first appearance of symptoms and diagnosis and treatment. For most people struggling with this condition, it takes at least 10 years between the onset of symptoms and a correct diagnosis" (Haycock, 2010:2, 28).
- "It takes an average of 8 years from the onset of BD to the diagnosis" (Last, 2009:24).

- “The gap between first symptoms and diagnosis may be as long as 10 years. This leads to extended morbidity” (Berk & Dodd, 2005:12).
- “Many people report that it took a long time for their BD to be correctly diagnosed and treated” (Berk et al., 2008:3).
- “It is a myth that BD is easily diagnosed and treated” (Hines-Martin & Thomas, 2003:244).
- “BD is very difficult to diagnose. On average, there is an 8-year lag between a first episode of depression or manic symptoms and the first time the disorder is diagnosed and treated” (Miklowitz, 2011:13).
- “Diagnosing BD can be a challenge, and delays of **up to 20 years** between the onset of symptoms and initiation of treatment have been reported. A recent survey of 600 patients with BD found that two-thirds were initially misdiagnosed. Factors that can confound the diagnostic process include overlapping symptomatology, comorbidities, and the late occurrence of manic or hypomanic symptoms in patients with recurrent depressive illness” (Vieta, 2009:36, 37).

The researcher’s conclusive viewpoint is that patients and families suffer unnecessarily because they might know something is wrong with them or their loved one, but they are uncertain of exactly what, until a diagnosis is made. The diagnosis usually gives them hope, because then the correct treatment may be implemented.

2.5.5 An overview of manic and depressive symptoms

Figure 2.2 provides a brief overview of manic and depressive symptoms that can be expected during the course of BD.

Figure 2.2: **An overview of manic depressive symptoms (http://www.google.co.za,manic and depressive symptoms images,Bipolarbandit.wordpress.com)**

2.5.6 Cross-sectional diagnosis

BD is generally an **episodic**, lifelong illness with a very variable course. The first episode may be manic, hypomanic, mixed, or depressed (Vieta, 2009:19). According to Last, (2009:33) BD is a recurrent disorder, with multiple episodes being the rule rather than the exception. AACAP (2007:110) states that in adults, the disorder is considered to be **cyclical** in nature, with episodes of illness representing a significant departure from an individual's baseline functioning and mental status examination. One can think of BD as a dysregulation of **drive states** as well as of **mood**. A change in normal motivational drives, such as those that govern eating, sleeping, sex, interacting with others, and achievement is part and parcel of the bipolar pendulum. The normal drives that guide our behaviour become intensified in mania and diminished in depression (Miklowitz, 2011:20).

Sadock and Sadock (2003:552) **describe** the two basic symptom patterns in mood disorders as **depression** and **mania**. Depressive episodes can occur in both major depressive disorder and BD. In many studies, researchers have attempted to find reliable differences between BD depressive episodes and episodes of major depressive disorder, but the differences are elusive. In a clinical situation, only the patient's history, family history, and future course can help differentiate the two conditions.

Berk et al. *(*2008:3) concur with other experts that BD involves "episodes" of illness and Miklowitz (2011:16, 36) describes **an episode** (hypomanic, manic, depressive or mixed) as follows:

- A set of symptoms that go together, with a **prodromal** phase, a middle **acute (active)** phase, and a final **recovery** phase (refer **Figure 2.3**: The phases of a **manic** episode). A single episode progresses in stages. Prodromal signs are those early indicators that a person's mood state is changing. Some people's signs might be more subtle than that of others. The prodromal phase is the period from the first onset of symptoms to the point at which symptoms reach the height of their severity (Miklowitz, 2011:192-222). The researcher holds the opinion that there will be overlapping between the different phases, because in the acute phase symptoms are very severe and the patient might be psychotic. In the researcher's experience, this phase may even last months and it is at this point that the patient might become chronically ill, staying in hospital on a semi-permanent basis. Some patients are treatment resistant. The researcher views the recovery period as the period when the patient is improving and eventually might be symptom free, but unfortunately, a person does not recover fully from BD and will still have to take medication. It is thus clear that the length and severity of bipolar episodes varies from person to person.

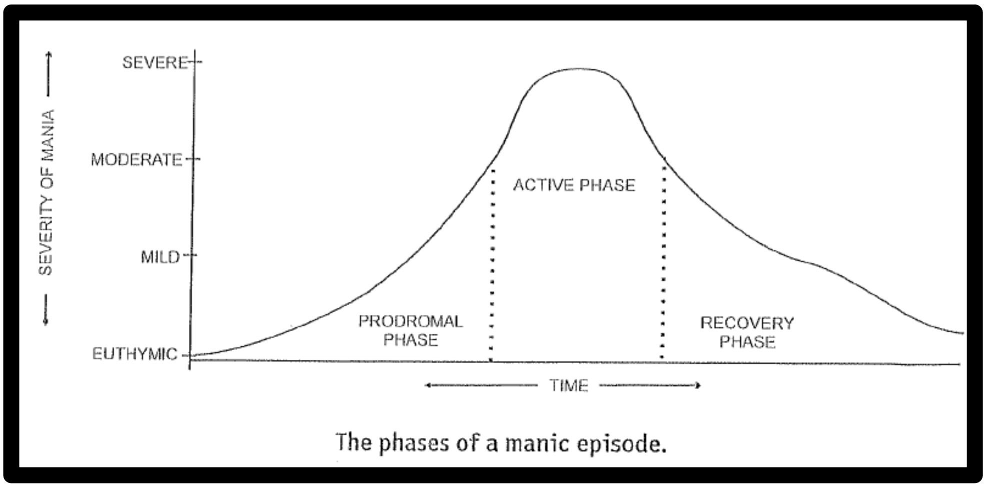


Figure 2.3: **The phases of a manic episode (Miklowitz, 2011:36)**

- The **polarity** of an episode may be depressed, manic, hypomanic, or mixed. For a diagnosis of BD to be made, a person will have experienced an episode of **mania** or **hypomania**, or **mixed** episode, at some stage in their life (Berk et al*.,* 2008:3). It needs to be noted that in the DSM 5 (2013:127, 149) "…with mixed features" is mentioned as a **specifier**. The mixed features specifier can apply to the current manic, hypomanic, or depressive episode in bipolar I or bipolar II disorders.
- Episodes can last anywhere from a few days to several months.
- Some people switch polarities in the middle of an episode. A 19-year-old man with BD described the switch from mania to depression like this:
  "I'm like a porpoise. I fly high up in the air and then I yell, 'I'm going down again! And then I go underneath the water, and all the air, sunshine, and the ocean breeze just vanish" Miklowitz (2011:22).

2.5.6.1 An episode of mania

Mania is a complex mood state characterised by a rapid and major change in the individual's usual behaviour. Mania has a diverse clinical presentation; a constellation of symptoms (Vieta, 2009:2). According to Sadock and Sadock (2003:553), an **elevated, expansive, or irritable mood** is the hallmark of a manic episode. The elevated mood is euphoric and often infectious. Although uninvolved persons may not recognise the unusual nature of a patient's mood, those who know the patient recognise it as abnormal. Patients often exhibit a change of predominant mood from euphoria early in the course of the illness to later irritability.

A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy, lasting **at least one week** and present most of the day, nearly every day, or for any duration, if hospitalisation is necessary, is **required for diagnosis** of a manic episode (DSM 5, 2013:124). During the period of mood disturbance and increased energy or activity, **three** or more of the following symptoms will have persisted (**four** if the mood is only irritable) and will have been present to a significant degree:

- Inflated self-esteem (grandiosity)
- Decreased need for sleep
- More talkative than usual or pressure to keep talking
- Flight of ideas or subjective experience of racing thoughts
- Distractibility

- Increase in goal-directed activity or psychomotor agitation
- Excessive involvement in pleasurable activities that have high potential for painful consequences (e.g. engaging in unrestrained buying sprees or sexual indiscretions).

Furthermore: The mood disturbance is sufficiently severe to cause marked impairment in social or occupational functioning or to necessitate hospitalisation to prevent harm to self or others, or there are psychotic features. The symptoms are not due to the direct physiological effects of a substance or a general medical condition.

Ghaemi, Saggese and Goodwin (2006:6) present a useful mnemonic aid for mania: **DIGFAST**

Distractibility: An inability to maintain one's concentration.
Insomnia: A decreased need for sleep.
Grandiosity: Inflated self-esteem.
Flight of ideas: A subjective experience of racing thoughts.
Activities: An increase in **goal-directed** activities (social, sexual, work, home)
Speech: Pressured or increased talkativeness.
Thoughtlessness: Commonly called *risk-taking behaviour* for example, sexual indiscretions, spending sprees, impulsive travelling and reckless driving.

Ghaemi, Saggese and Goodwin (2006:7) conclude by saying that mania is diagnosed when euphoric mood is present for **one week** with three of the DIGFAST symptoms, or irritable mood with four symptoms, and there is significant social or occupational dysfunction.

Sadock and Sadock (2003:553-556), Haycock (2010:3, 6, 9), Fast and Preston (2004:25) present an overview of manic episodes. **Table 2.1** compares manic and depressed episodes.

Mania is compared to depression because in the case of BD, it is part of the same illness. Depressive episodes are discussed separately in 2.5.6.4.

Table 2.1: Comparison of symptoms during Manic and Depressive episodes (Sadock & Sadock, 2003:553-556, Haycock, 2010:3, 6, 9, Fast & Preston, 2004:25)

	Manic Episodes	Depressive Episodes
General description	Manic patients are excited, talkative, sometimes amusing, and frequently hyperactive. At times, they are grossly psychotic and disorganised and require physical restraints and the intramuscular injection of sedating drugs. The **treatment** of manic patients in an inpatient ward can be complicated by their testing of the limits of ward rules, their tendency to shift responsibility for their acts onto others, their exploitation of the weaknesses of others, and their propensity to create conflicts among staff members. Outside the hospital, manic patients often drink alcohol excessively, perhaps in an attempt to self-medicate. Pathological gambling, a tendency to disrobe in public places, wearing clothing and jewellery of bright colours in unusual combinations are also symptomatic of the disorder. Patients act impulsively and at the same time with a sense of conviction and purpose. They are often preoccupied by religious, political, financial, sexual, or persecutory ideas that can evolve into complex delusional systems.	Generalised psychomotor retardation is the most common symptom, although psychomotor agitation is also observed, especially in older patients. Classically, a depressed patient has a stooped posture, no spontaneous movements, and a downcast, averted gaze.
Mood, affect and feelings	Manic patients classically are euphoric, but they can also be irritable, especially when mania has been present for some time. They also have a low frustration tolerance, which may lead to	Depression is the key symptom. Family members often bring these patients for treatment because of social withdrawal and generally decreased activity. Depression

	Manic Episodes	**Depressive Episodes**
	feelings of anger and hostility. They may be emotionally labile. Mania can be characterised by a strong sense of euphoria, but this euphoria can switch to anger or hostility very quickly. Mania can fuel intense anger or mistrust and can result in spontaneous harm to self or others.	can involve anger and irritability which fluctuates with anxiety, fear and agitation.
Speech	Manic patients cannot be interrupted while they are speaking. Their speech is often disturbed. As the mania gets more intense, speech becomes louder, more rapid and difficult to interpret. Associations can become loosened and the ability to concentrate fades.	Many depressed patients evidence a decreased rate and volume of speech; they respond to questions with single words and exhibit delayed responses to questions.
Perceptual disturbances	Delusions occur in 75 % of all manic patients. Moreover, delusions can be **“mood congruent”** or **“mood incongruent”**. Mood-congruent manic delusions are often concerned with great wealth, extraordinary abilities or power.	Depressed patients with delusions or hallucinations are said to have a major depressive episode with psychotic features. Delusions and hallucinations that are consistent with a depressed mood are said to be **mood congruent** and would include those of guilt, sinfulness, worthlessness and failure. The content of **mood-incongruent** delusions or hallucinations is not consistent with a depressed mood and would involve grandiose themes of exaggerated power, knowledge and worth.
Thought	Cognitive functioning in the manic state is characterised by an	Depressed patients customarily have negative views of the world and of themselves.

	Manic Episodes	**Depressive Episodes**
	unrestrained and accelerated flow of ideas.	Their thought content often includes non-delusional ruminations about loss, guilt, suicide and death.
Sensorium and Cognition: Orientation	Patients may have minor cognitive deficits.	Most depressed patients are orientated to person, place and time. **Memory:** About 50 to 75 % of all depressed patients have a cognitive impairment, sometimes referred to as depressive pseudo dementia.
Impulse control	About 75 % of all manic patients are assaultive or threatening.	About 10 to 15 % of all depressed patients commit suicide, and about two thirds have suicidal ideation. Patients are at increased risk of suicide as they begin to improve and regain the energy needed to plan and carry out a suicide.
Judgement and Insight	Impaired judgement is a hallmark of manic patients. According to Haycock (2010:4), insight and self-reflection fade. It can be extremely difficult to convince someone experiencing mania that something is not right and that they should seek help. Mania is often associated with risk-taking behaviour. This can include spur-of-the-moment marriages, compulsive gambling and sudden and unplanned trips. Another symptom of mania is increased sexual activity. It is not uncommon for someone with years of untreated BD to have a long list of marriages and/or people with whom she has had sexual contact.	Depressive patients' insight into their disorder is often excessive; they overemphasise their symptoms, their disorder and their life problems.

	Manic Episodes	**Depressive Episodes**
Reliability	Manic patients are notoriously unreliable in their information.	Depressed patients may overemphasise the bad and minimise the good.
Psychomotor activity	One feature of manic episodes is accelerated **psychomotor activity** – an increase in bodily activity: pacing, walking and fidgeting.	In contrast, depressive episodes are typified by psychomotor retardation; body movement is less rapid and active, due to diminished mental activity.

Miklowitz (2011:26) states that virtually all people with BD experience **disturbances** of **sleep** during their mood swings. When a person becomes manic, he/she may feel no need to sleep (hypersomnia). During depression, sleep can feel like the only thing that is welcomed (insomnia). Are sleep problems a symptom of BD, or do they actually cause problems in mood? It appears that they are both symptom and cause. People with BD are particularly **vulnerable to changes in the sleep-wake cycle**.

Vieta (2009:35) refers to the fact that mania may manifest without **psychotic features** or with psychotic features, such as delusions, hallucinations, excessive motor activity, flights of ideas that might be so extreme that the person is incomprehensible or inaccessible to ordinary communication.

Mania is usually described as either **euphoric** or **dysphoric** (Fast & Preston, 2004:25). Vieta (2009:2) refers to mania as sometimes being categorised as euphoric mania (with expansivity and elation) or **irritable** mania (with anger, aggressiveness). In the early phases of **euphoric** mania, the person may actually experience a sense of tremendous well-being. However, often as energy begins to escalate, thoughts can become more rapid and can disintegrate into chaos and confusion. Euphoric mania includes feelings of heightened self-esteem and, frequently, grandiosity, an intense desire to be active (this takes many forms, such as agitation and restlessness) and often very poor judgement as well as substance abuse. Upbeat moods quickly collapse into intense irritability and the person in the manic episode loses their ability to function normally. Psychosis may be present. **Dysphoric** manias also exhibit high energy, racing thoughts, poor judgement and restlessness, but no sense of well-being.

As Sadock and Sadock (2003:545) point out, DSM-1V-TR specifically states that manic episodes clearly precipitated by antidepressant treatment do not indicate BMD I and antidepressant - induced hypomanic episodes are not diagnostic of BMD II. DSM 5 (2013:124) indicates that a full manic episode that emerges during antidepressant treatment, but **persists** at a fully syndromal level beyond the physiological effect of that treatment, is sufficient evidence for a manic episode and, therefore, a bipolar I diagnosis. Colom and Vieta (2006:8) conclude that in distinguishing it from **hypomania**, in mania the change must be serious enough to bring about a sharp deterioration in sufferers' social/job activity, or to require them to be hospitalised so that they are protected from hurting themselves or others.

Manic episodes typically have a rapid onset (hours or days) but may evolve over a few weeks. Ninety percent of persons who have a single manic episode are likely to have another. As the disorder progresses, the time between episodes often decreases (Sadock & Sadock, 2003:558). The severity of a manic episode will differ from patient to patient and the researcher has experienced that the duration of an episode is also very specific to the individual. It is clear that a manic episode is also extremely taxing on the caregiver and if the caregiver does not understand that a manic episode is beyond the control of the patient, it might cause serious relationship problems.

2.5.6.2 Hypomanic episode

Hypomania is a difficult syndrome to detect. The borderline between hypomania and non-pathological elevated emotions is difficult to identify, especially in highly educated individuals (Colom & Vieta, 2006:8). Vieta (2009:4) and Haycock (2010:13) mention that hypomania is often **undiagnosed**, mentioning that hypomanic episodes are less likely to signal that someone needs hospitalisation or is otherwise in serious danger. An individual may be misdiagnosed as simply depressed. It is very important to remember that hypomania is related to depression in bipolar II and is part of the same illness. Where there is hypomania, there will be depression.

Vieta (2009:4) furthermore refers to the fact that hypomania is an attenuated form of **mania** that by definition is **not associated with psychosis** or delusions. It refers to a clearly abnormal mood state with mild-to-moderate symptoms of mania that may last for a few days or for many months. The key distinctions from mania are that hypomania can be diagnosed after **4 days** and, although the disorder is associated with an unequivocal change in functioning, there is no marked impairment. The disturbance in mood and the change in functioning are observable by others. The episode is not attributable to the physiological effects of a substance (e.g. a drug of abuse or a medication). Hypomanic episodes are common in bipolar I disorder but are not required for the diagnosis of bipolar I disorder (DSM 5, 2013:125).

Since patients often underestimate interpersonal dysfunction, **family reports** become essential. It is difficult, if not impossible, to rule out or diagnose BD without a family, or another third person, report. The researcher knows from experience that the psychiatric social worker can play an important role in this regard by obtaining collateral information from family members and in compiling a psycho-social report.

Fast and Preston (2004:26) refer to the fact that hypomania is seen in bipolar II and is much less intense than full-blown mania. Often, during hypomanic episodes people feel extremely well and are very gregarious and highly productive. This type of mania can last for a few days or go on for months. It is hard for friends or family members to do anything as the person is still basically functioning. Often beneath the veneer of this upbeat mood lurks irritability. Most people experiencing hypomania do not recognise this mood state as a part of their illness; rather they feel that it is simply ”feeling good” and is a welcome relief from depression.

A patient describes it as follows:

> It truly feels good to spend money. Everything is heightened: smells, tastes, colours and feelings. The problem is that if the behaviour isn’t noticed I can really make some terrible and life-changing decisions. This hypomania is always followed by a depression for me (Fast & Preston, 2004:27).

Hines-Martin and Thomas (2003:232) refer to the important aspect that despite the relatively mild nature of hypomania, the prognosis for clients with bipolar type II disorder is poorer than that for recurrent major depression and there is some evidence that the risk of rapid cycling (four or more episodes per year) is greater than with bipolar type I. Vieta (2009:23) concludes that the signs and symptoms of mania and hypomania are similar, but in hypomania, they are less severe and do not cause significant functional impairment. The researcher has found in practice that it is sometimes difficult to distinguish between the person’s “normal self” and an episode of hypomania. The patient might even find the hypomanic episode enjoyable and family members may be relieved by what they perceive to be the disappearance of the depressive state that often precedes the energised one. This again may lead to poor compliance and the patient might go on to develop full mania.

2.5.6.3 An episode of major depression

Berk et al. (2008:3) state that a depressive episode occurs when a patient experiences depressive symptoms for at least **two weeks** that cause distress and affect relationships, work or daily activities. According to DSM 5 classification (2013:125), an episode is diagnosed when *five or more* of the symptoms listed below are present. **At least one** of these symptoms is:

- Depressed mood
- Loss of interest or pleasure in things, which lasts nearly all day, almost every day.

The other possible symptoms include:

- Lack of energy nearly every day
- Restlessness or alternatively a marked lack of activity
- Noticeable changes in appetite and weight, either up or down
- Sleep problems (insomnia or hypersomnia nearly every day)
- Feelings of worthlessness and excessive or inappropriate guilt
- Difficulty in concentration and/or poor memory or difficulty in making decisions
- Persistent thoughts about death and suicide or feelings of hopelessness.

In addition, the episode is not attributable to the physiological effects of a substance or another medical condition (DSM 5, 2013:125).

The researcher wishes to emphasise the importance of the the clinician/therapist to always being very observant with regard to these symptoms when working with a patient, because sometimes patients might hide symptoms and might even be a suicide risk.

Sadock and Sadock (2003:546) also mention that two of the cross-sectional features (melancholic and atypical) are limited to describing depressive episodes. Two other features, *viz.* catatonic features and with postpartum onset, may also be applied to depressive and manic episodes. It is common for people in a depressed state to complain of physical aches and pains that have no physiological cause. Someone in this state typically has difficulty making decisions about even the smallest things (Haycock, 2010:5, 6).

Major depressive episodes range from **mild to severe**, depending on how intense symptoms are and how much they interfere with your daily life, relationships and safety. It is important to note that the symptoms of depression are not always static throughout an episode (Berk et al., 2008:24). Some people still experience a few symptoms of depression, even when the full episode is over. These are referred to as *residual* or *subsyndromal* symptoms and may make it harder to cope than usual, and increase risk of relapse (Berk et al., 2008:26).

Sadock and Sadock (2003:535) state that the presence of symptoms that are less severe than those of major depressive disorder characterises a **dysthymic disorder**. DSM 5 (2013:169) refers to **persistent depressive disorder** (dysthymia) and mentions that the essential feature is a depressed mood that occurs for most of the day, for more days than not, for at least 2 years.

2.5.6.4 Bipolar depression

The International Consensus Group on the Evidence-Based Pharmacologic Treatment of Bipolar I and II Depression (2008:1632) points out that the degree of disability associated with episodes of bipolar depression is disproportionately greater compared with episodes of bipolar mania and that patients with bipolar depression experience significantly greater psychosocial impairment. This is of particular importance, given that patients with bipolar I disorder are likely to experience depressive symptoms approximately three times more frequently than symptoms of mania. Furthermore, bipolar depression is a major cause of suicide, such that the lifetime prevalence of a suicide attempt is approximately 29 % in these patients.

Ghaemi, Saggese and Goodwin (2006:3) mention that although depression is the most common presentation of BD, a history of **mania** or **hypomania** is required for its diagnosis. Identifying these two behaviours defines the **diagnostic problem** that bipolar depression represents: when faced with a depressed patient, it can be extremely difficult for the clinician to validate the depression as stemming from BD. Generally speaking, determining that a patient currently meets criteria for a major depressive episode is straightforward. What is not straightforward, and therefore demands attention, is determining whether the patient’s history is consistent with unipolar or bipolar depression. This researcher regards this as being the point at which the psychiatric social worker can assist the multi-disciplinary team by conducting interviews with the patient’s significant others. A reliable history of any psychiatric symptoms (duration and frequency) is very important.

Ghaemi, Saggese and Goodwin (2006:11) contend that it is important to realise that the most common first mood episode in BD appears to be a major depressive episode, rather than a manic episode. About 90 % of people with BD experience depression at some time (Berk et al., 2008:17).

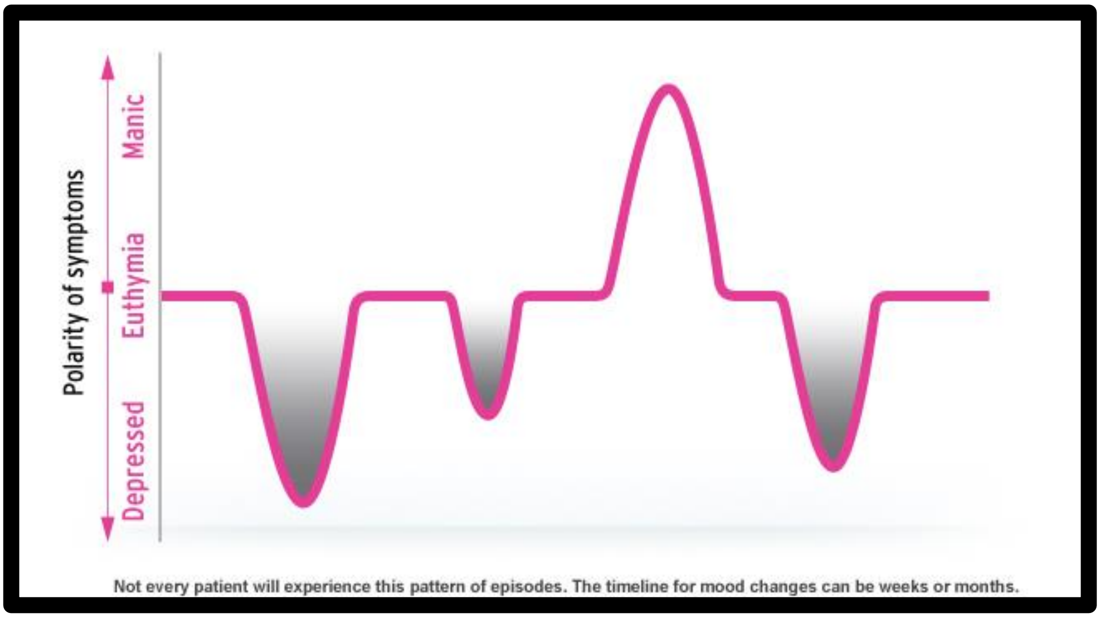
Although bipolar depression and “unipolar depression” share similar qualities, the distinction between the two is important, particularly because of the implications for **treatment**. The pharmacological treatment of major depression is different from the approach taken for manic-depression (Last, 2009:21). According to Young and Nemeroff (2010:294), effective treatment of depression in bipolar disorders represents a key therapeutic challenge. Inaccurate diagnosis often results in the implementation of inappropriate treatment, which may compromise long-term outcomes. Diagnostic accuracy may be improved by intensive scrutiny for the presence of manic/hypomanic, psychotic or reverse vegetative symptoms in every patient presenting with depressive symptoms, in establishing whether there is a family history of BD, and whether the patient had a pre-pubertal onset of depression. A vegetative state is the clinical condition of unawareness of the self or the environment (*Oxford Concise Medical Dictionary*, 2010:772).

Vieta (2009:4) refers to the fact that there is little agreement on the differences between unipolar and bipolar types of depression. Somatic and anxiety residual symptoms may be more common in unipolar depression, whereas atypical features may be more prevalent in bipolar depression. Berk et al. (2008:23) **also** mention that the experience of depression may be subtly different for people with BD and those who have unipolar depression. A pattern of so-called **atypical depression** may occur more often in people with BD. One of the reasons this pattern is called atypical is that instead of having insomnia, loss of appetite, and being very sad and tearful, which are all characteristic of unipolar depression, people need to sleep and eat more, and feel flat and slowed down when depressed. Colom and Vieta (2006:11) mention in this regard that the depressive phase of bipolar disorders displays some features that distinguish it from unipolar endogenous depression. It is often accompanied by apathy predominating over sadness, psychomotor inhibition over anxiety, and hypersomnia over insomnia. In bipolar depression, there is less anorexia and weight loss while emotional liability and the probability of developing psychotic symptoms in severe cases are greater. **Table 2.2** refers to clinical features that may distinguish between major depressive disorder (unipolar depression) and bipolar depression.

Table 2.2: **Clinical features that may distinguish between major depressive disorder (unipolar depression) and bipolar depression (Vieta, 2009:38, Ghaemi, Saggese & Goodwin, 2006:8)**

Unipolar depression	Bipolar depression
Typically emerges after the age of 25 years	Typically emerges before the age of 25 years
May be preceded by an extended period of gradually worsening symptoms	Episodes may be abrupt in onset (hours or days)

Unipolar depression	Bipolar depression
No history of mania or hypomania	Often periodic or seasonal
	Treatment-emergent mania/hypomania during antidepressant monotherapy may be suggestive of bipolarity
	Highly heritable; BD often runs in families, and a thorough family history is a vital diagnostic step
	A history of mania, hypomania, or increased energy and decreased need for sleep
	Atypical symptoms, psychosis, anxious/agitated depression, and irritability/anger attacks are more common in bipolar than in unipolar depression.



Not every patient will experience this pattern of episodes. The timeline for mood changes can be weeks or months.

Figure 2.4: Episodes of depression and mania as well as periods of euthymia

(https://www.google.co.za/search?q=bipolar+disorder+images&rlz=1C1SFXN)

2.5.7 Longitudinal diagnosis: classification

2.5.7.1 Types of Bipolar disorder

Berk et al. (2008:7) refer to the fact that people experience different **patterns** of **episodes** which characterise their specific type of BD. **Figure 2.5** provides an overview of mania, hypomania, subsyndromal depression and major depression and **Figure 2.6** an image of BD mood cycling.

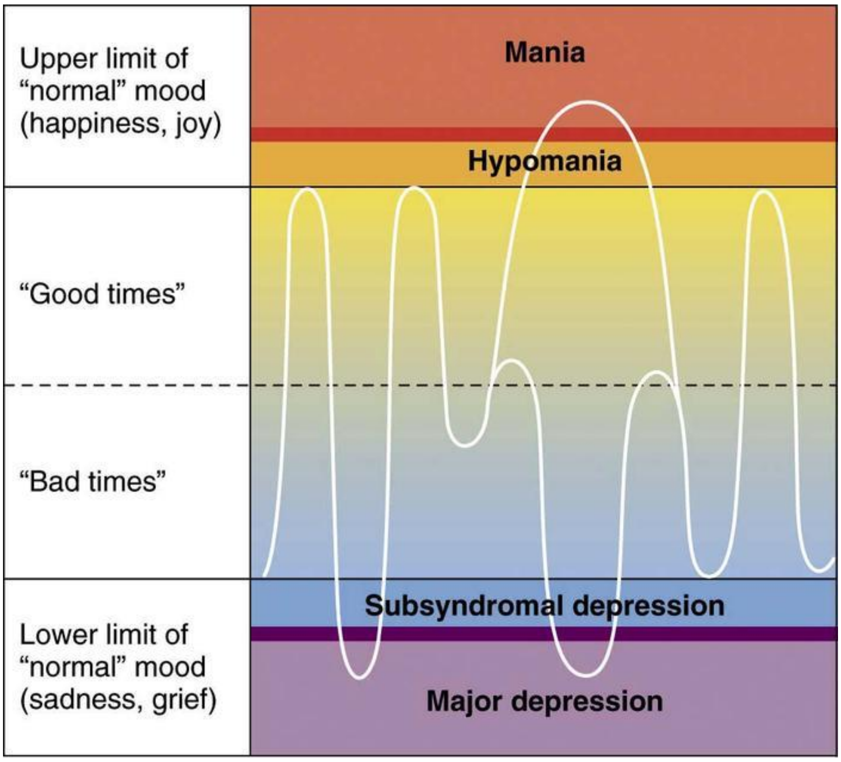


Figure 2.5: **Mania, hypomania, subsyndromal depression and major depression (Khalife, Singh & Muzina, 2010:1)**

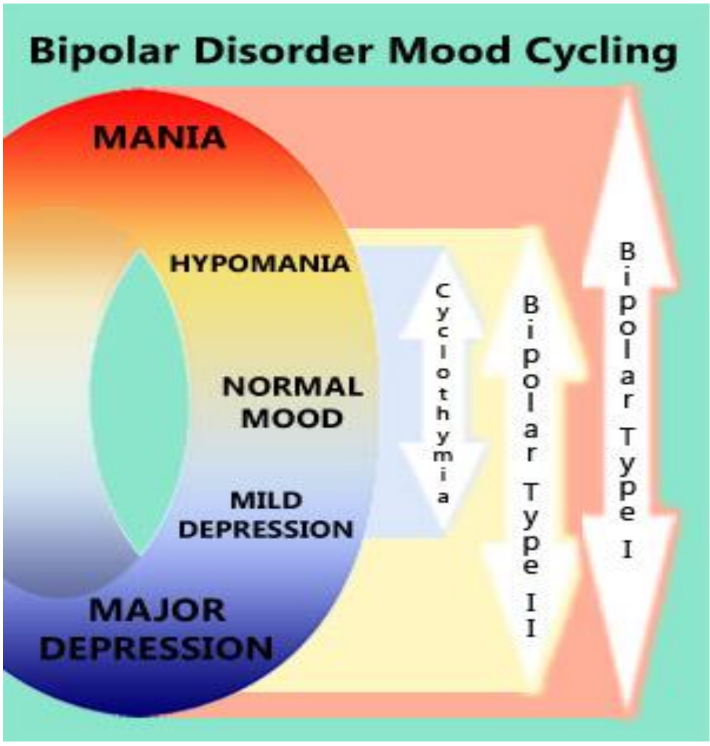


Figure 2.6: **BD mood cycling (IMHRO, Global Innovation for Brain Health)**

According to DSM 5 (APA, 2013:123-154) the different diagnoses are:

2.5.7.1.1 Bipolar I disorder

It is necessary to meet criteria for a **manic episode** (DSM 5, 2013:124). The episodes represent a significant departure from the individual's baseline function (AACAP, 2007:108).

In most cases, a person with bipolar I disorder will also have had, at some point in life, a minimum 2-week period with five or more symptoms of **major depressive** illness during which there was a deterioration in everyday functioning (refer to 2.5.6.3: An episode of major depression). People with bipolar I disorder may experience episodes of mania and depression in different sequences; for instance, manias followed by depressions followed by euthymic mood or depression followed by manias, which are then followed by euthymic mood (Miklowitz, 2011:32, 33).

According to Colom and Vieta (2006:12) type I bipolar disorder correspond to the classical pattern of the disorder, and its basic distinguishing feature is the presence of mania. The most frequent pattern is mania followed by major depression. The psychotic symptoms can appear both in the manic phase and in the depressive phase, but may also be absent. Fast and Preston (2004:22-23) refer to the fact that some people switch directly from manic to depressive episodes (or vice versa), but many will experience times between episodes when there is no apparent mood problem (euthymia, a neutral mood state).

Sadock and Sadock (2003:558) note that no identified **personality traits** are specifically associated with bipolar I disorder. BD I disorder often starts with depression (75 % of the time in women, 67 % in men) and is a recurring disorder. Most patients experience both depressive and manic episodes, although 10 to 20 % experience only manic episodes. Haycock (2010:9) says that it is also possible that a person will, although not necessarily have experienced a major depressive episode in the past. Berk et al. (2008:7) state that although less common, some people experience episodes of mania without ever experiencing a depressive episode. In practice, the researcher has also dealt with patients that did not report depressive symptoms and become either manic or hypomanic when they relapse.

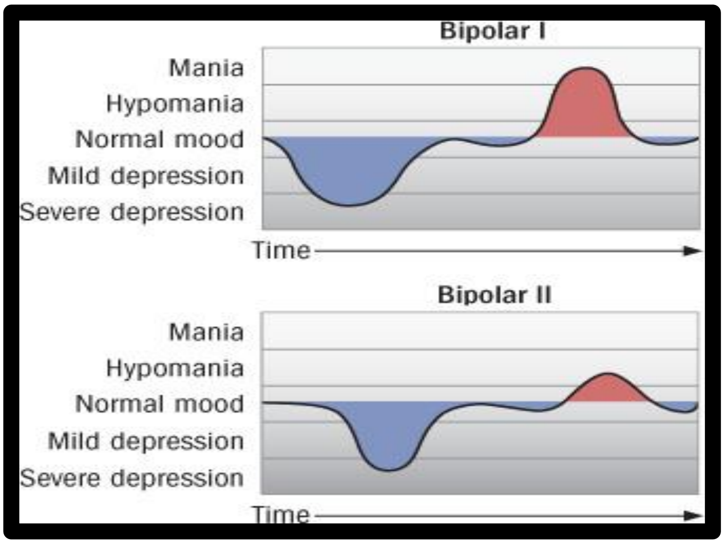


Figure 2.7: **The difference between bipolar I and bipolar II disorder (http://eng12202-arcc.wikispaces.com)**

2.5.7.1.2 Bipolar II disorder

It is necessary to meet criteria both for a current or past **hypomanic episode** and for a current or past **major depressive** episode. The number of symptoms required is the same; that is, three if the mood is elated, four if the mood is irritable (Miklowitz, 2011:33). According to Benazzi (2007:727-729, 735), the observable change in functioning should not be severe enough to cause marked impairment of social or occupational functioning, or to require hospitalisation.

The distinction between BP II and BP I disorder is **not clear-cut**. Bipolar II is not a less severe variant of BP I. As BP I and BP II seem to be subtypes along a continuum, sharing both similarities and differences, the correlated biological differences should support differences in **treatment**. What works for BP I may not work for BP II, and vice versa. Unfortunately, Bipolar II is currently undertreated and its treatment much understudied. At present, it is unclear whether a disorder such as BP II, which is frequently recurrent and impairing, should be treated prophylactically by antidepressants alone, by mood-stabilising agents alone or by a combination of antidepressants and mood-stabilising agents. In this regard, there is a great need for controlled pharmacological studies. Parker and Ketter (2010:342) agree that despite the lifetime rate of bipolar II disorder exceeding the bipolar I disorder rate, there is little consensus as to how bipolar II disorder should be optimally managed. The treatment of the bipolar II disorder must be approached with caution, as treatment for depressive episodes with antidepressants can frequently precipitate a manic episode (Sadock & Sadock, 2003:572).

Berk and Dodd (2005:11-13, 17) are of the opinion that Bipolar II disorder comprises a complex course and outcome and presents **several difficulties** for the treating doctor. **Recognition and diagnosis** of the disorder is the first issue. Depression is the presenting symptom, while hypomania is seldom spontaneously reported and is often not remembered by the patient as abnormal; therefore, collateral information is essential. Although type II is associated with greater clinical **benignancy**, it often proves to be less benign as it evolves, in the sense of the eventual occurrence of a larger number of episodes. Many type II bipolar patients are diagnosed and treated as if they were unipolar patients, because the patient only consults the doctor when he or she is depressed. All depressed patients should be asked, if possible with family input, about any history of hypomania (Colom & Vieta, 2006:12).

Symptoms are often **clouded** by behaviour and personality, as well as feelings of well-being that occur intermittently. Denial of hypomania is frequent and **comorbidity**, such as that of substance abuse, can cloud the presentation. Without an appropriate diagnosis, no management plan is likely to serve the patient’s needs. There is substantial **morbidity** with the disorder, especially if it becomes chronic, undiagnosed or inappropriately treated. High rates of occupational, leisure and relationship dysfunction are common. There are higher rates of family dysfunction, divorce or separation than in either bipolar I or unipolar disorder. Bipolar II disorder may be a more **recurrent** disease than bipolar I disorder. It is associated with a significant **mortality** risk. Evidence indicates that patients with **bipolar II** disorder are at greater risk of both attempting and completing suicide than patients with bipolar I disorder and major depressive disorder (Sadock & Sadock, 2003:553).

Many patients, if treated, are placed on unipolar depression type management algorithms. There is a significant theoretical **risk** that this may worsen the long-term course of the disorder. Given the paucity of controlled clinical and therapeutic data, many more questions than answers in this neglected area remain. Hines-Martin and Thomas (2003:235) mention that the diagnosis remains **underused** because hypomania is frequently not recognised, especially when occurring in the context of atypical depression.

Bipolar II depression persists for longer periods of time than bipolar I depressions - nearly twice as long. Moreover, for both forms of the illness, but particularly strikingly so for bipolar II disorder, the total percentage of time people are depressed is much higher than the total percentage of time they are manic or hypomanic (ratios are 3:1 and 37:1 for bipolar I and II, respectively) (**Figure 2.8** refers). Thus, if someone has bipolar II disorder, it is likely that most of the time she/he will be fighting depression, not hypomania (Last, 2009:37).

Miklowitz (2011:34) concurs, mentioning that ongoing depressions appear to be the major difficulty experienced by people with bipolar II disorder, with one study finding that patients spent 37 weeks depressed for every I week they spent hypomanic.

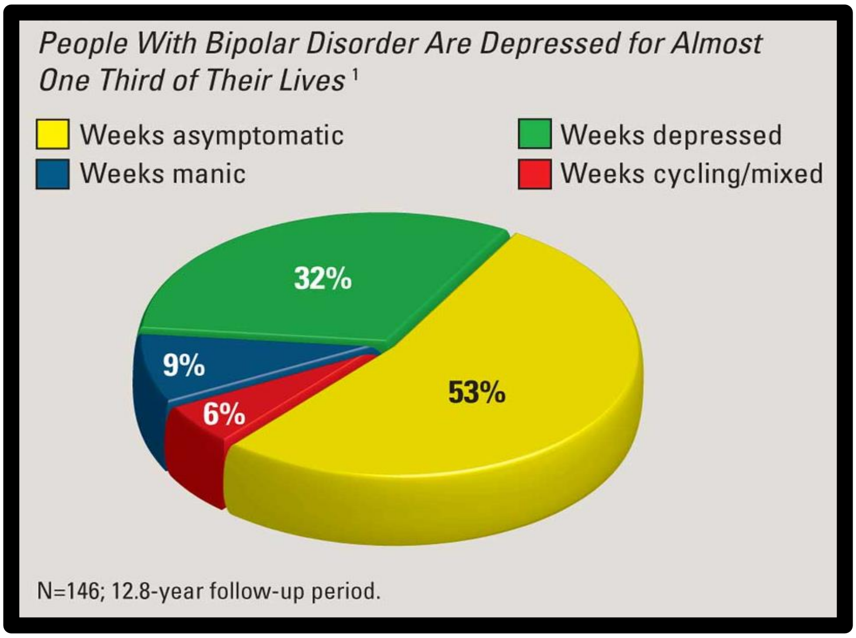


Figure 2.8: **People with BD are depressed for almost one third of their lives (Keck, McIntyre, Shelton, 2007:1)**

Last (2009:40, 56) mentions a **positive fact**; namely, that people with bipolar II do not, by definition, exhibit psychotic features during their highs, and are less likely than people with bipolar I to experience psychotic features during depressions, suggesting that they have a greater chance of complete remission in between mood episodes. The question of whether BD II can develop into BD I is a valid one. Very few BD II individuals - estimates range from 5 to 15 %, - ever develop true manic episodes. Some experts believe that this finding supports the notion that BD I and BD II disorders are separate, although related, illnesses.

Ghaemi, Bauer, Cassidy, Malhi, Mitchell, Phelps, Vieta and Youngstrom (2008:120) state that the concept of type II BD is based primarily on phenomenology and functional impairment: the occurrence of manic symptoms without significant social or occupational impairment of function identifies the hypomanic episode. The epidemiology literature indicates that bipolar type II disorder is relatively common, more so apparently than type I BD, and according to at least some genetic data, this presentation may be the most common phenotype of bipolar illness in the community.

In conclusion, bipolar II disorder, (**Figure 2.9** refers) is still evolving as a diagnostic entity, but evidence implies that it is a valid diagnosis, which is prevalent in the psychiatric population and common in the general community (Ng, Cahill, Malhi & Berk, 2009:98).

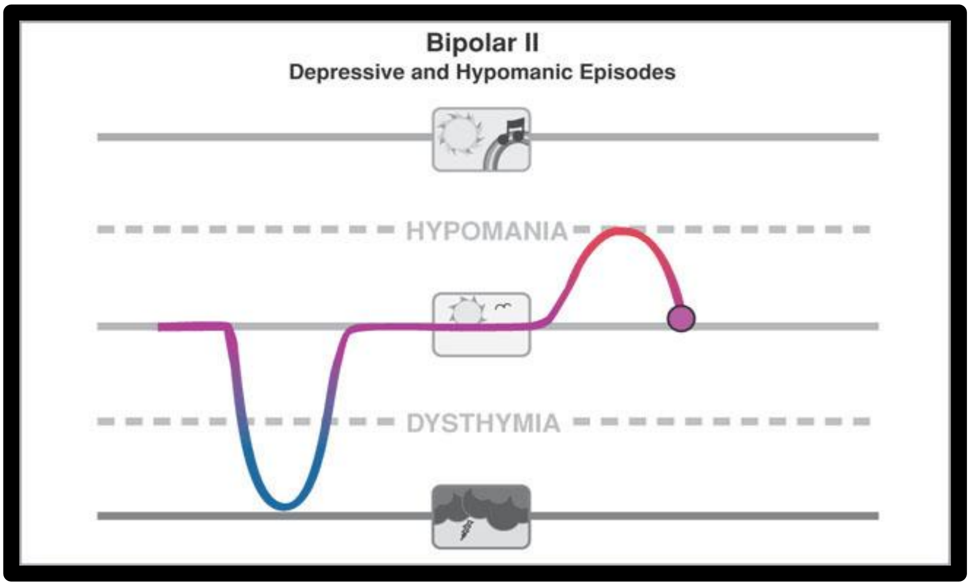


Figure 2.9: Bipolar II disorder (www.discoverccs.org/wp-content/uploads/2011/09 Bipolar-Disorder ppt.)

2.5.7.1.3 Cyclothymic Disorder

The essential feature is a chronic, fluctuating mood disturbance involving numerous periods of hypomanic symptoms and periods of depressive symptoms that are distinct from each other. During the initial **2-year** period, the symptoms must be persistent and any symptom-free intervals should last no longer than 2 months. The diagnosis is only made if the criteria for a major depression, manic, or hypomanic episode have never been met (DSM 5, 20I3:140). Colom and Vieta (2006:13) refer to the fact that cyclothymia is considered a **minor variant** of BDs, characterised by a **chronic course** and high frequency of episodes. The behavioural changes that accompany the episodes involve psychosocial complications. Many cyclothymic patients are diagnosed with **borderline personality disorder**.

Sadock and Sadock (2003:578) point out that alcohol and other **substance abuse** are common in cyclothymic disorder patients, who use substances either to self-medicate; for instance with alcohol, benzodiazepines and marijuana, or to achieve even further stimulation with substances such as cocaine, amphetamines, and hallucinogens when they are manic. About 5 to 10 % of all patients with cyclothymic disorder have substance dependence.

Last (2009:23) refers to **research** which shows that about one-third of people with cyclothymic disorder go on to develop BMD II. The psychiatrist, Hagop Akiskal, views cyclothymia as a disturbance of temperament that predisposes people to BD. About one in every four people with cyclothymia progresses to bipolar I or II disorder over periods of two to four years (Miklowitz, 2011:45).

It has been the researcher's experience that these patients receive less attention, perhaps because their symptoms are less dramatic and of a lesser intensity. They will not necessarily be admitted to a psychiatric hospital, because symptoms can usually be contained on an outpatient basis.

Table 2.3: Summary of manic and depressive symptom criteria in DSM-IV-TR mood disorders (Vieta, 2009:34)

Disorder	Manic symptom criteria	Depressive criteria
Major depressive disorder	No history of mania or hypomania	History of major depressive episodes (single or recurrent)
Dysthymic disorder	No history of mania or hypomania	Depressed mood more days than not, for at least two years (but not meeting criteria for a major depressive episode)
Bipolar I disorder	History of manic or mixed episodes	Major depressive episodes are typical but are not required for diagnosis
Bipolar II disorder	One or more episodes of hypomania; no mania or mixed episodes	History of major depressive episodes
Cyclothymic disorder	For at least two years, the presence of numerous periods with hypomanic symptoms	Numerous periods with depressive symptoms that do not meet criteria for a major depressive episode
BD not otherwise specified	Mania symptoms present, but criteria not met for bipolar I, bipolar II, or cyclothymic disorder	Not required for diagnosis

The researcher can comment that this table helps one to understand that mood disorders are on a spectrum (see 2.5.9). As was noted, the **BD not otherwise specified** category is no longer in the DSM 5. The new categories in DSM 5 (2013:142-149) are:

2.5.7.1.4 Substance/medication - induced bipolar and related disorder

The diagnostic features are essentially the same as those for mania, hypomania, or depression. There is evidence from the history, physical examination, or laboratory findings, of symptoms that developed during or soon after substance intoxication or withdrawal or after exposure to a medication.

2.5.7.1.5 Bipolar and related disorder due to another medical condition

The essential features are the presence of a prominent and persistent period of abnormally elevated, expansive or irritable mood and abnormally increased activity or energy predominating in the clinical picture that is attributable to another medical condition.

2.5.7.1.6 Other specified bipolar and related disorder

This applies to presentations in which symptoms characteristic of a bipolar and related disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the bipolar and related disorders diagnostic class.

2.5.7.1.7 Unspecified bipolar and related disorder

This category is similar to the one above, but is used in situations in which the clinician chooses **not** to specify the reason that the criteria are not met, and includes presentations in which there is insufficient information to make a more specific diagnosis (e.g. in emergency room settings).

2.5.8 Psychosis

Severe episodes of mania or depression may include **psychotic symptoms**, such as delusions and/or hallucinations. Psychotic symptoms do not occur in hypomania (Vieta, 2009:24). The psychotic symptoms are often categorised as either **mood congruent**, that is, in harmony with the mood disorder (reflecting the prevailing mood state) or **mood incongruent**, not in harmony with the mood disorder (Sadock & Sadock, 2003:546). In the DSM 5 (2013:127), psychotic features are specifiers.

According to Baumann (2007a:457), psychosis is an ill-defined, generic term. In broad terms, it refers to the spectrum of severe psychiatric disorders that lead to disorganised behaviour and impaired function. A lack of insight is a core function. Psychotic disorders are broadly divided into functional disorders and psychotic disorders, due to medical conditions. The two principal functional disorders are the schizophrenias and the bipolar disorders, with a considerable overlap between the two groups. Psychosis may be described as a severe break with reality that can occur with mania or depression. In this state, a patient's thinking may become extremely disorganised, possibly resulting in very poor judgement, accompanied by intense fear and anxiety. The ability to reason may be completely lost (Fast & Preston, 2004:28).

Delusions

Delusions are fixed beliefs that are not amenable to change in the light of conflicting evidence. Their content may include a variety of themes (e.g., persecutory, referential, somatic, religious, grandiose) (DSM 5, 2013:87).

Hallucinations

Hallucinations are perception-like experiences that occur without an external stimulus. They are vivid and clear, with the full force and impact of normal perceptions, and not under voluntary control. They may occur in any sensory modality (DSM 5, 2013:87).

Paranoid symptoms

When people are psychotic, they may have completely unrealistic and unsubstantiated beliefs that other people are out to harm them, take advantage of them, or to be unfaithful. Paranoia is very disruptive because it feels entirely real to the sufferer, although it has no basis in reality. The person suffering from severe paranoid symptoms may believe that their spouse is trying to poison them or is in a conspiracy with the local mental hospital to have them permanently committed (Fast & Preston, 2004:29).

2.5.9 The bipolar spectrum as a diagnostic perspective

Phelps (2008:16) refers to the fact that psychiatric diagnosis is currently based on a system of categories. A parallel diagnostic system has developed alongside the categorical system of the DSM, sometimes referred to as a dimensional view, in which related psychiatric conditions such as Major Depressive Disorder (MDD) and BD are regarded as polar endpoints of a spectrum (**Figure 2.10** refers). This view emphasises a clinically derived perspective, which suggests that patients populate a **continuum** between these two extremes, without any natural dividing points to separate the two. In a categorical model, hypomania is either present, as in BP II, or absent, as in major depression. In the spectrum model, varying degrees of bipolarity are possible.

Ghaemi, Saggese and Goodwin (2006:15) comment that the notion of a bipolar spectrum begins from the fact that many patients do not meet classical definitions of unipolar depression or BD types I or II. It is important to realise that the bipolar spectrum concept is derived from Kraepelin's original manic-depressive illness concept. In his view, the key feature of manic-depressive illness was **recurrence**. This contrasts with the current nosology, which views **polarity** as the primary basis for diagnosing these mood disorders.

According to Berk et al. (2008:10, 16), a person may have predominant symptoms of depression as well as minor experiences of mood elevation that are too mild or brief for him or her to be diagnosed as having BD. These symptoms fall into the bipolar spectrum. BD therefore includes a spectrum of different manifestations between classical BD and depression, as well as milder manifestations of the illness.

Haycock (2010:10) mentions that symptoms such as changing moods, impulsive behaviour, and irritability are not limited to BD. Some psychiatrists who see these symptoms in patients with other disorders suspect that bipolar I and II are part of a spectrum that may include eating disorders, substance abuse, and recurrent major depressive disorder. The case for bipolar spectrum illness, however, requires more proof before it can be accepted by most psychiatrists. The authors Merikangas, Akiskal, Angst, Greenberg, Hirschfeld, Patukhova and Kessler (2007:543) are of the opinion that there is growing recognition that BD has a spectrum of expression that is substantially more common than the 1 % BD I prevalence traditionally found in population surveys. Sub-threshold BD is common, clinically significant, and under-detected in treatment settings.

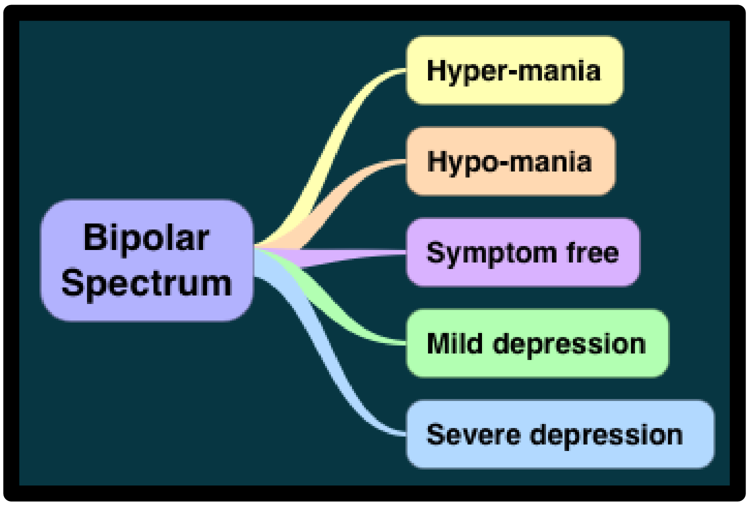


Figure 2.10: Bipolar Spectrum (www.bipolarspectrum.org)

2.5.10 Specifiers/other variations

Haycock (2010:15) indicates that because patients are seen at different stages in the course of their illnesses, and symptoms vary, psychiatrists have developed a variety of classifications to describe the different types of problems for which patients seek help. For example, someone might have bipolar I with a single manic episode or someone with recurring mood fluctuations might be described as having recurrent BD with a recent episode of mania or hypomania. Sadock and Sadock (2003:550) indicate that the DSM-IV-TR includes criteria for **three** distinct course specifiers for mood disorders in order to qualify the most recent episode:

- **with rapid cycling**

Zetin, Hoepner and Kurth (2010:37) mention that rapid cycling is a specifier of a long-term course and can be applied to either bipolar II or bipolar I disorder. Rapid cycling exists when a person experiences **four** or more episodes of major depression, mania, hypomania, or mixed symptoms within a year, each cycle lasting for a relatively short time (NIMH, 2010:3; Fast & Preston, 2004:23; Haycock, 2010:16). Five to 15 % of persons with BD have four or more episodes per year and may be classified as **rapid cyclers** (Sadock & Sadock, 2003:558). According to Fast and Preston (2004:23), Haycock (2010:17) and Miklowitz (2011:35) it is seen in bipolar I and II (but is more common in bipolar II) and is more common in women than men. Some people may exhibit more than four episodes per year and are said to have **ultra-rapid cycling**. There is also increasing evidence that substance abuse may be a key factor in causing or aggravating rapid cycling. Berk et al. (2008:11) and Sadock and Sadock (2003: 571) agree that the development of rapid cycling in patients with bipolar I disorder has been associated with the use of conventional antidepressants, especially tricyclic drugs, and with the presence of hypothyroidism.

- **with seasonal pattern**

Last (2009:44) and Fast and Preston (2004:23) point out that some people have a seasonal pattern to their BD. Although the psychiatric classification system acknowledges this only for episodes of depression, there have been many reports of people displaying a seasonal pattern to mania and hypomania as well. Knowing these patterns can be useful as one can find ways of preventing or reducing the severity of the episode. The term “seasonal affective disorder” is used to describe depressive symptoms people experience during certain seasons, most commonly during the winter months (Last, 2009:23). There are studies that suggest the condition predisposes people to develop cyclothymia and/or BD.

- **with or without full inter-episode recovery**

The DSM 5 (2013:149-153) provides the following specifiers: with anxious distress, with mixed features, with rapid cycling, with melancholic features, with atypical features, with mood-congruent psychotic features, with mood-incongruent psychotic features, with catatonia, with peripartum onset and with seasonal pattern. The diagnosis should also be specified whether the illness is in partial or full **remission** and if the current **severity** is mild, moderate or severe.

2.5.11 Diagnostic Challenges

2.5.11.1 Under diagnosis, misdiagnosis and over diagnosis

According to Hines-Martin and Thomas (2003:235), failure to recognise the subclinical symptoms or expressions of mania contributes to frequent **under diagnosis** of BD. Ghaemi, Saggese and Goodwin (2006:13, 17, 19, 24) state that BD remains frequently **misdiagnosed** - numerous clinical studies now confirm that about 40 % of persons with BD are initially misdiagnosed with unipolar depression.

Despite the evidence that bipolar misdiagnosis has not decreased in the past decade, there is also concern about possible **over diagnosis** of BD. A topic of heated controversy is thus whether BD is over diagnosed at the expense of personality disorders, such as borderline personality disorder. Swann (2006:56) is of the opinion that the most practical tool for identifying BD is still the careful characterisation of the course of illness.

Haycock (2010:1, 2, 34) concludes by saying that the disorder can be difficult to diagnose because the symptoms vary with the passing of time. The presence of reasonable strong mood swings does not necessarily indicate BD. Several other disorders can produce similar symptoms, a fact that can and does, lead to misdiagnoses. Other symptoms of BD, considered in isolation, can also lead to misdiagnoses. Only when the complete picture of bipolar symptoms is inventoried and considered, is an accurate diagnosis possible.

2.5.11.2 Differential diagnosis

For those people who wonder if they have BD, there is little awareness of the **variety of alternative diagnoses** that may be more accurate. The right diagnosis is the first step in receiving the right treatment. As was previously stated, it is important to remember that many mood, personality, and anxiety disorders, as well as other medical conditions can produce symptoms, such as those seen in BD (Haycock, 2010:xiii, 49).

Sadock and Sadock (2003:556, 557) mention that failure to obtain a thorough clinical history or to consider the context of a patient's current life situation may lead to diagnostic errors. When a patient with BD I experiences a depressive episode, the differential diagnosis is the same as that for a patient being considered for the diagnosis of a major depressive disorder. When a patient is manic, however, the **differential diagnosis** includes bipolar I disorder, bipolar II disorder, cyclothymic disorder, mood disorder caused by a general medical condition, and substance-induced mood disorder.

Possible differential diagnoses, as reviewed by the researcher:

- **Recurrent major depressive disorder**

Hypomanic, manic or mixed episodes distinguish BD from **unipolar depression**. As was mentioned, people with BD tend to seek out professional help when depressed but, on the other hand, are unlikely to visit a doctor when manic or hypomanic, unless someone else brings them in. As a result, doctors usually see patients when they are in a depressed state, and unless they probe carefully for past periods of mania or hypomania they may make a diagnosis of major depression, instead of BD (Haycock, 2010:42; Last, 2009:24).

- **Schizophrenia or schizoaffective disorder**

Unlike BD, schizophrenia and schizoaffective disorders are classified as psychotic disorders, not mood disorders. Nevertheless, their symptoms overlap enough to sometimes make diagnosis difficult (Haycock, 2010:41). Schizophrenia is associated with blunted moods. While people with schizophrenia may become depressed, their psychotic symptoms do not occur only in the presence of a manic, hypomanic or depressed episode, as they do in BD (Berk et al., 2008:12). Last (2009:26) mentions that schizophrenia has a different type of history and course than BD: schizophrenia is chronic and **unremitting**, while BD is **episodic**. In schizophrenia, the hallucinations and delusions tend to be rather bizarre. In contrast, hallucinations and delusions that occur in psychotic mania or depression tend to be less bizarre and more mood congruent.

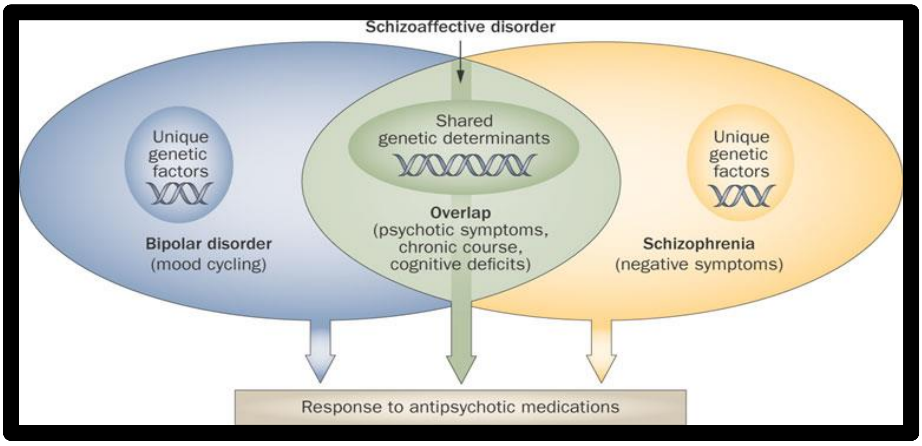


Figure 2.11: **Schizoaffective disorder**

Schizoaffective disorder (**Figure 2.11** refers) is essentially a hybrid category with elements of **psychotic** and **mood** disorders (Haycock, 2010:41, 42). Bipolar type applies if a manic or major depressive episode is part of the presentation (DSM 5, 2013:106). For a schizoaffective disorder, there must be, at some point during the illness, a period of at least 2 weeks when hallucinations or delusions are present *in the absence of* prominent mood symptoms. This, of course, contrasts with bipolar episodes that display psychotic features where the hallucinations or delusions occur only during a manic, mixed, or depressed state (Last, 2009:27). These distinctions are important in relation to prognosis. The long-term outcome for schizophrenia is worse than for bipolar or schizoaffective disorder. There are also implications for treatment (Miklowitz, 2011:50). In practice, the researcher has observed that the diagnosis of schizoaffective disorder can be very controversial (an “in-between” diagnosis) and the diagnosis is also difficult for the patient and caregiver to understand.

- **Personality Disorders**

Personality disorders are described as persistent, maladaptive emotional responses and behaviours that stem from a distorted view of oneself and the world (other people and events). This may begin in adolescence or early adulthood and cause the affected individuals distress and/or impair their functioning. Certain types of personality disorders can be difficult to distinguish from BD. To complicate matters further, personality disorders frequently **coexist** with BD. One personality disorder, **borderline personality disorder**, specifically exhibits a number of features that are quite **similar** to experiences which bipolar people have: mood instability, impulsivity, suicidal thoughts and behaviour, paranoid thoughts, intense anger, irritability, wasteful spending, risky sex and extreme impatience (Last, 2009:28). Haycock (2010:36) agrees that borderline personality disorder symptoms can sometimes be misconstrued as indications of BD.

A key **difference** between BD and borderline personality disorder is that BD is an **episodic** illness while borderline personality disorder is stable and consistently present across time; for example, the person always suffers from unstable moods and is constantly impulsive. Mood swings are common in borderline personality disorder (BPD), but these do not usually last as long and are not as marked as the moods in BD. Magill (2004:551) is of the opinion that the boundary between BPD and BD is a controversial subject. Clinically, it can be difficult to diagnose patients who present with **both** affective instability and impulsivity. In diagnostically challenging situations, careful consideration of a patient's **longitudinal history** is essential.

For manic symptoms, borderline, narcissistic, histrionic and antisocial personality disorders need special consideration. Patients with borderline personality disorder often lead a severely disrupted life, similar to that of patients with bipolar II disorder, because of the multiple episodes of significant mood disorder symptoms (Sadock & Sadock, 2003:557, 558).

- **Attention-deficit/hyperactivity disorder (ADHD)**

The symptoms of **adults** with attention deficit hyperactivity disorder (ADHD) might resemble some of the manic or hypomanic episodes of BD. They may be distinguished by the consistency of ADHD symptoms and the come-and-go mood swings common to BD (Haycock, 2010:37, 38).

- **Intermittent explosive disorder**

Haycock (2010:40) states that some evidence suggests there may be an association between **intermittent explosive disorder (IED)** and substance abuse, anxiety, eating and mood disorders, including BD. It is important that a thorough evaluation be made to distinguish the pattern of rages and their relationship in time to episodes of mania, depression, and relative calm.

- **Secondary mood disorders**

These consist of two broad categories - **substance-induced mood disorder** and **mood disorder due to a general medical condition**. Sadock and Sadock (2003:584-586) state that these categories must be considered in the differential diagnosis of any patient with mood disorder symptoms.

Recreational drug use and abuse often results in symptoms similar to those of BD. Recreational drugs fall into **three** main categories:

- **Stimulants**, such as crack (cocaine)
- **Depressants**, such as alcohol
- **Hallucinogens**, such as marijuana, or LSD.

Many people with BD, between 40 and 60 %, have a long-term substance use disorder as well. Substance abuse can produce symptoms very similar to those of BD. Stimulants can mimic manic states. It can be very difficult to determine quickly if someone has substance use (induced) disorder, major depressive disorder, BD or a combination (Haycock, 2010:43, 44). Berk et al. (2008:13) agree, stating that some temporarily altered states, which are brought on by taking certain illicit **drugs**, may **mimic** episodes of BD, but the effects of intoxication wear off rapidly and do not constitute BD. Miklowitz (2011:52) refers to the fact that mood disorders which are the direct result of substances are usually short-lived and treated through detoxification and chemical dependency programmes.

Antidepressant medications can trigger mania. **Alcohol** can precipitate or aggravate bipolar **depression**. Common prescription and over-the-counter medications that can cause or exacerbate depression include certain antihistamines, some tranquillisers, barbiturates, the acne drug Accutane, oral contraceptives, and certain blood pressure medications (anti-hypertensives) (Last, 2009:47, 49).

Austin, Palmer, Rosen-Sheidley, Veach, Gettig and Peay (2008:28) state that some **drugs** can trigger the onset of psychosis in **genetically-vulnerable individuals** and it can be quite complex to determine whether the psychosis was developing prior to drug use, and if it remained after the intoxicating substance had been eliminated from the body.

The researcher has noticed that in a controversial way, substance use/abuse can sometimes be considered a useful prognostic factor, because if it is only the substance causing the psychiatric symptoms, the condition can still be reversed. However, substances may contribute to the onset of the first episode of BD, which then takes on a course of its own.

Last (2009:48) reports that **medical conditions** that are well known for triggering mania-like or depressed mood states involve the endocrine system, specifically the thyroid and the adrenal glands. Hyperthyroidism and Cushing’s disease, a rare disorder caused by excessive production of cortisol by the adrenal glands or the excessive use of steroids, can cause mania-like states. Depressed mood can be due to hypothyroidism and Addison’s disease, an uncommon condition caused by a serious reduction in the function of the adrenal glands. A vitamin B12 deficiency has been reported to precipitate manic behaviour as well as depression. Steroids also have been known to cause mood swings. Berk et al. (2008:13) add that a condition such as multiple sclerosis can also mimic BD. Hines-Martin and Thomas (2003:235) mention that classic examples of mood disorders caused by general medical conditions include the depressive syndromes associated with dominant hemispheric strokes and hypothyroidism. In practice, the researcher has observed that as the incidence of HIV related illnesses increases patients being admitted may present with a picture that might initially resemble manic symptoms.

- **Generalized anxiety disorder, panic disorder, post-traumatic stress disorder, or other anxiety disorders**

These disorders need to be considered in the differential diagnosis as either the primary disorder or, in some cases, a comorbid disorder (DSM 5, 2013:131).

2.5.11.3 Comorbidity

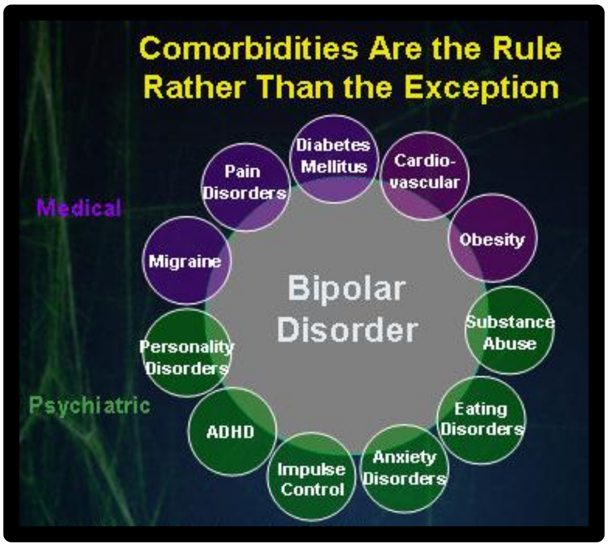


Figure 2.12: Comorbidity (Ketter, http://www.medscape.org)

According to Salloum, Pani and Cooke (2010:353), comorbidity is a term that originated in general medicine to account for the impact of associated clinical entities, which includes disease states but also non-disease states such as pregnancy, on the management and prognosis of the index disease. Miklowitz (2011:44) explains that the term comorbidity refers to the co-occurrence of two or more psychiatric disorders in the same person. Many people have more than one DSM-IV-TR psychiatric disorder (also true of the DSM 5).

It has often been said that comorbidity represents **the rule** more than the exception in BD (see **Figure 2.12**). Berk and Dodd (2005:13) state that patients are twice as likely to have comorbid as non-comorbid bipolar II disorder. Observational studies indicate that about two-thirds of individuals with BD have at least one additional Axis I diagnosis, while nearly half have two or more. From a diagnostic standpoint, the frequent comorbidity of other psychiatric problems in tandem with bipolar illness may partly contribute to the oft-noted lengthy delays from initial symptom onset to actual diagnosis, or the frequent “misdiagnosis” of other conditions (Goldberg, 2009:221, 222). Salloum et al. (2010:353) furthermore say that considering the chronic course of BD and the likely need for polypharmacy throughout its treatment, management of comorbidity and presenting psychosocial and pharmacological complexities must constitute an integral part of an individualised treatment plan for these patients.

Frye and Perugi (2010:31) refer to the fact that the *current* DSM-IV TR and ICD-10 based diagnoses have operationalised criteria for the specific diagnosis of bipolar I, II, which are not otherwise specified with delineating course specifiers and subtype patterns. They state that these criteria fail to capture the dimensional aspects and multisystem involvement of BD. Comorbid symptoms are highly prevalent and clinically relevant in the management of BD. The researcher is not certain if the DSM 5 (2013) is really going to provide more clarity.

Vieta (2009:11), Berk et al. (2008:13) and the International Consensus Group on the Evidence-Based Pharmacologic Treatment of Bipolar I and II Depression (2008:1632) are also some of the experts who point to the fact that BD is associated with a high rate of **psychiatric comorbidity**. Indeed, it is uncommon to find a patient with BD who does not meet criteria for at least one other DSM-IV-TR disorder. These comorbidities can have a detrimental effect on the disease course. It is possible to have BD and ADHD, BD and a borderline personality disorder, and BD and cyclothymic disorder (Miklowitz, 2011:45).

According to Salloum et al. (2010:353) **substance abuse** and **anxiety disorders** are the **most common** comorbidities in BD and may have a significant impact on its course and treatment. Vieta (2009:11) adds attention deficit disorder (ADD) and mentions that all these conditions greatly increase a patient’s overall psychosocial vulnerability. Several epidemiological studies have documented the association between BD and eating disorders.

- **Substance abuse disorders**

About 60 % of people with BD have had an alcohol or substance use disorder at some point in life: a rate that is much higher than the rate of the general population, at 10-20 % (Miklowitz, 2011:44, 52; Mondimore, 2006:177). According to Colom and Berk (2010:417) the risk that a bipolar patient will suffer a substance related problem is six-fold higher than that of the general population. Substance use is associated with poorer outcome, including increased episodes of depression, increased adherence problems and delayed symptomatic recovery. Berk et al. (2008:13) indicate that while some people with BD do not experience **alcohol or drug problems**, there are many (50 to 70 % of people with BD) whose lives are complicated by these additional difficulties. The risk of relapse, mixed episodes, rapid cycling, suicide and violent behaviour is increased in people with BD who also display drug or alcohol problems. Last (2009:55) agrees, stating that bipolar individuals are at a greatly increased risk of alcohol or drug abuse or dependence: more than 60 % of patients are so affected. Substance abuse can mask BD. It can worsen the course of the disorder by lengthening mood episodes and increasing their severity.

Mondimore (2006:181, 182) declares that he advises persons with a mood disorder to scrupulously **avoid any and all intoxicating substances** in any quantity whatsoever. He also reports on the research finding that persons with mood disorders and who also abuse alcohol or drugs have a greatly increased risk of completed suicide. Severe depression complicated by alcoholism or drug abuse has been found to be one of the most frequent diagnostic pictures in study after study of the psychiatric diagnoses of suicide victims.

Many people turn to alcohol or drugs during manic episodes. Substance use problems and addictive behaviours are not essential symptoms of BD, but they can become intertwined with mood disorder symptoms in such a way that each worsens the other. A patient described the role alcohol played in his depressions as follows:

When I ‘m down, drinking for me is like a security blanket (Miklowitz, 2011:27).

It is important to determine whether the mood symptoms were present before the substance abuse began or if the mood changes are the result of the substance abuse. If it is clear that the person has both substance abuse and BD, both conditions should be treated simultaneously, without delay. The **optimal treatment** involves an integration of treatment modalities, rather than merely consecutive treatment with a specific focus on either substance abuse or BD. It can be managed on an outpatient basis, preferably by staff trained to deal with both disorders. However, sometimes it will be necessary to admit patients to the hospital or a rehabilitation facility (Kowatch et al*.*, 2005:11, 12). Some psychiatric hospitals in South Africa have now started to offer a substance rehabilitation programme for in-patients, because patients with a comorbid substance abuse problem are often not properly treated at other rehabilitation units - especially if there are no trained psychiatric staff involved.

Many people with BD **self-medicate** with street drugs and/or alcohol. This can make the symptoms worse over the long term (Haycock, 2010:25). In practice, self-medicating is frequently observed; sometimes because patients cannot obtain their prescribed drugs. Sadock and Sadock (2003:553) consider that the abuse of substances may be involved in precipitating an episode of illness or, conversely, may represent patients' attempts to treat their own illnesses. More than any other associated condition, drug and alcohol abuse makes the course of BD much worse (Miklowitz, 2011:27).

- **Anxiety disorders**

This is not an unusual situation; estimates range from 60 to 90 %, that people with a BD will also have an **anxiety disorder**, such as post-traumatic stress disorder, panic disorder, specific phobias, obsessive-compulsive disorder, and generalised anxiety disorder at the same time (Haycock, 2010:38). Berk et al. (2008:4) agree that many people with BD experience anxiety, which may be most common in people with **bipolar II** disorder and in **females**. Last (2009:55), adds that the anxiety disorders, in addition to the BDs, can precede or follow the onset of BD, but in either event, they will be important to deal with since anxiety often precipitates the development of a mood episode, particularly hypomania and mania.

- **Physical illnesses**

Bipolarity is associated with a range of **non-psychiatric** (medical) comorbidities including diabetes, obesity, cardiovascular disorder, hypertension, hyperlipidaemia, thyroid disease and migraine as well as infectious diseases including hepatitis (Merikangas & Peters, 2010:57; NIMH, 2010:3; Vieta, 2009:12). It has been the researcher's experience that there seems to be a high incidence of HIV and AIDS among psychiatric patients, but this has merely been a casual observation, and such an incidence could be contributed to by the increased indiscriminate sexual behaviour during mania or psychosis. The bipolar patient's lifestyle, especially during manic episodes, might make this population more prone to sexually transmitted infections.

According to Kilbourne, Goodrich and Bauer (2010:453) patients with serious mental illnesses such as BD, are more likely to experience a substantial burden of **general medical comorbidities** than the general population, due in part to the organisational and professional separation of mental and physical care. They furthermore mention that patients with BD often incur the most health care costs of any mental illness, and costs from general medical conditions can be up to 40 % higher than mental health care costs amongst these patients. It is, according to Kilbourne et al. (2010:454), important to remember that patients with BD are also exposed to different classes of psychotropic medications, all of which have side effects that can lead to adverse health outcomes, such as thyroid or kidney disease, bone density loss and metabolic syndrome. Likely, the most important aspect of comorbidity in BD is **recognising its presence** (Goldberg, 2009:246).

From the above-mentioned discussion, it should be clear that a person with BD can also experience problems with substances, anxiety, a personality disorder or a general medical condition which relates to the importance of obtaining a proper diagnosis and ruling out other diagnoses. Knowing the **diagnostic criteria** for BD and understanding how these symptoms manifest themselves is empowering (Miklowitz, 2011:53). When a child **does not respond** to treatment, it is important to consider factors frequently associated with non-response, such as misdiagnosis, non-compliance, presence of comorbid disorders and exposure to environmental and biological stressors (Kowatch et al*.,* 2005:4). It is the researcher’s opinion that this is also true in the case of adults.

In conclusion, the researcher agrees with Last (2009:26) who says that although nobody wants to have BD, individuals **should know their diagnoses** so that they can learn about their illness and ways in which they can help themselves. Knowing about the course, prognosis, genetic component and treatment of the disorder can assist people in making good decisions for their future. The researcher however also thinks that the professional should be sure that an individual is **ready** to hear his/her diagnosis: timing is thus of utmost importance.

2.5.12 Neurocognition in BD

Torres and Malhi (2010:69) indicate that BD has traditionally been conceptualised as a dynamic illness involving the alternation between transient periods of mood instability and periods of symptomatic remission. Early conceptions posited that in between mood episodes, patients returned to a normal functional state, and this was an important basis for differentiating mood disorders, such as BD, from schizophrenia. The idea that patients with BD in fact return to a fully functional state between mood episodes is no longer accepted as truth, and much of this is based on findings from the rapidly emerging literature on cognitive functioning in BD. This body of research has revealed that cognitive impairment is a prevalent clinical feature of BD, persisting even in patients who are in a remitted or euthymic state. Cognitive impairment thus appears to occur independently of mood state and represents a core clinical feature of bipolar illness. The researcher has also observed this trend in patients that she has known for years; after a few relapses and hospitalisations, a patient is seldom able to resume his or her premorbid level of functioning.

2.5.13 Mortality risks in BD

According to Frye and Perugi (2010:31) bipolar affective disorder is an illness with substantial morbidity and mortality, characterised by episodic recurrence of mania/hypomania and major depression. It is a sad fact that the mortality rate is twice as high for people with BD as for people of the same age who do not have the illness (Last, 2009:56). Recent data suggests that the top three causes of death for bipolar individuals, in their order of frequency, are:

2.5.13.1 Cardiovascular disease (CVD)

One risk factor for heart disease that is potentially modifiable, is smoking. Several studies have shown that 55 % of those with BD smoke cigarettes. Nicotine is a biphasic drug; it can both stimulate and, alternatively, relax people, depending on the dose. People struggling with bipolar symptoms, might be using cigarettes as a mood stabiliser.

Another cardiovascular risk factor is the presence of the *metabolic syndrome,* defined as a person having three or more of the following five conditions:

- Abnormal obesity
- Elevated triglycerides
- Elevated cholesterol
- High blood pressure
- High fasting blood glucose levels

Unfortunately, several **medications** that are very effective for bipolar illness have been shown to increase the likelihood of developing the metabolic syndrome. Kilbourne et al. (2010:454) state that CVD is the leading cause of morbidity and mortality amongst patients with BD.

2.5.13.2 Suicide

Ostacher and Eidelman (2006:117) quote Virginia Woolf’s suicide note:

> Dearest, I feel certain I am going mad again. I feel we can’t go through another of those terrible times. And I shan’t recover this time. I begin to hear voices, and I can’t concentrate. So I am doing what seems the best thing to do.

Vieta (2009:45) mentions that suicide attempts by patients with BD have a very high risk of fatality; one in five suicide attempts by bipolar patients are completed, versus one in 10-20 in the general population.

The lifetime rate of suicide in BD has been estimated to be as high as 19 %, equalling, and perhaps surpassing, that of major depressive disorder (Ostacher & Eidelman, 2006:117; Hines-Martin & Thomas, 2003:240). Taylor (2006:12) states that between 10 and 15 % of patients suffering from bipolar illness in the United States will take their lives. Last (2009:57) and Haycock (2010:xv, 103) concur, pointing out that studies show that the rate of suicide deaths in bipolar I and II individuals is 10 to 15 % and that about 25 %, at one time or another, **make an attempt** on their own lives. Rihmer and Fawcett (2010:62) even consider that about half of bipolar patients make one or more suicide attempts during their lifetime. Sixty percent of people with BD who commit suicide were abusing drugs or alcohol when they took their lives (Haycock, 2010:xv, 103).

Seriously depressed people can seem strangely energised before taking their own lives (Haycock, 2010:6). Family or friends might even think that the person is “getting better” Vieta (2009:45). The risk of suicide may be greater in bipolar II than bipolar I disorder, in the light of the greater preponderance of recurrent severe depression.

However, Ostacher and Eidelman (2006:117, 118, 138) indicate that while the majority of suicides, such as that of Virginia Woolf, occur during the depressed phase of the illness, many occur during periods of mixed or even manic symptoms. Co-ordinated treatment planning with the patient, the patient’s family and persons with whom the patient has significant relationships, may provide a means for identifying risk and avoiding suicidal behaviour. A patient is never completely safe from suicide risk, and assessment of suicide must be part of each clinical encounter. Suicide assessment must be undertaken, during both acute and maintenance treatment and interventions appropriate to the patient’s symptoms and history must be offered. People often use their own medication to commit suicide, something that is readily available to them, which in sufficient quantity can be lethal (Last, 2009:57).

About four times more males than females die of suicide, though females are more likely to attempt it. The method used seems to account for some of the difference. Firearms account for about 56 % of the suicides by males and only 31 % of suicides by women. Women more often resort to poisoning (40 %) compared to men (13 %). Suffocation accounts for similar percentages in the two sexes: 23 % for males and 19 % for females (Haycock, 2010:104).

Table 2.4: **Prominent risk factors for suicide in BD Vieta (2009:46); Ostacher and Eidelman (2006:137); Kowatch et al. (2005:12); Last (2009:57); Haycock (2010:104)**

Presence of suicidal or homicidal ideation, intent, or plans
Access to means for suicide and the lethality of those means
Presence of command hallucinations, other psychotic symptoms
Concurrent substance use
History and seriousness of previous attempts
Family history of or recent exposure to suicide
Early age at onset
Early in course of illness
Period immediately after hospital admission and hospital discharge
Social isolation
Comorbid anxiety disorder
Cluster B personality disorder
Impulsivity
Mixed state or mania with significant depressive symptoms
Male gender
Lack of support
Presence of acute stressors

Table 2.5: **Some interventions to reduce suicide risk (Vieta, 2009:62)**

Non-specific interventions	Specific interventions
Sustain therapeutic relationships	Increase social contacts
Abstain from alcohol	Attend AA/NA meetings
A treatment contract with doctors and significant others	Exercise
Keep a daily mood chart	Maintain good sleep hygiene and regular schedule
To minimise opportunity	To minimise opportunity
Restrict access to firearms	Minimise time spent in isolation
Educate significant others regarding risk of suicide	Consider hospitalisation

Educating patients and their carers about the **risk of suicide** in BD is an important part of the long-term treatment plan (see **Table 2.4** for risk factors for suicide and **Table 2.5** for interventions to reduce suicide risk). This may also involve: discussing the importance of long-term treatments, particularly lithium, in lowering suicide risk, identifying early warning signs of relapse and developing a plan of action should prodromal symptoms arise (Vieta, 2009:48).

The following **suicide protective factors** must be mentioned: good family and social support, pregnancy, having many children, holding strong religious beliefs and restricting lethal suicide methods. The most extensively studied suicide protective factor in BDs is the acute and long-term **pharmacological treatment** that results in a marked decline in all forms of suicidal behaviour in this high-risk patient population. However, targeted **psycho-social intervention** improves the efficacy of pharmacotherapy (Rihmer & Fawcett, 2010:65). The researcher concludes that the high risk for suicide among this population is very clear; it is therefore most important always to monitor this population of patients extremely carefully, while the caregiver system should also be aware of the warning signs and risk factors.

2.5.13.3 Accidents

Manic delusions may lead people to carry out activities that might cause them harm even though they may not intentionally be trying to hurt themselves (Last, 2009:58).

2.6 BD AND CRIME

BD can play a role in serious crimes. Recent studies suggest significant connections between BD and spousal and child abuse. A person with untreated BD is potentially vulnerable to other troubling scenarios. There is an association between severe, untreated mental illness in general, and violence. When violence is committed by someone who is ill, the victim is most often a family member. However, the majority of people with mental illnesses are not violent. In fact, due to conditions such as homelessness, they are more likely to be victims of crime than perpetrators of it (Haycock, 2010:3, 105). Friedman, (in Haycock, 2010:106) concluded: “The challenge for medical practitioners is to remain aware that some of their psychiatric patients do in fact pose a small risk of violence, while not losing sight of the larger perspective – that most people who are violent are not mentally ill, and most people who are mentally ill are not violent”. When someone with BD does become violent, this is usually linked to substance abuse and the effects of a serious manic or depressive episode. The person might also have anti-social personality traits.

2.7 THE GENIUS-INSANITY DEBATE: FOCUS ON BIPOLARITY, TEMPERAMENT, CREATIVITY AND LEADERSHIP

There is a popular belief that creative people are prone to BD. Preliminary evidence supports this widely held view, although the studies are small in scale (Haycock, 2010:45). Last (2009:59) also mentions that much has been written on the relationship between creativity and BD and the seemingly large number of very accomplished writers, painters, and musicians who have had the disorder. Research studies have shown that this perception is supported by fact: astonishingly, 30 to 50 % of successful artists suffer from bipolar illness, a prevalence rate that is at least ten times that of the general population. The list of artists, writers, and musicians who apparently struggled with at least some form of depression or showed signs of bipolar tendencies is long and impressive. It should convince people that the apparent presence of depressive or bipolar symptoms need not prevent someone from achieving extraordinary **success** in life (Haycock, 2010:50).

In this respect, Socrates thought that mental illness was a divine gift while Plato linked creativity to the inspiration derived from madness. Aristotle observed that eminence had something to do with the melancholic temperament and in some instances to diseases arising from “the black humour”. In Roman times, Seneca posited that “no great mind is immune from a little insanity” (Akiskal & Akiskal, 2010:83). The same authors (2010:85) postulate the hypothesis that it is the “dilute” temperamental form of bipolarity that subserves eminence and creativity. They support the role of **cyclothymia** (labile with rapid shifts in mood, unstable in energy, intense in emotions) in artistic creativity and of **hyperthymic** (outgoing, fun-loving, eloquent, risk-taker) temperamental traits in eminence. It does seem to the researcher that the link between creativity and bipolar mood disorder is definitely more complex than meets the eye.

2.8 SUMMARY

In this chapter, the psychiatric condition BD, was discussed and it was emphasised that it is indeed a highly complex and heterogeneous condition. Attention was drawn to the history and the etiology. The epidemiology included an overview of the incidence and prevelance, age of onset, gender, marital status, ethnicity, geography and socio-economic status. The diagnostic considerations and clinical features consisted of mood disorders, diagnostic evaluation, course of illness, time frame, cross-sectional diagnosis, longitudinal diagnosis, types of BD, psychosis, bipolar spectrum, specifiers, diagnostic challenges, neurocognition and mortality risks. The issue of BD and phenomena such as crime was discussed and lastly the genius-insanity debate. It became clear to the researcher that although this illness has been well documented, there are still many knowledge gaps and challenges for the patients, caregivers, the therapists and researchers.

In the next chapter, living with BD, its treatment and intervention are discussed.

3. CHAPTER 3: LIVING WITH BIPOLAR DISORDER (BD) - TREATMENT AND INTERVENTION

3.1 INTRODUCTION

> Bipolar disorder can incapacitate you if left untreated. It can disrupt not only your life, but the lives of those close to you (Haycock, 2010:56).

Bipolar disorder I and II dramatically influence people’s lives at the personal and societal levels. The estimated disability-adjusted life years of BD outrank all cancers and primary neurologic disorders such as epilepsy and Alzheimer’s disease, primarily because of its early onset and chronicity across the life span (Merikangas & Peters, 2010:52).

With adequate containment of their condition, patients with BD can improve their social and occupational functioning, sustain high work productivity, and achieve acceptable health-related quality of life (**HRQoL**), which in turn should reduce service utilisation and lifetime healthcare costs (Vieta, 2009:13). Michalak et al. (2010:254) mention that patient outcomes in BD have **traditionally** been determined by the assessment of **objectively** measured clinical information, such as rates of relapse, the number of times a patient is hospitalised or clinician-rated symptom reduction. In recent years, however, they mention that we have seen a shift towards the concomitant assessment of more subjective, patient-centred measures of well-being such as functioning and Quality of Life (QoL). These authors quote Colom and Vieta (2004) who observed that a very important **change of paradigm** in the treatment of BD started a few years ago when crucial findings, on the impact of BD on QoL and social, cognitive and occupational functioning, suggested that therapy **targets should be changed** from **symptomatic recovery to functional recovery**. Restoration of QoL, which encompasses more than restoration of functioning per sé, should be a **primary treatment goal**, over and above minimising the symptomatic burden experienced by the individual.

3.2 DEFINITIONS

3.2.1 KEY CONCEPTS

Adherence: The degree to which a patient follows medical advice (*Oxford Concise Medical Dictionary*, 2010:11).

Non-adherence: This has two broad categories - **intentional** non-adherence involves the patient making a decision not to follow medical advice; and **unintentional** non-adherence in which the patient forgets or misunderstands the advice (*Oxford Concise Medical Dictionary*, 2010:11).

Concordance: Congruence between the plan made with the physician and the plan carried out by the patient (Miklowitz, 2011:114).

Non-concordance: The patient has not followed the physician's recommendations in taking medications or has stopped altogether, against the former's advice (Miklowitz, 2011:114).

Evidence-based refers to those studies conducted using randomised, controlled trials. Psycho-social interventions in the evidence-based literature include psycho-education, cognitive behavioural therapy, family-focused therapy, and interpersonal and social rhythm therapy (Buila, 2009:573).

Health-related quality of life (**HRQoL**) encompasses more than restoration of functioning per sé (Michalak et al., 2010:254). It measures a person's wellbeing (*Oxford Concise Medical Dictionary*, 2010:619).

Multi-disciplinary team (MDT): refers to a group of individuals who share the common goal of promoting the patient's mental health. In any "team", each individual has a distinct role to play (Last, 2009:127).

Psychoeducation: refers to information-based **behavioural** training aimed at assisting the person to adjust his/her lifestyle to cope with BD to improve outcomes, including enhancement of illness awareness, treatment adherence, early detection of relapse and avoidance of potentially harmful factors, such as illegal drugs and sleep deprivation. Hence, psychoeducation is an intervention that involves good medical practice and which seeks to empower the patient with tools that allow him or her to be more active in his or her own therapy process. Optimally, this involves a change of paradigm from the excessively personal psychiatric or psychological involvement to a therapeutic team approach (Colom & Berk, 2010:412, 413).

3.2.2 MEDICAL TERMS

Antipsychotics: Two kinds of antipsychotics are used today: the "older" (first-generation) or "conventional" types and the "newer" (second-generation) or "atypical" types. Atypical describes a group of more recently developed drugs that are, in theory, associated with fewer extrapyramidal effects than first-generation antipsychotics (*Oxford Concise Medical Dictionary*, 2010:43).

Benzodiazepines: A group of pharmacologically active compounds used as anxiolytics and hypnotics (*Oxford Concise Medical Dictionary*, 2010:78).

Catatonia: A state in which a person becomes mute or stuporous or adopts bizarre postures (*Oxford Concise Medical Dictionary*, 2010:120).

Cognitive-behavioural therapy (CBT): A mode of treatment based on the idea that certain unhelpful types of **thoughts** and **behaviours** can trigger, escalate, and lengthen mood episodes. CBT focuses on the interplay among thoughts, behaviours, and emotions (Last, 2009:115).

Complementary and alternative medicine (CAM), as defined by the National Center for Complementary and Alternative Medicine, is a group of diverse medical and health care systems, practices, and products that are not currently considered to be part of conventional medical practice. *Alternative medicine* refers to unconventional treatments as an alternative to allopathic treatments (conventional medical modalities); *complementary medicine* refers to unconventional treatments as adjuncts or cotherapy to usual medical care (Zetin et al., 2010:15).

Electroconvulsive therapy (ECT): The essential ingredient of electroconvulsive therapy is the induction of a seizure within specific regions in the brain, most likely involving the prefrontal cortex, orbitofrontal cortex and the connections to limbic structures. The seizure produces the therapeutic effect. However, a generalised seizure, while necessary for the therapeutic effects of ECT, is insufficient if induced in the wrong regions of the brain (George, 2010:384).

Euthymia: A normal (i.e. nondepressed) mood state, often referred to in mental state examinations. The term also refers to a neutral mood state in a person with bipolar affective disorder (*Oxford Concise Medical Dictionary*, 2010:260).

Genetic counselling: A communication process which deals with the human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family (Finn & Smoller, 2006:109).

Hypothalamus: The region of the forebrain in the floor of the third ventricle, linked with the thalamus above and the pituitary gland below. It contains several important centres controlling body temperature, thirst, hunger and eating, water balance and sexual function. It is also closely connected with emotional activity and sleep and functions as a centre for the integration of hormonal and automatic nervous activity (*Oxford Concise Medical Dictionary*, 2010:362).

Limbic system: A complex system of nerve pathways and networks in the brain, involving several different nuclei, that is involved in the expression of instinct and mood in activities of the endocrine and motor systems of the body. Among the brain regions involved are the amygdala, the hippocampal formation and the hypothalamus (*Oxford Concise Medical Dictionary*, 2010:419).

Metabolic syndrome: A common combination of insulin resistance and type 2 diabetes with central obesity, high blood pressure, and hyperlipidaemia (*Oxford Concise Medical Dictionary*, 2010:456).

Mood stabiliser: A drug used in the treatment of bipolar affective disorder to reduce the severity of manic and depressive episodes. Mood stabilisers include lithium and carbamazepine (*Oxford Concise Medical Dictionary*, 2010:470).

Neuroleptic malignant syndrome: It is a very rare but extremely serious complication of nearly all antipsychotic drugs. The symptoms include rigid muscles that prevent movement, racing heartbeat, difficulty in breathing, and confusion. It is crucial that the patient is immediately taken to a hospital so these life-threatening symptoms can be treated (Haycock, 2010:82).

Prophylactic (preventative) treatment: An agent that prevents the development of a condition or disease (*Oxford Concise Medical Dictionary*, 2010:599).

Psychotropics: A term describing drugs that affect mood. Antidepressants and antipsychotics are psychotropic (*Oxford Concise Medical Dictionary*, 2010:609).

Tardive dyskinesia (TD): This condition causes muscle movements that commonly occur around the mouth. A person with TD cannot control these movements. TD can range from mild to severe, and cannot always be cured (NIMH, 2010:12).

Tolerance: Drug tolerance may develop after taking a particular drug over a long period of time (*Oxford Concise Medical Dictionary*, 2010:736).

Treatment algorithm: A diagnostic algorithm or therapeutic algorithm consists of a stepwise series of instructions with branching pathways to be followed to assist a physician in coming to a diagnosis or deciding on a treatment strategy (*Oxford Concise Medical Dictionary*, 2010:20).

Treatment-resistant (refractory): Unresponsive; applied to a condition that fails to respond satisfactorily to a given treatment (*Oxford Concise Medical Dictionary*, 2010:629).

Tremors: A rhythmical and alternating movement that may affect any part of the body (*Oxford Concise Medical Dictionary*, 2010:746).

3.3 TREATMENT ADHERENCE/COMPLIANCE/CONCORDANCE IN BIPOLAR DISORDER

It is the researcher's understanding that the terms adherence, compliance and concordance are synonyms; different authors use different terms. The researcher believes and has experienced that treatment will be useless if the patient does not comply with the treatment regimen. A person may initially be treated against his/her will, but if this person does not believe that he/she has an illness, he/she will cease the treatment and relapse after a time. The researcher therefore views treatment **adherence** and the **therapeutic relationship** as the basis of any treatment for the bipolar patient.

Almost 50 % of bipolar patients stop taking medication without indication from their psychiatrist, especially during euthymia. It is well known that adherence problems are the most common cause of relapse amongst bipolar patients, but the reasons for this behaviour are quite unspecific and patient-dependent, although substance and personality comorbidities play a role. The risk of hospitalisation is four times higher amongst patients who do not fully comply with their maintenance treatment (Colom & Berk, 2010:417).

The safe and successful delivery of efficacious treatments for bipolar disorders relies upon the patient's (and often their caregiver's) ability and willingness to **accept** and **engage** with the services provided and to adhere to an agreed regime of medication and/or other interventions that make up the individual's treatment plan. Collaboration between the clinician and patient is a critical first step if patient outcomes are to reflect the **goals** of both parties (Scott & Tacchi, 2010:275). In the South African context it is the reality that most psychiatric patients are treated in government hospitals where there are frequent changes from one doctor to the next (not enough time to build a trusting relationship); it is the researcher's opinion that this factor also influences treatment adherence. Regular contact with a caring mental health professional that collaborates with one (the patient) on his or her health care will increase one's feelings of hopefulness. Almost all therapy is more effective if the patient is with a therapist he or she can respect and trust, with whom there is a good **relationship** and whom one feels genuinely cares about her or him (Miklowitz, 2011:100, 128). NIMH (2010:8) agrees, saying that treatment may become more effective when people work closely with a doctor and talk openly about their concerns and choices.

There is a growing literature base suggesting that **cognitive impairments** (rather than insight alone) may adversely affect adherence (Scott & Tacchi, 2010:276). Colom and Berk (2010:417) also point out that an association between the lack of insight and neuropsychological impairment has been solidly reported. **Side effects** were considered to have a detrimental effect on adherence in early studies, but it seems that the *fear* rather than the *actual experience* of side effects may be a better predictor of non-adherence. The exploration of individual beliefs is proving to be increasingly fruitful; for example, patients dislike the idea that their moods are controlled by medication and they also dislike taking medication, as it reminds them that they have a chronic illness (Scott & Tacchi, 2010:276). The researcher has also heard patients saying that the medication is "stealing their personalities" and patients do not understand why they should take medication when they feel well.

An important factor mentioned by Scott and Tacchi (2010:276), was the finding that non-adherent individuals with BD were more likely to be living with **family** members who were significantly less knowledgeable about BD and its treatment and were more critical of the patient than families of adherent subjects. According to findings by the same authors it does seem that individuals with BD living in **highly expressive emotional environments**, particularly if accompanied by a negative affective style of interaction or high caregiver burden, are at higher risk of non-adherence and relapse. Scott and Tacchi (2010:279) furthermore refer to the fact that the views of the patient's significant others towards treatment are important, as these may influence the patient's **beliefs** about their problems and/or attitudes towards proposed treatments. The researcher is convinced that these aspects emphasise the importance of providing family psychoeducation and support to the family to relieve their burden.

Patients with BD are frequently ambivalent about treatment. Unfortunately, as indicated above, treatment non-adherence is an important cause of disease recurrence, as well as being associated with higher rates of both hospitalisation and suicide. There are many explanations for the high rates of non-adherence with treatment among bipolar patients. Patients often lack insight and may not believe that they have a serious illness (Vieta, 2009:58).

Table 3.1: Some of the factors influencing treatment adherence (Vieta, 2009:59)

Negative factors	Positive factors
Younger age	Older age
Early onset	Marriage
History of non-adherence	High level of education
History of grandiosity	Social support
Male gender	Realise threat of illness and/or benefits of treatment
Personality	External locus of control or dependence
Denial of severity of illness, poor insight	Recognition of adverse consequences of illness
Comorbid drug/alcohol abuse	
'Missing highs' ; especially in women	

Table 3.1 reflects factors influencing treatment adherence. The researcher has experienced that unless a patient admits that he/she has a serious chronic illness and **understands** the benefit of **adhering** to the treatment, it becomes very difficult to convince such a person to

take treatment. It is possible that maturity and insight may develop with increasing age and that a patient might, after a few relapses, start realising the negative impact of non-adherence. It also points towards the importance of social support and thus the role of the caregiver. In practice, the researcher has observed that male patients may be less willing to adhere to treatment.

In conclusion, it is clear that it is very important that adherence to treatment should be emphasized by ongoing psychoeducation of patients and caregivers. To reiterate, Colom and Berk (2010:417), state that the efficacy of psychoeducation in improving adherence has been proven.

3.4 INTERVENTION

3.4.1 General aspects

According to Colom and Berk (2010:412) and Kilbourne et al. (2010:453) BD is a biological illness that deserves proper pharmacological treatment. It is a **chronic, complex** and **recurrent** condition with pervasive behavioural, cognitive and emotional symptoms that may be triggered by personal and environmental factors. Impairment in occupational and social functioning is prevalent, even between episodes. The quality of care and subsequent patient outcomes remain suboptimal. Psychiatric treatment of BD is complicated by the fact that patients vary with respect to the uniqueness of their symptoms, life circumstances and comorbid psychiatric issues.

As this illness has negative consequences for the patient as well as for their family, friends, and the wider society (Vieta, 2009:49, 52, 53), BD requires a comprehensive and **long-term programme** of medical care to help patients overcome the symptoms and functional impairment associated with the condition. Although, as previously explained, there is **no cure** for BD, effective treatment can decrease the associated morbidity and mortality. A long-term, **preventive strategy** that combines medication and psychosocial treatments is optimal for managing the disorder over time. Haycock (2010:1, 2) also emphasises healthy lifestyle choices. The extremes in mood swings of BD, unless treated, can seriously affect sufferers' wellbeing by damaging relationships, sabotaging education and careers, and threatening financial security and personal safety. According to NIMH (2010:8), control of BD is best when treatment is continuous, rather than intermittent.

Strategies that underpin the production of an integrated, comprehensive treatment **plan** may include clinical assessment, education, intervention (e.g. medication, psychological counselling or psychotherapy, support groups) and multidisciplinary collaboration. Despite the proliferation of treatment algorithms and guidelines, managing BD challenges even the most experienced clinician (Haycock, 2010:66). Effective treatment requires a well-informed patient, a supportive family and an understanding social network. Fast and Preston (2006:xi) emphasise an **approach** that looks at the whole picture of BD and manages the disorder through a variety of treatment ideas from many different disciplines and health care professionals. A comprehensive treatment plan does not focus solely on one treatment, such as medication. Instead, it examines all the person's **needs**, from medication, psychotherapy, physical health as well as emotional, financial and personal needs.

3.4.2 Goals of intervention

Sadock and Sadock (2003:560) insist that the treatment of patients with mood disorders must be directed toward several goals:

First, the **patient's safety**, as well as that of **those around him or her**, must be guaranteed. It is important to assess the patient's level of functioning to decide the optimum treatment setting. The goals of treatment of an acute manic episode are to alleviate symptoms and allow a return to the usual levels of psychosocial functioning. Achieving rapid **control** of agitation, aggression, poor judgement and impulsivity is particularly important to ensure the safety of patients and those around them and to allow the establishment of a therapeutic alliance (Vieta, 2009:49, 77). Keck, McElroy and Hawkins (2010:285) concur, stating that the primary goal of treatment of manic and mixed episodes is rapid symptom improvement.

Second, a complete **diagnostic evaluation** of the patient must be carried out. Sometimes symptoms attributed to BD may be caused by a different serious condition. Patients with bipolar symptoms should receive a complete **physical examination** to exclude metabolic diseases or ailments such as Huntington's disease, brain tumours, or other medical conditions. Initial treatment of BD requires a thorough assessment of the patient, as well as attention to possible comorbid psychiatric or medical illnesses. Proper diagnosis and treatment helps people with BD to lead healthy and productive lives (Haycock, 2010:67; NIMH, 2010:3; Vieta, 2009:49). The taking of a thorough personal and family history, as well as noting any drug use or serious life changes a person may have experienced, is at the heart of a comprehensive evaluation. The physician should always inquire about blood relatives who may also have had the illness. Clues to a possible bipolar diagnosis in these relatives may be to ask about psychiatric hospitalisations, a history of numerous business ventures, severe alcohol or drug abuse, mood swings, suicide or whether a relative was married three or more times (Fast & Preston, 2006:12).

Third, a **treatment plan** that addresses not only the immediate symptoms but also the patient's prospective wellbeing must be initiated. Although current treatment emphasises pharmacotherapy and psychotherapy addressed to the individual patient, **stressful life events** are also associated with an increase in relapse rates among patients with mood disorders. Thus, treatment must reduce the number and severity of **stressors** in patients' lives. Mood disorders are chronic and the patient and the family must be advised about future treatment strategies.

According to Vieta (2009:49) **subsequent goals** of intervention include establishing and maintaining a therapeutic alliance, monitoring the patient's psychiatric status and response to treatment, providing education about BD to the patient and family, enhancing treatment compliance, promoting regular patterns of activity and sleep, anticipating stressors, identifying new episodes early, and minimising functional impairments. In their writings, Keck et al. (2010:285), emphasise the importance of full remission of symptoms and recovery of vocational and psychosocial function.

NIMH (2010:3, 5, 8) holds the perspective that the goal of treatment is to help people with BD to live **symptom-free** for longer periods and to recover from episodes more rapidly. Proper treatment helps most people with BD gain better **control** of their mood swings and related symptoms. Because BD is a chronic and recurrent illness, people with the disorder need long-term treatment to maintain control of their symptoms.

At each follow-up visit, the patient's clinical status should be determined and recorded in a systematic manner. In view of time-constraints, it can be very helpful if patients complete a **self-report form** in the waiting room, as well as **daily mood charts** that they bring to the consultation. Active patient collaboration with routine assessment not only increases the time available for more unstructured talk but also improves rapport by providing documentation of the patient's subjective experience. The clinician can also benefit from using **graphical charting**, since knowledge of an individual patient's **disease course** is perhaps the most useful guide to planning treatment (Vieta, 2009:56). These practices do not seem to happen in the government health care sector and the researcher strongly **recommends** that these aids are implemented.

Swann (2010:304) indicates that BD is treatable, but that we do not yet have curative treatments or effective measures for primary prevention. He therefore states that **successful maintenance treatment** is the goal in BD. The researcher agrees with this author and is convinced that every episode prevented improves the subsequent course of the illness.

3.4.3 Holistic approach

Comprehensive care should be provided at all levels of delivery. This includes primary prevention, assessment, treatment and rehabilitation. Attention must be given to the physical, emotional, functional and spiritual needs of an individual. In psychiatry a biopsychosocial framework is used to ensure that all the needs of an individual are met in terms of intervention (Thom, 2007:6).

The treatment of BD requires a holistic approach that involves pharmacologic and psychotherapeutic interventions (Antai-Otong, 2003:244). The biopsychosocial model combines generic and specialist healthcare with assessment and therapeutic interventions. It focuses on the person as a whole, viewing much of health problems as rooted in social conditions and poverty (Smith, 2007:639) (Chapter 1 refers). In the hospital in which the researcher is working, a bio-psycho-social-psychoeducational model is followed which therefore includes the patient, as well as his/her broader context. In this broad biopsychosocial approach the patient is less a passive recipient of care than an active participant in the care plan (Baumann, 2007b:17).

The researcher has noticed that some authors refer to a biopsychosocial framework, others to a model or approach, but it seems that all are referring to the same concept.

3.4.4 Multi-disciplinary team (MDT) approach

Last (2009:127) **defines** the “treatment team” as a group of individuals who share the common goal of promoting the patient’s mental health. In any team, each individual plays a distinct role. It is the researcher’s opinion that the team also includes the **caregiver** whose **roles** might include learning about BD, staying in contact with the patient’s therapists and knowing about early warning signs of mania and depression. The **patient**, too, must feel that he/she is part of the team and can take part in decision-making (this is also in line with a patient’s rights). A well-informed patient may sometimes be viewed as “demanding”, but that should not prevent the MDT being honest with the patient and showing him/her the necessary respect.

Due to the incurable, chronic and sometimes unpredictable nature of bipolar illness, symptom management by a mental health team may offer the best option. This team could consist of the consultant psychiatrist, registrar, psychiatric nurses, social worker, occupational therapist, clinical psychologist, pastoral worker, dietician and physiotherapist. Other members, such as music therapists, or volunteers rendering different services, might also be incorporated into the team. A multidisciplinary approach may also enhance long-term patient outcomes, such as mood stability, occupational and social functioning and overall quality of life (Vieta, 2009:50, 64).

It has been the researcher's experience that the **social worker** forms a very important part of the team, although this position and the respect of others must be earned by hard work (i.e. it is not a given). The social worker is often the glue of the team and the team member who negotiates with the caregivers and other resource people. Communication with the rest of the team is of paramount importance. He/she should always be aware of the **climate** within the team and address any conflict or tension, so that the team is able to provide quality patient care.

3.4.5 Location of intervention

Patients should be treated at the most appropriate level of care, depending on their severity and treatment considerations (Vieta, 2009:52). It must be decided if a patient should be **hospitalised** or treated as an **outpatient**. Clear indications for hospitalisation are the need for diagnostic procedures, the **risk** of suicide or homicide, and a patient's grossly reduced ability to obtain food and shelter. A history of rapidly progressing symptoms and the rupture of a patient's usual support systems are also indications for hospitalisation.

Patients with mood disorders are often unwilling to enter a hospital voluntarily, and may have to be committed **involuntarily**. These patients might not be able to make decisions because of their slow thinking, negative "*Weltanschauung*" (worldview), and sense of hopelessness. Sadock and Sadock, (2003:560) point out that manic patients often have such a complete lack of insight into their disorder, that hospitalisation seems absurd to them. Keck et al. (2010:285) refer to the fact that manic and mixed episodes are amongst the most serious acute psychiatric syndromes, often constituting a medical **emergency** and the need for hospitalisation to ensure safety and allow aggressive treatment. Untreated, these can have tragic consequences (Haycock, 2010:5). Miklowitz (2011:5) comments that patients can find the hospital experience confusing and frustrating. In this regard it is especially difficult for patients to be in “closed” wards, but when a patient is aggressive and psychotic he/she needs to be treated within a structured environment.

The researcher is in agreement with CAMH (2000:20), stating that **discharge planning** begins immediately following admission to hospital. Patients should be expected to leave hospital as soon as reasonable follow-up arrangements are in place and their symptoms have improved enough to ensure they are able to function safely and care for themselves at home. Staying in hospital **after** symptoms have improved may not benefit the patient. It may in fact cause difficulties, by reducing the patient’s connection to family and social supports and possibly undermining his or her independent living skills.

The experience of the researcher is that once a patient is admitted to a hospital, MDTs are under considerable pressure to **discharge quickly**; as a result proper psychoeducation and discharge planning are not always achieved. Important aspects are frequently not dealt with because mental health providers simply do not have time to include assessment of the triggers that caused the relapse as well as carry out realistic future planning. This may lead to a patient discontinuing his/her medication, **relapsing** and being **readmitted (revolving door)**. It is also very important that the MDT should liaise with the community resources such as the community clinics, mental health organisations, halfway houses and even the patient’s private psychiatrist (where applicable), to ensure continuation of care and rehabilitation. Psychiatric **aftercare** is a fundamental part of the recovery process.

The international trend in psychiatric care is towards reducing the amount of time spent in hospital. In South Africa, the cuts in hospital budgets and other fiscal and legal constraints, as well as the financial status of medical aid funds, have led to many patients being discharged too early from hospital. This means most patients are still in a phase of recovery and very vulnerable when they are removed from the protective environment of the hospital to return to the community (Richards, 2002:i).

3.4.6 Phases of intervention

Both Miklowitz (2011:100) and Vieta (2009:50, 52) distinguish between an **acute** phase (during which the goal is to treat and stabilise the existing illness episode, especially for patients in the manic/hypomanic phase, with the goal of remission) and a **maintenance** phase, when the goal is to prevent future episodes. Treatment during this phase is called **prophylactic** (preventative) treatment. In the maintenance phase, the goal of treatment is to optimise protection against the recurrence of any mood episodes. Regarding comorbidity, Salloum et al*.* (2010:357) state that treatment for BD and its associated comorbidities may be conceptualised in two broad, interconnected phases: (1) an acute stabilisation phase to address the acute episode or the need for acute treatment of the comorbid disorder, e.g. a need for medically supervised detoxification; (2) an ongoing maintenance phase to consolidate recovery, prevent relapse and maximise health restoration and functioning.

3.4.7 Biological intervention

3.4.7.1 Medication

Pharmacotherapy has been the cornerstone of treatment for bipolar manic and mixed episodes since the 1950s, but the therapeutic armamentarium has expanded greatly since then, especially over the past 15 years (Keck, et al., 2010:285). Last (2009:33, 95) avers that the single largest contributor to remaining free from mood disturbance is taking medication prophylactically. **Staying well means, among other things, taking medication exactly as prescribed every day of one's life**. Most people with BD take multiple medications to keep their illness in check. Medication is the first-line of treatment for BD and treatment without appropriate **medication** is doomed (Miklowitiz, 2011:98; Taylor, 2006:15).

Psychopharmacologic agents are prescribed to manipulate the processes of neurotransmitter production and absorption, so as to re-establish normal neurochemical balance. Mental disorders are **not** simply the result of too little or too much neurotransmitter substance. Levels and combinations fluctuate with important brain function, individual responses and processes of growth and aging. Many questions remain regarding the complexity and role of neurotransmitters in mental illnesses (Antai-Otong, 2003:46, 47).

It is important that **before starting** a new medication, people with BD should talk to their doctor about the possible **risks** and **benefits**. Severe side effects from medication should be discussed with the doctor who prescribed it as soon as possible. She or he may decide to change the dose or prescribe a different medication. People being treated for BD **should not stop** taking a medication without talking to a doctor first. Suddenly stopping a medication may lead to "rebound" or worsening of BD symptoms (NIMH, 2010:6). In practice, the researcher has found that the patient or family might contact the social worker regarding problems with medication; then the social worker needs to focus the doctor's attention on the problem.

According to Miklowitz (2011:103) in the best-case scenario, a medication regimen should do **three things** for a patient:

- Control and help resolve an episode that has already developed.
- Delay future episodes and minimise the severity of those that do occur.
- Reduce the severity of the symptoms a patient experiences between episodes.

Pharmacologic treatment of BD often requires a combined pharmacologic approach. This may involve an antidepressant and a mood stabiliser (Antai-Otong, 2003:244, 245). Vieta (2009:77) reports that the most widely used medications in the acute setting are lithium, some anticonvulsants, standard antipsychotics, atypical antipsychotics and benzodiazepines. Whenever possible, oral therapy should be offered first, but intramuscular injections are an alternative if oral therapy cannot be reliably administered. The researcher agrees with Swartz, Frank, Zajac and Kupfer (2010:432), who argue that in the instance of a physician-clinical treatment team, the non-physician therapist must also develop familiarity with the major classes of medications used to treat the disorder and their side effects so that he or she can help their patient recognise medication-related problems and collaborate with the physician to manage them (also refer to the role of the social worker in the MDT).

Three major categories of psychotropic medications are used in the successful treatment of BD:

3.4.7.1.1 Mood stabilisers

For decades, mood stabilisers have been the **mainstay** of pharmacological treatment for BD. They are used both in the treatment of **acute** mood episodes and as **maintenance** medication (prophylaxis) (Last, 2009:96). Mood stabilising medications are usually the first choice to treat BD. In general, people with BD continue treatment with mood stabilisers for years. Except for **lithium**, many of these medications are **anticonvulsants** which are usually used to treat seizures, but they also help control moods (NIMH, 2010:5).

Miklowitz (2011:103, 104) indicates that to be **defined** as a mood stabilizer, a medication has to be effective in:

- treating acute manic, mixed, and/or depressive episodes of BD without causing a switch to the opposite pole of the illness or rapid cycling and

- preventing future episodes from occurring. Fortunately, mood-stabilising medications are not addictive. The main mood stabilisers today are lithium carbonate and the anticonvulsants, typically, divalproex sodium or valproate, lamotrigine (Lamictal), or the older agent carbamazepine (Tegretol). Certain of the atypical antipsychotic medications, such as quetiapine (Seroquel), aripiprazole (Abilify), and olanzapine (Zyprexa), also qualify as mood stabilisers.

This class of medication is now discussed in more detail.

Lithium Carbonate

This was the **first** medication proven to **stabilise** mood in BD and to **prevent** recurrence of **manic** or depressive episodes. This psychotropic, prophylactic agent is still the first choice for bipolar I **depressive** or **manic** episodes. It is rarely recommended for depressive illnesses of the unipolar type (Colom & Vieta, 2006:5; Miklowitz, 2011:104 and SAMF, 2010:469).

Lithium is a complex substance and how it works remains unknown, although there are various theories in this regard. It takes 1 to 3 weeks before it becomes effective and it is not habit forming (Stahl, 2006:257, 259). According to El-Mallakh (2006:147, 160) lithium has been the **gold standard** for the treatment of bipolar illness for over 50 years. Keck et al. (2010:285) agree, noting that there is more clinical and research experience with this drug than any other used to treat bipolar illness. Lithium has extensive data supporting its utility in both acute bipolar depression and relapses.

Although various forms of lithium bromide were used during the late 1800s to quell agitation or overexcitement, the discovery of lithium as a treatment for BD is usually attributed to John Cade (1949), as indicated earlier. According to Colom and Vieta (2006:5) the **history** of bipolar disorders is marked by the discovery of lithium salts. Lithium was tested on human beings for the first time in 1949 when the Australian scientist, John Cade, described its “tranquillising” properties. Due to its molecular simplicity and therapeutic specificity, lithium continues to be a fascinating drug and its prophylactic effect has even today not been surpassed.

Different **experts concur** that **lithium carbonate** has a well-documented **anti-suicide** potency. According to Levine and Chengappa (2009:283) there is substantial data to suggest a role for lithium in the prevention of suicides in bipolar and other mood disorders.

The data regarding long-term use of lithium are compelling. It is associated with an eight fold reduction in suicide and reported attempts in adults with BD (Kowatch et al., 2005:13). Lithium exerts a **prophylactic effect**, reducing the frequency, duration, and severity of future episodes of mania and depression and dramatically lowering the risk of suicide. It may also have particular efficacy, despite its risk of toxicity and high lethality in overdose (Last, 2009:96; Miklowitz, 2011:100 and Vieta 2009:46). Haycock (2010:52) mentions another advantage of lithium: it may **reduce dementia**. This is the conclusion of a 2010 Danish study, which found that people who took lithium recorded lower rates of dementia than people who took antipsychotics, antidepressants, or anticonvulsants.

Before the initiation of lithium therapy, baseline laboratory assessments should include complete blood cell counts, thyroid function tests, blood urea nitrogen, creatinine and serum calcium levels, as well as a pregnancy test (AACAP, 2007:119). People with BD often have **thyroid gland** problems. Lithium treatment may also cause low thyroid levels in some people. Hypothyroidism has been associated with rapid cycling in some people with BD, especially women (NIMH, 2010:5).

Sadock and Sadock (2003:571) agree that lithium is still a standard treatment for bipolar I disorder. The **adverse effects** that may limit the use of lithium include renal, metabolic and thyroid effects; its use therefore requires **careful monitoring** of patients’ renal and thyroid status. A blood level of 0.8 to 1.2 mEq/L (a chemical measure of lithium concentration in the blood) is the effective range. Miklowitz (2011:104) emphasises that a correct dosage is one that brings one’s blood level into a **therapeutic range**. Doctors will determine whether the dose of lithium is in the “therapeutic range” by measuring the level of the substance in the bloodstream. These blood tests are performed frequently early on in treatment to ensure that the level is at a point where it will be effective and not too high, since in high doses lithium can be toxic. Thus, regular blood tests are required to prevent **lithium toxicity**. Miklowitz (2011:109) indicates that this state (lithium toxicity) is extremely **dangerous** and even potentially deadly and it is therefore important to know the signs of toxicity so that the patient can get in to see the doctor as soon as possible. Some symptoms are problems with balance and coordination, blurry vision and disorientation. Last (2009:97) adds that **warning signs** may include **gastrointestinal symptoms** (such as severe nausea and diarrhoea), **muscle coordination problems** (severe tremors, slurred speech) and **altered consciousness** (confusion or seizure). If lithium toxicity is suspected, the patient must go to the emergency room to receive the proper treatment for this condition.

Side effects of lithium may be related to the dosage the patient takes. Many doctors adopt the "**start low, go slow**" approach, in which the medication is started at a low dosage and gradually increased to the therapeutic dosage level as a way of keeping the side effects in check (Miklowitz, 2011:108). **Common side effects** of lithium carbonate, the dosage of which may vary from 300-2,400 mg per day, might, according to Miklowitz (2011:115), NIMH (2010:6) and Last (2009:98) include weight gain, fatigue, sedation, stomach irritation, bloating, indigestion, or diarrhoea, joint or muscle pain, increased thirst, dry mouth, frequent urination, metallic taste in the mouth, hand tremor, thyroid dysfunction, acne or psoriasis, mental sluggishness or memory problems, kidney clearance problems, restlessness, brittle nails or hair.

The researcher, while acknowledging all the advantages of lithium, contends that having to take this medication can also be demanding and the **patient and the caregiver** should therefore be well informed about the rationale for the medication. In addition, their relationships with the MDT need to be founded on transparency and honesty.

Anticonvulsants

El-Mallakh (2006:147) points out that for over three decades, antiepileptic drugs (AEDs) have been integral to the treatment of bipolar illness. Last (2009:98), Miklowitz (2011:109) and Antai-Otong (2003:245), all mention that although anticonvulsant medications were not initially developed for BD as they were initially approved for use in treating epilepsy, many of them were discovered to have mood-stabilising properties, which are effective in the treatment of BD.

As Sadock and Sadock (2003:570) note, lithium, divalproex and olanzapine (Zyprexa) are standard treatments for the manic phase of BD, but carbamazepine is also a well-established treatment. Topamax is another anticonvulsant showing benefit in bipolar patients. The most frequently used are valproic acid and carbamazepine (Tegretol). Miklowitz (2011:112), however, states that the use of carbamazepine is tapering off. Efficacy data for **valproate** now suffice to warrant its use as a first-line drug and it has replaced lithium as a first-choice therapy in the United-States (Sadock & Sadock, 2003:571 and Miklowitz, 2011:109).

Pre-treatment workup for valproate includes a complete blood cell count as well as liver function tests. A **pregnancy test** is necessary as this drug can cause neural tube defects in developing foetuses. NIMH (2010:7) states that women with BD who are pregnant or may become pregnant face special challenges. Stopping medications, either suddenly or gradually, greatly increases the risk that bipolar symptoms will recur during pregnancy.

NIMH (2010:5) warns about the fact that valproic acid may increase levels of testosterone in teenage girls and lead to polycystic ovary syndrome in women who begin taking the medications before age 20. Young girls and women taking valproic acid should therefore be carefully monitored by a doctor.

Consensus and practical guidelines concerning the treatment of bipolar disorders indicate the efficacy of newer agents such as **lamotrigine** (Lamictal) and **topiramate** (Topamax). Sadock and Sadock (2003:571) observe that lamotrigine does not require blood monitoring while topiramate has the unique property of causing weight loss. According to Last (2009:101) and Miklowitz (2011:112), a potential problem of using lamictal is that 5-10 % of people who use it develop a skin rash within 2 to 8 weeks of beginning treatment. This typically mild rash can, in rare instances, lead to more serious skin conditions such as **Stevens-Johnson syndrome**, a potentially life-threatening condition.

As noted by Miklowitz (2011:115) and NIMH (2010:6) the most serious side effect of carbamazepine, although quite rare, is a bone marrow reaction known as **agranulocytosis**, which involves a dramatic drop in white blood cells.

In the researcher’s experience, the side effects that bother patients the most are weight gain, increased thirst (dry mouth) and fatigue.

3.4.7.1.2 Antipsychotics

The search for the ideal treatment for mental illness experienced a major breakthrough in the discovery of tranquillisers in the 1950s. Over the past decade, the effectiveness of these agents has increased because of improvements made in their ability to target behavioural manifestations of the complex neurobiological processes, such as those located in the hypothalamus and other regions of the limbic system. Psychotropic medications appear to act on neurochemical mechanisms that modify, alter or interfere with behavioural patterns (Antai-Otong, 2003:65).

It is limiting to think of antipsychotic drugs as having only antipsychotic actions. Individual antipsychotics variously possess sedative, anxiolytic, antimanic and antidepressant properties (Taylor, Paton & Kapur 2009:145). According to El-Mallakh (2006:185), antipsychotics are among the most frequently used medications in bipolar illness. Antipsychotics are frequently an adjunct to antidepressant therapy, employed to treat psychotic symptoms of either acute mania or depression in the client with BD until the mood stabiliser becomes effective (Antai-Otong, 2003:245). Psychotic symptoms (hallucinations, delusions or formal thought disorder) are present in **more than half** of all episodes of mania and are clear indications for aggressive treatment. Clinical guidelines vary in their recommendations for first-line treatment of psychotic mania. Some favour anticonvulsants over lithium when psychotic symptoms are present, while others recommend the combination of a mood stabiliser plus antipsychotic medication (Vieta, 2009:85, 86).

Two kinds of antipsychotics are used today: the "older" or "conventional" types and the "newer" or "atypical" types.

- **Conventional antipsychotics (first-generation)**

Serious problems can occur with the use of conventional antipsychotics, such as their potential to develop tardive dyskinesia (TD), described earlier. A person with TD cannot control the resulting movements. TD can range from mild to severe, and is not always curable (NIMH, 2010:12). According to Lippi (2009), the most common **side effects** are tremors, dystonia, slow movements and restlessness as well as loss of facial expression, tiredness, dry mouth, urinary retention and constipation.

- **Atypical antipsychotics (second-generation)**

Atypical antipsychotic agents currently available in South Africa include clozapine, olanzapine, risperidone, quetiapine, ziprasidone and aripiprazole (SAMF, 2010:471). As Haycock (2010:75) indicates, clozapine (Closzaril) was the first in this category. Hailed as a breakthrough in the early 1990s, it remains a potentially good option for people who do not respond to other mood stabilisers or antipsychotic medications.

Today the **atypical antipsychotics** are usually the first choice for clinicians. Various serotonin mechanisms are the targets of the newer atypical antipsychotics. These agents appear to cause fewer extra pyramidal side effects (SAMF, 2010:462). Patients are increasingly being treated with atypical ("second-generation") anti-psychotics instead of, or in addition to, mood stabilisers. Many of these atypical antipsychotics qualify as mood stabilisers; they control acute episodes, decrease the vulnerability to future episodes, and do not worsen the course of the illness (Miklowitz, 2011:114). Atypical antipsychotics are evolving, becoming the **new standard for long-term treatment of BD**, even in individuals with no history of psychosis (Last, 2009:101).

According to NIMH (2010:5) **Olanzapine** (Zyprexa), when given with an antidepressant medication, may help relieve symptoms of severe mania or psychosis. Some studies show that people taking olanzapine may gain weight and experience other side effects, which can increase their risk for diabetes and heart disease. **Aripiprazole** (Abilify) is approved for treatment of manic or mixed episodes, while **Quetiapine** (Seroquel) relieves the symptoms of severe and sudden manic episodes. As Miklowitz (2011:117) remarks, some doctors believe that quetiapine has the best record of *any* medication for treating both depression and mania in bipolar disorder. Two other atypical medications: **Risperidone** (Risperdal) and **Aripiprazole** have antimanic properties and are often recommended as adjuncts to mood stabilisers if a person has manic or psychotic symptoms that do not resolve with a single medication. NIMH (2010:5) also mentions Ziprasidone (Geodon) as an alternative, atypical antipsychotic that may be prescribed for controlling manic or mixed episodes.

NIMH (2010:7) reports on **side effects** of atypical antipsychotic medication that can cause major weight gain and changes in a person's metabolism. This may increase a person's risk of contracting diabetes and developing high cholesterol. A doctor should regularly monitor a person's weight, glucose levels and lipid levels while they utilise these medications. Closzaril, Seroquel and Zyprexa are renowned for their tendency to increase people's weight and to cause **metabolic syndrome** (Last, 2009:102).

3.4.7.1.3 Antidepressants

The **SSRIs** (selective serotonin reuptake inhibitors) are the most widely used antidepressants in the United States. They are the agents of choice because of their effectiveness, ease of use and relative lack of adverse effects, even at high dosage levels (Sadock & Sadock, 2003:566). According to Lippi (2009), they may also be used to treat anxiety.

There has been some **alarmism** about the use of antidepressants for individuals with bipolar depression. Patients with bipolar I disorder, who are being treated with conventional antidepressants, must be observed carefully for the emergence of **manic symptoms**. Antidepressants are used for the depressed phase of BD, with dosages and side effects being similar to those used to treat unipolar depression. Antidepressants are usually prescribed in combination with mood stabilisers or atypical antipsychotic medications, and not by themselves. Nonetheless, given the suffering and impairment that bipolar depressions cause, most clinicians consider them an option, especially if a patient has not responded to mood stabilisers or atypicals such as lithium, lamotrigine, or quetiapine (Antai-Otong, 2003:245; Miklowitz, 2011:118-120 and Sadock & Sadock, 2003:566). Floxetine

(Prozac), Sertraline (Zoloft) and Bupropion (Wellbutrin) are examples of antidepressants that may be prescribed to treat symptoms of bipolar depression (NIMH, 2010:6).

One of the most serious concerns about anti-depressants, alluded to earlier, is that they can cause people to become **suicidal** (their lethality when taken in **overdose**) while another is that they can bring on **hypomanic**, **manic**, or **mixed** states and cause rapid cycling. Sadock and Sadock (2003:566) are of the opinion that adequate patient education about the use of **antidepressants** is as critical to treatment success as is choosing the most appropriate drug and dosage. It should be stressed that the patient **will not become addicted to antidepressants**, because the drugs do not give immediate gratification. Further, it will probably take 3 to 4 weeks for the effects of the antidepressant to be felt. The **risk** of **suicide** in patients with mood disorder must always be considered. Most antidepressants are lethal if taken in large amounts. It is unwise to give large prescriptions to most patients with a mood disorder when they are discharged from the hospital, unless another person monitors the drug’s administration.

The most common clinical mistake leading to an unsuccessful trial of an antidepressant drug is the use of too low a dosage for too short a time. Antidepressant treatment should be maintained for at least 6 months or the length of a previous episode, whichever is greater (Sadock & Sadock, 2003:566). In this regard, Vieta (2009:72) states that the goals of treatment in bipolar depression are to resolve depressive symptoms and establish a stable mood. In general, **that which makes a patient well is likely to keep them well too**. Most guidelines recommend that antidepressants should be discontinued within 3-6 months of remission. The rationale for this approach is influenced by a concern that continued antidepressant treatment might induce switches into mania or cycle acceleration. According to Kowatch et al. (2005:9) it is recommended that antidepressant medication should be continued for at least 8 weeks after there is a depression remission.

Side effects of antidepressants may include headache, nausea, sleep problems (insomnia or somnolence), agitation and sexual problems (can include reduced libido and problems having and enjoying sex) (NIMH, 2010:7).

In conclusion, El-Mallakh, Karippot and Ghaemi (2006:167, 180) state that treatment and prevention of bipolar depression is a major challenge in the long-term treatment of bipolar illness. While about one-third of patients may experience adequate prophylaxis with lithium or valproate, the majority of patients continue to be symptomatic. Antidepressants can have a role in the treatment of BD, but particular caution needs to be exercised to find that minority of patients for whom antidepressants can be helpful, and to avoid that minority for whom they can be harmful.

3.4.7.1.4 Benzodiazepines

Benzodiazepines are anti anxiety agents frequently utilised in the acute phase of mania or the accompanying symptoms of overwhelming **anxiety** and **panic**. These medications are used for a very limited time, until the long-term medications prescribed become therapeutic (Antai-Otong, 2003:245). Vieta (2009:84) and Miklowitz (2011:121) explain that benzodiazepines are often used as adjuncts to lithium, anticonvulsants, or antipsychotics, for the treatment of symptoms such as agitation, anxiety, or insomnia. Potential disadvantages of their use include the **risk of dependence**. People may need increasingly higher dosages over time to experience the same effects (tolerance) and may have withdrawal symptoms when stopping them, including seizures. Lippi (2009) also mentions that these medications are addictive and should not be prescribed for longer than 2 weeks unless prescribed by a psychiatrist. Benzodiazepines have been shown to be efficacious for the treatment of adult anxiety disorders. Common benzodiazepines include Lorazapam (Ativan), Alprazolam (Xanax), Diazepam (Valium) and Oxasepam (Serepax) (Kowatch et al*.,* 2005:11).

In this regard, the following scenarios should be treated as **emergencies**:

- Patient has a convulsion and does not have epilepsy.
- When patient suffers neuroleptic malignant syndrome or serotonin syndrome.
- An overdose has been taken (Lippi, 2009).

In practice, it is found that patients may deny the abuse of benzodiazepines and will go to different doctors to obtain prescriptions. They also use these to self-medicate in order to feel better, but this does not provide a long term solution to their problems.

3.4.7.1.5 Anticholinergics

These are used to treat the tremors and muscle stiffness caused by antipsychotics. The most common side effects are dry mouth, constipation and inability to urinate (Lippi, 2009). AACAP (2007:118-119) refers to the fact that the clinician must balance the potential deleterious impact of symptom reoccurrence with that of the **side effects** of the medications. Any attempts to discontinue prophylactic therapy should be made gradually, while closely monitoring the patient for relapse.

3.4.7.1.6 Thyroid Supplements

People with BD often have hypothyroidism, while certain mood stabilisers, such as lithium, tend to suppress thyroid hormones. It is therefore not unusual for doctors to recommend thyroid medications; a thyroid supplement may help bring a patient back to a normal energy level (Miklowitz, 2011:121; Haycock 2010:80). Last (2009:114) mentions that research indicates that 30 to 50 % of people who do not experience complete alleviation of their depression by traditional psychiatric drugs benefit from increasing their levels of T3 (the active form of thyroid hormone) with the prescription medication Cytomel, even if they do not test positive for hypothyroidism. Rapid cyclers and women are most likely to benefit from thyroid augmentation.

3.4.7.1.7 Complementary and Alternative Medicine: Herbs and Supplements

(Refer to 3.2.2 where complementary and alternative medicine (CAM) was defined). NIMH (2010:8) reports that, in general, not much research has been undertaken into **herbal** or **natural supplements**. Little is known about their effects on BD. A herb called St John’s Wort (Hypericum perforatum), often marketed as a natural antidepressant, may, in some people with BD, cause them to become manic. It might also make other medications less effective, including some antidepressant and anticonvulsant medications. There is no evidence that any natural substance is both free of side effects and effective as a mood stabiliser or antidepressant (Miklowitz, 2011:107). The said Hypericum (St. John’s Wort) can cause high blood pressure and headaches and, as stated above, has the potential to trigger manic episodes in certain individuals (Haycock, 2010:99).

Scientists are also researching **omega-3 acids** (most commonly found in fish oil) to measure their usefulness for long-term treatment of BD. Miklowitz (2011:122) refers to this popular alternative: the **omega-3 fatty acid plan**. In an early randomised trial, fish oil performed more efficaciously than placebo tablets in prolonging periods of wellness among people with BD who were also receiving mood stabilisers. Subsequent studies of omega-3 have not really evolved satisfactorily, although it may have some weak effects on depression. In that some people generally want a “quick” cure, they will therefore try anything they think may alleviate their symptoms.

The researcher’s opinion is that **maintenance medication** is very important, and therefore includes a report here on the views of a few experts:

Vieta (2009:87) states that maintenance medication is generally recommended following a single acute manic episode, in view of the 95 % lifetime risk of recurrence. The choice of pharmacological prophylaxis will be determined by the patient's history and response to prior trails. The goals of maintenance treatment include:

- Relapse prevention.
- Reduction of suicide risk.
- Reduction of sub threshold symptoms. A threshold can be explained as the point at which a stimulus begins to evoke a response (*Oxford Concise Medical Dictionary*, 2010:729).
- Improvement in overall function.

According to Kowatch et al. (2005:13) current research supports the efficacy of lithium, lamotrigine and olanzapine as **maintenance treatments**. The APA Practice Guideline for the treatment of patients with BD recommends that treatment with a maintenance agent should continue for a minimum of 18 months after stabilisation of a manic episode. However, there are no clear answers that definitely inform clinicians regarding how long treatment should be continued. Sadock and Sadock's (2003:571) opinion, regarding maintenance, is that the decision to maintain a patient on lithium (or other drug) prophylaxis is based on the severity of the patient's disorder, the risk of adverse effects from the particular drug, and the quality of the patient's support systems. Maintenance treatment is generally indicated for prophylaxis of bipolar I disorder in any patient who has had more than one episode. The rationale for this practice is the relative safety of the available drugs, their demonstrated efficacy, and the significant potential for psychosocial problems if another bipolar I disorder episode occurs. During long-term treatment, laboratory monitoring is required for lithium, valproic acid, and carbamazepine.

NIMH (2010:8) warns that people with BD should tell their doctor about **all the prescription** drugs, over-the-counter medications (OTCs), or supplements they are taking. Certain medications and supplements taken simultaneously may cause unwanted or dangerous effects. There is a need to treat as many symptoms as possible with the **minimum** use of medications. Doses should also be as low as possible to minimise side effects and drug interaction (Haycock, 2010:78).

In conclusion, patients and families must be thoroughly educated as to the early signs and symptoms of mood episodes so that, if necessary, resumption of treatment occurs as soon as possible. The patient's diagnostic status should be reviewed over time to ensure that the course of medication therapy is justified (AACAP, 2007:118-119). Miklowitz (2011:60) refers to the challenge which inconsistency among people with BD regarding taking their medication brings about, with more than 50 % **discontinuing** their drug regimen at some time in their lives. He (Miklowitz 2011:132) concludes, "Committing to a long-term program of medications is an important personal decision".

3.4.7.2 Somatic Treatments for bipolar disorder

3.4.7.2.1 Electroconvulsive Therapy (ECT)

(Refer to 3.2.2 where ECT was described). Keck et al. (2010:289) are of the opinion that ECT remains an important non-pharmacological treatment option for patients who do not respond well to or tolerate pharmacotherapy or who have severe, psychotic or catatonic symptoms. ECT is one of the more powerful treatment options available for people with BD and other severe forms of depression. ECT works quickly and efficiently and is fundamentally an acute treatment (Miklowitz, 2011:123). Antai-Otong (2003:246) agrees that ECT is an effective and often **lifesaving** treatment for mania or depression if pharmacologic interventions fail or if symptom severity requires immediate relief.

The researcher has observed that patients are often scared of this procedure and they do not know what to expect. When this treatment is considered, it is therefore very important that the patient and the caregivers should be well informed about the procedure and its possible side effects. It might be that the patient is too sick to give consent for the procedure and that the head of the health establishment will have to sign consent.

Criticism against ECT

Because of the difficult and turbulent history of ECT, people with BD and their family members often do not want to consider it, even in the direst of circumstances. This is unfortunate, because ECT is lifesaving in many cases. Many physicians recommend ECT only reluctantly, because one of its **side effects** is a loss of memory. It appears that about two-thirds of people who receive ECT experience problems in memory functioning, but the problems seem to be temporary and usually disappear with time (Miklowitz, 2011:123). AACAP (2007:19, 119) and Antai-Otong (2003:246) concur that potential side effects include short-term cognitive impairment (temporary memory loss, which recedes usually after the course of treatment), anxiety reactions, disinhibition, headaches and an altered seizure threshold.

ECT continues to be criticised by some but remains a safe and effective treatment with minimal side effects as long as modern methods are used. Clients receiving ECT are anaesthetised in a closely monitored medical setting and typically receive 6 to 10 treatments over a few weeks. ECT treatments last from 30-90 seconds on average. People who have ECT usually recover after 5-15 minutes and are able to go home on the same day (NIMH, 2010:8).

Candidates for ECT

In adults, ECT is an effective treatment for mania, but it is generally offered only for patients who have **not responded to standard medication treatment** (AACAP, 2007:119). Vieta (2009:91, 92) and Sadock and Sadock (2003:571) concur ECT may be considered in patients with severe or treatment-resistant (refractory) mania or treatment-resistant mixed episodes. The treatment of acute, treatment-refractory bipolar depression is complex and poorly based on evidence. When first and second options fail, the most effective alternative is, again, ECT.

According to AACAP (2007:119), ECT is generally considered the treatment of choice for BD in the following clinical situations:

- **Pregnancy**: Miklowitz (2011:124) agrees, remarking that although it may sound surprising, it is considered a safe option for women who are pregnant and severely depressed or manic. Most mood stabilisers and antidepressants carry some risk of harm to the unborn baby, but ECT does not, when administered under standard medical conditions.
- **Catatonia**: (refer to 3.2.2 for definition).
- Neuroleptic malignant syndrome.
- **Any other medical condition** in which more standard medication regiments are contraindicated.

Lam, Chan and Howard (2009:413) also include these indications: acute suicidality; psychotic features; rapidly deteriorating physical status due to complications from depression, such as poor oral intake; history of poor response to medications; history of good response to ECT; patient preference; manic delirium; acute mania; unresponsiveness to medications; mixed states and rapid cycling; unresponsiveness to medications. Lam et al. (2009:417) mention the use of maintenance ECT (in which a single treatment is given every 1-8 weeks or longer) for selected patients to maintain a positive response.

3.4.7.2.2 Phototherapy

Light therapy or phototherapy consists of daily exposure to bright artificial light (Lam et al., 2009:417). According to Sadock and Sadock (2003:566), phototherapy is a novel treatment that has been used with patients with a **seasonal pattern** to their mood disorder. Last (2009:113) alludes to the fact that people experiencing specifically wintertime depressions often benefit from increasing their exposure to light. Phototherapy involves full-spectrum white, bright light exposure, aimed directly onto the eyes, using a light box or light visor as the source of illumination. It may be that changes in exposure to light during the different seasons mediate changes in people's mood states (Miklowitz, 2011:125). Lam et al. (2009:417, 420) do however refer to the strong suggestion that light therapy is also beneficial in non-seasonal bipolar and unipolar depression, and add that some investigators have recommended wider use of light therapy as an adjunctive treatment for non-seasonal depression. Light therapy may, however, precipitate hypomanic or manic responses in susceptible patients.

3.4.7.2.3 Sleep deprivation (wake therapy)

Disturbances in the sleep-wake cycle are cardinal symptoms of BD. Patients have a reduced need for sleep during manic episodes, while insomnia or hypersomnia is experienced during bipolar depression. It is well recognised that disruption of the sleep-wake cycle can precipitate mania. Hence, manipulation of the sleep-wake cycle has been investigated as a treatment for BD (Lam et al., 2009:422).

According to Last (2009:114), there is consistent evidence that depressed patients, including those with bipolar depression, experience an improvement in mood following a night of missed sleep. Sleep deprivation as a treatment for depression remains controversial and should only be used under the close supervision of a doctor who has prescribed it. Colom and Berk (2010:418) similarly make the point that whilst total sleep deprivation has been reported to be associated with remission in unipolar depression, its use in BD is much more controversial.

3.4.8 Psychotherapeutic/Psychosocial interventions in bipolar disorders

According to Berk et al. (2008:93), psychotherapy refers to a **process** that uses techniques and strategies designed to enhance a person's life and wellbeing. Miklowitz (2011:126) lists some of the **objectives** of psychotherapy for persons with BD as being:

- Understanding the **illness** (and the biological and genetic origins of the disorder).

- **Acceptance** and **adaptation** to a long-term medication regimen.
- Identification and development of **strategies for coping** with the illness.
- Improving of patient functioning and **family** relationships.
- Discussing long-term planning and vulnerability to future episodes.
- Dealing with **comorbid** disorders such as **substance** abuse.

The foundation of **treatment** for BD is pharmacotherapy, but it has long been recognised that most individuals either achieve only **partial** symptom control with medication or struggle to adjust to the consequences of developing a “life course illness”. The functions of psychosocial interventions for BD may be broadly conceptualised in three distinct categories, with considerable overlap. The first role is to provide basic **education** about the illness, including its symptoms, course, treatment and sequelae, both treated and untreated. A second role for such interventions is to provide **symptom relief** and prevent relapse. Finally, a third role for these interventions is to provide understanding and healing for immediate **crises**, such as disruptions in relationships and work, and to address the emotional scars resulting from episodes of illness. Developing a psychosocial treatment for BD is surely more complex than for other psychiatric disorders, given the plethora of acute clinical presentations that formally manifest as manic, mixed or depressive episodes and the fact that comorbidity, with other Axis 1 or 11 disorders, is the rule rather than the exception (Parikh & Scott, 2010:422).

Colom and Berk (2010:412) allude to the fact that despite advances in pharmacological treatment, BD (a biological illness) has **psychosocial** consequences both for the patient and the family. These factors, together with the huge gap existing between treatment efficacy and effectiveness and adherence problems, point to an urgent need to complement the available treatments for BD with some clinically-based psychological approaches. Psychotherapies that address **psychosocial difficulties** and enhance illness management (i.e. medication adherence, detection of warning signs of relapse) may play an important role in bridging the gap between symptom improvement brought about by medications and a full recovery from illness (Swartz et al., 2010:430). Parker and Ketter (2010:349) emphasise the need to address those **psychosocial factors** that **risk** exacerbating the underlying condition and “unbalancing” the individual. Thus, psychological interventions should also address psychosocial factors predisposing or precipitating an episode, and the consequences of an episode, while there can frequently be benefit in the therapist seeking to pre-empt the collateral damage that may occur with episodes or after them.

Psychotherapeutic and counselling strategies may frequently be more cogent, effective and appreciated if other relevant parties (e.g. family members and even employers) are involved at appropriate times. Psychotherapy should also seek to address and pre-empt stigma and events which are the consequence of illness, such as compromised self-esteem, demoralisation and suicide risk as well as relationship issues. The psychotherapist needs, like the patient, to be aware of early warning signs and to introduce strategies that can minimise precipitating factors and ones that work towards relapse prevention.

Psychotherapies for BD offer both specific and non-specific benefits, with the non-specific benefits (e.g. empathy, understanding, support) being substantive. Any psychotherapeutic engagement (whether provided by the prescribing doctor or by another therapist) advances the patient’s sense of being “heard” and “understood” as an individual human being, as well as being an active participant in their care (Parker & Ketter, 2010:348). The researcher considers the **psychiatric social worker** as someone who has a therapeutic role towards patients and caregivers. In practice, the work of the psychologist, social worker and occupational therapist overlaps in certain areas and it is important that the **psychiatric social worker** should earn a place in the MDT. The researcher is of the opinion that the social worker also has an important role in supporting the caregiver (spouse, parent or the person taking responsibility for the patient).

Berk et al. (2008:93) observe that a growing body of evidence supports the use of psychological interventions **in conjunction** with medication in the treatment of BD. Last (2009:115) agrees, mentioning that recent scientific studies have demonstrated powerful effects for “skills-oriented” psychological therapies. Estevez and Suppes (2009:129) complement this opinion when they state that, while pharmacotherapy is essential for effective treatment of BD, an increasing amount of evidence suggests the utility of **adjunctive** psychosocial treatments to reduce morbidity, decrease residual symptoms, enhance drug compliance, and help to prevent relapses. They also comment that high levels of critical, hostile, or emotionally over involved attitudes (high levels of expressed emotion (EE)) in parents or spouses are associated with high rates of relapse, poor symptomatic outcomes, or both. (Refer to 3.3 where this aspect was also discussed).

Although medications help with the core symptoms of the illness, they do not necessarily address the associated functional and developmental impairments and the frequent need for support and skills building. **Substance abuse** disorders and confounding **psychosocial** issues may require **additional** and specific treatments related to those problems, once the affective episode has been stabilised. Psychotherapeutic interventions are required to promote medication compliance and avoid relapses. In the literature for adult patients, psychoeducational, family and individual, interpersonal and social rhythm therapies are the best supported adjuncts to medications (AACAP, 2007:120-121). Vieta (2009:64) is in agreement with this position, indicating that psychosocial treatments with the greatest supportive evidence are psycho-education, cognitive-behavioural therapy, interpersonal and social-rhythm therapy as well as family-focused therapy (FFT).

Yatham, Kennedy, Schaffer et al. (2009:227) argue that, when used adjunctively to pharmacotherapy, psychosocial interventions such as group psychoeducation, cognitive behaviour therapy and interpersonal and social rhythm therapy have demonstrated a number of significant **benefits**. These include **decreased**: relapse rates, mood fluctuations, need for medications and hospitalisations; as well as **increased** functioning and medication adherence. Therefore, providing psychoeducation is an especially essential part of management of patients with bipolar disorder. Psychoeducation should be the essential component of clinical management of BD for all patients.

Vieta (2009:64) also includes the importance of emotional and **family support**, early identification of prodromal symptoms and coping with psychosocial consequences of past and future episodes. The researcher concurs with AACAP (2007:121) which emphasises that the ultimate judgement regarding the care of a particular patient must be made by the clinician in the light of all the circumstances presented by the patient and his/her family, the diagnostic and treatment options available and available resources.

The researcher distinguishes between:

Psychosocial/psychological interventions:

- during the **acute** phase of the illness
- during the **maintenance** phase of the illness.

There **is however**, still an overlap between interventions and it will depend on the particular patient, their particular need at any given time and the skills of the therapist, to determine which intervention will be used at a given time. Psychoeducation, for example, will be important **throughout** the illness process.

3.4.8.1 The acute phase of the illness

3.4.8.1.1 Psychoeducational therapy

The work of the **psychoeducation therapist** is to give patients the information they need so they know where they are and can decide where to go. Psychoeducation can therefore empower patients. It is an intervention whose need is obvious in the case of bipolar patients. Nevertheless, being obvious does not necessarily mean that it will be efficacious. One of the functions of the scientific method is precisely to prove the obvious and, happily, psychoeducation has abundantly demonstrated its efficacy in prevention of relapses in bipolar disorders (Colom & Vieta, 2006:xv, xi). Treatment of BD without psychoeducation can be considered inappropriate (Colom & Vieta, 2006:29).

Every good therapist is also a **teacher**, in the broad sense of the word. They help patients to understand their illness and cope with life stressors in a growth-promoting way (Zetin et al., 2010:209). The researcher has devoted a substantial section to this aspect, because it forms an integral part of the research topic. Recognition of the right of patients to be informed about their illness, and that health beliefs and behaviour influence the course of illness, has led to the development of psychological approaches based on psychoeducation to augment medical treatment (Colom & Berk, 2010:412). For Parker and Ketter (2010:349) psychoeducation is the most common non-specific component of psychotherapies for BD, highlighting the importance of education across the broad range of patients with BD.

- **Description of psychoeducation**

According to Colom and Berk (2010:412, 413), as an adjunctive treatment for BD, psychoeducation interventions go **far beyond** information. Psychoeducative interventions provide information and knowledge about the disorder as a key element, but the **mere transmission** of information about the illness does not appear to have any therapeutic effect. Psychoeducation is, rather, an information-based behavioural training aimed at assisting the person to adjust their lifestyle to cope with BD to improve outcomes, including enhancement of illness awareness, treatment adherence, early detection of relapse and avoidance of potentially harmful factors such as illegal drugs and sleep deprivation. Hence, psychoeducation is an intervention that involves good medical practice and seeks to empower the patient with **tools** that allow him or her to be more active in his or her own therapy process. Optimally, this involves a change of paradigm, from the excessively personal psychiatric or psychological involvement, to a therapeutic team approach.

Haycock (2010:xiii) defines **psychoeducation** as the education offered to people who live with psychological disturbances. Baumann (2007a:477) considers that psychoeducation differs from cognitive-behavioural therapy in that it does not aim to modify beliefs but rather to impart information to **patients** and **families** in order to help them cope more effectively with the illness.

Berk et al*.* (2008:96) state that **group psychoeducation** has shown good results in reducing bipolar relapses, and psychoeducation may be offered on an individual, couple or family basis. The Canadian Network for Mood and Anxiety Treatments cited in Vieta (2009:50) refers to *robust psychoeducation,* which would include preparing the patient to become actively involved in self-management. The researcher supports this notion, because the patient cannot just be a passive bystander in her or his own life.

- **Aims (goals) of psycho-education**

As for any chronic medical or psychiatric condition where “control” is the objective other than “cure”, education is fundamental. It is the **right of the patient** to be informed about his/her condition, management options and factors that can influence the outcome. There is a **dislocation** process that follows the impact of receiving a diagnosis of a “bipolar disorder” and the therapeutic aim of the education here is to progressively advance the patient’s **sense of mastery** over his/her condition, to ensure that he/she is **not defined by the condition** and that he/she can learn ways to bring it under greater control (Parker & Ketter, 2010:348).

Haycock (2010:xiii) furthermore states that the **goal** is to help the patient understand and be better able to deal with the illness. Vieta (2009:96), Berk et al. (2008:95) and NIMH (2010:7) are in agreement that psychoeducation aims to provide patients with a theoretical and practical approach to understanding and coping with the consequences of their illness. This treatment helps people recognise **signs of relapse** so that they can seek treatment early, before a full-blown episode occurs. It is usually imparted in a group and may also be helpful for family members and caregivers.

As Colom and Vieta (2006:25) state, the primary purpose of any treatment, whether psychological or pharmacological, should always be the curing of a disorder, or at least an improving of the symptoms. The usefulness of long-duration group psychoeducation with patients includes:

- Reduction in number of episodes of both polarities and their severity and as a result, a reduction in the number of hospitalizations (prophylactic effectiveness).
- Improvement in quality of care.
- Learning the importance of early detection of the warning signs of mania.
- Avoiding the pathogenic model of relationship between a “healing” physician and a passive patient. Instead, it provides an appropriate therapeutic alliance based on collaboration, information and trust.
- A psychoeducated patient ceases feeling guilty and instead feels responsible. This step is the beginning of accepting the need for treatment.
- As psychoeducation sessions progress and the patients understand their disorder, they experience the growing sensation of being understood.

Psychoeducation helps to reinforce the patients’ own strengths, resources, and coping skills, so they can become **active participants** in their health and well-being. In addition, **friends and family** members are frequently confused about what is happening to their loved ones. Often, the normal, supportive responses are not helpful, and families are afraid to say or do “the wrong thing”, thereby potentially making things worse. They wonder what went wrong, what they can do to help, and what the future holds for the patient (Haycock, 2010:xiii).

- Mechanisms of action of psychoeducation.
- According to Colom and Vieta (2006:30) the action mechanisms of psychoeducation may be described as functioning on three levels:
- At the **first level**, one finds those basic mechanisms that comprise partial objectives *per se,* those mechanisms whose lack of fulfilment leads one to say simply that psychoeducation has not worked. They include providing the patient with an adequate awareness of their disorder, improving pharmacological adherence and facilitating early detection of new episodes.
- At the **second level**, there are second-order mechanisms, desirable partial objectives that are nevertheless not the exclusive responsibility of the psychoeducational programme. They include aspects such as controlling stress, avoiding substance abuse and use, achieving regularity in lifestyle and preventing suicidal behaviour.
- Desirable objectives considered part of an “excellent scenario” are found at the **third level**. These objectives are achieved once the previous levels have been covered, such as improving social and interpersonal activity between episodes and increasing well-being and improving the quality of life.

- **Treatment for patients as well as caregivers**

As was mentioned above, the AACAP (2007:120) also states that information should be provided to both the **patient and their family**, regarding the symptoms and course of the disorder, treatment options, the potential impact of the illness on psychosocial and family functioning, and the heritability of the disorder. Kowatch et al. (2005:16) concur with this position, stating that families can benefit greatly from sessions with a professional who can help them to recognise symptoms, learn problem solving skills to manage these, and develop stress reduction strategies necessary for family preservation. As said earlier, BD tends to be a chronic illness such as diabetes and epilepsy, so that when a therapeutic alliance is formed the families can experience tremendous support.

Historically, little information of any kind was given to caregiving relatives when the patient left the hospital. Families have a burning desire to know all they can about the strange disorder called “mental illness” (Hatfield, 1987b:201). This has also been the researcher’s experience (twenty years ago) raising the question of how families can assist and support the patient if they know nothing.

Colom and Berk (2010:413) are other experts who declare that psychoeducation can be aimed at caregivers, as they could be crucial in reinforcing the patient’s positive behaviour towards the illness. This approach views the individual as interacting in a dynamic ecological system, and recognises that the illness affects **more than** the patient alone. The burden of oddness extends to the family. There is evidence that stressful events inside the family environment are often related to exacerbations of BD; EE has been described as an important predictor of relapse. Thus, **BD affects family relationships, and family relationships affect BD**.

Swann (2010:309) emphasises that if the **family** or those close to the patient do not understand the illness and its need for treatment, successful treatment is difficult, if not impossible. An increased burden for family members is related to poor understanding of the illness, more than to severity, and predicts a poor outcome. He also considers that perhaps the most cost-effective approach is **caregiver group psychoeducation**, educating and supporting caregivers - thereby reducing the caregiver burden in BD. The researcher strongly agrees with this statement, hence the rationale for her study.

- **Different settings**

Psychoeducation may be conducted in different settings involving individuals or groups. Individual patient psychoeducation in BD has been used as a standalone, adjunctive psychosocial intervention when health behaviour targets are very specific; for example, to teach people to respond to early warning signs. In the delivery of psychoeducation, many interventions actively engage the social milieu. People are considered to exist within a social context that influences their perceptions, attitudes and behaviour. For this reason, and since it is cost-effective, psychoeducation is sometimes conducted with patients in a group format where mutual support and acceptance reinforce the use of positive health behaviour (Colom & Berk, 2010:413).

According to Haycock (2010:91), several studies conducted in Spain showed that people who attended programmes that educated patients about BD experienced fewer recurrences over 2 years. These helped them maintain regular lifestyles, which are less likely to promote mood episodes, and it enabled them to spot symptoms early on, which in turn allowed them to seek treatment and head off or limit episodes. Colom and Vieta (2006:14-21) mention that group therapy, specifically the **psychoeducational** approach, is the best strategy if patients are to adequately manage their disorder and improve their social and interpersonal adjustment.

- **Evidence-based psychoeducational approaches**

A few significant findings of studies as reported by Colom and Berk (2010:413-416) follow:

- Teaching patients to recognise the early symptoms of manic relapse yields important **clinical gains**.
- Group psychoeducation has shown its efficacy, even in those patients whose disorder is made more complex by a comorbid personality disorder.
- Integrated care, including psychoeducational contents, has also been shown to be effective for bipolar patients with **substance dependency**.
- Group psychoeducation is the first psychotherapeutic intervention for BD that shows **long-term efficacy**.
- Apart from the evident clinical benefits, **cost-efficacy** issues need to be considered. A recent study has shown that group psychoeducation saves health resources and expenses, particularly those related to hospitalisations.

These randomised, controlled trials of individual, group and family/caregiver interventions involving psychoeducation have transformed the traditional medical treatment of BD. They have emphasised that actively informing patients and caregivers/families, as well as training them in constructive ways of dealing with BD, is an essential part of good medical treatment.

- **Limitations of psychoeducation**

According to Colom and Berk (2010:416) psychoeducation is not effective as a monotherapy, which means that it should always be considered as an add-on to pharmacotherapy and that family/caregiver based therapies are not always practical (about 40-60 % of bipolar patients, depending on the cultural context, are not residing with their family). Another limitation is that generally, psychoeducation based interventions are not effective in treating acute episodes, but only in **preventing** them. The researcher is, however, of the opinion that psychoeducation with caregivers should start immediately, even though the patient might still be acutely ill.

- **Ingredients of psychoeducation**

Colom and Berk (2010:416) list a number of **core** psychoeducation ingredients that have been applied with different emphasis in many psychosocial interventions. The main areas covered in psychoeducation for BD include illness awareness, treatment adherence, identification of early warning signs, avoidance of substance misuse and regulation of habits.

In conclusion, Colom and Berk (2010:419) are quite clear that there has been considerable growth in evidence-based adjunctive psychoeducation treatments for BD. They argue that the evidence to date suggests that there is increasingly effective help for people and families affected by BD.

3.4.8.1.2 Family-focused therapy (FFT)

After reviewing the relevant literature, the researcher has come to regard the late Michael Goldstein and David Miklowitz as the originators of FFT (Miklowitz, 2008:ix). They developed a psycho-educational intervention, which they entitled Family-Focused Treatment. This therapy is also mentioned in chapter seven that discusses programmes. Miklowitz (2008:7-1) defines the **objectives** of FFT as follows:

- Assist the patient and relatives in integrating the experiences associated with episodes of BD.

- Assist the patient and relatives in accepting the notion of a vulnerability to future episodes.
- Assist the patient and relatives in accepting a dependency on mood-stabilising medication for symptom control.
- Assist the patient and close relatives in distinguishing between the patient's personality and his/her BD.
- Assist the patient and family in recognising and learning to cope with stressful life events that trigger recurrences of BD.
- Assist the family in re-establishing functional relationships after the episode.

Miklowitz (2010b:443) points to the importance of considering the family or marital context when understanding the symptomatic fluctuations and functional consequences of BD. If nothing else, BD creates **havoc and emotional pain for family** members, to the point where they develop health and mood problems themselves. The compromised emotional state of some caregivers can have a negative influence on the patient's course of illness. On the other hand, a spouse or parent who develops an **understanding** of the nature, course, triggers and treatment of the disorder may help create a milieu which helps protect the patient against recurrences.

FFT consists of **three stages**: **psychoeducation** about the nature, aetiology, treatment and self-management of BD; **communication** enhancement training in which patients and caregivers rehearse effective speaking and listening skills; and **problem-solving** skills training, in which patients and caregivers define problems, generate and evaluate solutions and implement solutions to specific conflicts in the family. FFT is considered adjunctive to pharmacotherapy, not a substitute for it (Miklowitz, 2010b:444).

Other authors have also commented on FFT. Vieta (2009:98) describes FFT as being similar to psychoeducation, but mentions that FFT places greater emphasis on achieving the support and cooperation of family and caregivers as integral components of successful treatment. According to Last (2009:121), FFT was originally designed to strengthen social support and reduce "expressed emotion" that consists of critical, hostile, or over involved attitudes and behaviours that family members may exhibit toward the ill individual. The heart of the therapy is educational.

Berk et al*.* (2008:99) contend that FFT is an inclusive approach that involves the person with BD, as well as members of their family. The **aim** is to strengthen healthy interaction and support between family members and to help resolve any existing conflict in the family. The family works together to prevent relapses. FFT helps enhance family coping strategies, such as recognising new episodes quickly and helping their loved one (NIMH, 2010:7). According to Last (2009:122), recent results from a large-scale multisite investigation of the treatment of BD showed that FFT was as effective as other skills-oriented therapies, including CBT and IPSRT (refer to 3.4.8.2.1). FFT is effective in stabilising bipolar mood symptoms and delaying recurrences and rehospitalisation. It also appears to benefit family relationship functioning. Combining family psychoeducation with pharmacotherapy has broad effects on patients' symptoms (time to recovery, time to recurrence, symptom severity) and psychosocial functioning (Miklowitz, 2010b:477, 448).

BD significantly affects social and family functioning. Psychosocial interventions are required to address the myriad of disruptions that emerge in the wake of the disorder. Efforts to enhance family and social relationships, including therapies directed at communication and problem-solving skills, are likely to be helpful. Cultural issues must be taken into account when devising psychotherapeutic strategies (AACAP, 2007:120).

It is clear that a psychiatric social worker can apply the principles of this therapy and sessions can even be conducted with a co-therapist such as an occupational therapist.

3.4.8.1.3 Genetic counselling/Education

There is substantial evidence that supports the role of genetic factors in major psychiatric disorders. Clinicians are increasingly confronted with questions from patients and families regarding **risks** of disorders for themselves or their children. Genetic counselling has been **defined** as "a communication process which deals with the human problems associated with the occurrence or the risk of occurrence, of a genetic disorder in a family" (Finn & Smoller, 2006:109).

Peay, Veach, Palmer, Rosen-Seidley, Gettig and Austin (2008:7, 8, 16) point out that psychiatric disorders are complex, fraught with diagnostic ambiguity and phenotypic variability and that they engender feelings of stigma. The uncertainty associated with psychiatric disorders poses challenges for genetic counsellors, because the current state of science does not allow the provision of conclusive information regarding aetiology, risk, or consequences of the disorder on any given individual or family. Despite the many sources of uncertainty, it is important not to underestimate the potential importance of genetic counselling for families affected by mental illnesses. An understanding of the cause of the illness may be an important component of successful adaptation to that illness or to the risk of the illness. Genetic counsellors are able to:

- Help clients to better understand the cause of the mental illness in their family.
- Provide a safe forum for clients to discuss their experiences of living with mental illness in the family and concerns for others in the family.
- Help to recognise when psychiatric disorders within a particular family may in fact be syndromal.
- Discuss the range of disorder phenotypes, especially related to signs for which to watch in young people in the family, and the importance of early intervention.
- Help clients manage the uncertainty surrounding **risk** in offspring.
- Co-counsel with a mental health professional who can suggest appropriate follow up.

In conclusion, sometimes those who have a family member with BD wonder if there is some chance that they might also develop BD. Unfortunately it is an unavoidable truth that currently there are very few genetic counsellors or mental health professionals who specialise in this type of service provision. Austin, Palmer, Rosen-Seidley, Veach, Gettig and Peay (2008:28) do emphasise that psychiatric genetic research is progressing rapidly so that our understanding of the contributions of genes to the development of major psychiatric illness will continue to develop. However, for the time being, the single greatest known risk factor for developing a psychiatric disorder is having a positive family history.

3.4.8.1.4 Substance abuse treatment

According to Last (2009:188) and Haycock (2010:06) substance abuse is extremely prevalent among people who have bipolar disorder, appearing at some time during the course of the illness in at least 60 % of individuals who are so diagnosed. Last (2009:192) gives the following descriptions:

Substance abuse: recurrent significant negative consequences from repeated use of substance; does not meet criteria for substance dependence.

Substance dependence: Repeated use of the substance results in the development of tolerance, withdrawal, and compulsive drug-taking/drug-seeking behaviour.

Alcohol is commonly used by bipolar people to **self-medicate** both in manic and depressive episodes; although research indicates it is more commonly used during manic or mixed states. Alcohol compromises the efficacy of pharmacological treatments and dramatically increases the risk of suicide. In addition to alcohol, bipolar people may use street drugs or abuse prescription drugs to self-medicate and “manage” their moods (Last, 2009:188, 192).

Haycock (2010:67) emphasises that substance abuse **treatment** will be necessary if a person is addicted to or abuses drugs, including alcohol. These substances prevent the medications from working properly and can promote bipolar symptoms. Last (2009:191) suggests that those who have a **dual diagnosis** (BD and alcohol abuse or dependence) can attend a 12-step programme such as Alcoholics Anonymous or receive individual therapy. It might also be that a person needs a residential programme; however, it is important that the specific programme deals with people who have dual diagnoses. It has been the researcher’s experience that it is difficult to access substance abuse **treatment** for psychiatric patients, because treatment centres would first want the psychiatric condition to be stable before starting their treatment and vice versa.

Lastly, Miklowitz (2011:177) warns that if a patient uses alcohol and/or drugs, the patient is likely to become inconsistent as regards his/her medication regimen and will encounter more difficulty becoming stable as a result. Worst of all, alcohol and drug use puts a patient at a much greater risk for committing suicide.

3.4.8.1.5 Problem-solving therapy

The central premise of problem-solving therapy is that weak problem-solving skills lead to vulnerability and depression (Zetin, et al., 2010:213). The researcher is of the opinion that this lack can lead to any mood **instability** (even becoming irritable). Life problems are more challenging when one is depressed, and acquiring the skills to deal with problems helps to increase a sense of **self-control**, which may prevent depressive recurrences. The goals of treatment are to link depression to problems in living; for example, defining and setting realistic goals for dealing with the problems and teaching a structured procedure for problem solving that leads to positive experiences. Multiple solutions are evaluated and compared, and after a feasible solution is chosen and implemented, the outcome is evaluated. Generally, a person will experience several problems during his/her life. In such cases, it is best to establish a hierarchy and start with easier problems in order to build positive success experiences.

Miklowitz (2011:279) notes that BD sometimes generates **practical** problems which need to be addressed as a family or couple, particularly in the aftermath of an illness episode. These can include financial problems, difficulties related to resuming work or family roles, problems relating to the treatment or medications, or relationship and living situation conflicts. Often, these unresolved but relatively specific problems fuel relatives' expressions of criticism or resentment. The researcher has experienced that if the therapist can help direct conversations with family members toward identifying and solving specific problems, there will be less tension during the recovery period.

3.4.8.1.6 Crisis intervention

In practice, it does happen that a patient becomes psychotic and/or aggressive or may threaten suicide or homicide. The MDT then needs to act immediately, even involving the police if necessary, and arrange admission to the hospital.

3.4.8.2 The maintenance phase of the illness

Estevez and Suppes (2009:108) hold the view that there has been a recent shift among clinicians in the focus of treatment for BD, from simply treating a manic or depressed phase acutely, to a long term approach that incorporates psychopharmacological, psychosocial, familial factors, and the consideration of comorbid medical conditions. According to DSM-IV, 2 months of sustained recovery is considered sufficient for remission, and this is where the maintenance therapy phase begins. The researcher also believes that the maintenance phase is very important, because if aftercare services are not provided, patients are very quickly readmitted to hospital. The clinician must recognise the chronic relapsing nature of the disorder.

The basic **goals of maintenance treatment** include prevention of relapse and recurrence, reduction of sub-threshold symptoms, suicide risks, affective cycling, mood instability, reduction of social and vocational morbidity and promotion of wellness (Kowatch et al., 2005:13).

3.4.8.2.1 Individual psychotherapy and group therapy

Individual therapy is considered for maintenance rather than as treatment for an acute episode. A patient should find a psychotherapist who can work in a **cognitive-behavioural** or an **interpersonal** framework. These are the two types of individual therapy that have garnered the most research support in terms of improving the course of BD when given alongside medications (Miklowitz, 2011:129).

- **Cognitive-behavioural therapy (CBT)**

CBT is a mode of treatment based on the concept that certain unhelpful types of **thoughts** and **behaviours** can trigger, escalate, and lengthen mood episodes. CBT focuses on the interplay among thoughts, behaviours, and **emotions**. The **cognitive** component helps people learn how to identify and then challenge their unhelpful, distorted thoughts and beliefs. The **behavioural** component of CBT could contain a number of techniques that may be useful to those with bipolar disorder. Education about bipolar illness is presented, after which people monitor their moods every day and learn to be **vigilant** for their own idiosyncratic early warning signs of impending mood episodes. Other important components of the behavioural aspects of treatment include making lifestyle modifications, such as maintaining good sleep hygiene, keeping a regular routine or daily schedule and identifying and controlling cues and triggers of mood episodes. CBT is recommended for people who are relatively stable following an episode of illness (Last, 2009:115, 116, 117). Application of CBT during acute **mania** is not recommended. Data on the utility of CBT during acute bipolar **depression** is only now beginning to emerge (Parikh & Scott, 2010:422).

Other experts recommending CBT for people with BD include NIMH (2010:7), Haycock (2010:89) and Berk et al. (2008:96), all of whom make the point that the cornerstone of this approach is to alter particular thought patterns and beliefs that may negatively change behaviour and increase the risk of developing or worsening a patient’s mood. CBT can help the patient recognise and manage potential mood-episode **triggers**. NIMH (2010:7) reminds the therapist that the number, frequency and type of sessions should be based on the treatment needs of each person.

Despite the fact that many experts recommend CBT for people with BD, Vieta (2009:96) reports that one of the largest studies could not prove any advantage of CBT over the usual treatment as regards relapse rates. CBT was even harmful in patients who had experienced 12 or more episodes in their lifetime. Parikh and Scott (2010:425, 426) also state that CBT in BD is currently a generic, non-specific psychoeducation intervention that incorporates some cognitive and behavioural techniques, not a specific empirically driven approach based on a cognitive formulation and primarily focused on cognitive style and processing. They conclude that CBT is of limited value to the average bipolar patient. In summary, there is conflicting evidence supporting the use of CBT in BD.

- **Mindfulness-based cognitive therapy (MBCT)**

Berk et al. (2008:102) includes meditation techniques through which people are taught to become aware of sensations, thoughts and feelings, and to change their typical automatic responses to them. For people who have experienced a number of unipolar depressive episodes, these techniques may be useful in managing depressive thoughts and feelings.

- **Dialectical behaviour therapy (DBT)**

DBT was developed for the treatment of **borderline personality disorder**, but because BD shares some of the key features of the latter disorder, the treatment is now being used increasingly for those with BD. The treatment uses some of the same methods for change that are part of the traditional CBT, but also includes a focus on “acceptance” - teaching the bipolar person how to accept emotional states and circumstances that can’t immediately be changed. The treatment focuses much attention on methods for eliminating impulsive, mood-dependent, high-risk behaviours (Last, 2009:118, 119).

- **Interpersonal and Social Rhythm Therapy (IPSRT)**

Diverse authors, such as Miklowitz (2011:130), Berk et al. (2008:100), Haycock (2010:89, 90), NIMH (2010:7) as well as Colom and Vieta (2006:14-21) discuss the use of Interpersonal and Social Rhythm Therapy (IPSRT) for BD patients. Colom and Berk (2010:418) declare that **regular habits** and **stress management** are extremely important in BD and constitute the foundational ingredient of IPSRT. Moreover, developing regular habits and routines by means of IPSRT is efficacious in preventing recurrence of episodes in bipolar patients. Sleeping and social-rhythm disruptions have mood-destabilising effects.

Miklowitz (2011:130) explains that this is a form of interpersonal therapy that includes monitoring sleep-wake rhythms, patterns of daily activity, and levels of daily social stimulation. It was shown to delay recurrences of BD and increase the stability of daily routines and sleep-wake cycles. IPSRT is a tool to facilitate a full recovery from illness and promote long-term wellness. It integrates psychoeducational, interpersonal, and behavioural strategies in order to reduce symptoms, improve functioning and prevent recurrence of episodes. IPSRT fuses three distinct interventions - psychoeducation, social rhythm therapy and interpersonal therapy - into a single psychosocial treatment (Swartz et al., 2010:430, 431). Regular daily routines and sleep schedules may help protect against manic episodes (NIMH, 2010:7).

IPSRT was specifically created to treat BD. It concentrates on improving relationships with others and organising or managing daily routines, including sleep schedules. Since lack of sleep and disrupted daily rhythms can trigger or worsen the severity of mood episodes, IPSRT encourages patients to establish and maintain **regular** eating, sleeping, working and relaxing routines while improving skills for **interacting** with others (Haycock, 2010:89, 90).

According to Berk et al. (2008:100) IPSRT emphasises the role of interpersonal relationships in mental wellbeing. It recognises the role of **loss and grief** in dealing with BD, and offers clients the opportunity to express this and develop personal ways of adjusting. The other key element of IPSRT in dealing with BD relates to the patterns of daily life, our *social rhythms.* This approach emphasises how a disruption of regular social rhythms can trigger an episode of illness. There is evidence that regular day-night (**circadian**) rhythms are important in maintaining stable mood in BD (Chapter 2, section 2.3.4.3 refers). The DSM 5 (2013:390) contains a specific section discussing Circadian Rhythm Sleep-Wake disorders.

The patterns of daily life include such factors as the time we get up and go to bed, and our usual activities, such as going to work or a regular morning meeting with friends. People involved in this therapy are encouraged to monitor their sleep/wake cycle (circadian rhythm), patterns of daily activity and levels of daily stimulation, such as the number of people with whom they come into contact. This allows them to regulate their daily patterns so their mood is not disrupted. Haycock (2010:90) also makes it clear that one of the techniques on which this individual therapy relies is self-monitoring. Its value lies in preventing episodes, more than in speeding recovery from them. To help stabilise their daily routines, people are asked to record their mood states, events, activities and level of social stimulation each day on a "social rhythm" chart (Last, 2009:120).

Swartz et al. (2010:440) report that the current research suggests that IPSRT successfully promotes rhythm stability, and when used as an **acute** treatment leads to decreased likelihood of affective episode recurrence, increased occupational functioning, and quality of life when compared to clinical management interventions. The researcher contends that the patient must be apsychotic and stable before this therapy is applied. It is nonetheless a relevant therapy, because BD patients need routine and structure to their day and in their life to be able to function optimally. This is an advantage of hospitalisation, because **in the hospital** there are strict routines. Patients and caregivers should be encouraged to continue monitoring the patient's rhythms and patterns of daily activity when he/she is at home and if any disturbance to the pattern is noticed, they should report it to the MDT. The "social rhythm" chart can be a valuable tool; it is something concrete to use when discussing a complex situation.

- **Group therapy**

As Zetin et al. (2010:216) describe it, group therapy provides treatment in a format with one or more therapists and six to ten participants, often suffering from related problems. The participants improve not only from the interventions of the therapist, but also from observing others in the group and receiving feedback from group members. In social work, this is one of the basic methods being used.

Many people benefit from **educational support groups**. In groups, people with BD get together and discuss feelings, attitudes, and experiences related to the disorder; sometimes the groups are educational and skill orientated, and at other times they are free form (Miklowitz, 2011:131). Groups might be solely for people with BD, for family and friends or for both people with BD and their significant others (Haycock, 2010:97). The researcher has experienced that this mode of treatment may be utilised with patients as well as caregivers, on an inpatient as well as outpatient level. The group format offers several advantages, including the fact that it provides support; for psychoeducation, it is also cost effective and provides feedback from different perspectives as well as the opportunity to learn from others; also, new behaviours can be tried out in the safety of the group.

Grimbly (2010:209) holds an interesting view: that in social work the practitioners are constantly confronted by situations in which complex tasks may be completed, whilst balancing individual needs and risks within systems comprising configurations of many **groups**. Each assessment of an adult with mental health problems, for example, takes place within a group context of family, social network, MDT and so on. The work may be facilitated or hindered by the unconscious, or unexpected, dynamics of the various groups. For an advanced practitioner, a willingness to explore and reflect on these processes as an individual worker and within groups may be crucial in ensuring that the service user is offered practice that is containing, thoughtful and constructive.

3.4.8.2.2 Relapse prevention (also refer to 3.3)

Education should be provided to the patient and family regarding the impact of noncompliance with medication, the recognition of emergent relapse symptoms, and other factors that may precipitate relapse (e.g. sleep deprivation, substance abuse). Stress reduction and the promotion of stable social and sleep habits may be particularly helpful areas to target. Medication noncompliance is a major contributor to relapse. Therefore, efforts must be made to educate both the patient and family about the importance of ongoing treatment as well as dealing with the psychological resistance to taking medication. Establishing a strong therapeutic relationship and providing regular follow-up assessments are important in maintaining compliance (AACAP, 2007:120). It is important to develop **relapse prevention plans** - the patient (and caregiver) should know his/her moods, triggers and warning symptoms and develop a healthy lifestyle to enrich the quality of life (Berk et al., 2008:94).

3.4.8.2.3 Diet and Exercise

Poor physical health may require a person to take medications that interfere with BD medicines. Besides avoiding drugs and alcohol, diet and exercise are two of the most straightforward ways to increase the odds of their regaining and maintaining health. Walking is exercise - a half hour per day can improve one's heart rate, muscle tone, and disposition (Haycock, 2010:94, 96).

3.4.8.2.4 Spirituality

Spirituality has many meanings - a religious belief, a non-denominational philosophy or an attitude. Whatever form it takes, it will not cure or control bipolar illness, but a spiritual orientation that satisfies a patient's needs might give that patient strength to help him/her deal with this disorder. The patient and caregiver should avoid spiritual groups or practices that claim that mental disorders can be "cured" through non-medical means. Unproven alternative treatments that promise a cure are unethical and can lead to unfortunate consequences when a patient not only suffers a relapse but is made to feel weak or ashamed for having failed (Haycock, 2011:98). The researcher has experienced that patients are very vulnerable and sometimes feel **guilty** about having become ill or about receiving treatment (a sign of disbelief in God). It has happened that patients have thought that they are God or His son or even Mary. Such delusions can be very disturbing to the caregivers; usually the patients are grateful for being "chosen". The pastor/minister/priest/faith leader working with such patients should preferably have or acquire knowledge of psychiatric disorders. It remains important that the therapist should always respect a patient's spiritual background.

3.4.8.2.5 Self-help/Support groups

Bipolar patients who have achieved a level of mastery value highly the lessons which they have learned and introduced **themselves** that keep their mood states in check. This points to the need for individuals with BD to recognise "self-management" as a singularly distinctive factor – that it is central to bringing the condition under control or "into balance", and needs to be encouraged by the managing clinician (Parker & Ketter, 2010:349).

Last (2009:124) also points out that bipolar self-help groups can be very useful as an adjunct to skills-orientated psychological treatments. **Family support groups** are a suitable place to interact with other partners of bipolar people. The researcher has often attended a particular bipolar support group (SADAG) which meets once a month in the evenings and has always found it most informative. The group is run by somebody who has been diagnosed with BD. Each group will, however, be different. Patients and caregivers should be encouraged to attend such groups, because it extends their support network. **Social workers** can also start such groups, but then these should not depend on the social worker - they should "belong" to the patient system.

Spaniol, Jung, Zipple and Fitzgerald (1987:169) report that not only must family members learn how to cope with their disabled family member; they must also learn how to cope with **mental health professionals**. Families have reported that service providers are not always helpful and can be negligent in encouraging families to be part of the treatment process. As a result, some families rarely turn to professionals for help, but seek support and guidance from self-help groups. In addition, self-help groups may be able to meet needs such as the desire to share problems with people who are experiencing similar difficulties, to perform advocacy functions, and to receive practical information, all of which professionals are often unable to meet.

Hatfield (1987b:199) states that there is considerable agreement among social scientists as to the ways in which self-help groups benefit their members:

- Members serve as role models to each other.
- Help giving is reciprocal and inherently therapeutic.
- Opportunities for learning are provided.

3.4.8.2.6 Wellbeing plans

Parker and Ketter (2010:350) refers to patients with BD II as having wellbeing plans, but the researcher considers that BD I patients can also benefit from this concept. There is no uniform format for a wellbeing plan. It may range from a private decision by an individual to adopt a certain strategy, through to a formal document drawn up by an individual to consult family, friends and health professionals. A primary consideration is "what will work best for the individual involved?" The individual needs to feel confident that the plan will serve their particular interest and circumstances, both in the short and the long term. Wellbeing plans should incorporate experiences from the past, identify early warning signs and triggers, set out action plans for minimising or preventing future episodes, and include QoL commitments to advance the individual beyond the goal of merely "managing" episodes.

According to Colom and Berk (2010:412) **suicide risk** is still a common complication of BD (2.5.12.2 refers) with rates ranging between 15 and 25 %; therefore, the researcher is of the opinion that suicide prevention should also form part of the wellbeing plan.

3.4.8.2.7 Vocational training and Occupational support

Vocational training and occupational support may also be important needs to address (AACAP, 2007:120). In the context of the researcher's workplace, this is an important task of the occupational therapist. However, the **social worker** does also play a coordinating and a facilitating role as regards the employer.

3.4.8.2.8 Delivery system design

Part of the chronic disease management model is to provide clinical care and self-management support that patients understand and that fits with their cultural background. The care team should ensure regular follow-ups, with defined tasks for different team members (Vieta, 2009:51).

3.4.8.2.9 Internet-based psychosocial treatment

An interesting development in evidence-based psychological approaches is the establishment of increasingly more sophisticated internet-based psychosocial treatment alternatives used in a wide variety of illnesses. The idea of internet interventions is to enable patients to easily access treatment interventions in the privacy and convenience of their own homes, to overcome distance, time and cost restraints, and the perceived stigma sometimes connected to participating in face-to-face interventions (Colom & Berk, 2010:416). In the South African context, however, there are still many patients and caregivers that do not have access to the internet and the researcher also has reservations about the reliability of some information accessible on the internet. In addition, the internet offers no therapeutic relationship.

3.5 THE ROLE OF THE SOCIAL WORKER IN THE PSYCHIATRIC HOSPITAL

Mental health needs to become fully integrated into all aspects of general healthcare as part of the comprehensive primary healthcare approach, in recognition of the fact that all health problems are interrelated and moreover, are frequently perpetuated by **psychosocial** pathology and the stigma attached to mental illness. Social work employs a developmental approach that seeks to empower those who are socially disadvantaged. There are various **roles** that a social worker may adopt towards this end. These roles fulfil the functions of resource management (e.g. community networker), caring and protection (e.g. encourager), education (e.g. trainer), development (e.g. social planner), healing and restoration (e.g. therapist) (Smith, 2007:637, 640).

It has been mentioned that the social worker applies different psychosocial **interventions** during the **acute** and **maintenance** phases of the bipolar illness. Certainly, psychosocial interventions should be considered as important adjunctive therapies that complement treatment with medication for persons with BD (Buila, 2009:583).

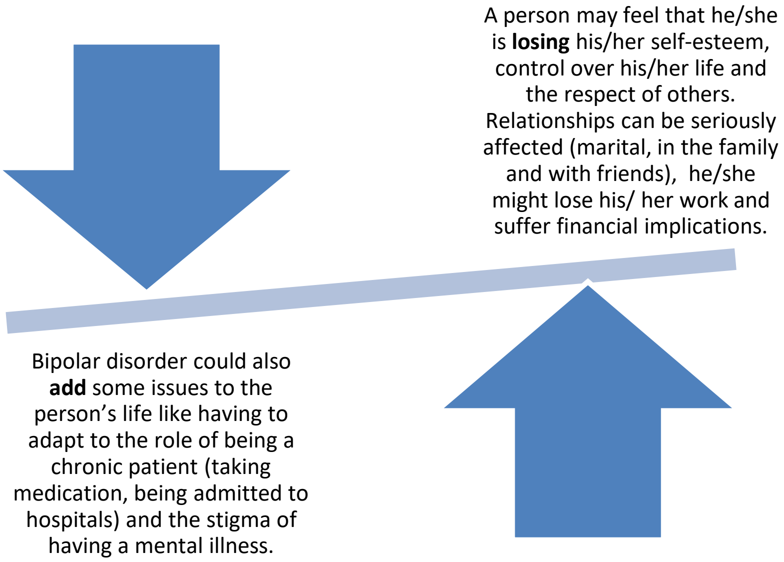


Figure 3.1: Graphically illustrates the effect of BD on the patient - losses and unfortunate additions (Source: Researcher)

In practice, the researcher has experienced that patients suffer losses as a result of BD, but the disorder also adds challenges to the patient's life. The losses from and additions to the person's life can, of themselves, contribute towards mood instability.

Trails have indicated that social work is at least as effective as psychological or pharmacological approaches to mental health problems. However, the evidence base for social interventions that are at the disposal of mental health social workers is small, incomplete and disproportionate in size to that available to psychologists or psychiatrists (Webber, 2010:108, 111).

The social worker in the psychiatric hospital works within the **framework** of basic social work methods of casework, group work and community work. Hence she or he must **assess** the patient’s situation on an ongoing basis. Psychosocial assessment and intervention form part of the rehabilitation process for those whose mental illness or disability impairs their ability to function in society (Smith, 2007:639). The researcher has developed an **assessment guideline** (**Appendix 3.1** to aid in this process).

The patient should be encouraged to learn all he/she can so he/she can take charge and control to the fullest extent of his/her ability.

It is important that the social worker take cognisance of the reasons for high readmission rates. The researcher agrees with Smith (2007:644, 647) that these might include lack of knowledge and insight, substance abuse, violence and high-risk behaviours, lack of support, lack of resources, inadequate or disorganised care pathways and non-adherence to treatment. Psychosocial stressors also play an important role.

All the members of the MDT strive towards improving the psychosocial function of the patient while in hospital and after discharge. Good **aftercare** may serve as **preventing relapses** and **readmissions**. It has been the researcher’s experience that it is primarily the social worker in the team who reaches out to and supports the **family/caregiver**. It has long been established that family interventions which reduce EE within households also reduce the likelihood of relapse or hospital admission for people with psychosis (Webber, 2010:112).

In **Figure 3.2** it is indicated that intervention is not a linear process - it is circular: **good aftercare = prevention of relapse**. Both the social worker and client system (patient and caregiver) should most definitely acknowledge the risks and protective factors, trying to **minimise** the former factors and **maximise** the latter.

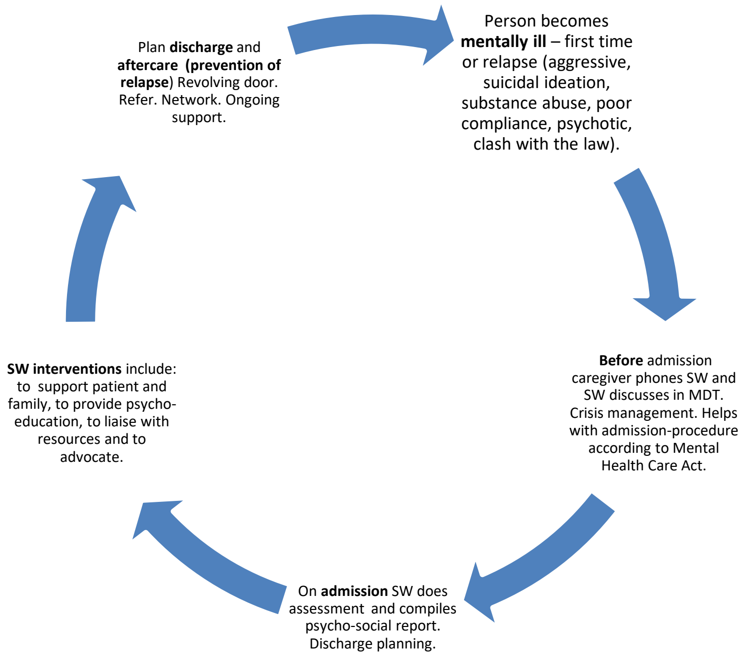


Figure 3.2: **Biopsychosocial model - within ecological framework (Source Researcher)**

Table 3.2 provides an overview of risk and protective factors in BD. Once the client system is aware of these factors, its members can take co-responsibility for the patient to obtain and retain stability. The social worker can contract with the client system in deciding on which priority areas to work; by acknowledging the client system's role in this manner, empowerment should occur rather than the creation of a dependency relationship. The client system must know there are choices, but along with choices, there are consequences.

Table 3.2: **Risk and Protective Factors in BD (Miklowitz, 2011:157) Risk factors that increase chances of becoming ill**

RISK FACTORS	EXAMPLES
Stressful life changes	Loss of job, gaining or losing a new relationship, birth of a child
Alcohol and drug abuse	Drinking binges; experimenting with cocaine, LSD, or Ecstasy; excessive marijuana use
Sleep deprivation	Changing time zones, cramming for exams, sudden changes in sleep-wake habits
Inconsistency with medications	Suddenly stopping mood stabilisers, regularly missing one or more dosages

RISK FACTORS	EXAMPLES
Family distress or other interpersonal conflicts	High levels of criticism from a parent, spouse, or partner; provocative or hostile interchanges with family members or co-workers

Table 3.3: Protective factors that may prevent the patient from becoming ill

PROTECTIVE FACTORS	EXAMPLES
Observing and monitoring one's own moods and fluctuation triggers	Keeping a daily mood chart or social rhythm chart
Maintaining regular daily and nightly routines	Going to bed and waking up at the same time; having a predictable social schedule
Relying on social and family supports	Clear communication with relatives; asking one's significant others for help in emergencies
Engaging in regular medical and psychosocial treatment	Staying on a consistent medication regimen, obtaining psychotherapy, attending support groups

The patient should be connected to other community resources to enhance her/his support and autonomy (Vieta, 2009:50). Social intervention within a developmental context in South Africa is increasingly focussing on how to use scarce resources to maximum effect (Smith, 2007:637). Patients and families often benefit from participating in community support and advocacy programmes (AACAP, 2007:120). It is very important that the social worker should know about the **resources** available in the community to be able to utilise them. Consultation may be needed with other community and/or social welfare programmes involved, such as residential services/treatment. The **social worker** has an important role to refer a patient to community resources, but also to assist such resources, should readmission become necessary or should their personnel need any consultation. In practice, many psychiatric patients are referred to shelters for homeless people, because that is the only place they can afford on a disability grant. Most shelters are managed by lay people who need to be empowered with knowledge. These staff members should be taught about mental illness and signs of relapse to enable them to establish when to bring a patient back to the hospital or when to consult with a member of the MDT.

The social worker also plays an important role by involving and coordinating **volunteers** to offer support to the patients. Social support is associated with better outcomes for people with depression and BD (Webber, 2010:111).

It has been the researcher’s experience that **research** by social workers is underutilised and that the latter as a rule do not publish articles - even if these are about their day-to-day work and what they experience. If they were to be bold enough to share with other colleagues, everybody could benefit.

Evidence based practice has the potential to deliver more effective and efficient services to recipients of health and social care. The **lack of** high-quality evidence concerning the effectiveness of social interventions should not prevent practitioners from working towards goals such as social inclusion, enhanced social networks, increased access to social capital and improved quality of life (Webber, 2010:113). Buila (2009:583), in this regard, asserts that studies of psychosocial interventions demonstrate effectiveness with respect to medication adherence, relapse prevention, decreased hospitalisations and improved social and occupational functioning. Improved social and occupational functioning will lead to improved **quality of life**. Further research is clearly needed to assist the mental health practitioner with techniques for initiating treatment and engaging the person with BD.

The researcher concurs with Smith (2007:647) that termination of social work at the level of the psychiatric hospital with a careful handover and referral for follow-up in the community can ensure the necessary continuity of care.

3.6 LIFE GOALS COLLABORATIVE CARE MODEL (LGCC)

Kilbourne, Goodrich and Bauer (2010:453, 456, 460) proposed a collaborative treatment model, entitled Life Goals Collaborative Care, (LGCC) which seeks to improve the quality of health care for patients with BD by: (1) improving coordinated care management; (2) empowering patients to take an active role in self-management of mental and physical risk factors; and (3) providing decision support to clinicians that ensures patients receive concordant care. The LGCC’s core elements include patient self-management, enhanced access via care management provided by a health specialist (e.g. RN or MSW) contacts and information systems, as well as enhanced decision support. The LGCC element of decision support aims to improve the provider’s knowledge and skills about evidence-based care for persons with BD. The **goal** of LGCC is to help patients with BD achieve personal wellness goals through application of the three core treatment elements that simultaneously promote healthy lifestyles and bipolar symptom management. It combines best practices in patient self-management, education and collaborative care. The researcher is of the opinion that this is a holistic model which respects the patient’s autonomy, the need for prevention and follow up. In the South African context, psychiatric services are still **fragmented** and it is often the social worker in the MDT who becomes the link to the community resources and even the coordinator of services within the MDT. If the rest of the team becomes “stuck”, the patient’s problem often becomes a “social” issue and other team members may become frustrated with the lack of progress.

3.7 NOVEL TREATMENT

- **New electrical stimulation techniques**

Rapid transcranial magnetic stimulation (rTMS) is an alternative to ECT and is a simpler and less invasive way to stimulate the cerebral cortex. It does, however, not appear to be as effective as ECT for depressed people (Miklowitz, 2011:124). Last (2009:112) indicates that **rTMS** (repetitive) is a way of stimulating the brain which does not induce “seizure” activity and does not require anaesthesia. The technique relies on the principle of electro-magnetism. Preliminary findings are promising; they suggest that this treatment may be effective for both depression and mania without causing the memory problems associated with ECT. However, since the procedure (and the research conducted on it) still is very much in its infancy, the availability of this treatment is limited. George (2010:391) also reports that there is no firm evidence of TMS being useful as an antimanic treatment.

According to Miklowitz (2011:124), there are two new treatments that are starting to gain traction for people with treatment-resistant depression or rapid cycling: **vagus nerve stimulation (VNS)** where a stimulator device that sends electrical signals to a person’s left vagus nerve will be implanted under a person’s skin and **deep brain stimulation (DBS)** which involves the surgical implantation of a “brain pacemaker” that sends electrical impulses to various parts of the brain believed to be important in depression. Although **VNS** was originally developed for epilepsy, the discovery of its mood-enhancing effects led to research into its efficacy in alleviating depression (Last, 2009:113). George (2010:385) reports that the concept of stimulating the vagus nerve in order to modify central brain activity has been pursued for over 100 years. However, it was not until the mid-1980 that methods became available to efficiently stimulate the vagus in humans and animals. George (2010:387) refers to long-term open-label data that suggest that VNS may be an efficacious and well-tolerated treatment option for treatment-resistant rapid-cycling bipolar patients.

- **Medications that act on different systems**

Machado-Vieira, Manji and Zarate (2010:395) comment on the efficacy and safety of novel therapies for BD, being medications that act on different systems such as the dynorphin opioid neuropeptide system, the melatonin and serotonergic system and protein kinase C system. It is beyond this study to expand further on these developments, but it is still encouraging to take note that research is always ongoing.

3.8 NO TREATMENT

What happens **without treatment**? If everyone who has BD could receive the right medical treatment for their manic and depressive symptoms, the disorder itself would be much less of a problem than it is. Unfortunately, some people never receive the right treatment, while some never receive treatment at all (Haycock, 2010:103).

Despite the grandiosity that often accompanies mania, many people with untreated BD are unable to take care of themselves as independent adults. They can end up homeless, living in poverty, or under the guardianship of an uncaring person (Haycock, 2010:106). If untreated, a patient with BD is likely to experience more than 10 episodes during their lifetime. The natural history of BD often includes periods of remission but, without treatment, people with BD will always relapse (Vieta, 2009:20).

In **conclusion**, Miklowitz (2011:132) states that there are numerous treatments for BD. None of these is perfect, but many can effectively treat a person’s acute symptoms and, in all likelihood, level out the course of his/her illness over time. Adding psychotherapy or support groups to a medication regimen helps ensure that the **person** is treated, not just the disorder, and that he or she develops strategies for coping with stress. The selection of therapies providing specific attention to dysfunctional attitudes and circadian rhythms ought to be based on patient needs and preferences. As BD may be progressive when episodes accumulate, and it may be relatively more responsive to interventions early in the course of illness, efforts to engage patients early on in the treatment alliance, are particularly important (Parker & Ketter, 2010:349, 350). Vieta (2009:50, 52) alludes to the importance of establishing and maintaining a therapeutic **alliance**. Treatment should be based on a collaborative relationship with the patient and family. It is very clear to the researcher that the only approach that may be successful in the treatment of BD is that of an integrated, holistic approach.

3.9 PSYCHIATRY IN THE SOUTHERN AFRICAN CONTEXT

In South Africa, much needs to be done to improve psychiatric care. Resources, particularly in the rural areas, need to be developed and psychiatric services need to be better integrated into primary healthcare services (Emsley & Seedat, 2007:38). The researcher agrees that resources are totally inadequate for the psychiatrically challenged patient. One hopes for the development of equitable, accessible and high-quality, appropriate mental health services for everyone in South Africa.

Another important aspect to consider is the **role of traditional healers** in treatment. It is recognised that such healers play a significant role in healthcare provision in South Africa. While high levels of satisfaction have been reported by people who encounter problems of daily living and lifestyle, those with serious mental illness were largely dissatisfied with the treatment received (Emsley & Seedat, 2007:44). The researcher does have the experience of patients telling her that they were abused by traditional healers and were also financially exploited. Collaboration between traditional healers and mental healthcare workers is likely to be beneficial. However, care needs to be taken that those individuals with psychiatric disorders, requiring specific evidence-based intervention, are able to access this treatment.

The researcher would like to **recommend** the concept of mobile outreach teams to assist patients and families at home when a crisis arises, because families must often call on the help of the police who are not equipped to handle psychiatric emergencies. There should also be wraparound services such as programmes for assertive community treatment and early intervention when a patient starts relapsing, thereby preventing admission to psychiatric hospitals.

It is essential that the mental health practitioner be aware of the South African National Mental Health Policy Framework and Strategic Plan 2013 to 2020. This document identifies key activities that are considered catalytic to further transforming mental health services and ensuring that quality mental health services are accessible, equitable, comprehensive and are integrated at all levels of the health system, in line with the World Health Organization’s (WHO) recommendations (2013:3).

3.10 PROGNOSIS

According to Sadock and Sadock (2003:546), the following factors have been associated with a poor prognosis for patients with **mood disorders**: long duration of episodes, temporal dissociation between the mood disorder and the psychotic symptoms, and a poor premorbid history of social adjustment. The presence of psychotic features also results in significant treatment implications. These patients typically require antipsychotic drugs in addition to antidepressants or mood stabilisers and may need ECT to obtain clinical improvement.

Sadock and Sadock (2003:558, 559, 560) report that mood disorders tend to have long courses and patients tend to experience relapses. About 40 to 50 % of BD I patients may have a second manic episode within 2 years of the first episode.

Table 3.4: Comparison of poor and good prognostic features

Poor Prognosis	Good Prognosis
BD I poorer prognosis than patients with MDD	Short duration of manic episodes
Premorbid poor occupational status	Advanced age of onset
Alcohol dependence	Few suicidal thoughts
Psychotic features	Few coexisting psychiatric or medical problems
Depressive features	
Male gender	
Interepisodic features	
Failure to accurately identify and diagnose patients with BD	

Results of one 4-year follow-up study of patients with bipolar I disorder

On long-term follow-up:

- 15 % of all patients with bipolar I disorder are well
- 45 % are well but have multiple relapses
- 30 % are in partial remission
- 10 % are chronically ill.

One third of all patients with bipolar I disorder have chronic symptoms and evidence of significant social decline. Of almost all individuals who have this illness, more than 90 %, will go on to have future mood episodes. It is known that without medication people have on the average of four episodes in 10 years, with 80 % of individuals having a recurrence within 3 years and many much sooner (Last, 2009:33). Research undertaken by Michael Gitlin and his colleagues at UCLA found that a person who has had a manic or depressive episode has a 60 % chance of having another one within 2 years and a 73 % chance over an average of 4-5 years (Miklowitz, 2011:99).

Vieta (2009:24) notes that several recent long-term outcome studies have confirmed the recurrent and often persistent nature of psychopathology in BD, with high relapse rates. Functional recovery appears to lag behind symptomatic or syndromic recovery, even after a single manic episode. BD proves fatal in a high proportion of patients from complications of risk-taking behaviour, comorbid medical illnesses, and suicide. A prospective study with over 30 years of follow-up found that standardised mortality rates were significantly elevated in bipolar patients, with circulatory disorders and suicide being the most frequent causes of death.

It is well known that in the case of bipolar patients the immediately **preceding** course is the best prognostic indicator of the immediately **subsequent** course, so ensuring at least 6 months of stability for some patients has the effect of putting them on track, namely **"tracking"**, which clearly improves the subsequent course (Colom & Vieta, 2006:28).

A major consequence of the failure to accurately identify and diagnose patients with BD is to worsen their long-term prognosis. Delayed diagnosis allows complications and comorbidities, including substance misuse, to progress (Vieta, 2009:37).

The hunt for genes that might contribute to bipolar and other disorders continues. Medical science has already cured many diseases and now is faced with complex diseases with multiple causes, often multiple genetic influences, and complicated interactions between the environment and genetics (Haycock, 2010:31, 32).

3.11 SUMMARY

In this chapter, different treatment modalities (biological and psychotherapeutic) were discussed. It was stated that treatment should be holistic and according to the biopsychosocial model. The researcher emphasised that in her practical experience, no treatment can take place without a therapeutic relationship and outside the context of the MDT. The role of the social worker in the psychiatric hospital, novel methods of treatment, psychiatry in the Southern African context and prognostic features were other areas that were highlighted.

Fortunately, medications and psychological counselling are available that assist the overwhelming majority of people who are diagnosed with BD. Although symptoms may periodically return, it is possible to live a happy and productive life after being diagnosed with this disorder.

Chapter 4 reviews the needs and psychosocial challenges for caregivers.

4. CHAPTER 4: NEEDS AND PSYCHOSOCIAL CHALLENGES OF CAREGIVERS IN RELATION TO THE INDIVIDUAL WITH BIPOLAR DISORDER (BD)

4.1 INTRODUCTION

> Interviewer: What have you missed most as a result of having a mentally ill relative at home with you? Respondent: My life (Terkelsen, 1987a:128).
>
> The fiancé of a patient (Aiken, 2010:142, 143) states that **thick skin** and **patience** are handy attributes to have with a bipolar partner while the wife of a patient says that **stamina** and **guts** are important attributes for the carer.

The appearance of **mental illness** in a family member is invariably a **disaster** for the whole family, a disaster in which all become victims of the event and its sequelae. No one and no part of the emotional life of the family remains unaffected. Children, siblings, and parents feel the effects of direct involvement, while grandparents, aunts, uncles, cousins and more remote relations usually learn of the affliction from those closer in. The illness even reaches those to whom its existence is never exactly disclosed: kept from direct involvement, they develop elaborate explanations for the patient’s mysterious, erratic inaccessibility, drawing on gossip, if not on fact. The illness touches everyone, affecting attitudes toward self and toward life, producing symptoms in other members, altering family structure, influencing life choices, and many other aspects (Terkelsen, 1987a:128). This has also been the researcher’s experience, having worked with the families of mentally ill patients for more than twenty four years.

In the past, parents and siblings were thought to be responsible for many mental illnesses, during which time clinicians sought to explain these disorders solely in a behavioural context. As a consequence, **family members** felt demoralized and were blamed for their loved one’s illnesses. Recently, however, neurobiological and genetic research findings have helped clinicians and researchers begin to understand the biological component of mental illness, particularly in terms of brain function and dysfunction, genetics, immunology, and endocrinology (Antai-Otong, 2003:65). It is therefore the researcher’s opinion that families must be given this information: it will alleviate some of the **guilt feelings** that are often present in family members. In this regard, Lefley (1987b:121) states that it is grandiose for families to believe that they have caused or are able to cure a phenomenon as overwhelming as mental illness. They can only try to modify their own behaviour to make life more comfortable for themselves and their mentally ill relatives.

Patients with a BD and their relatives are confronted with a lifelong disease causing significant consequences for their lifestyles. BD is associated with a considerable degree of illness - related morbidity, profound suffering, occupational impairments, and social burdens (Goossens, Van Wijngaarden, Knoppert-Van der Klein & Van Achterberg, 2008:303). Hayden and Nurnberger (2006:69) agree, saying that the frequent appearance of BD, in conjunction with suicidality, psychiatric comorbidity, and pronounced impairment in psychosocial functioning, exacts a great toll on patients and their families. Even with adequate treatment with a mood stabilizer, **one-third** of bipolar patients **relapse within 3 years**. The researcher has experienced that bipolar patients are frequently readmitted to hospital, even if they have been compliant with their treatment regime, perhaps demonstrating their vulnerability to stress in their lives.

Taylor (2006:12) elaborates on the effect of BD and states that it affects multiple neurological and body systems, creating disabilities, pain, and grief about a person’s moods and emotions that cannot be explained in simple descriptive terms. This illness has biological, social and economic repercussions. Periods of frightening manic and depressive episodes can lead to divorce, loss of one’s job, decreased opportunities, homelessness, alcohol and substance abuse, and **hardships for family members**. The enduring psychosocial consequences of BD include work loss and unemployment, increased health care use and costs, and poorer overall functioning and quality of life (Aschbrenner, Greenberg & Seltzer, 2009:298). These authors furthermore mention that recent research has documented elevated levels of **burden** among family members caring for a relative with BD, which has been linked to poor physical and mental health and low levels of social support.

No one welcomes a **diagnosis** of BD. It is a serious illness that has the potential to devastate individuals and wreak havoc in families. Although a person may feel that his/her life is over, being **diagnosed** with BD really **is a beginning**: the start of **making sense** of the emotional roller coaster ride the patient (and family) has been on, and the beginning of getting help, the right kind of help, for the illness (Last, 2009:9). If this were to be the attitude of families, caregivers and professionals, the researcher is of the opinion that this could instil some **hope** in a potentially very challenging situation.

There is a growing understanding that BD should be treated as a **family condition**. When family members **first learn** about the patient’s BD they may be supportive, intrusive, anxious or angry. Some may be eager to help, while others subject the patient to overt rejection (Haycock, 2010:261). Even after everyone has seemed to adjust to life with BD in the family, difficulties often reappear with the next bipolar episode (Miklowitz, 2011:279). Last (2009:31) concurs, pointing out that one of the most difficult aspects of living with BD, both for the person who has the disorder and that person's significant other(s), is the **uncertainty surrounding the recurrence** of mood episodes. Miklowitz (2011:viii) mentions that people with the disorder wish for more understanding from relatives, friends, and co-workers. Their family members, in turn, want to know how best to help their bipolar relatives without becoming angry, controlling, or overprotective. How can people with the disorder achieve better mood stability and lead more fulfilling lives, while taking medications and dealing with the realities the illness imposes? What is important is that most persons who are affected by this illness want nothing more than to get back to their **everyday lives** after they or their family members have been diagnosed with the disorder (Mondimore, 2006:ix).

As suggested by Ogilvie et al. (2005), there is, therefore, a need to **understand caregivers'** views and perceptions of the stresses and demands arising from caring for someone with BD in order to develop practical, appropriate, and acceptable interventions and to improve the training of professionals working with bipolar patients and their caregivers. It is the researcher's opinion that if this should happen, the overall quality of service will definitely improve. Professionals therefore need to reach out to caregivers and join hands with them.

It has been mentioned in previous chapters that the theoretical framework of this research is an integrated biopsychosocial model, within an ecological systems perspective. This model also addresses aspects like the stigma of mental illness, burden of care, destructive relationships, losses and various forms of exploitation and abuse (Smith, 2007:639).

In this chapter, the emphasis will fall on the **needs** and **psychosocial challenges** of the caregivers as well as on shedding some light on the needs of the patients. The researcher will attempt to create a picture of the context of the day to day life that the caregiver finds him/herself in.

4.2 DISCUSSION OF KEY CONCEPTS

4.2.1 Needs

In 1979, Hatfield undertook a study assessing the needs of families of mentally ill patients (Hatfield, 1987a:21). It was her contention that families might have a different view of their **needs** from that of the clinicians, and of what kind of services were helpful. The families listed the help they most needed as:

- Assistance in understanding the patient's symptoms
- Specific suggestions for coping with patient's behaviour

- Opportunities to relate to persons with similar experiences
- Substitute care for family respite
- A different living situation for the patient.

While the researcher does agree with these needs, she has experienced that caregivers do have a broader range of needs; such as being able to deal with their own **emotions** in relation to the illness. They also have a need to be **educated** about the specific mental illness that the patient has; the family often receives different diagnoses, which confuse them. Comorbidity is also something that needs clarification. Parents have a need to know what will happen to their mentally ill child when they (the parents) are no longer there. Parents and children are sometimes worried about the genetic component of the illness. The most important need is therefore **knowledge**, because knowledge empowers. How well families do in the face of a severe mental illness may depend to a significant extent on how well their needs for support are met (Hatfield, 1987b:191). It is the researcher's opinion that this still rings true today.

Lefley (1987a:52) refers to the necessity of what cross-cultural researchers call the "**emic**" approach; that is, the outsider must learn to perceive the situation through the eyes of the subject, rather than superimposing his or her own external model of reality. Among psycho-educational therapists, this involves learning the family's experience of the illness, their theories about causes and their views of roles. Rather than observing a putatively maladaptive "system" through the lenses of theory, the therapist helps the family build survival skills within the framework of their expressed needs. In this study it was also very important to discover the real needs of the caregivers, before starting a programme.

4.2.2 Caregiver (Chapter one refers)

The Older Persons Act 13 of 2006 defines a caregiver as any person who provides care. The training manual on this legislation from the Department of Social Development, South Africa ([sa]:5) adds that the persons may be professional or voluntary, and states that most caregivers in South Africa are family members who accept the responsibility of caregiving.

Ostacher, et al. (2008:50) suggest the following criteria for identifying the primary caregiver (the person must meet at least three of these criteria): she or he

- is a spouse, parent or spouse equivalent
- has the most frequent contact with the patient
- helps to support the patient financially

- has most frequently been a collateral in the patient's treatment and/or
- is contacted by treatment staff in case of an emergency.

The researcher concurs with the definition given by Ostacher et al. (2008:50), but would like to add that a caregiver might also be a child of the person diagnosed with BD. In short, for the purpose of this study, a caregiver will be considered as any layperson who cares about and is in frequent contact with the person diagnosed with BD.

4.2.3 Psychosocial challenges

A challenge is a difficult or demanding task (*Oxford Advanced Learner’s Dictionary*, 1989:185). It can therefore be regarded as anything that can be considered as challenging on a psychological or social level.

4.2.4 Burden

The primary task of the mental health service is the **prevention** and **treatment** of mental disorders in the population. However, for most patients, the family is the most important carer, and the caregiving role is associated with a considerable **burden**. It is more the exception than the rule that the mental health service has developed routines for taking care of the family, who often feel overlooked and forgotten. When the support system contributes to humiliating, invasive and devaluating experiences for the next of kin, their burdens are amplified (Tranvag & Kristoffersen, 2008:5).

Living with and loving somebody who has BD is a daunting task (Last, 2009:9). Taylor (2006:12) refers to the fact that the **burden** that a disease causes is estimated by calculating the severity of pain, suffering, disability, and deaths attributed to the disorder. In addition to disabilities, bipolar illness ends in **suicide** for many patients, as indicated earlier.

Available data suggest that the caregiver burden is high and largely neglected in BD and is a matter of increasing clinical concern. Patients living with an “over-burdened” caregiver may have an increased risk of relapse (Ogilvie et al., 2005:25, 29).

The caregiver’s burden may influence the clinical outcome of BD (Reinares, Vieta, Colom, Martinez-Aran, Tottent, Comes, Goikolea, Benabarre, Daban & Sanchez-Moreno, 2006:158). Ogilvie et al. (2005:25) state that the **caregiver burden** has been described as the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient’s significant other(s), e.g. members of the household and/or the family; although significant others can be considered to include close and supportive friends.

In an attempt to achieve more clarity about family burden, Hoenig and Hamilton (1966) cited in Hatfield (1987a:16) suggested the need to discriminate between the **objective** and the **subjective** burdens involved in providing care. They applied the concept of “objective burden” to describe the adverse effects on the household of such factors as heavy financial costs, the effect on health, and the intrusion and disruption of the lives of family members. The “subjective burden” was defined as the sense of loss, grief, guilt and anxiety due to the abnormal behaviour of a member. Perlick et al. (2008:484) also used these terms, but refer to objective burdens as increased expenditure of time and money and emotional burdens, such as worry, tension and grief. They declare that 93 % of caregivers of patients with BD reported a moderate or higher degree of caregiving strain when their relative was admitted to a psychiatric facility. Van der Voort, Goossens and Van der Bijl (2007:679) refer to the fact that high burden is associated more with severity of symptoms (than diagnosis), difficulties in the relationship with the patient, lack of support and stigma. These authors mention that 75 % of patients with BD remain functionally impaired with inter-episodic symptoms.

When caregivers of patients with bipolar illness experience a **high burden**, patient outcome is adversely affected. The experience of burden appears to initiate a sequence of caregiver and patient behaviours that affects clinical course and outcome, in part by reducing medication adherence (Perlick, Rosenheck, Clarkin, Maciejewski, Sirey, Struening & Link, 2004:1029, 1034).

Chadda, Singh and Ganguly (2007:923) indicate that severity of illness and symptom characteristics are important **predictors** of burden, with disorganized behaviour being especially associated with higher levels of burden. Caregivers develop different kinds of **coping strategies** to deal with the burden, which include finding a reasonable solution, looking for support from friends or other near ones, or trying to avoid the situation by indulging in activities such as smoking or substance abuse. Caregivers experience higher levels of burden when they have limited coping resources. Reduction in the perceived burden has been reported in the caregivers who adopt less emotion focused coping strategies.

Perlick, et al. (2008:484-490) identified **3 groups of caregivers** with different patterns of stress appraisal, coping and health outcomes over time:

- **Effective** caregivers had low stress appraisal related to the patient's problem behaviour, exercised adaptive coping, practiced good health behaviour, and had superior health outcomes.
- **Burdened** caregivers had high stress appraisal related to the said behaviour, practiced less adaptive coping and self-care, and recorded the poorest health outcomes.
- A third group with high stress appraisal related to perceived stigma (**stigmatized** caregivers), recorded low mastery and inadequate self-care, but used effective coping and had good health outcomes.

The results of this study can be used **prospectively** to identify caregivers at **risk** for adverse health outcomes associated with caregiving, and to target them for a prevention-focused intervention.

Reinares et al. (2006:157) state that identifying and modifying burdensome aspects might reduce the level of burden and their negative effects both on caregivers and patients' outcome. Most studies evaluate acutely ill patients, whereas the most relevant problems may be related to **sub threshold symptoms** and long-term outcome. The result of their study was that the highest levels of distress were reported regarding the patient's **behaviour**; the most distressing behaviours were hyperactivity, irritability, sadness and withdrawal. Regarding the patient's **role** performance, the most worrying aspects were those associated with the patient's work or study and social relationships. Regarding adverse effects on others, caregivers were especially distressed by the way the illness had affected their emotional health and their life in general. Poorer social and occupational functioning, an episode in the last two years, history of rapid cycling and the caregiver being responsible for medication intake explained a quarter of the variance of the caregiver's subjective burden.

Holden and Lewine (1982), cited in Hatfield (1987a:18), studied 203 members of seven family self-help groups affiliated with the National Alliance for the Mentally Ill and confirmed the finding that the lives of families were adversely affected by the circumstance of mental illness. While health problems were seen as stress related, the most frequently mentioned were depression, insomnia, hypertension, heart attack and alcoholism.

Clinicians should **assess symptoms** of caregiver distress. When this is noticed, efforts should be undertaken to support the caregiver and teach them skills to cope effectively with the consequences they experience, in order to stay well (Goossens et al., 2008:303).

Caregiver burden does **not remain the same** over time (Van der Voort et al., 2007:681-682). **Four** interpretive junctures may be identified in the relationship between caregiver and patient:

- Period **prior** to diagnosis in which caregivers experience fear, anxiety and despair.
- Period of empathy, concern, hope and the use of medication, following the **establishment** of the diagnosis.
- Period where feelings of frustration and anger can arise when the caregivers start to **realize** that things are not going to improve; these feelings may become stronger when the belief is held that the patient is not doing everything in his or her power to get well.
- Finally, caregivers reach a state in which it is **recognized** that they are dealing with an incurable disease which cannot be controlled; such recognition can give rise to feelings of release and relief. When so desired, the caregiver can withdraw from caregiving tasks without feeling guilty and regain some personal space.

In the context of this study it is important that the concept of burden should be understood, because it is the researcher's goal to alleviate the caregivers' burden and in such a way as to improve the patient's prognosis.

4.3 FAMILIES AS CAREGIVERS: A HISTORICAL PERSPECTIVE

In 1987, Hatfield (1987a:3, 7) stated that with the movement away from institutional care in favour of providing care in the community, families are increasingly involved in the lives of their disabled relatives and are often themselves in the role of primary caregiver. Originally, families were the sole source of care and the community took little responsibility; subsequently a movement toward **institutional care** removed most patients from the home in the 19th and early 20th centuries; and finally, in another sharp reversal in the 1950s, home and community were once again the favoured place and patients were rapidly **deinstitutionalized**. There was a **lack of planning** and patients were inadequately prepared for **community** living; there was an inadequate range of services; fragmentation and lack of coordination; treatment was inaccessible and families experienced severe stress. While the hospital census was reduced, replacement with alternative types of community care did not occur. Goossens et al. (2008:304) agree, stating that treatment and patient care shifted towards outpatient care and that there had been an increase in informal care tasks provided by family members. This regrettably describes the case in South Africa today. It does appear that we are not learning from mistakes made by a country such as the USA; we are repeating the same pattern that occurred there more than 50 years ago.

Families need community support programmes to relieve some of the burden placed on them (McElroy, 1987:230). The researcher, in her day-to day work, finds that there is a tremendous lack of equipped community **resources** to which mentally ill patients and their families can be referred, especially in the more remote areas. Budgets are constrained. The resources that are able to provide a good service are usually very expensive. The bulk of the patients cannot afford private psychiatric services. There are often demands on the caregiver that cannot be dealt with; he or she then withdraws from the patient and the latter becomes the state's responsibility. The researcher is not arguing that the caregiver can or must not play a role - his/her role is of utmost importance, but in conjunction with the necessary support.

4.4 NEEDS AND PSYCHOSOCIAL CHALLENGES

Caregivers of people who have been diagnosed with BD have certain **emotional reactions** to the illness, but also **certain needs** that pose definite **challenges**. The emotions, needs and challenges will differ, depending on the **role** of the specific caregiver in the system. There are also further aspects related to both the patient and caregiver, others related specifically to the caregiver or to the patient and finally also those related to the family.

4.4.1 Caregivers and patients

Like many chronic illnesses, BD **afflicts** one but **affects** many in the family. It is important that *all* those affected receive the help, support, and encouragement they need (Mondimore, 2006:258).The researcher does however want to emphasize an important aspect: **transparency** regarding the diagnosis. If the diagnosis is not discussed with the patient and (with the **patient's consent**) with the family, they may not know what is wrong; then it becomes very difficult to face this illness. It has not always been the case that psychiatric diagnoses have been discussed with patients and their families, but nowadays it seems to be the norm. Usually, it is a relief for families once a diagnosis is made, because then appropriate treatment can be given. A comorbid diagnosis, such as HIV, may also be present, in which case confidentiality is very important. Aiken (2010:122) states that the wishes of the person with BD should be respected and he/she should make it clear to professionals if they want their family to be involved. The person can even put this in writing so it can be kept on the file. This is an important aspect when the social worker contracts with the patient.

4.4.1.1 Relationships

People who do not have BD have no concept of how terrible it is to suffer from it, while those with the illness have no concept of how terrible it can be to live with someone who has BD

(Fast & Preston, 2004:112, 113). Antai-Otong (2003:243) agrees, stating that the marked changes in mood, personality, thinking and behaviour that are part of the disorder often have significant effects on **interpersonal** relationships across the life span.

Family, peer and work relationships may have become problematic and stressed as a result of increasingly severe and unpredictable symptoms, rather than the patient’s symptoms having been triggered or increased by negative environmental factors (Taylor, 2006:15). No symptom should be seen in isolation. When assessing a situation, the context must be taken into consideration.

Family and interpersonal conflicts may be **risk** factors in the course of the illness. Family members, when describing the emotional volatility of their bipolar partner, sibling, child, or parent, tend to emphasize the **intimidation** they feel in the face of sudden outbursts that they do not feel they have provoked. In the extreme manic states, family members become worried that the patient will hurt him/herself or someone else. Family members and friends will be particularly upset and scared by the patient’s suicidal thoughts, if such are expressed to them (Miklowitz, 2011:97, 19, 23, and 25).

When a patient **re-enters** his/her everyday world following a mood episode, even well-intentioned family members do not know how to interpret the changes in his/her behaviour (for example irritability or lack of motivation). They often mistakenly think that the person is acting this way on purpose and could control this behaviour if he/she only tried harder. As a result, they become critical, evaluative, and judgemental. They may also mistakenly think the patient cannot take care of him/herself and try to do things for him or her that the person is more than capable of doing (Miklowitz, 2011:9). Last (2009:141, 142) also warns that a caregiver **should not be overprotective**, always stepping in, because as a result the patient does not use whatever skills he/she possesses, or develop ones for him/herself, and, consequently, becomes increasingly dependent and helpless.

There must be a balance between protecting patients and trusting them to make their own decisions. Relatives may repeatedly remind the patient to take medications, or go behind the patient’s back to talk with the physician (Miklowitz, 2011:282). The researcher has observed that this may cause the patient to become defensive or even apathetic. However, should a patient start to relapse, it is very helpful if the caregiver supervises and reports, to the MDT, whatever is observed (verbally or in written format).

Sometimes caregivers start to feel so disempowered and even afraid that they totally withdraw to the point where they are not prepared to allow the patient (when hospitalized) to come home for weekends or ever to come home again; they do not visit and avoid the hospital (and responsibility). The researcher has found that a sibling or child of a patient might say that his or her spouse said the patient may not visit them - blaming another party.

The **aftermath** of a mood episode can be as difficult to cope with as the episode itself. If the relationship is to survive, the caregiver will need some way to deal with the feelings he/she experiences so that the event can be placed in the past (Last, 2009:260).

- **Marital and/or cohabitant**

When someone one loves becomes less able to function because of any type of chronic illness, it is very sad and at the same time very stressful. The caregiver may have to take over roles the patient used to perform and give up aspects of the life they used to have together. They, as a couple, will have to adjust their expectations (Last, 2009:42).

Relationships, even for couples who do not have to contend with mental health problems, are difficult; bipolar illness increases that level of difficulty, particularly when it is untreated or treated inadequately (Last, 2009:277).

It is difficult to conduct a loving and intimate relationship when one partner is a caretaker and the other is a patient. It is important that they should talk about what both **want** and **need** from the relationship (Fast & Preston, 2004:175, 12).

The most important point to remember is that **anxiety** or discomfort about being close is a natural part of coping with BD as a couple, particularly during the recovery period (Miklowitz, 2011:299). Withdrawing from one’s spouse or partner and considering divorce may seem the only way out of an intolerable situation (CAMH, 2000:33). A person should however not make major decisions, such as whether or not to divorce, when severely ill. The researcher has experienced that hospitalization often serves as a **cooling off** period. When the patient has been aggressive or unfaithful towards his/her spouse, it becomes a challenge to remember that the behaviour is mostly illness related. Berk et al. (2008:256) are of the opinion that sometimes a relationship becomes too destructive, so that it must end. Then both parties may need time to grieve and to receive input from their support network.

There is a possibility that a person might cease being attracted to his/her sick partner who does not take care of him or herself. A partner may have a tough decision to make regarding the relationship if his/her emotions (and their partner's) are too intense to handle. It may be that for the partner's emotional well-being he/she need to make some space between himself/herself and the partner (Fast & Preston, 2004:135, 145).

Fast and Preston (2004:163, 174) furthermore point out that there is nothing romantic about BD. **Issues** may include the patient's **lack of sexuality** when depressed, **excessive sexuality** when manic, and a general lack of affection toward the partner when too ill to have a fulfilling and intimate relationship as well as the side effects of medications. Couples can and do recover from the sexual problems caused by BD. If they are clear on what they both want and need and understand which problems are caused by the illness, it makes sense that if they can learn to modify and stop the BD itself, their sexual situation has a great chance of improving.

Tranvag and Kristoffersen (2008:6, 9, 10) indicate that due to lack of security, the spouses are in a constant state of alertness to enable them to identify stress factors in their surroundings and changes in their partner's mental health. Self-doubt may also be present. These authors do, however, also emphasize reconciliation with life as it is and new hope; reconciliation opens a path to new goals and ideals for living together.

Men whose wives have BD might need to make more of an effort to develop a support system. In general, women are more likely than men to have a support system outside the nuclear family unit (Haycock, 2010:209).

The researcher has encountered a number of cases where both partners have been diagnosed with BD. This becomes a very challenging scenario indeed.

- **Parent – child (parent is caregiver)**

Aschbrenner et al., 2009:298, 303 state that parents may provide decades of extended caregiving for their adult son or daughter with BD during times when debilitating symptoms produce obstacles to social and occupational functioning and independent living. **Parents** of adults with serious mental illness are at an increased **risk** for poorer health and mental health and marital disruption. Despite this risk, many parents of adult children with BD were able to maintain a reserve of psychological and social resources although they were experiencing considerable distress in other life domains. These findings add to an emerging body of research, which has begun to identify strengths and **resilience** among families coping with a relative's mental illness. These **strengths** must be acknowledged and the focus should not always just be placed on the pathology. Wellness must be encouraged.

- **Child – parent (child is caregiver)**

Children can feel an overwhelming sense of responsibility, even blaming themselves for the parent's disorder. Sometimes the child might experience feelings of anger, sadness, fear, insecurity, worry, confusion, loneliness, pain, stress, helplessness and frustration (Aiken, 2010:83, 88, 90). In a case study (Aiken, 2010:107), a daughter said that after her father died, she spent many years abroad, just enjoying not being burdened with the weight and worry she had grown up with. Another adult child, whose mother was ill (Aiken, 2010:107-109) reported that the **inconsistency** was the worst aspect - never knowing what one would find when one arrived home from school. She ended up hating her mother, because she had trusted her and been let down. The child might also develop a **psychiatric condition**, such as the daughter of a parent, who was diagnosed with obsessive compulsive disorder.

A child of someone with BD might experience a **role reversal** that leaves the child feeling more like the parent than the child. Children may feel responsible for events involving family life such as marital strife, divorce, illness, and tragedy that are, in fact, outside of their control (Haycock, 2010:209, 210).

Children might become suspicious, withdrawn and fearful when the parent is sick and hospitalized. When sharing information about the disorder with school-aged children, it must be simplified to fit their developmental level. Age-appropriate terms should be used when describing the disorder, like "happy", "excited" or "sad" rather than "manic" or "depressed" (Miklowitz, 2011:279, 284).

Explaining mental illness or BD to children can be awkward and difficult. Children can feel confused and worry about how their parent's behaviour has changed (Centre for Addiction and Mental Health, CAMH information guide, 2000:40-43). It is helpful, when sharing information, to cover three areas:

Children must know that the family member has a sickness called "BD."
Children need to know they did not cause the illness.
Children should be reassured that it is not their responsibility to make the ill person well.

- **Siblings**

Siblings might think it is not their problem or responsibility to deal with the sick sister/brother. This attitude does especially become a problem when the parents are deceased or too old or ill to continue taking care of the patient. Having a brother or sister with BD can be a source of minor or major **tension**, depending on relationships in the nuclear family. A sibling might tire of providing support, feeling that the sacrifice is too much. The sibling might feel resentful, especially if this person feels he or she is doing more than other close relatives (Haycock, 2010:212, 213).

- **Extended family**

It does sometimes happen that a person becomes the caregiver of a grandparent, aunt, uncle or cousin. The level of involvement will, for instance, depend on the nature of the family relationships, geography and culture. The researcher has experienced that in Traditional African families the extended family is more involved.

A situation becomes more challenging when more than one person in a family is afflicted with BD - this includes a parent, sibling or any other relative. This does take place, because the illness is genetically predisposed (Miklowitz, 2008:36).

- **Employer**

It may occur that the employer also becomes the caregiver (in the absence of relatives) which could create a role conflict for the former. Haycock (2010:221) recommends that it is important that a manager should encourage frank, open communication with a worker with BD.

4.4.1.2 Communication with the ill person

Stable relationships are based on good communication. BD often robs a person of their ability to reason, which means the person with the illness often says and does things that are not part of their real behaviour or an honest reflection of their true and deeper feelings (Fast & Preston, 2004:115).

Relatives should be very aware of **how** and **what** they communicate to the patient. The relative may convey a direct or indirect message about how he/she liked the patient before he/she began medicine or therapy. This may make the patient ambivalent toward accepting treatment. Effective communication is a very important component of managing family or marital relationships and may even help facilitate recovery from an episode of illness. When a person is psychotic, communication becomes even more of a challenge (Miklowitz, 2011:283, 287). Having to deal with a psychotic person can be very traumatic for a caregiver, especially the first time.

Mondimore (2006:252) emphasizes the importance of honest and open communication. One could ask the person with the illness about his or her moods, make observations about behaviours and express concerns in a caring, supportive way; accompany one's family member to doctors' appointments, and share one's observations and concerns during the visits in his or her presence. Thus it is evident how important a supportive relationship is.

4.4.1.3 Stigma

Stigmatization involves a separation of individuals labelled as different from "us" and who are believed to possess negative traits, resulting in negative emotional reactions, discrimination as well as loss of status. Stigmatization of individuals diagnosed as having serious mental illnesses has been globally observed, and the family members who help care for them report feeling stigmatized themselves as a result of their association with the loved one who suffers from mental illness (Gonzalez, Perlick, Miklowitz, Kaczynski, Hernandez, Rosenheck, Culver, Ostacher, Bowden & the STEP-BD Family Experience Study Group, 2007:41).

Perlick, et al. (2004:1031, 1034) state that caregivers' **perceptions** of stigma, in relation to their relatives' BD, contributed to **caregiver burden**. It is suggested that perceived stigma may represent a greater source of distress to caregivers than has previously been recognized. Van der Voort et al. (2007:683) agree that the stigma associated with mental illness has been found to increase the burden on caregivers; that is, people in the surrounding community appear to devalue patients with a mental illness as well as their caregivers.

Stigma has long been and remains a challenge for people with mental disorders and their families. However, **advocacy groups** are making progress in fighting the ignorance that fuels misconceptions surrounding psychiatric care (Haycock, 2010:237).

The researcher concurs that caregivers are also influenced by the stigma which exists about being mentally ill: children may be teased if a parent is admitted to a psychiatric hospital and it might be difficult for a spouse to explain to colleagues at his/her work that the wife/husband has been diagnosed with a mental illness. Even friends might not understand the illness; as a result the caregiver might feel it is better to tell no one about it, thereby limiting possible support. BD carries a social stigma not associated with medical illnesses. Even though BD is clearly a disorder of the brain, and its genetic and biological underpinnings are well documented, it is still treated as a "mental illness" (Miklowitz, 2011:10). Mondimore (2006:239) refers to the fact that persons with psychiatric conditions are too often **regarded as untreatable** and thus unpredictable and dangerous, or at the very least unreliable and incompetent. He also states that accurate information about what BD is and **is not** provides an excellent defence against prejudiced thinking and bad decisions based on misinformation.

Mental illness stigma is prevalent among caregivers of persons with BD who display **active** symptoms as well as for caregivers of those with **remitted** symptoms. Stigma is typically associated with factors identifying patients as "different" during symptomatic periods. At a community level, interventions which decrease mental illness stigma might increase the likelihood that family members will seek social support when it is needed. Social support is an important correlate of stigma for caregivers during all phases of the relative's illness. In treatment for caregivers, improving the quality and quantity of **social support** should be a primary recommendation (Gonzalez et al., 2007:41, 43, 47).

In society there are still many **myths** about mental illness and discrimination still prevails, even in the workplace; thus patients and caregivers would rather remain quiet than face the stigma.

4.4.1.4 Co-dependency

This term refers to both the excessive neediness of the caregiver to be needed and the insatiable neediness of the care recipient, as well as the unproductive role these two forces can play in a relationship (Last, 2009:139).

4.4.1.5 Respect for boundaries, autonomy and independence (caregiver and patient)

Some people become overinvolved in their role as caregivers and feel the need to step in and take over, even when their loved one is relatively well. One might expect that if a relative was very protective, involved and self-sacrificing in response to a loved one's BD, the result would be improved rates of adherence to prescribed medication regimes and better health outcomes. On the contrary, however, people whose caregivers tend to be **overinvolved** exhibit poorer adherence to medication and are more likely to develop further episodes of illness (Berk et al*.,* 2008:271-272).

The caregiver's and patient's boundaries must be respected (Last, 2009:124). Aiken (2010:125) refers to the fact that she had always been close to her mother, but she felt it was important to put a few boundaries in place. She was obliged to do so in order to have a healthy "mother/daughter" relationship, as opposed to a "friendship". She needed a mum.

Fast and Preston (2004:180) state that the caregiver should adopt an **anti-rescue** perspective that says:

> I'm not responsible. I care, and I'll help, but ultimately I don't assume full responsibility for fixing everything.

This involves a humble acknowledgment of the caregiver's limitations as a human being. It is acceptable to be human and have limits - even when it seems that the patient desperately needs the caregiver.

Parents tend to be more emotionally overinvolved than **spouses** and emotional **over-involvement among mothers** is the best predictor of patients' relapse (Perlick, et al., 2004:1034). In practice, the researcher has also observed that some mothers take over the child's life, even where this child might be married. It might be that this serves the function that the mother still feels needed by her child.

In this regard Haycock (2010:234-235) mentions that it is important for the caregiver to remember there are certain things he/she cannot do and then state certain boundaries:

- One cannot make the disorder go away
- One cannot fully predict when an episode will start or end
- One cannot make someone having a full-blown manic episode calm down or make someone having a major depressive episode become cheerful
- One cannot control whether or not someone decides to go off medication.

Perlick et al. (2004:1030) refer to the fact that families who reported experiencing higher levels of **burden** displayed higher levels of emotional **over-involvement** than other families.

Berk et al. (2008:272, 273, 267) consider that maintaining healthy boundaries may relieve distress and prevent the build-up of anger. They mention some things the caregiver can do to maintain healthy boundaries:

- Acknowledge that one has feelings and needs, too. Coping well does not mean sacrificing oneself
- Focus on getting through one day at a time

- Arrange time out
- Take care of one's health
- Use communication skills to set clear limits about what one can and cannot do in different phases of the illness.

A caregiver may come to know that they are giving **too** much when they feel tired most of the time, feeling overwhelmed, irritable, depressed, resentful; or present with recurrent physical signs of stress, like headaches (Last, 2009:139).

It is important to respect a patient's **autonomy**, but when he/she poses a danger to him/herself or others, steps, such as involving the police and/or involuntary admission to a hospital, might need to be taken.

4.4.1.6 Illness

Even during remission, **residual** symptoms may still be present in a high proportion of patients and, although **syndromal recovery** may be achieved soon after hospitalization, **functional recovery** seems to be more difficult to achieve. BD has a significant impact on the patient's perception of the quality of life both within and outside the family. Every episode of the illness is a stressful life event for all the family members and, even when the illness is stabilized, the fear of new relapses is often present (Reinares et al., 2006:157-158).

BD has been called "a confusing and life-changing" disorder (Aiken, 2010:15). There are certain aspects of the illness that specifically involve both the patient and the caregiver:

- **Triggers**

In CAMH's information guide (2000:11) it is stated that too much stress or difficult family relationships **do not cause** BD. However, these factors may "trigger" an episode in someone who already has the illness. The patient and family must be assisted in recognizing and learning to cope with stressful life events that trigger recurrences of BD (Miklowitz, 2010c:10).

- **Symptoms of being ill**

When presenting a psychoeducational programme, it is important to discuss the diagnostic criteria for episodes of mania, depression and psychosis. The reasons for acquainting caregivers with the symptoms of BD include the fact that in learning this material they become able to identify the **prodromal** symptoms of new episodes and can more aggressively **intervene**. Caregivers can also learn that behaviours which they had previously attributed to “laziness” or a patient’s “hyperactive nature” are really symptoms of the illness that may not be controllable by the patient (Miklowitz, 2010c:111).

It must never be forgotten that BD can occasionally precipitate truly **dangerous** behaviour. A less frequent, but nevertheless very real risk, is the violence toward others that can occur in **mania**. This can also result in acts of vandalism. If there are children involved, their emotional and physical safety must be taken into consideration. Avoid a power struggle with the person who has BD (Mondimore, 2006:255; Haycock, 2010:204, 208). It has been the researcher’s experience that violence towards others is very often the reason that caregivers refuse to take a patient home. They must first regain their trust in the patient and they must know that they have support and that they will be safe.

- **Diagnosis**

Diagnostic classification has **two** purposes in medicine: to make predictions about the course of an illness and to aid the clinician in selecting the treatment most likely to be effective (Mondimore, 2006:28). The differential diagnosis of BD is very difficult to make. The boundaries between bipolar and other disorders have been debated for years; it is still unclear where the disorder ends and other disorders begin. The diagnosis is often of great concern to patients and family members (Miklowitz, 2010c:31). “Bipolar” can be a very scary word, especially when it is used to describe someone one loves (Last, 2009:7). Some deny the reality of the disorder, some overcommit to the diagnosis and others reluctantly agree to the diagnosis, but continue living their lives as if they were illness free (Miklowitz, 2010c:51).

- **Comorbid conditions**

Co-occurrence of two or more psychiatric disorders in the same person can happen; this was discussed in Chapter 2. When a patient has comorbid conditions, these will place additional stress on the caregiver.

- **Hospitalization**

In Chapter 3, the location of intervention was discussed; often a patient does need hospitalization. Hospital stays can be extremely traumatic and frightening for the patient and his/her family and friends. Such a stay is however often a lifesaving necessity when a mood swing is too intense to take care of at home or if the patient is suicidal or homicidal (Fast & Preston, 2006:185; CAMH, 2000:19).

One of the adult children cited in Aiken (2010:103) states how she felt she betrayed her dad by leaving him in hospital, because every time the family visited him he begged them not to leave him there.

One of the most difficult actions a person might be called to perform for a family member with BD is to initiate **involuntary** treatment. Nevertheless, given the power of this illness to cloud judgement and create dangerous situations (especially bipolar I), there is sometimes no choice but to force the treatment issue in this way. It is always a last resort, but it can literally be lifesaving. Treatment is given to persons against their will if clouded judgement prevents them from making good decisions about their treatment (Mondimore, 2006:253).

Another aspect is the involvement of the **police**. Their help is sometimes needed to take an ill person to hospital. Family members often feel very guilty about having contacted the police. It has been the researcher's experience that the police are not always very helpful and they are often not able to handle psychiatric patients. It does seem that intensive training is needed to equip them. In Section 40 of the Mental Health Care Act (17 of 2002), it is stated that the police should take a patient with mental illness to the nearest health establishment.

Given the fact that hospitalization can be **an alarming proposition** it can however, amongst other things, provide a person with a much-needed rest or break from the stressors of day-to-day life (Miklowitz, 2011:207). Mondimore (2006:244) also refers to the fact that hospital stays of all types are becoming shorter and that psychiatric hospitalization is no exception. Patients are discharged as soon as possible and no longer hospitalized in a psychiatric unit for weeks or months. This has been the researcher's experience - twenty years ago patients were still kept in psychiatric hospitals for decades, but now the emphasis is on acute treatment, stabilization and discharge. This too, puts more strain on the caregivers. Although hospitalization can be traumatic for caregivers, **discharge** of a loved one can also challenge the caregiver and the patient. In this regard, Surdat (1998:443) observes that for many patients, being discharged from hospital is just as stressful as an admission, because one has been in a protective, structured environment. The challenge of transition from hospital life to community life is often underestimated.

Moreover, private hospitalisation is also very expensive and medical aids mostly only cover a few weeks per year.

Re-admission to hospital can be prevented by implementing aspects such as knowing the symptoms of the illness and obtaining immediate help. Compliance with treatment and avoiding substance use/abuse are also able to delay hospitalisation (Fast & Preston, 2006:197).

- **Adherence to treatment**

It was mentioned in Chapter 3 that people with BD frequently discontinue their medication. This fact poses a serious challenge for caregivers and patients. Estimates vary, but the consensus seems to be that **more than half** of those with BD stop taking their medications at some point in their lives. Accepting a programme of pharmacotherapy to treat BD is a long-term commitment and thus, a very important personal decision (Miklowitz, 2011:135, 138). There is no way anyone can *force* a person to take responsibility for his or her treatment. Unless the patient makes the commitment to do so, no amount of love and support or even threatening can make someone take this step (Monimore, 2006:257). It was also previously pointed out that patients whose caregivers were more emotionally **overinvolved** were less adherent to medication (Perlick, et al*.,* 2004:1033).

- **Suicide**

Suicide may be accomplished in a sudden impulsive act or a carefully planned event. It usually occurs during a depressive or a mixed episode, but some people with BD kill themselves accidentally or on impulse when they are psychotic and in the manic phase. By some estimates, people with BD are at **15 % times** the risk of committing suicide as are people in the general population. Of the BD population, up to 15 % die by suicide, and as many as **one in three** attempt suicide at least once in their lives. One of the risk factors for committing suicide exists if a person is **isolated** from friends and family members (Miklowitz, 2011:241, 242).

Chessick, Perlick, Miklowitz, Kaczynski, Allen, Morris, Marangell and the STEP-BD Family Experience Collaborative Study Group (2007:482) report that up to 59 % of BD patients may experience suicidal behaviour at some point in their lives and up to 56 % may make a suicide attempt at some point. Mondimore (2006:x, 247, 256) also refers to the fact that BD can be a fatal disease, but mentions that death can be prevented, because very effective treatments for this illness exist. The period of recovery from a depressive episode can be one of especially high risk for suicidal behaviour. ***Relapse*** prevention is ***suicide*** prevention. It must be remembered that the emergence of self-destructive thoughts and impulses is frightening both to the patient and to those around him or her.

Chessick et al. (2007:482) furthermore report that the suicide attempt of a spouse or family member is an experience that has enduring effects on the caregiver, even years after the event. Their study also found that **caregivers** of those with BD who are experiencing current suicidal ideation or who have made a suicide attempt report significant health difficulties.

- **Insight**

For many years psychiatrists and the therapists who work with them in treating patients with BD have had a sort of intuition that there are fewer relapses among patients who understand their illness and their treatment better, who work on learning to cope better with the stresses and difficulties that everybody faces, and whose family members are also **informed** and supportive. Psychiatrists have also observed that factors such as **life stresses** and difficult relationships at home seem to bring on symptoms and to impact the course of the illness (Mondimore, 2006:146).

The researcher has found that if caregivers gain insight re the illness and treatment, it definitely improves the patient's prognosis. The MDT also intervenes to stabilize family relationships before discharge.

4.4.1.7 Coping strategies (refer to 4.7.1)

Both the caregiver and patient should set coping strategies in place. Some possibilities are such as to go for a walk; to utilize community resources; to address practical issues; to listen to music; to have a hobby; to develop a network of a few people one can trust; to join a support organization and to laugh (Aiken, 2010:144, 157).

4.4.1.8 Cultural aspects

Social and cultural background may most certainly play a role in the burden of caregiving and caregiver perceptions of such (Van der Voort et al., 2007:685). In this regard it is important to look at **culture-bound syndromes**. These are recurrent, context-specific patterns of aberrant behaviour and may or may not be linked to a particular, recognised diagnostic category in western terms. Of specific relevance are **amafufunyane**, of which the aetiology is broad based, including spirit possession, witchcraft and pollution, and that of **ukuthwasa**, a condition representing being called to be a healer, sangoma, ngaka or igqira (Seape & Drennan, 2007:57-59). If a patient and his/her family believe that he/she has a **calling** to become a traditional healer, it can become virtually impossible to convince them of the existence of a mental illness.

In addition, some patients also believe that if they take their medication, this proves that their faith in God is not strong enough.

In conclusion, it is clear that BD cannot be seen in isolation; focus areas that are relevant for caregivers and patients have been discussed. The researcher is of the opinion that context must always be considered.

4.4.2 The caregiver

As discussed above, in the same manner as any other serious illness may, BD affects not only the person who suffers from the disease, but family, friends, and colleagues as well. **Family** support is crucial to the effective management of symptoms. The disrupted relationships and interpersonal conflicts that the symptoms of the illness can cause make BD all the more difficult and complicated to treat (Mondimore, 2006:x).

4.4.2.1 Emotions

Reinares et al. (2006:161) reported that, regarding adverse effects on others, nearly 70 % of caregivers were distressed by the way the illness (BD) had affected their **emotional health** and their life in general.

At first caregivers might react with **shock and disbelief**, but they may also describe a sense of **relief** when a **diagnosis** is finally made, knowing it is an illness which causes the patient to act the way he/she does (Last, 2009:viii). Nonetheless it is the researcher's experience that not all caregivers do **accept** the illness, so that even after years of the initial diagnosis, they might still be in denial.

Family members and friends may experience a **number of conflicting emotions** when someone they love is diagnosed with BD e.g. shock, grief, shame for having judged the patient for erratic behaviour and so forth (Fast & Preston, 2006:1). Tranvag and Kristoffersen (2008:13) refer to the fact that a partner's illness resulted **in loss** of important aspects of life. In time, this recognition led to **grief** over loss. Feelings of helplessness, fear and worry are experienced by spouses and partners of people with BD (Last, 2009:3; Miklowitz, 2011:36). In practice, the researcher has often experienced that families become very fearful of what a patient might do (being manic, depressed and/or psychotic). Last (2009:4, 9, 32, 261) also mentions the feelings of being overwhelmed, without hope, confused and having resentment towards the patient. Feelings of shame and secrecy may be part of the bipolar experience. It is possible that a caregiver might feel **pressured** when having to look after the patient (often without support). He or she might even feel trapped

(“I feel so responsible for him and yet I’m dying in this relationship. It’s all about him. I feel like I am in a jail”) (Fast & Preston, 2004:137, 139).

Parents may feel **guilty** for having had passed on the illness to their child or not having raised their child in the right manner.

The researcher agrees with Miklowitz (2011:279, 280, 281) that family members might act out **rejection** at some point; such as being angry, critical, intolerant of the patient’s apparent inability to function, blaming, labelling, using the illness as a weapon against the patient and being **overprotective** or exhibiting **over-involvement** where, for instance, relatives watch the patient very carefully, resulting in the patient possibly feeling they are being treated like a child at times. A 34 year old son who takes care of his bipolar mother during her manic and depressive episodes puts it as follows (Miklowitz, 2011:295):

> Bipolar illness is so taxing emotionally to the family and most families don’t have the skills for knowing how to deal with it. We feel overwhelmed and our skills are exceeded, and we can’t get answers from the mental health system. All the while we see our loved one in pain. Who wouldn’t get overprotective under these circumstances?

They might also experience **confused** feelings about the illness and confusing thoughts about how to help. Sometimes family members might speak to a patient in derogatory psychiatric jargon, such as: “That’s your mania talking”. They end up feeling frustrated and burdened by the effort required of them to adapt to the disorder and therefore often say and do things that are critical or unhelpful. Relatives may **under-identify** with the disorder (attributing behaviour changes to the patient’s personality) or **over-identify** with it: attributing all or most of the patient’s behaviours, even normal ones, to the illness.

Relatives under-identifying with the disorder may believe the patient’s changes in behaviour are caused by his/her lack of effort. They may also believe that the patient has more control over his/her mood swings than is really the case. **Negative emotions** of family members are often at their peak during the **recovery period**, following an episode (Miklowitz, 2011:281, 282).

Miklowitz (2011:280) alludes to the fact that caregivers go through inevitable ups and downs in reaction to the patient’s disorder. CAMH (2000:30-33) distinguishes between feelings of others when the patient is **depressed** or alternatively **manic**. Watching a loved one struggle with **depression** can trigger many emotions in those who are close to the person. These may range from sadness, concern, fear, helplessness and anxiety to guilt and anger. How a person behaves during a **manic** episode stirs up intense feelings in everyone, especially family members. They may feel frustrated and annoyed, or even **anger** and hatred. Particularly frightening in a manic episode is the situation where a family member seems to be replaced by a stranger. For example, a reserved, responsible woman may become loud and sexually uninhibited. Being with someone who is severely manic has been compared to walking in a **minefield** - one never knows when there will be an explosion. Some severely manic people have extramarital affairs, which might cause their partners to feel humiliated and betrayed.

Some caregivers become **frustrated with the professionals** and blame them for not doing enough, quickly enough, to "cure" the patient.

In conclusion it is clear that caregivers are confronted with a **spectrum** of possible emotions when their loved one is diagnosed with BD. As also stated by CAMH (2000:38) it is important that caregivers should **acknowledge** and **accept** their own feelings and also the fact that it is normal to experience conflicting emotions when a loved one is diagnosed with BD. Caregivers should be afforded the opportunity to work through their thought processes and emotional reactions through guidance dialogues (Tranvag & Kristoffersen, 2008:15).

4.4.2.2 Needs of caregivers

Caregivers must remember their **own** needs, should share responsibilities with others and stop BD from taking over family life (CAMH, 2000:39). One of the daughters of a person with BD states that with plenty of knowledge, information and close monitoring, counselling and new medical research, they may together be able to control BD rather than the BD controlling the victim (Aiken, 2010:115).

The researcher has highlighted some of the most pertinent needs articulated by different authors in **Table 4.1**.

Table 4.1: Needs of Caregivers

EDUCATION ABOUT THE ILLNESS
Families need to **know** about the illness of their relative if they are to be informed consumers and expected to help the recovering individual (McElroy, 1987:227). Family members of people with BD are usually hungry for **information** about the disorder, particularly during or after a manic or depressive episode, whether or not the episode involves hospitalization. Relatives may harbour many **misconceptions** about the illness. Well-meaning relatives who do not understand the disorder may view drug

treatment or psychotherapy as crutches. They should understand that the patient’s behaviour is at least partially biologically and chemically determined (Miklowitz, 2011:5, 283, 284, 286). It is important that everyone in the family learns as much about the illness as possible in order to know what they are dealing with (Aiken, 2010:121).Relatives should remember that nobody chooses to become bipolar.

PROFESSIONAL SUPPORT

Van der Voort et al. (2007:684) states that there is little research on the **need for professional support** for caregivers of patients with BD. Other important aspects include immediate access to hospitalization, should it be needed, information about the illness and treatment and being able to talk about their experiences and observations with a professional, with whom they can communicate and whom they like. Professionals should not judge the caregivers.

SPECIFIC SUPPORT

The “terrible sense of isolation” described by one parent is overcome for many relatives upon meeting others performing similar roles in other families. That “sense of being a pariah…a creature to be pitied” is reduced by being with other caregivers and hearing that others have experienced the same unpleasantness, the same despair, anger, and anxiety. The capacity to endure in the face of a tenacious problem depends on the existence of a **community of fellow sufferers** who affirm and protect one’s sense of worth, even when the evidence of the moment is ambiguous or contrary, who share and keep alive a common interest in the midst of a wider society that does not care, who provide counsel and concrete assistance, and who foster a belief in the future when all others fail to do so (Terkelsen, 1987a:148, 149).

GENERAL SUPPORT

Last (2009:272, 274) states that she has found in her work as a psychologist that the well spouses of bipolar patients **need** as much support as (if not more than) their mates - someone to listen to them, help with solving problems or resources made available to them. She furthermore mentions that people that **cannot** offer support are the **disbelievers** (“there is no such thing as BD”), **fortune-tellers** (he’s never going to get better”) and the **avoiders** (“let’s talk about something else”).

CONTEMPLATING WHAT DOES THE FUTURE HOLD?

Relatives may wonder what the future holds for everybody involved. The **uncertainty** of the future thus may create anxiety amongst relatives (Miklowitz, 2011:283). Caregivers may also be concerned about the future because bipolar illness is a largely genetic disorder and it might have an influence on the couple’s children. The unpredictable nature of this illness can be a huge obstacle to making plans. Uncertainty about the

future may cause a caregiver to feel as if they are in **limbo** (unable to move forward owing to the fear that the illness will re-emerge) (Last, 2009:3, 31). CAMH (2000:38) refers to the caregiver's fear about what the future holds. On occasions, it can prove impossible to **plan ahead** of time due to the varying episodes caused by the sufferer's mood (Aiken, 2010:121).
INVOLVEMENT IN DISCHARGE PLANNING The provision of an **aftercare plan** that includes the family's recommendations, capabilities, and resources for their relative's rehabilitation programme needs to be considered, if the discharge plan is to be viable (McElroy, 1987:227).
PRACTICAL ADVICE/PLANS It is important to develop an advance directive/relapse plan (Haycock, 2010:207). This can empower caregivers.
REFERRAL ASSISTANCE Hospitalization has become shorter, as noted, and it is therefore important that caregivers must be informed about resources in the community and that proper referrals should take place. Van der Voort et al. (2007:685) refer to the need for greater **community care**, an increase in adequate housing and better employment support.
SKILLS Caregivers do experience a need for skills, such as how to communicate with the ill BD patient, what to do if the patient becomes suicidal as well as other coping skills. Family members do not always know what to do when the relative with BD reacts negatively to their attempts to help (Miklowitz, 2011:97, 281).
NEGLECTING OWN NEEDS BD can lead to the carer losing his/her social life, which in turn can make him/her feel extremely lonely and isolated. Supporting a person with BD who is very ill can prove exhausting, often to the point where the carer neglects their **own needs** (Aiken, 2010:121).

This table has given an overview of caregivers' needs; it is clear that these do cover a broad spectrum. Professionals should be able to identify these needs and then offer appropriate support.

4.4.2.3 Roles of caregivers

In this section the terms **caregiver** and **caretaker** convey the same meaning; it was found that different authors prefer different terms.

It is possible that when a person married that neither member of the couple had any illness and this relationship was entered as a partnership, but as the one partner has become ill, the other one has ended up in the **caretaker-type** role (Last, 2009:267). It has been the researcher's experience that such a person might still have a **choice** to assume the caretaker/caregiver role, but usually a parent or child of an ill relative has less of a choice. Certain **expectations** are placed on such relatives.

One of the challenges for the caregiver of the person being diagnosed with BD is to be part of his/her loved one's "**treatment team**" - the group of individuals who share the common goal of promoting the patient's mental health.

According to Last (2009:127) the caregiver's **role** may include:

- Learning about BD (being proactive)
- Staying in contact with the patient's doctors (treatment team)
- Knowing the patient's early warning signs of mania and depression
- Taking care of him/herself by setting personal boundaries, putting time aside for him/herself, possibly joining a support group or entering therapy to help him or her to cope with the patient's illness.

When one's partner is ill, the caregiver takes care of the house, the finances, and the children. One calls the doctors, sometimes the police. This role becomes as important as any member of one's partner's health care team (Fast & Preston, 2004:1, 2).

The role of the family includes **support**, understanding and encouragement of the person who is ill (Mondimore, 2006:248, 252). CAMH (2000:39) warns that the caregiver should try to do things **with** their relative rather than **for** him or her. Last (2009:267) agrees, emphasizing it will be important not to extend the level of assistance beyond that which is necessary.

It is the opinion of the researcher that the caregiver is often also an **observer** of the behaviour of the patient and should report to the MDT. One of the most valuable ways a family member can help is to provide a clear, undistorted **view** of the situation to the clinical team treating the illness. Family members are frequently the first to pick up on subtle changes in behaviours and attitudes that signal the beginnings of a relapse (Mondimore, 2006:252). The researcher has found that the **history** of the course of the illness that the caregiver can provide is of enormous value (if he or she is able to be a good historian).

Mondimore (2006:236) refers to the fact that an astute friend or family member who knows how to communicate observations in a caring, non-provocative manner upon noticing sustained changes in mood is one of the best **supports** a patient can have.

A close family member or significant other can also go along to the consultation with the psychiatrist. This person can offer a different perspective on the patient's symptoms and life experiences, which may be quite useful to the mental health professional who makes the diagnosis and is responsible for the treatment (Miklowitz, 2011:43). Berk et al. (2008:263) support this view, pointing out that many people with BD, and the research evidence, support a **collaborative approach** to managing the illness that includes the patient, the loved ones and the clinician involved in the treatment. A patient noted the following:

> It was hard when my wife came along to my appointment with my doctor. Initially I felt a bit awkward, but it turned out to be beneficial. She has become part of the treatment team with my doctor, and she now has a better sense of my day-to-day struggles. This has strengthened our relationship.

It is important to safeguard the **financial assets** of individuals with severe, poorly controlled BD (Mondimore, 2006:255). It might become the next of kin's responsibility to approach an attorney or the Master of the High Court so that an Administrator can be appointed.

If a person's spouse is manic, that person may become a **buffer** between the patient and the community who might demand that the patient be controlled (CAMH, 2000:33). It has been the researcher's experience that the community will not understand that the person is ill and may lay a charge with the police.

The caretaker role does not have to be permanent. In fact, it needs to end at some point. This is especially true when the caretaker is the partner. The goal is to learn to leave the caretaking role while still being an important part of the patient's treatment plan. Once the patient and his/her partner create a treatment plan and learn how to manage BD, the partner will **not** have to play the caretaker role anymore. He/she can be a partner, a friend and a lover again, once the illness is properly managed. The partner who was once the caretaker might have a difficult time adjusting to the fact that the ill partner now has strength, a self, and a life. The relationship will change when the patient starts to become well. Some relationships do better when one partner is ill; the roles are clearly defined and there is a caretaking system in place that is familiar and safe. When the ill partner gets better, everything changes. There will be new roles to play. Joyous recovery can be short-lived when people are **stuck** in their old roles (Fast & Preston, 2004:181, 186, 200).

A person **does not have** to be a caregiver; if the situation becomes more than the person can handle, this should be discussed with the doctor or another therapist (Haycock, 2010:235). It might however become a problem when caregivers withdraw, because of the lack of resources in the community and because patients definitely need support from caregivers.

Family roles are shaped by **cultural** and **social class expectations**; for example, in a relationship characterized by traditional gender roles, the care burden experienced is likely to differ substantially, depending on whether the husband or wife is the patient (Ogilvie et al., 2005:27).

Other roles that the researcher could mention include those of mediator, facilitator, crisis manager, advocate, provider, enabler, agent of change, motivator, single parent and breadwinner.

In summary, it is clear that roles are dynamic and specific roles are not permanent.

4.4.2.4 Reactions of caregivers

Reactions of caregivers in the midst of BD are very **individual**. It may be easy to **rationalize** some BD behaviour. **Denial** is one of the most daunting obstacles to treatment. Denial on the part of family members is especially elevated during calm periods **between** bipolar episodes. It is then that the last episode can more easily be dismissed as an aberration; something that, although unpleasant, will not happen again (Haycock, 2010:115).

Often relatives **blame** themselves when a patient becomes depressed or manic. Recognition and **acceptance** of the illness might be a lifelong challenge.

4.4.2.5 Psychosocial challenges for caregivers

The first challenge facing family and friends is to **change the way** they look at behaviours that might be symptoms of the illness. They should not always take behaviours and statements at face value, but must learn to ask themselves if the behaviour could be a symptom before reacting, while also being careful of the other extreme: interpreting *every* strong emotion in a person with a mood disorder as a symptom. They should recognize the person’s capabilities and potential. Just because a person has a psychiatric illness does not invalidate him/her (Mondimore, 2006:249).

Mondimore (2006:257) reminds us that perhaps the most difficult challenge is that posed by a family member with BD who is **resistant** to receiving treatment. It is the experience of the researcher that if the family must have the patient certified the latter may blame a family member for having done so.

Even when they are not experiencing mood episodes, bipolar individuals can be very "**high maintenance**"; they repeatedly impose both large and small **demands** on their spouses (Last, 2009:141). These individuals can be very demanding with whoever they come into contact with - be this the employer, the neighbour or the members of the MDT. Last (2009:2, 260) refers to both the patient and spouse/partner when she mentions that: "Whether it's meeting expectations at work, keeping up with friends and family, pursuing hobbies and interest, and, at times, even just taking care of the basics of sleeping, eating, and grooming, BD makes day-to-day life a challenge". There will be challenges on an on-going or intermittent basis throughout the caregiver and patient's lifetime together.

BD poses many challenges that are hard for anyone, except those suffering from it, to understand (Miklowitz, 2011:313). Perhaps professionals similarly do not understand the **challenges** that face the **caregiver**, but a possible few can be mentioned:

- **Being insulted and critiqued:** People in the midst of a manic or depressive episode may say insulting, dismissive, and hurtful things (Haycock, 2010:227). It is sometimes very challenging to remain calm, to have patience and to be forgiving.
- **Having to deal with typical illness behaviour such as:** infidelity, overspending, aggressiveness, irresponsibility, impulsiveness and breaking the law. Attempting suicide, assaulting another person, stealing, speeding, creating a public disturbance and lewd conduct are among the more common ways in which a person might break the law during a bipolar episode (Haycock, 2010:198).
- **Having realistic expectations:** The caregiver should have realistic expectations of him/herself, of the patient and also of the "treatment team" (Last, 2009:138, 143); respecting everyone's limitations and boundaries. CAMH (2000:34) makes it clear that the caregiver should not become caught up with the patient's euphoria or their unrealistic expectations. He/she must not try to convince the patient that his/her plans are unrealistic. The caregiver should also realize that segments such as the hospital, work, church, friends and society might have certain expectations of him/her in caring for the patient.
- **Maintaining health and happiness in the midst of BD:** The caregiver should not be so consumed with the illness that he/she ends up losing her/himself (Last, 2009:260).

The challenged of the **shortage of trained psychiatrists** and **community-care facilities** predictably increases the international costs and suffering related to this disorder (Taylor, 2006:13) which is particularly evident in South Africa.

In summary, the researcher has highlighted challenges for the caregiver from literature, but also from her personal experience with caregivers of mentally ill people.

4.4.2.6 Dealing with losses/limitations

It has been the researcher's experience that the loved one, be they parent, child, spouse or other relative, also has to deal with the multiple losses that the illness implies. Having been diagnosed with a serious mental illness, a person is often perceived as being disabled or dysfunctional, which also affects the others in her/his life. A caregiver might experience that the person is "absent" when being ill and that the relationship is "temporarily suspended" (Last, 2009:227). CAMH (2000:38) agrees, saying it is normal to experience a deep sense of loss when a person's relative is behaving in ways that one does not recognize.

Kowatch et al. (2005:3) concur; they declare that clinicians need to be sensitive to helping parents through the process of **grieving the loss** of their healthy child (family member), especially in the event of acute onset of BD.

4.4.2.7 Effect of patient's behaviour on caregiver

When enough is enough

> Sometimes I feel I can't go on this way anymore. I know that I made a commitment to this person, but I don't think it's fair for me to have to spend the rest of my life this way. But then I think, 'She doesn't want to be like this,' and I feel guilty for even considering leaving. After all, what would she do without me? Who would take care of her? (Last, 2009:277).

Family members or significant others are not likely to understand the widely fluctuating experiences of BD and are likely to focus on how the patient's behaviour affects them and other family members (Miklowitz, 2011:28). Again, Aiken (2010:104) states that anyone who has actually lived with someone with BD will know that this is definitely one of the hardest situations to deal with. A mother's report in Aiken (2010:141), states that it is like living with a volcano: you hope it doesn't happen but you know it could erupt any time.
Haycock (2010:107-109) refers to a few specific areas in which loved ones are affected:

- Loss of **sleep, time and energy**. Being awakened at odd hours, having to listen to someone, or drive him someplace or bailing him out of jail becomes a full time job.
- Loss of **money**. A person with BD might ask for financial assistance to get out of trouble that can be traced to the illness. Many people find that being close to someone with untreated BD is expensive.
- Loss of **direction**. If someone spends a great deal of their life caring for or worrying about a patient with this illness, they might find their own accomplishments and sense of satisfaction limited. The goals and plans of the caregiver may fade as he or she instead tries to save or protect the person being looked after. A person with BD could take over a caregiver's life if the latter does not protect him/herself.

In this section the researcher discussed relevant aspects pertaining to the life of the caregiver of somebody with BD. Some focus areas overlapped: emotions, needs and challenges, but the researcher tried to separate them for analytical reasons.

4.4.3 The patient

> Well, even in that deep misery I felt my energy revive and I said to myself: In spite of everything I shall rise again. I will take up my pencil, which I have forsaken in great discouragement, and I will go on with my drawing, and from that moment everything has seemed transformed in me (Vincent van Gogh).

According to Fast and Preston (2006:28) Vincent van Gogh had BD and was a classic case of Bipolar I.

Subsequently, various aspects relating to the patient will be discussed.

4.4.3.1 Emotions

Being labelled as having a serious mental illness can provoke certain emotions. It is said by patients that BD not only affects the way they live, it affects the way they see the world (Aiken, 2010:82).

> When I'm mad, nobody better get in my face. I feel like crushing everything and everybody. Every little thing will provoke me. I **hate** everybody; I hate my life and want to kill myself in some really dramatic way. It's like a sharp-edged, pointed anger, like a burning feeling - A 23 year old woman with bipolar II disorder (Miklowitz, 2011:19).

Addressing patients, Miklowitz (2011:148) makes it clear that: "You are not alone in your struggle to **accept** the disorder and its required treatments". People with BD and other depressive disorders often feel **hopeless**, as if nothing will ever change for the better (Miklowitz, 2011:241).

Many people with the diagnosis of BD **deny** this diagnosis. Other feelings might include **worthlessness**, **guilt, failure, anger, shame, frustration, resentment** and **loss of control** related to having a psychiatric illness (Mondimore, 2006:228, 249, 251, 252). CAMH (2000:32) mentions that the depressed person can feel very **lonely** and **isolated**. A patient could also be self-pitying (Fast & Preston, 2004:144).

Aiken (2010:39) says that there was a time when she felt that she would rather suffer from a terminal illness than from bipolar, because she would be able to predict the end result. Other emotions she refers to include **fear** and **anger, jealousy** towards her sister who could offer her daughter stability, and **grief** for the life before BD (Aiken, 2010:76, 125, 159).

A sufferer must remember that BD is something that they have, but **it is not who they are**. Knowing this difference may keep the person from rejecting the diagnosis or, at the other extreme, giving their life over to the illness (Miklowitz, 2011:57).

The researcher has experienced that a person with BD is sometimes so sick (especially when psychotic) that one tends to ignore emotions like worthlessness and isolation that the person might be feeling. BD is an illness of mood, but it is still very important to observe the emotions “behind” the mood, for example that a manic person might still feel rejected or insecure.

4.4.3.2 Needs of patients

When the patient is ill, he/she will need help with the usual responsibilities. Patients might also need assistance with effective **parenting skills**, because aspects like discipline and stability become very difficult to instil if the parent is ill. Aiken (2010:84) mentions that a lot of parents **over-compensate** when they feel stable.

Michalak, Yatham, Kolesar and Lam (2006:27-36) conducted a qualitative study in which they asked people with BD what they **need** in order to have a good quality of life: some of the aspects that were mentioned included routine, independence, social support, the need to restore their sense of self-worth and identity. The relationship between BD and spirituality; in particular, the struggle to disentangle “real” spiritual experience from hyper-religiosity (a possible symptom of BD when hypomanic or manic), was discussed. BD can impact upon life quality, or people’s ability to *love, work and play.*

4.4.3.3 Roles of patients

- **Patient role**

In BD the patient ultimately determines how well *any* treatment is going to work, because it is the *patient* who puts treatment recommendations into action (or not). Patients might be **ambivalent** about the need for treatment. It is important that individuals with any incurable but treatable medical problem must learn how to walk the fine line between not taking their illness seriously enough and taking it *too* seriously (Mondimore, 2006:228, 229, 238).

According to Aiken (2010:26, 28, 29) the patient should be an informed and pro-active partner in treatment and management. A person must **recognize** his/her **relapse signature** (an individual's personal warning signs of illness) (Berk et al., 2008:284). It is the researcher's opinion that by doing this, the patient takes ownership of his/her illness.

The patient should be allowed to accept some responsibility for the administration of and compliance with the treatment.

- **Parent role**

Individuals with BD need to be alert to signs and symptoms of mood disorders in their children and to place them into treatment if such symptoms occur (Mondimore, 2006:202).

Dr Spender (a psychiatrist specializing in children and adolescents) was asked by Aiken (2010:59-64) to make some comments regarding the effects of BD on children and families. The researcher will highlight some of the important aspects that were mentioned.

Living with a mother or father with BD is hard work. The earlier in a child's development that parental BD starts, the more likely it is to have a significant impact on the child's relationship with their affected parent and their development. **Protective** factors include the establishment of "good enough parenting" before the onset of the illness and the formation of strong, healthy attachments to the affected parent, before or despite the illness, and the child's own **resilience**. Having an affected **father** is more likely to result in loss of income and a reduction in living standards. Having an affected **mother** is more likely to result in disrupted or intermittent parenting. Children may experience a parent's mental illness in a variety of ways:

The child may witness the symptoms (seeing parent being manic)
The child's experience of parenting may be affected (feeling insecure)
Both child and parent may be affected by consequences of the BD (divorce, domestic violence)
A young person may fear inheriting the disorder.

Aiken (2010:81, 92) indicates that there are times when the child takes over the parental role (**role-reversal**). Her daughter stated: “When she is low I do feel like *her* mum and I really don’t like it because it does upset me”. Another daughter (Aiken, 2010:111) reported that her life changed. She became her mother’s mother. She had to take care of her little brother, help her dad and do all the household chores. She was obliged to encourage her mum to have a bath, change her clothes and eat.

- **Advocates for research**

A commitment of those, with the illness, to taking part in research, for rapid, accurate diagnosis and more effective treatment, with fewer adverse effects that can be tailored to the individual, is required (Aiken, 2010:30).

A few roles of patients have been discussed, but there may still be others, such as breadwinner or spouse. It is important to realize that a person may be simultaneously confronted with multiple roles.

4.4.3.4 Reactions of patients

Patients may **blame** their behaviour on people they might think provoked them - typically family members. Some **over-identify** with the illness, viewing all of their problems, emotional reactions, attitudes and habits as part of the disorder. A patient should try to avoid blaming others for their role in the illness and must accept that in most cases family members are trying their best to be helpful and often do not know what to do or to say. Managing family relationships is an important element of maintaining wellness (Miklowitz, 2011:59, 66, 97).

4.4.3.5 Psychosocial challenges for the patient

Making peace with the illness and the idea of staying in treatment is much more difficult than healthy people realize (Mondimore, 2006:257). CAMH (2000:24, 25) refers to some tips for preventing relapse and promoting wellness; the researcher opines that to keep to these can also be a **challenge** to the patient. Some of the aspects include:

- Becoming an expert on one’s illness
- living a healthy lifestyle (avoiding substances, eating a healthy diet, exercising, developing healthy sleeping habits)
- finding strategies to cope with stress
- avoiding isolating oneself (a strong social network can buffer one against stress)

- trying to balance one's life (moderation is the key)
- monitoring one's symptoms closely (knowing one's own signature pattern of symptoms - it seems to be similar across episodes)
- identifying family and friends as support systems (they can recognize typical bipolar symptoms)

People with BD face significant challenges in the **workplace**, with some of these challenges arising from the stigma of BD and the reaction of others. The bigger challenge, however, is finding a job that is satisfying but also helps keep a person from mood cycling (a shift job is not a good idea). It is difficult to balance severely fluctuating moods with a stable work life. Maintaining a stable mood is essential to functioning well at a job (Miklowitz, 2011:300).

While it has been the researcher's experience that many patients wish to apply for a disability grant, the fact that BD is a treatable disease makes this process challenging. It is the researcher's opinion that a person with BD who complies with treatment can work and lead a relatively normal life which could provide routine and structure, but on the other hand may also be very stressful.

A sense of **humour** might be difficult to cultivate, but it may help to release stress and to be less serious about a very serious matter!

4.4.3.6 Dealing with losses and gains

- **Losses**

Miklowitz (2011:58) quotes a 26 year old woman who had just been hospitalized for her second manic episode. She verbalized her losses:

> I want to go back to the place where I used to live, back before this mess started. Who knows? Maybe the apartment I lived in is still available. People liked me there. I sometimes think if I go back there, I'll find the old me sunning herself under some big old palm tree.

Miklowitz (2011:60) reports that Ellen Frank (a professor at the University of Pittsburgh) has termed the emotional issues underlying the denial of BD "**grieving the lost healthy self**". People with BD were often very energetic, popular, bright, and creative before they became ill. Then, once their illness is diagnosed and people around them start treating them like a "mental patient", they become resentful and start yearning for who they used to be. They experience deep feelings of loss over the dramatic changes the illness has brought. A patient might also lose status, work, and money or compromise relationships. Aiken

(2010:35) wrote that after her diagnosis of BD, her marriage broke down, she lost her job and she temporarily lost her children – she felt as if she had lost her life. She also avers (Aiken, 2010:57, 159) that most of the patients she had contact with expressed a feeling of grieving for their **past persona**.

- **Gains**

According to Aiken (2010:159, 160) she realized that when she reflected on the difficult years since having been diagnosed with BD there are also positive aspects that have come about as a direct result of the illness. She refers to better relationships with her family and friends and adds that she became more appreciative of life, taking nothing for granted any more.

4.4.3.7 Illness

The aspects etiology, comorbid conditions and women and BD has been discussed in chapter 2 and will therefore not be repeated in this chapter.

According to a patient's report (Aiken, 2010:157) BD is a **life-altering**, devastating condition that can **ruin one's life if you let it**. The patient adds that his BD does not define who he is - it is just a "thing" that he has to live with. The researcher agrees with Haycock (2010:214) who states that a person is not the disease they have been diagnosed with. He/she should not be defined by an illness, no matter how dominating or devastating it is. It might seem to be a pedantic or trivial point, but such labels can have a significant effect on how we regard others and how they regard themselves. A person with BD is a complex human being with many more aspects to their character than the phrase "bipolar person" implies.

- **Mania and depression**

The elated, euphoric periods of the **manic** experience **feel exceptionally good** to the person with the disorder. Kay Jamison (a well-known psychiatrist suffering from BD) has written extensively about the wondrous feelings that might accompany manic episodes and how the desire to sustain these feelings may lead a person to resist taking medications. Another person, however, described his manic states as "tired but wired" (Miklowitz, 2011:19, 20). Miklowitz (2011:187) also reports that a manic episode can wreak havoc with a person's life. It might drain finances, ruin marriages and long-term relationships, destroy a person's physical health, produce legal problems, and lead to loss of employment. It may even lead to loss of life. Miklowitz (2011:20) quotes one man who bluntly expressed how he experiences his **depression**:

> My depressions eat me alive. I feel like I'm in a fish tank that separates me from other people. It's all just hopelessness, and I don't see any future for myself.

Another aspect during the depressive episodes is the fact that many patients experience a cripplingly low self-esteem, feel suicidal or make a suicide attempt (Aiken, 2010:56).

- **Cure**

There is no cure for BD, only treatment and management. It is a **relentless** illness whose symptoms inevitably and repeatedly return to torment its sufferers. The only way to keep it at bay is for the **patient** to be relentless as well - relentless about getting needed treatment and sticking to it (Mondimore, 2006:227).

- **Functioning (lack of)**

Aiken (2010:17, 21) reminds us that BD is able to affect a person's ability to function. The manic person's creativity develops into an impossible mission; happiness becomes elation and the high functioning turns into agitation. A patient in Aiken (2010:73) talks about how she will hurry back to the safety of her lovely bed - her best friend. In another scenario a daughter describes her mother's lack of functioning, reporting that the mother had lost all her confidence and found it very hard to manage her day-to-day responsibilities (Aiken, 2010:113).

4.4.3.8 Quality of life

One of the people who sent their life story to Aiken (2010:54) mentioned that "bipolar is not a nice friend. It is your enemy". Another person, on the other hand, wrote: "being bipolar is **challenging**, even frustrating at times, but I don't think I'd wish to live without it. I've learned to embrace it as a part of myself. I am me. I don't want to be anyone or anything else" (Aiken, 2010:51). There is a complex, multifaceted relationship between BD and QoL. When asked to prioritize the areas they thought most important in determining QoL, the majority of participants in a study (Michalak et al., 2006:25) ranked **social support** as most important. Most of the affected individuals reported that BD had a profoundly negative effect upon their life quality, particularly in the areas of education, vocation, financial functioning as well as social and intimate relationships. However, some people also reported that having BD opened up new doors of opportunity.

In conclusion, the researcher acknowledges that BD does seriously affect the patient and his/her life. However she does deem it important that the patient should set **appropriate expectations** for him/herself and also take cognisance of his/her own **strengths** and, by doing so, build resilience.

4.4.4 The family

The ways in which different family members have **experienced** bipolar affective disorder have been investigated only to a limited degree in the past (Tranvag & Kristoffersen, 2008:6). Conventionally, the difficulties associated with BD on the personal level are vivid for the **patients** themselves. However, for their families, who frequently have to provide support and care for them, the consequences of the illness may also be far-reaching and the rate of marital and long-term partnership breakdown is very high (Ogilvie et al., 2005:26). This has also been the researcher's experience in her practical interactions with BD patients and families.

Belardinelli, Hatch, Olvera, Fonseca, Caetano, Nicoletti, Pliszka and Soares (2008:299) are of the opinion that BD is a **familial** disorder, which is influenced by genetic and environmental factors. Among the environmental factors considered as most important is the **family environment**. Previous studies link a disordered family environment with a poor prognosis in BD.

Mondimore (2006:225) and Aiken (2010:121, 125) agree with the above mentioned authors and refer to the fact that BD does not affect just the individual with the diagnosis of the illness. Inevitably, family and friends are affected in countless ways, both directly and indirectly. When a family member has BD, the illness may profoundly affect the whole family. It is a sad fact, but BD not only destroys the mind; unfortunately, due to lack of understanding, it can also destroy the dynamics of relationships.

As a person with BD spirals out of control, friends and **family** might feel as though they have lost her or him, since the person they used to know does not seem to be there anymore (Haycock, 2010:106). It is also said that people with BD often have high levels of family or relationships conflict or tension (Miklowitz, 2011:131).

The researcher has observed that families are becoming more aware of the fact that they are also affected by their loved one being mentally ill. Perhaps this is because the media are reporting more on issues of mental illness and people have become better informed. In the following section the researcher discusses some pertinent aspects related to the family.

4.4.4.1 Expressed emotion studies

Expressed emotion (EE) studies focus on the discovery that psychiatric patients who have returned to live with families who expressed a high level of criticism and emotional over-involvement, tend to relapse and need hospitalization more frequently than those families low in EE (Lefley, 1987a:30).

When trying to understand the experience of BD, family members or significant others may entertain the perspective of emphasizing the patient's **personality** or viewing the deviant behaviour in historical perspective; for example, "She's always been moody". These family members or significant others are unlikely to understand the widely fluctuating experiences of bipolar disorder and will more probably focus on how the patient's **behaviour** affects them and other family members. Patients who return to high-conflict, high-intensity families are more likely to undergo manic and depressive recurrences within nine months after their discharge than those who return to low-conflict families. **Family and interpersonal conflicts** can be **risk factors** in the course of BD (Miklowitz, 2011:13, 28, 96, and 97). The researcher is therefore of the opinion that if caregivers can be helped to deal with the illness, the patient's prognosis becomes much better.

Although Ogilvie et al. (2005:25, 30) mention that caregivers of bipolar patients (partners or parents) may have high levels of expressed emotion, including critical, hostile, or over-involved attitudes, the researcher wishes to warn that one cannot generalize.

Chadda et al. point out that maladaptive ways of functioning in the family and the expressed emotions are associated with an increase in the perceived **burden** and affect caregiving. **Coping styles** are also affected by caregiver burden and distress (Chadda et al., 2007:928).

4.4.4.2 Family-Healthcare staff dissonance

Another issue arising is that not being understood by professionals can exacerbate the distress of families and unnecessarily increase their burden (McElroy, 1987:228).

Many experts in the psychiatric field have reported about the need to respond to the families of the seriously mentally ill in a more helpful manner and to reduce dissonance; when negative **stereotyping** occurs it has an impact on families. Families are sometimes characterized as "psychovermin" by many of those charged with helping them. Sometimes professionals' actions have suggested a lack of awareness of the **grief** experienced by the families (McElroy, 1987:227). It is thus clear that the complexities faced by family members caring for a relative with a chronic mental disability are not always understood.

Families often begin their relationships with professionals with the expectation that **information** and **guidance** will be forthcoming. It is the researcher's experience that this does not often happen. Families with severely mentally ill relatives who do not respond to medication or who exhibit disruptive behaviour would predictably be under more stress than others. These families may project dissatisfaction onto professionals for failing to help their relatives. In turn, the professionals may withdraw from these families at the time of their greatest need (McElroy, 1987:228, 231).

Too often, professionals view the family as **unidentified patients** needing treatment rather than as **adult learners** attempting to deal with a major mental illness. The special **expertise** that families possess is relevant to quality care and the family's expressed needs must therefore be given priority (McElroy, 1987:238, 240). The researcher has come to realize that professionals should acknowledge the families' **strengths** (4.7 refers) and not always focus merely on their weaknesses. It has also become clear to the researcher that the professionals sometimes act from a position of feeling helpless and frustrated with the situation. Some caregivers are seen as very demanding; requesting time, attention and information.

In one of Aiken's (2010:105) case studies, the daughter stated that she is in some ways angry with the medical system, because she felt it let him (her father) down to some degree. Tranvag and Kristoffersen (2008:11) comment that admission to a psychiatric institution may lead to **care** and **information** vs. being **overlooked** or **turned away** by health personnel. In their study they found that awareness and an empathic attitude gave spouses/cohabitants of a person with BD a feeling of being understood. It seems that it is important that caregivers can share their worries, to receive information about the illness, the treatment and prognosis, as well as advice in how to adjust their behaviour and communication to the situation and their loved one's condition.

4.4.4.3 The evolution of family responses to mental illness through time

The ways **families** respond to mental illness vary as a function of time. Any response undergoes its own patterned temporal development, a pattern that transcends individual differences in response disposition (Terkelsen, 1987b:151).

Terkelsen (1987b:152-164) mentions the following stages:

- Ignoring what is coming
- The first shock of recognition

- Stalemate
- Containing the implications of illness
- Transformation to official patient hood
- The search for causes
- The search for treatment
- The collapse of optimism
- Surrendering the dream
- Picking up the pieces.

The researcher is of the opinion that caregivers undergo a **process** of different **emotions** when first confronted with the illness and that they also need time before they come to accept and adjust to the situation. The material for **Table 4.2** is derived from personal and clinical longitudinal experience with families (over more than twenty four years) and adapting the above model (Terkelsen, 1987b:152-164). There is, however, great variation in the pace at which **individual** members of **families** move along this path.

Table 4.2: The evolution of family responses to mental illness through time (Terkelsen, 1987b:152-164)

STAGE	CONTEXT	EMOTIONS and responses of CAREGIVERS
1. Unaware of mental illness (may last for years)	Patient starting to behave in a strange way. Experiencing problems at work, in the family and society (neighbours may complain).	Ignoring the illness, minimizing changes, providing assistance, concerned, are becoming anxious. Naiveté about mental illness.
2. Becoming slowly aware	Something serious happens: patient might commit a crime. Recognition of possible mental illness.	Tell the affected person to “pull himself together”, denial (emotional distance) and shock, bewildered, disruption in family, intensified anxiety and panic. Experience stress. Taking all the responsibility.
3. Aware of illness	Behaviour due to the illness (e.g. aggression, psychosis, withdrawal) can no longer be ignored. The patient may not be aware that he/she is ill.	Start to seek help (e.g. **from** traditional healer or western medicine). Fear of the unknown.

STAGE	**CONTEXT**	**EMOTIONS and responses of CAREGIVERS**
	Conflict between family members might happen.	Feeling ashamed because of stigma and having judged. Embarrassment. Uncertainty. Overwhelmed. Sense of helplessness, unable to act effectively. May however still be optimistic and hopeful. Unrealistic expectations and lack of insight. Want a "quick fix".
4. Social status transformed to psychiatric "patient"	The patient becomes out of control. His/her life or someone else's is threatened. Hospitalization might follow. Eventually a diagnosis is made, although it might still change.	Overprotective (visit every day). Anxiety and fear. Relief that a diagnosis is made. Emotional pain. Grief of losing the "well" personality.
5. Search for causes and treatment	Pre-existing belief system of family about the nature of mental illness. Challenge to family's capacity to cope with ambiguity, controversy, and unanticipated outcomes of treatment. Challenge of the institutional policies and practices within the mental health system. Demands on family to take patient home.	Guilt feelings. Blame the health system, the patient and also themselves. Loss of internal cohesiveness in family. Search for information on mental illness. In chaos, regarding what action is to be taken. Flight into health (minimizing the effect of the illness). Some caregivers may become depressed. Marital strain, disrupted social life, hardships for siblings. Unrealistic expectations of the patient.
6. Collapse of optimism (months to years)	Family start to realize that the illness is chronic in nature and although patient might get better, he/she suffers relapses	Over-concern. Avoidance: family might start to withdraw and might also reject the patient.

STAGE	CONTEXT	EMOTIONS and responses of CAREGIVERS
	and does not return to previous level of functioning. Total remission is unlikely. Family must cope with the burden of the illness.	Hopelessness. Resentments. Frustration. Anger. Mourning the loss of idealized internal images of the affected member. Grief reaction. Letting go of dreams. Family members restructure their lives so as to reduce contact with the patient.
7. Restoring equilibrium	Seeing the illness in perspective. Compartmentalize the illness so that it is seen as one of an array of challenges in the life of the family, rather than the central problem. Sought-after balance is hard to discover and harder to maintain. Letting go can be very difficult.	Adjust to the realities of long-term caregiving. Becoming realistic. Understanding, acceptance. Loneliness and isolation. Tolerance. Call attention to the inadequacy of currently available social supports and clinical services. Some caregivers might still reject the patient or might adopt a “don’t care” attitude.

If the professional is **aware of this process**, there is a better chance that unrealistic expectations will not be placed on the caregivers and that even professionals will have more tolerance towards the demands that caregivers present with.

4.4.4.4 Mental illness in a family

BD runs in families, and people with BD tend to find mates who themselves have mood disorders (known as *assortative mating*) (Miklowitz, 2011:61, 77). It has been the researcher’s experience that sometimes couples do meet in a psychiatric hospital and even marry, but such relationships are usually not sustainable. It has long been recognized that BD exists in clusters within families and seems to be inherited in some individuals (Mondimore, 2006:198).

4.4.4.5 Reaction of other family members

In her report, Cara Aiken's **sister** (2010:132) says that although she knows it sounds awful, she always feels the need to distance herself when Cara is ill. She declares she never knows what to say to her and she cannot listen to the same symptoms over and over again. She wishes she could do something that would cure her of her mental illness, but she cannot. All she can do is be there for her and try to ease the burden.

Cara Aiken's **mother** (2010:135) reports that it is awful standing by and watching one's child go from a happy-go-lucky child and teenager, into someone who seems so troubled, and who has such irrational thoughts. Another mother (Aiken, 2010:141) had to section (certify) her daughter who then released all her venom onto her mother and she (the mother) was 'the devil incarnated'.

It is usually the parents who will persevere with supporting the patient in spite of everything he/she might do or say. It seems to be more difficult for the siblings to have this non-judgemental attitude.

4.4.4.6 Belief system in family

Caregivers' previous experiences of health services may influence their beliefs concerning the illness (Ogilvie et al., 2005:25). The **illness beliefs** of the caregiver have been found to strongly relate to the degree of experienced burden. To the extent that the caregiver believes that the patient can influence his or her symptoms but is not making an effort to do this, the higher the degree of experienced caregiver burden becomes (Van der Voort et al., 2007:686). The researcher concludes that it is therefore very important that members of the MDT should become aware of the family's belief system and even any rituals that they need to perform. Their beliefs should be respected. A thorough assessment needs to be done in this regard.

In conclusion, if families **realize** that there is a process (which will take time) that they are going through when being confronted with a serious illness like BD, it could instil some hope in them.

4.5 ASPECTS THAT MAKE BIPOLAR DISORDER MORE DIFFICULT/EASIER FOR CAREGIVERS

Based on personal professional **experience**, the researcher wishes to table some aspects that might make BD more difficult/easier for caregivers. This may also be considered as a list of **risk** and **protective** factors. It is important that caregivers and professionals should take cognisance of these.

Table 4.3: Aspects that make it more difficult/easier for caregivers

More Difficult	Easier
Substance abuse Substance abuse exacerbates bipolar illness (Last, 2009:45).BD symptoms and substance abuse seem to trigger and reinforce each other (Mondimore, 2006:181). Even the abuse of analgesics or benzodiazepines can become a problem.	No substance problem, or substance problem addressed.
Lack of insight by the patient as well as by the caregiver(s).	Patient and caregivers accept and understand the diagnosis.
Poor compliance with treatment and follow up appointments.	Patient takes responsibility for his/her illness, attends appointments and devises strategies to prevent a relapse. All role players' work together to ensure better compliance.
Financial implications Patient uses no discretion and planning concerning cost of living.	Patient is aware that he/she might overspend when being manic and has put measures in place for controlling this behaviour. An Administrator is appointed by the Master of the High Court when necessary.
Work problems When the patient is not able to hold a job this impacts on the whole family system. The patient might develop guilt feelings for not being able to provide for his/her family.	Patient does discuss the illness and need for treatment with his/her employer (being transparent). The professionals give psycho-education to the employer. Certain adjustments could be negotiated at the workplace.
Severity of the illness (with psychosis) Delusions and hallucinations are particularly scary to significant others (Miklowitz, 2011:24).	The patient and caregivers know that they must immediately seek medical attention should he/she become psychotic. They act in a preventative manner.
Suicidal thoughts/ideation	The patient reports his/her suicidal thoughts before they become worse and lead to a

More Difficult	Easier
Friends and family members will be particularly upset and scared by the patient's suicidal thoughts (Miklowitz, 2011:25).	suicide attempt. The caregivers are alert to suicidal ideation and have an emergency plan ready.
Stigma and stereotyping of mental illness is still real and may well cause caregivers rather to avoid the patient.	Caregivers who are informed consumers will be less affected by stigma. They will be able to cope better if they are able to challenge stereotypes. It is important to maintain perspective.
Aggressiveness (verbally or physically) When the patient is very aggressive at home or in the community it may be necessary to summon the help of the police, which might be very difficult for the caregiver. The patient might assault somebody, resulting in a subsequent criminal charge.	If the patient is not aggressive, usually family relationships are less negatively affected. The patient and the caregiver can be taught skills to address the anger and it will become easier for both to do so. Any aggressive behaviour should be reported to the MDT. Treatment may be adjusted or the patient might have to be admitted
Comorbid conditions e.g. personality disorder, substance abuse, cognitive impairment or HIV The prognosis for a personality disorder is very poor. A person with cognitive impairment might be more impulsive and present with behavioural problems which are a challenge to manage. The caregiver might not be aware of the patient's HIV status and this illness can complicate the picture.	Substance abuse can be treated (if the patient is motivated). If the caregiver is able to understand the dynamics of the personality disorder, the situation might become easier. It would also help if the caregiver were to place fewer demands on a patient who is cognitively challenged. If the positive HIV status can be shared with the caregiver, this might lead to better understanding (although there is no guarantee of this).
Support Lack of family or professional support, or lack of understanding from the community, intensifies the caregiver's burden.	Building a social support network is a way to lower the risk of caregiver burnout (Haycock, 2010:193).

It is the researcher's opinion that if this view presented in **Table 4.3** could be shared with the caregivers, it might help them to identify some possible potential stressors and cope better with the many challenges they face. These aspects could be utilized by professionals to facilitate meaningful engagement with the caregivers.

4.6 HOW CAREGIVERS TAKE CARE OF THEMSELVES

4.6.1 The scenario

Caregivers may well spend a significant amount of time and effort worrying, enough to sometimes threaten their own health and well-being (Haycock, 2010:107). They may experience physical signs of **stress** like headaches, stomach aches and back problems (Last, 2009:138). This stress appears to **increase** with the severity of the illness. The caregiver should watch for indications of depression, irritability, anxiety, frustration, anger, fatigue, insomnia or other sleep disturbances and difficulty concentrating. Another sign of having taken on too much is poor physical health due to a weakened immune system and exhaustion (Haycock, 2010:231-232). For many people being a caretaker 24/7 goes on for **too long**, until he or she finally collapses. This could take the form of physical exhaustion, depression, or just being fed up. One outcome may be that the caretaker gives up and just leaves (Fast & Preston, 2004:179).

It can be exhausting to live with a hypomanic person and frustrating to deal with a seriously depressed person day after day. The changes and unpredictability of the moods of someone with BD intrude into home life and may be the source of severe stress in relationships, straining them to the breaking point (Mondimore, 2006:256, 257).

If the caregiver is an especially sensitive and empathetic person, they may possibly **even have mood problems themselves** (Last, 2009:3). The caregiver must therefore pay attention to their own mental health (Fast & Preston, 2004:140).

Burnout is a serious consequence of caring for someone with a serious disease. The caregiver will not be able to help someone else or himself/herself if he/she burns himself/herself out or suffers a mental or physical health crisis (Haycock, 2010:184, 189). Spaniol (1987:211) agrees, pointing out that families' prolonged stress can lead to "burn-out", a depletion of personal resources to the point of loss of the energy necessary to fulfil necessary functions.

4.6.2 Possible strategies

CAMH (2000:36, 37) and Aiken (2010:122) stress that the caregiver should establish his/her own limits and make time for himself or herself. It is important to **recognize** signs of stress and the caregiver's physical and mental health must be looked after. The caregiver should keep up interests outside of the family and apart from the ill relative. It is essential for all family members to look after themselves, because if they become ill, they will not be able to care for anyone else. Mondimore (2006:256) agrees, adding that it is important for family members to recognize their own **need for support**, encouragement, and understanding in dealing with BD.

Van der Voort et al. (2007:684) enquire what coping **strategies** caregivers use. **Problem-focused** (seeking information with regard to the illness, positive communication with the patient) and **emotion-focused** strategies (avoidance, coercion, use of alcohol and drugs) were identified. Other adaptive strategies involve the maintenance of one's own interests, meeting other caregivers and talking with friends.

Families have developed a wide variety of **techniques** to take care of themselves and to prevent exhausting themselves while caring for their disabled family member. Spaniol (1987:212-220) mentions some useful **general coping** strategies and **specific coping** strategies:

General Strategies

- Family members' involvement in hobbies and physical activities;
- Have meaningful work away from home to obtain a balance in life;
- Maintain a familiar family life-style that is sensitive to the needs of the person with a disability and that respects the needs of other family members;
- Family support and advocacy groups are also a major source of the permission family members need at times to take better care of themselves;
- Families also report that personal strategies, such as accepting, distancing and **setting limits**, are ways in which they take good care of themselves. The researcher holds the opinion that the setting of **boundaries** is very important and that families should be aware that structure communicates caring;
- Families which are religious take care of themselves through prayer and fellowship with other believers;
- Independent living provides all family members, including the disabled member, with needed respite from the strains and stresses of continuous contact. It has been the researcher's experience that this is also why it is often a relief for the caregiver when a patient is admitted to a hospital and why it becomes very difficult should the patient be discharged again.

The researcher suggests a few ideas from other experts:

Connect with partners of bipolar people through the **Internet**; Last (2009:275, 276) mentions that many of the bipolar websites have forums that enable bipolar individuals and partners to communicate with each other; other resources could be a person's place of **worship** or visiting a mental health **professional**; some **activities** through which a caregiver can try to gain some peace and try to replenish personal resources include physical activity, socializing with friends, meditation or pursuing a favourite hobby; on the other hand, a husband (Last, 2009:ix) shared that he found the best coping strategy for him **was not to talk** to other people - it was to devote time to his hobbies and interests, which allowed him to take a mental break. The husband mentions that everyone has to find a way to let off steam and refuel in the face of a challenge such as BD; Fast and Preston (2004:205) advocate the healing power of **laughing** together and having time together in a "**bipolar-free** zone" (time together without talking, thinking or worrying about BD).

Specific Strategies

- **Adherence to medication**: Some families will constantly remind the disabled member to take the medication; others will confront, seek the help of professionals, or encourage the disabled member to assume responsibility. It is the researcher's opinion that this is a very individual matter and adherence will depend upon the patient's **accepting** that he/she is ill and needs the medication. If the patient is already very ill, he/she might have to be forced to take the medication against his/her will. This is easier to administer once a patient is admitted into hospital.
- **Abnormal behaviour management**: Some families might try to talk calmly with the patient and express concerns in a caring way. Other families will be firm and set clear limits or be confrontational. Physical contact may also be a resource for anchoring a family member in physical and emotional reality. Families might use humour or reassurance to allay the patient's fears.
- **Antisocial and aggressive behaviour management**: Setting limits and making these limits known in a firm and caring way appears to be a useful strategy for some families. Another resource for families is calling in outside help, such as a crisis clinic or even the police. In some cases, families report using hospitalization as a resource to manage these behaviours. Other families report using rewards for good behaviour, and even considering moving the family member to a separate apartment because the management issues are too difficult for them to handle on a daily basis.
- **Social withdrawal and isolation management**: Many families report that actively involving the person with the disability in family and social activities can be especially

useful. The patient could also be encouraged to become involved in a social rehabilitation programme - if it is available. Some families have found purchasing a pet useful. This provides an opportunity for some people to develop their caring and nurturing skills. The researcher has personal experience of the benefits of animal facilitated therapy, having completed her MA Degree in Social Work on this topic (Van der Walt, 1996). Finally, some families acknowledge the need their family member has for time and space by him- or herself.

- **Hygiene and appearance management**: Families report using many gentle reminders and encouragements to enhance their family member's personal hygiene and appearance. Another strategy is to focus on what the family member is already doing well. They deliberately enhance and enrich the positive self-image of their family member. Some families also report buying new clothes and shampoo for the patient.
- **Self-destructive and suicidal behaviour management**: This behaviour may generate profound feelings of anxiety, helplessness, anger, guilt and concern. Families report that listening sympathetically to the patient's concerns is a major coping strategy. They reaffirm that their family member is a valuable part of the family and that he or she is needed by other family members. Families may call a crisis centre or another family with a psychiatrically disabled member, for suggestions. If the patient has already acted on a threat, he/she may need immediate medical attention such as hospitalisation or pumping the contents of the stomach out.

Spaniol (1987:220) concludes by saying that the strategies used by the families which include a person with a psychiatric disability are not very different from the strategies used by families of the nondisabled. The difference lies in the intensity of the problems and their continuity over time.

The researcher is of the view that it is of utmost importance for the caregiver to maintain a balanced life style (relax, have hobbies, exercise). The caregiver should furthermore give him/herself **time** and practice to come to grips with the changes (and losses) in his/her life.

4.7 WHAT ARE THE FAMILY'S STRENGTHS?

Hatfield (1987b:193) refers to the tendency of professionals toward labelling relationships as **dysfunctional** simply because they do not fit the practitioner's model. One is struck by the amount of literature on mental illness in which families are labelled as "dysfunctional", "enmeshed", or "symbiotic". Hatfield (1987b:201) furthermore mentions that families are rarely seen in a positive light, their strengths recognized, or their heroic efforts to support a deeply disturbed relative acknowledged. The researcher questions the degree to which attitudes have really changed since 1987. As mental health care professionals we often emphasize the pathological and do not recognize the strengths of a family - the empathy and cohesiveness that still prevails within the system. A non- blaming stance broadens the possibilities of working with families as partners (Spaniol, 1987:209).

Families of the mentally ill have become increasingly **vocal** about the need for the restoration of long-term hospital services, provision of community residences in adequate numbers and an increase in funding for day programming and case management services (Terkelsen,1987b:165). This statement was made more than 25 years ago in the USA, but it is the researcher's experience that it is still a desperate need in the current South African milieu. Resources to support caregivers are seriously lacking, which often results in them giving up, with families becoming less vocal - they just become silent.

In South Africa, illnesses such as HIV and cancer invariably receive financial assistance and attention, whilst the effect of a mood disorder illness (also affecting a large segment of society) receives hardly any recognition.

4.8 THE RIGHTS OF CAREGIVERS OF PEOPLE WITH THE DIAGNOSIS OF BD

The researcher wishes to state unequivocally that caregivers possess rights. Some include:

- The right to be treated with respect by the patient, MDT and the community;
- The right to information about the illness and skills regarding how to approach it;
- The right to feel safe and not tolerate any threats from the patient;
- The right to ask for help;
- The right to be recognized and acknowledged;
- The right to be listened to;
- The right to have needs and dreams;
- The right to become tired and even angry;
- The right to feel emotions;
- The right to a break;
- The right to have choices;
- The right to support;
- The right also to have an opinion regarding the patient's symptoms and treatment;
- The right to decline or limit contact with someone who makes one's life unbearably difficult.

4.9 SUMMARY

The fact that mental illness has always been a dreadful experience for those who have suffered from it is beyond question. What has gone unrecognized through the years is how much their **families** have also been affected (Hatfield, 1987a:26). Hatfield (1987a:27) furthermore avers that there is an emerging interest in giving support to families. The success of these (in 1987 they were new) efforts will depend upon the degree to which professionals are able to understand the family experiences from a family perspective and to meet the **needs** that families identify. It is now 25 years later, but these statements are still relevant.

In this chapter the needs, challenges, relationships, roles, rights and other related aspects concerning caregivers, families and patients were discussed. Stigmas attached to mental illness and cultural differences were mentioned. The effect of BD on the different parties was also highlighted. It became evident that dealing with this illness is a process: something that needs time and support from the professionals and the community. The thorny question that remains is: how involved can and should the caregiver be in the patient's care? How much help can the caregiver give without cultivating helplessness in the patient, or helping so much that the caregiver is left depleted? The **caregiver** must contribute to the patient's well-being, but without sacrificing his/her own (Last, 2009:123). **The secret to dealing with the sense of being overwhelmed is to just do what one can at the particular moment, bit by bit**. Caregivers should pat themselves on the back (Fast & Preston, 2006:18). The researcher furthermore stressed that caregivers should take care of themselves, that their strengths must not be ignored and that they also do have rights.

In the end, as expressed by Aiken (2010:16):

> there really is life after a bipolar diagnosis and families should know that they are not alone.

The research methodology of this study is discussed in the next chapter.

5. CHAPTER 5: RESEARCH METHODOLOGY

5.1 INTRODUCTION

This chapter explores the methodology that was followed during the research process. The fact that the researcher has, for a number of years, been working on a daily basis with people who have a similar profile to those who were part of the research, contributed to a better understanding of participants' context. Trustworthiness and ethical aspects, such as respect for the participants, was also very important to the researcher.

The **primary goal** of this research was to carry out an **explorative descriptive study** on the **needs** of the caregivers of people diagnosed with BD (phase one). A **secondary goal** was to develop, implement and evaluate a **psychosocial educational programme** based on the needs of the caregivers of people diagnosed with BD (phase two). Such a programme may be considered as an adjunctive form of treatment. The **purpose** of the psychosocial educational programme was for caregivers of bipolar patients to become better informed, more able to accept the diagnosis and the need for sustained treatment, better prepared to recognise and cope with re-emerging symptoms, stressors or other 'warning signs,' and more adept at acquiring skills aimed at minimizing risk of major recurrences of illness. It strove to improve knowledge and skills and, by doing so, prevent a relapse by the patient.

In order to realize these goals, the more specific **objectives** of the proposed study included:

- Describing the BD spectrum and the specific appropriate patient profile;
- Describing the treatment and intervention options available;
- Identifying and exploring the needs and psychosocial challenges of caregivers of people diagnosed with BD;
- Describing and exploring any relevant psychosocial educational programmes for caregivers on a national and international level;
- Developing a psychosocial educational programme, relevant to South Africa, based on the possible needs and challenges of caregivers of people diagnosed with BD;
- Implementing a psychosocial educational programme for caregivers;
- Evaluating the programme that was developed and implemented; and
- Formulating recommendations regarding a psychosocial educational programme for caregivers of people diagnosed with BD in order to empower these caregivers as well as mental health care providers.

It needs to be emphasized that the theoretical framework of this study was the integrated biopsychosocial model and that this model served as the point of departure from which this research was conducted.

5.2 RESEARCH APPROACH

Most authors agree that in real life, human sciences research uses both quantitative and qualitative methodology; sometimes consciously, sometimes unconsciously (Fouché & De Vos, 2005a:103). Teddlie and Tashakkori (2009:4-7) add a third category, **mixed methods research**. Creswell and Plano Clark (2007:260, 261) define mixed methods research as a procedure for collecting, analysing and "mixing" both quantitative and qualitative data at some stage of the research process within a single study to understand a research problem more completely. Creswell (2014b:244) further states that it is an approach to inquiry that combines both qualitative and quantitative forms of research. It involves philosophical assumptions, the use of qualitative and quantitative approaches as well as the mixing or integrating of both approaches in a study.

Creswell (2014a:18) observes concerning mixed methods:

- it is a research methodology for conducting a study in the social, behavioural, and health sciences;
- it involves collection and analysis of both quantitative and qualitative data in response to research questions;
- it integrates the two sources of data, by combining or merging them;
- it incorporates these procedures into a design or plan for conducting the study.

In this study the researcher collected individual qualitative interview data as well as quantitative survey data. Ivankova, Creswell and Plano Clark (2007:260) point out that this type of approach allows for contextual interpretations, the use of multiple methods and flexibility in choosing the best strategies to address the research questions. Furthermore, Creswell (2005, cited in Ivankova et al., 2007:261) states that one of the reasons for combining quantitative and qualitative methods within one study is to use qualitative data to develop a "new measurement instrument" that is subsequently tested. The researcher's intention was to use qualitative information to develop a programme that was tested and it can therefore be asserted that a mixed methods approach was used in this study.

5.3 TYPE OF RESEARCH

A method of classifying research arises from the **reasons** for the research being conducted. Studies that primarily aim to solve a particular problem confronting a group of people are often referred to as **applied social research** (Bless, Higson-Smith & Kagee, 2006:43). The study fell into the category of applied research, because its aim was to design a programme to solve the problem of the possible lack of knowledge and skills of caregivers of people diagnosed with BD.

A type of applied research in the social sciences targeted at addressing the application of research in practice is "**intervention research**". It has been conceptualised by Rothman and Thomas (Rothman & Thomas, 1994) and the researcher directed the study according to their intervention design and development model (D&D).

Creswell (2014a:123) offers the following definition of intervention design:

> This advanced design builds on one of the basic designs. The intent of this design is to study a problem by conducting an experiment or an intervention trial and adding qualitative data into it. The researcher collects qualitative data before, during, or after an experiment and integrated it through embedding.

One important aim of intervention research is to create the means for improving well-being. A form of applied research, it examines relationships between conditions identified by clients as important and personal or environmental factors that contribute to such conditions. Intervention researcher's attempt, as far as possible, to fuse the dual purpose of applied science in the same endeavour: promoting understanding of individual and community conditions and contributing to their improvement (Fawcett, Suarez-Balcazar, Balcazar, White, Paine, Blanchard & Embree, 1994:25). The intervention design and development model (D&D) thus consists of research directed towards developing innovative interventions. The researcher developed a programme with the aim of enhancing the functioning and well-being of a certain population in practice.

5.4 RESEARCH DESIGN

A research design is a plan or blueprint of the manner in which one intends to conduct the research. It focuses on the end product and the logic of the research. Its point of departure is the research problem. Research design involves a set of decisions regarding the topic to be studied among what population, employing what research methods, for what purpose. Research design is the process of focusing the researcher's perspective for the purposes of a particular study (Babbie, 2007:112).

Since the researcher implemented mixed methods research one of the mixed methods designs was chosen. In the researcher's view the most applicable design was the **exploratory mixed methods design**. Creswell and Plano Clark (2011:71) discuss the exploratory sequential design. According to Ivankova et al. (2007:265), this design is used when a researcher first needs to explore a topic using qualitative data before attempting to measure or test data quantitatively. The qualitative data are collected and analysed during the first phase of the study. After the analysis of the qualitative data is completed, the researcher moves to a second phase where the quantitative data are collected and analysed. Creswell and Plano Clark (2011:71) mention that the researcher needs to interpret how the quantitative results build on the initial qualitative results.

Creswell and Plano Clark (2011:235-236) give an example of exploratory sequential design: the particular study used mixed methods research to adapt and evaluate a family strengthening intervention in Rwanda. The investigators sought to examine the mental health problems facing HIV - affected children in Rwanda. They began with an exploratory qualitative first phase of interviews with the children and their caregivers. From a qualitative thematic analysis of the data, they then performed an extensive review of the literature to locate standardized measures that matched their qualitative findings. They developed a survey instrument. The measures (e.g. family communication and good parenting) then became the pre-test and post-test assessments in an intervention study. For the intervention in the study, the researchers were led to a strengths-based, family-based prevention programme. The final step in the mixed methods process was to use the validated measures within a programme that features the prevention programme. This study illustrated a good, complex mixed methods project with an initial qualitative phase, an instrument development phase, and an experimental phase. It shows how an initial exploration qualitatively can be used to support a later quantitative testing phase.

The researcher cited the above example, because it displays a degree of correlation to her study. From the data, she explored the possible needs and challenges of caregivers of BD patients by identifying qualitative **themes**. This guided her to a subsequent, quantitative examination by developing and evaluating a psychosocial educational programme. The steps, as indicated by Ivankova et al. (2007:265) were:

- Qualitative data collection and analysis;
- Quantitative data collection and analysis; and
- Interpretation of how quantitative results build on the qualitative results.

Strengths of the exploratory design according to Creswell and Plano Clark (2011:89) include:

- Separate phases make it straightforward to describe, implement and report.
- The inclusion of a quantitative component is able to make the qualitative approach more acceptable to quantitative - biased audiences.
- It is useful when the need for a second, quantitative phase emerges based on what is learned from the initial qualitative phase.
- The researcher is able to produce a new instrument as one of the potential products of the research process.

Creswell (2014a:42, 43) refers to **advanced designs** where a feature is added to the basic design. One of the popular additions described in the mixed methods literature, is the intervention design where the intent is to study a problem by conducting an experiment or an intervention trial and adding qualitative data into it. The researcher presents the following diagram **(Figure 5.1)** as an illustration of the intervention design:

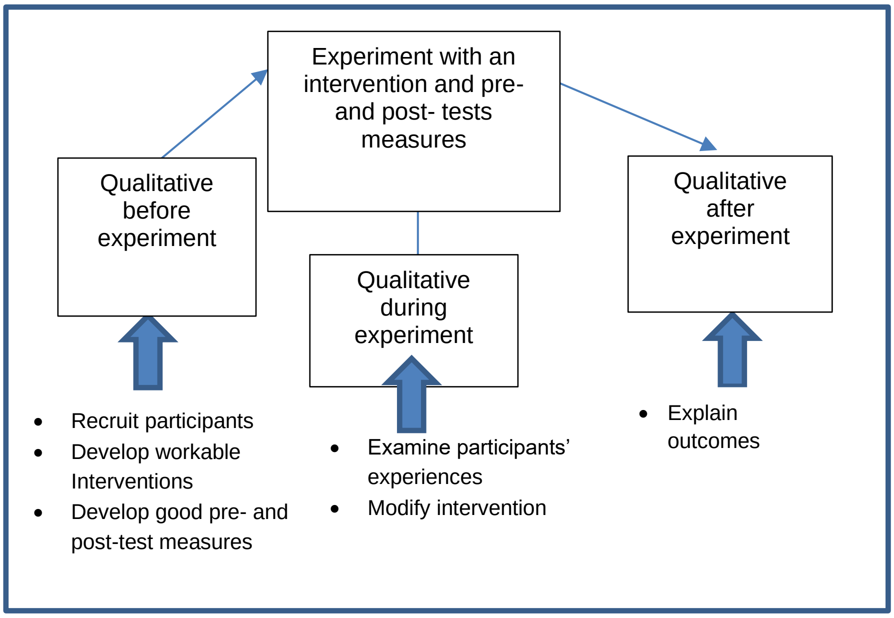


Figure 5.1: **Intervention Design** (Creswell 2014a:44)

5.4.1 Qualitative research design

The **case study** was the most appropriate design for the first phase of the study. The typical characteristic of case studies is that they strive towards a comprehensive (holistic) understanding of how participants make meaning of a phenomenon under study. A salient feature of case studies is to arrive at a deeper understanding of the dynamics of the situation (Nieuwenhuis, 2007a:75). This was exactly what the researcher wanted to achieve. In phase one, a **collective case study** design was used, which according to Fouché (2005:272), is a qualitative design that furthers the understanding of the researcher about a social issue or population being studied. When interviews with caregivers were conducted, the aim was to be able to understand their world and to see it from their perspective.

5.4.2 Quantitative research design

The specific experimental design that was chosen as being the most appropriate for the study was a pre-experimental design, termed the one group pre-test - post-test design. Creswell (2014b:172) mentions it as one of the designs to be used in mixed methods research. Welman, Kruger and Mitchell (2011:108) refer to it as a pre-measurement and post-measurement single-group design. The objective is to ascribe differences between the pre- and post-measurement to the experimental intervention. The researcher was aware of the limitations of this design, as described below, but it was still the design of choice.

Pre-experimental designs are not characterized by a random selection of participants from a population, nor do they include a control group (Fouché, Delport & De Vos, 2011:145). The researcher does realize that without either of these, the power of the research to uncover the causal nature of the relationship between independent and dependent variables is greatly reduced. Although this design involves some form of experimental intervention, it does not qualify as a true experimental design because it does not provide a sufficient basis of comparison unambiguously to ascribe changes in the dependent variable to the independent variable. (Welman et al., 2011:108). This design suffers from the possibility that some factor, other than the independent variable, might cause a change between the pre-test and post-test results (Babbie, 2007:228).

The pre-experimental design thus includes a pre-test measure followed by a treatment (intervention) and a post-test for a single group. There is measurement of a dependent variable in the one group pre-test post-test design, when no independent variable is present and subsequently an independent variable (the programme in this case) is introduced (Fouché, Delport & De Vos, 2011:147). This was followed by a repeated measurement (post-test) of the dependent variable (level of knowledge acquired) at a later stage.
Fouché, Delport and De Vos (2011:145-146) mention that it is important to remember that despite their limitations, pre-experimental designs are used when resources do not permit the development of true experimental designs. Challenges that may compel the researcher

to employ a pre-experimental design are practical problems and ethical constraints. Human service practitioners, especially, are likely to be confronted by these dilemmas.

A quasi-experimental design, namely the comparison group pre-test post-test, as discussed by Fouché, Delport and De Vos (2011:150), was initially planned for this phase of the study. (refer to 5.5.2.5.1 also). The researcher, however, realized that there would be too many challenges if this design were to be used. It was not possible to expect a control group of caregivers/respondents to come in for no programme, be tested and then come in later the same day to be retested with the experimental group. It would have been unethical not to have presented the same programme that was presented to the experimental group. Respondents agreed to voluntarily participate in the research if they could gain the benefit of the one day programme; furthermore it would not have worked to offer it at a later stage, because some respondents did not reside in Pretoria, resulting in financial and ethical implications.

The researcher offered the programme to two groups of respondents on two different days; namely, two consecutive Saturdays. An element that was added is that the researcher asked respondents to evaluate the programme afterwards. By doing so, this added a qualitative element to the process, and the feedback regarding the first presentation of the programme was used to improve the presentation of the second programme. The researcher had the help of an experienced and well-qualified occupational therapy colleague during the presentations, who gave feedback to the researcher too.

5.5 RESEARCH METHODS

5.5.1 Research population, sampling method and research sample

5.5.1.1 Research population

“Population” refers to individuals in the universe who possess specific characteristics or a set of entities that represent all the measurements of interest to the researcher (Strydom, 2005b:204). It is a term that sets boundaries on the study units. It is the totality of persons with which the research problem is concerned (Strydom, 2005b:193, 194). The population in this study consisted of:

- All the caregivers of people diagnosed with BD in a provincial psychiatric hospital in Pretoria, Gauteng. This did not include caregivers of patients that had previously been part of the researcher's caseload. Caregivers of in-patients and out-patients, who were part of the caseloads of other social work colleagues, were included.
- Caregivers of people diagnosed with BD, referred from a private psychiatrist, from Pretoria.
- Caregivers of people diagnosed with BD from a well-established bipolar support group in Pretoria, Gauteng.

5.5.1.2 Sampling method and research sample

A sample comprises elements of the population considered for actual inclusion in the study, or it can be viewed as a subject of measurements drawn from a population in which one is interested (Strydom, 2005b:194). The sample in this study was selected from the abovementioned population.

It was important to think critically about the parameters of the population and then to choose the sample accordingly. Clear identification and formulation of criteria for the selection of participants was of cardinal importance (Strydom & Delport, 2005b:329). The criteria for the selection of respondents for this study were as follows:

- Caregivers of adult people diagnosed with bipolar disorder;
- Caregivers who have been caregivers for at least three months;
- Caregivers who were aware of the diagnosis;
- Caregivers who were conversant in either English or Afrikaans;
- Caregivers who expressed the need for more knowledge and skills regarding bipolar disorder; and
- Caregivers could be male or female and a parent, a child, a sibling, a spouse or partner, a colleague or a good friend of the patient.

The selection process raised the question of how many respondents should be chosen. Greeff (2005:294) emphasises two aspects in this regard: sufficiency and saturation of information. Are there sufficient numbers to reflect the range of respondents and sites that make up the population so that others outside the sample might have a chance to connect to the experience of those in it? Saturation of information is the point in the study where the researcher begins to hear the same information repeatedly being reported and no longer gleans anything new.

The sample in the **first phase** (qualitative) of the research was small and purposively selected. The emphasis was placed on collecting individual, detailed and in-depth information. At the start of the research, it was difficult to estimate how big the sample in the first phase was going to be, because it was determined by the two aspects mentioned above.

Participants were generated from three sources: a support group, a private psychiatrist and a hospital. The researcher also made a pamphlet available for possible participants to obtain an overview of the study (**Appendix 5.1**). The participants from the **Bipolar Support Group** volunteered to participate after the researcher gave a talk at one of the monthly meetings regarding her study. Prior to the interviews, most arrangements regarding the date of the interview and location took place via e-mail and telephone calls.

The **private psychiatrist** who agreed to make patient caregivers available, if they were interested, told them about the study and asked them to provide their contact details if they were interested in participating. The researcher was then given their contact details and contacted them. Participants from the **hospital** where the researcher is working, were from her colleague’s case load and not her own, so as to avoid researcher bias. The colleague approached the caregivers, told them about the study and asked them to give their details if they wanted to participate; if so, this researcher contacted them.

Data saturation was reached after interviewing **eleven selected participants**. There was a clear repetition of themes and sub-themes throughout all of the interviews, particularly from the caregivers who were children or wives of patients.

The sample in the **second phase** (quantitative) of the research was also non-probability sampling (purposive). Singleton et al. (1988, cited in Strydom 2005b:202) states that in this type of sample the judgment of the researcher is important, because it is composed of elements that contain the most characteristic, representative or typical attributes of the population. The private psychiatrist approached some of his patients to participate in the study and the researcher also told caregivers at the support group about the programme. Those that were interested in attending the programme could then indicate that they wanted to participate. She informed colleagues at the hospital where she is working about the programme; they referred caregivers to her who were interested.

The researcher thus selected caregivers according to the criteria mentioned earlier. Twenty nine caregivers were invited, from a psychiatric provincial hospital in Pretoria and from the private sector, to attend the programme. Twenty seven caregivers attended but two were unable to.

5.5.2 Data collection and analysis

Epistemology is the science of knowing, while methodology (a subfield of epistemology) might be called the science of finding out (Babbie, 2007:4).

The researcher considered that it was also important to refer to data collection and data analysis applicable to mixed methods research. In that regard, Creswell (2014b:226, 227) mentions that data collection should occur in two phases: the initial qualitative data collection, followed by the second quantitative data collection. The challenge is how to use the information from the initial phase in the second phase. He points out that the qualitative data analysis may be used to develop an instrument. The researcher must analyse the two databases separately and use the findings from the initial exploratory database to develop these into quantitative measures.

The methodology will be described according to the principles of intervention research and Rothman and Thomas' **design and development model** (D&D 1994, cited in De Vos & Strydom, 2011:476-489) and Rothman and Thomas (1994). Thomas and Rothman (1994:8) mention that D&D emerged as an explicit paradigm, largely out of frustrations with the inability of conventional research methods to guide the generation of human service interventions.

Schilling (1997, cited in De Vos, 2005a:394) states that an intervention is an action undertaken by a social worker or other helping agent to enhance or maintain the functioning and well-being of an individual, family, group, community or population. Intervention research comprises studies being carried out for the purpose of conceiving, creating and testing innovative human service approaches so as to prevent or improve problems or to maintain the quality of life (De Vos & Strydom, 2011:475). D&D may be conceptualized as a problem-solving process for seeking effective interventive and helping tools to deal with given human and social difficulties (Thomas & Rothman, 1994:12).

The researcher followed the framework of the design and development model (D&D), (Thomas & Rothman, 1994:12), as a guideline on how to approach the processes of data collection and data analysis. Thomas and Rothman (1994:9) describe this model as consisting of six main phases (**Figure 5.2**). However, only the first five phases will be discussed in detail, because the last phase of this model will not be implemented as part of this study; namely, dissemination.

5.5.2.1 Phase One: Problem analysis and project planning

In the first phase, key problems are identified and analysed, a broad state-of-the-art review is initiated to provide general orientation to the problem, and the feasibility of the D&D project is determined (Thomas & Rothman, 1994:9). A definition of social problems follows: "…conditions of society which have negative effects on large numbers of people" (De Vos & Strydom, 2011:477).

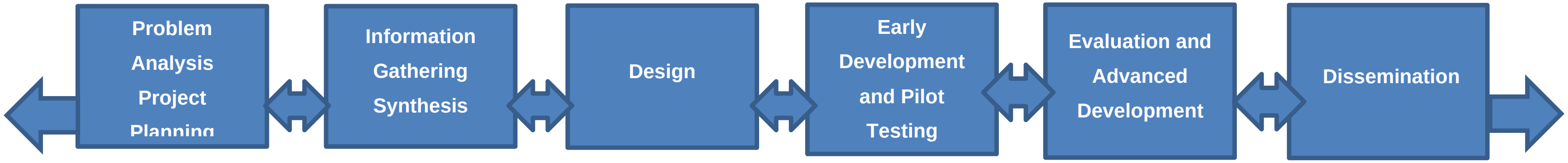
Consequently, it is important that a significant problem be identified that has a negative effect on large numbers of people in phase one. The problem situation that the researcher wanted to address (from clinical experience of more than twenty-four years in the field of psychiatric social work and confirmed in the problem formulation in Chapter one), was that of the challenges and needs of caregivers of people diagnosed with BD and their possible lack of knowledge and skills. The researcher therefore chose a problem which she had observed in practice. Creswell (2014a:65) agrees with this motivation when he says: "What problem needs to be solved or addressed? You might think about this issue as one arising out of practice".

There were five different steps that needed to be implemented in **phase one**:

5.5.2.1.1 Identifying and involving clients

Intervention researchers choose a population of interest with whom to collaborate. It is important to start where the clients are (De Vos & Strydom, 2011:477, 478). Research that addresses the critical strengths and problems of important constituencies has a greater chance of receiving support from the target population, professional community, and the general public (Fawcett et al., 1994:27).

The target population that the researcher focused on was caregivers of people diagnosed with BD. Factors such as the age, culture, marital status, gender and role (child, parent, and spouse) of the specific caregiver, were taken into consideration, and she attempted to select a sample that was representative of that population.



Identifying and involving clients		Using existing information sources		Designing an observational system		Developing a prototype or preliminary intervention		Selecting an experimental design		Preparing the product for dissemination
Gaining entry and cooperation from settings		Studying natural examples		Specifying procedural elements of the intervention		Conducting a pilot test		Collecting and analysing data		Identifying potential markets for the intervention
Identifying concerns of the population		Identifying functional elements of successful models				Applying design criteria to the preliminary intervention concept		Replicating the intervention under field conditions		Creating a demand for the intervention
Analysing identified concerns								Refining the intervention		Encouraging appropriate adaptation
Setting goals and objectives										Providing technical support for adopters

Figure 5.2: **Phases and operation of intervention research**

The researcher developed a psychosocial educational programme for the said caregivers, as determined in phase one, to empower them to face the challenges of a mentally ill family member with BD. This was undertaken after the first phase of the research where the needs, possible lack of skills and available strengths of this population, were investigated.

When the researcher identified respondents, it was important that the patient had been properly diagnosed as having BD. It has been the researcher's experience that BD has become a “popular” diagnosis and it was important that it should not be confused with other diagnoses, e.g. borderline personality disorder or a mood disorder resulting from substance abuse. However, if a patient had been misdiagnosed and the caregiver nevertheless attended the programme, it could also be of value to the caregiver to realize that the diagnosis was incorrect.

5.5.2.1.2 Gaining entry and cooperation from settings

Key informants are able to explain local ways of proceeding to researchers and introduce them to gatekeepers. By working together with those who can facilitate access, researchers gain the cooperation and support necessary to conduct intervention research (De Vos, 2005a:396). In the researcher's work environment, multi-disciplinary teamwork is a very important cornerstone of the job. The researcher was therefore in the privileged position of working closely with other colleagues who, knowing the purpose of the research, were able to refer possible participants for the research project. Caregivers were also recruited from the outpatient department of the hospital at which the researcher is working as well as from the private sector.

It was important to highlight the benefits for potential participants. The researcher did contact the Clinical Head of the institution, explaining the goals and objectives of the research. Colleagues of other disciplines in the institution were also consulted. Collaboration helped to provide a sense of ownership of the research. The researcher submitted her applications for ethical approval to the Research Ethics Committees of both the Faculty of Humanities and of Health Sciences of the university, receiving approval from both Committees, prior to conducting the research.

5.5.2.1.3 Identifying concerns of the population

It is very important to perceive the concerns from the population's viewpoint and not to project an external view of the problem and its solution onto them (De Vos, 2005a:397). Researchers can use informal personal contact, qualitative research methods and community forums (Fawcett et al., 1994:29).

In applied research researchers ask questions designed to provide data that could be used to improve a situation or solve a problem (Jansen, 2007:9). The researcher had to ask herself the question: What are the real needs? This is the reason that, in the first phase of the research, the researcher conducted individual in-depth interviews with caregivers to really get to the core of their concerns, needs and challenges, in order to develop an appropriate programme. The researcher has attended different seminars over the last few years as well as bipolar support group meetings once a month to be able to better understand the caregivers of the bipolar patients.

In the intervention model, "pilot testing" is only discussed in phase four. It was, however, the researcher's view that pilot testing should also take place in the first phase, before interviews were conducted with caregivers to identify their concerns. The pilot study is a prerequisite for the successful execution and completion of a research project. It forms an integral part of the research process. Its function is the exact formulation of the research problem and a tentative planning of the modus operandi and range of the investigation (Strydom, 2005a:205).

The researcher prepared an **information leaflet** and **informed consent form** as well as an **interview schedule** (**Appendix 5.2**). The measuring instrument (the semi-structured interview and interview schedule), was pre-tested with one respondent for the pilot study and the researcher made changes to the schedule as needed.

As mentioned before, in phase one of this research project qualitative data was collected when caregivers were interviewed by means of **semi-structured interviews**. May (1991, cited in Greeff, 2005:292) defines semi-structured interviews as those organised around areas of particular interest, while still allowing considerable flexibility in scope and depth. The researcher devised a set of predetermined questions on an interview schedule, which guided the interview. These interviews were conducted to assess the caregivers' real needs and challenges, lack of skills and knowledge, as well as their possible strengths.

5.5.2.1.4 Analysing concerns or problems identified

A critical aspect of this phase is analysing those conditions that people label as community problems. Some key questions help to guide the process of problem analysis; for example, whose behaviour "caused" or "maintains" the problem? (Fawcett et al., 1994:30).

De Vos and Strydom (2011:479) emphasize that it is important to distinguish between the "ideal" and the "actual" conditions that define the problem. Referring to this particular research, one would have liked caregivers to be able to handle the implications of a patient's illness in an efficient way, but in reality they struggled to do so.

When analysing the specific situation that confronted caregivers it was clear that relevant subsections of the situation needed to be taken into consideration. These are discussed as follows:

The illness: BD is a very serious chronic recurrent mental illness and often goes hand in hand with psychotic episodes that can be very disruptive for everybody involved. It frequently involves hospitalisation, which is sometimes against the patient's wish, and this may even require police involvement. The illness takes its own course and, without the proper treatment, may create havoc for the patient and the caregiver. Situations involving threats, aggression and totally inappropriate behaviour may develop. The patient might for instance, start spending money irresponsibly, impulsively leave home without a trace, engage in inappropriate sexual behaviour or abuse substances.

Treatment: Although there are different treatment modalities available for BD it is not an illness that is curable. Treatment can, however, help the patient to stabilize and to be functional. It is very important that the patient must become adherent to his or her treatment and it is the ideal that he or she should develop insight regarding the illness. If, however, the caregiver does not support the patient in being compliant with treatment, the prognosis is severely affected. It is therefore very important that a patient's support system must be made aware of how essential treatment is.

The caregivers: In this research the focus fell on the difficulties experienced by the caregivers. Those involved were in different roles in relation to the patient; for instance, being a parent, a child or a spouse. The results depended upon who the patient was and who the caregiver was. There were many potential negative consequences pertaining to the caregivers as well: such as the disintegration of their family system, stress on the marriage, loss and/or change of certain roles in the family, financial instability, loss of trust and mutual blaming within the family system.

Lack of skills, knowledge and support: When caregivers are confronted with this illness, they mostly do not know how to approach it. It has been the researcher's experience that families/caregivers feel that in spite of their losses, when the patient becomes ill, their needs are often ignored by the health system. There is usually a sense of shame in having a person with a mental illness in the family and therefore people might not seek help. Mental illness is sometimes frowned upon and people see it as a weakness. Psychiatric patients and their relatives might be rejected by others in society.

One can also ask why the problem exists and why interventions are not successful. People are continuously being diagnosed with BD. At the time that the research was conducted, there was no formal **programme** for caregivers of bipolar patients in the researcher's work environment.

Nieuwenhuis (2007b:99) mentions that qualitative data analysis endeavours to establish how participants make meaning of a specific phenomenon by analysing their perceptions, attitudes, understanding, knowledge, values, feelings and experiences in an attempt to approximate their construction of the phenomenon. Schurink, Fouché and De Vos (2011:402-419) propose certain guidelines for qualitative data analysis. They note that key steps are presented in a linear form, bearing in mind, however, that these main activities also move in circles and can never be followed rigidly. The steps can also overlap. The researcher will discuss these guidelines as follows and will also mention ways in which these guidelines were applicable to her study:

Planning for recording of data: The researcher planned for the recording of data in a systematic manner that was appropriate to the setting and participants. She did make sure that analysis would be facilitated. A tape recorder was used with the consent of participants. The researcher made sure that the machine produced good sound quality.

Data collection and preliminary analysis (the twofold approach): When conducting a qualitative study, an inseparable relationship exists between data collection and data analysis. It can even be argued that as the data are gathered, they are analysed. As was mentioned, the researcher used a semi-structured interview schedule; therefore, in this case, analysis took place during the fieldwork period as well as afterwards. Interviews were conducted in a private room, without any interruptions (e.g. telephone calls). The researcher mostly conducted the interviews at the participants' homes. She did her best to create a relaxing and positive atmosphere. The interview schedule guided the interview, although the researcher was flexible. It helped the researcher to do the home visits, because the environment could be observed and the participants could relax because they felt safe. This also contributed to gathering richer data. The researcher made field notes immediately after the interviews, reflecting on the participant as a person, aspects like the emotional state of the participant that was observed and even on the effect that the interview had on her in her role as researcher. Being at the home of participants, other family members (not being part of the research) could also be observed and the researcher could experience the atmosphere in the home.

Managing (organizing) data: It was important to organize data into file folders, or computer files. Schurink, Fouché and De Vos (2011:408) mention that getting organised for analysis begins with an inventory of what one has collected (getting a feel of the cumulative data as a whole). Labelling all the data with a notation system that will make retrieval manageable, is important. The researcher gave the recorded interviews to a reliable person who transcribed them verbatim and returned the material to her. It was filed together with the particular field notes that were made on the day of the interview. Nieuwenhuis (2007b:104) emphasizes that all data collected must be transcribed verbatim. Backup-copies of all the data were made throughout the research process.

Reading and writing memos: The researcher repeatedly read through the collected data to become familiar with it. Memos (short phrases, ideas or key concepts) were written in the margins of field notes and transcribed interviews, and this helped in the process of exploring the database.

Generating categories, themes and patterns and coding the data: Schurink, Fouché and De Vos (2011:410) make it clear that this step in the analytic process demands a heightened awareness of the data, a focused attention to it and an openness to the subtle and tacit undercurrents of social life. It is the most intellectually challenging phase of data analysis. However, for the researcher this step was not too difficult, because she had prepared an interview schedule, which was constructed according to certain categories and themes. It certainly also helped the researcher that she has years of experience in conducting interviews, that she works with caregivers on an on-going basis and that she possesses a good working knowledge of BD. Nevertheless, she did notice certain patterns that started to emerge as the transcribed interviews were studied. Different colours were used in the transcribed interviews to indicate themes.

Coding the data is the marking of the segments of data with symbols, descriptive words or unique identifying names (Nieuwenhuis, 2007b:105). It simply means that whenever one finds a meaningful segment of text in a transcript, one assigns a code or label to signify that particular segment. The researcher in the main used different colours to highlight the identified categories, themes and patterns.

Testing emergent understandings and searching for alternative explanations: It was important to evaluate data for their usefulness and centrality. One participant's wife, for instance, made a suicide attempt just before the interview took place and he therefore experienced a specific need to ventilate about that. Although the researcher needed to ask specific questions she had to be sensitive about his needs at that specific time.

The researcher was critical of the categories and patterns discovered in the data and challenged some of these apparent patterns. She tried to look beyond the obvious, being aware that the "unsaid" is also important. The researcher was a stranger to the participants and it must be understood that it might not always have been easy for them to open up to a person they did not know, even (and perhaps especially) if it was for the purpose of formal research.

Interpretation and developing typologies (systems for categorising concepts): Interpretation involves making sense of the data. Several forms exist, such as interpretation based on hunches, insights and intuition (Schurink, Fouché & De Vos, 2011:416). The researcher's experience of the particular group that was studied contributed towards her insight into the world of the caregiver.

Presenting the data: In the final step, the researcher presented the data in the form of a written report in which tables and figures were included (Chapter 6 refers).

5.5.2.1.5 Setting goals and objectives (refer to 5.1)

5.5.2.2 Phase Two: Information gathering and synthesis (also refer to 7.2 – 7.4)

This phase might be subtitled "Not reinventing the Wheel" (Fawcett et al., 1994:31). When planning an intervention research project, it is very important to know what others have done to understand and address the problem (De Vos & Strydom, 2011:480). Relevant knowledge must be selected and integrated. The outcome of this phase is a list of apparently functional elements that may be incorporated into the design of the intervention. The literature review and consultation with experts in the field of interest were important. In the beginning of the research process the researcher identified potentially useful resources and experts on the field of BD that could be used when constructing a programme, such as: *The Bipolar Disorder Survival Guide* (Miklowitz, 2011), and *Psychoeducation Manual for Bipolar Disorder (*Colom & Vieta, 2006). Based on the highly successful, evidence-based Barcelona Programme, Colom and Vieta's book is a pragmatic, therapist's guide on how to implement a psychoeducation group.

The three steps of **phase two** are discussed next:

5.5.2.2.1 Using existing information sources

De Vos and Strydom (2011:480) emphasize the importance of a literature review consisting of an examination of selected empirical research, reported practice and identified innovations relevant to the particular concern being studied. This may be called the “scholarship of discovery”. While the researcher utilized literature searches carried out for her by the relevant library consultant of the University of Pretoria, the literature search however, was on-going.

The researcher realized that it was important to look beyond the field of social work for literature. The fields of psychiatry, psychology, and any fields that offered access to information on programme development, were of paramount importance. Fawcett et al. (1994:32) also draws attention to the concept “scholarship of integration”, which entails establishing new linkages between concepts and methods of various disciplines. In this research there was, therefore, both discovery and integration.

5.5.2.2.2 Studying natural examples

A particularly useful source of information is observing how people who have experienced a specific problem have attempted to address it. Interviews with such people are also able to provide insights into which interventions might or might not succeed and the variables that may affect success. Studying unsuccessful programmes and practices may be particularly valuable, since negative examples also help researchers to understand methods and contextual features that may be critical to success (Fawcett et al., 1994:32 and De Vos & Strydom, 2011:481). The researcher had in this step observed how, in her case, caregivers of people diagnosed with BD, have attempted to address the challenges the illness poses them. Semi-structured interviews were conducted with this population group and, again, experts were also able to provide very useful insights into which interventions might or might not succeed. As previously mentioned, the researcher herself, was further enabled in her research by extensive experience in the field of working with people suffering from mental illness.

5.5.2.2.3 Identifying functional elements of successful models

Once information is gathered, researchers analyse the critical features of the programmes and practices that have previously addressed the problem of interest (whether successfully or unsuccessfully) (Fawcett et al., 1994:33). It was therefore important to investigate previous programmes that had addressed the problem in question. Analyses took place by asking pertinent questions about why and under which conditions these were either successful or had failed. By studying models, researchers identify potentially useful elements of intervention, which then helps to guide, design and develop activities. Functional elements of the models can then be incorporated into the new programme. The researcher did this by means of a literature study and also by consulting with experts.

More valuable resources that were identified (dates not indicated) are two workbooks on schizophrenia, developed by Fleischhacker and Hummer ([sa]) of Austria, namely:

- The Alliance Programme: A resource for patients with schizophrenia, their caregivers and mental health professionals. Workbook for mental health professionals.
- The Alliance Programme: A resource for patients with schizophrenia, their caregivers and mental health professionals. Workbook for patients with schizophrenia and their caregivers.

Although BD differs from schizophrenia, there are similarities concerning the caregivers' needs and some functional elements of these programmes were therefore useful. In **Chapter 7** psychosocial educational programmes for caregivers are discussed.

5.5.2.3 Phase Three: Design

This and the next section outline operations in the particularly interrelated phases of design and early development and pilot testing. Fawcett et al. (1994:34) refer to the fact that two types of products result from intervention research:

- Research data that may demonstrate relationships between the intervention and the outcomes that define the problem of interest, and
- The intervention, which may include a programme.

After the research problem had been analysed and information gathered and synthesised, the researcher needed to decide on the design of the programme. There were two steps in **phase three**:

5.5.2.3.1 Designing an observational system

Researchers must design a method system for discovering the extent of the problem and detecting effects following the intervention. The observational system is closely linked to the process of designing an intervention; it serves as a feedback system for refining early prototypes. Clients, especially those most affected by the particular problem, should be involved in specifying the environmental conditions that need to be changed (Fawcett et al., 1994:34 and De Vos & Strydom, 2011:482).

In **phase one** the researcher collected information concerning the caregivers' needs and challenges. In **phase two** of this particular research, a programme (the intervention) was developed and introduced to caregivers. Caregivers' knowledge and skills to deal with the particular illness were tested before the introduction of the intervention and also afterwards, to evaluate the effectiveness of the latter. They were further asked to evaluate the value of the programme because the researcher wanted to make the programme as effective as possible; one goal was that the programme should be improved on an on-going basis.

5.5.2.3.2 Specifying procedural elements of the intervention

By observing the problem and studying naturally occurring innovations and other prototypes, researchers can identify procedural elements for use in the intervention. These can include the use of information, skills and training for their acquisition and environmental change strategies. It is important that these procedural elements should be specified in sufficient detail to be able to be replicated by others. The embryonic observational system and intervention are refined in the next phase of intervention research (Fawcett et al., 1994:35, 36 and De Vos & Strydom, 2011:482).

In this research project the intervention was the psychosocial educational programme that the researcher presented to the caregivers of people diagnosed with BD. The procedural elements of an intervention often become part of an eventual practice model, which is the final product of the research (De Vos & Strydom, 2011:482).

5.5.2.4 Phase Four: Early development and pilot testing

Thomas (1989, cited in De Vos & Strydom, 2011:483) defines development as the process by which an innovative intervention is implemented and used on a trial basis, developmentally tested for its adequacy and thereafter refined and redesigned as necessary.

During the early development and pilot testing phase, a primitive design is evolved into a form that is able to be evaluated under field conditions. This phase includes the important operations of developing a prototype or preliminary intervention, conducting a pilot test and applying design criteria to the preliminary intervention concept (Fawcett et al., 1994:36).

Phase four includes the following steps:

5.5.2.4.1 Developing a prototype or preliminary intervention

By this stage in the design process, preliminary intervention procedures are selected and specified (Fawcett et al., 1994:36).

A prototype psychosocial educational programme for the said caregivers was developed as a synthesis of the researcher's knowledge, the literature study, input from experts in the field and the data obtained from the qualitative part of the study (phase 1). The researcher also designed a draft questionnaire that was given to caregivers before and after the implementation of the programme.

5.5.2.4.2 Conducting a pilot test (also refer to pilot test during phase one)

Pilot tests are designed to determine whether the intervention will work, "…to see if the beast will fly" (Fawcett et al., 1994:36).

In the second phase of the study, the literature study continued, and it was important for the researcher to orientate herself in terms of the field of study. The researcher consulted with experts on an on-going basis. During this step it was important to determine whether the intervention would work. The prototype programme was developed and presented to a group of caregivers, with a pre-test and post-test being conducted using the questionnaire. This programme was then refined using the suggestions, recommendations and comments of colleagues, supervisor and respondents for the second implementation.

An important aspect was the pre-testing of the measuring instrument (a questionnaire). The researcher, as part of the pilot study, gave questionnaires to a few caregivers who were not part of the study. The questionnaire was also discussed with other colleagues in the MDT and social work colleagues for their suggestions. It was then adapted according to feedback received.

5.5.2.4.3 Applying design criteria to the preliminary intervention concept

The design process is informed by common guidelines and values for the intervention research. Questions asked in this step included: Is the intervention effective, simple to use, practical and replicable? (Fawcett et al., 1994:37 and De Vos & Strydom, 2011:485). The researcher wanted to develop a user friendly, pragmatic programme that could be used in various contexts; therefore special attention was paid to these design criteria. The various contexts included that of also presenting it in future to other mental health care practitioners.

Feedback and recommendations during the first presentation were incorporated in the programme for refinement prior to the second implementation.

5.5.2.5 Phase Five: Evaluation and advanced development

Intervention research is distinguished from pure activism by its use of research methods to examine how and why a change programme does or does not work. Using pilot tests and field replications to test and refine the intervention sets intervention research apart from mere programme evaluation (Fawcett et al., 1994:37).

There are four steps to **phase five**:

5.5.2.5.1 Selecting an experimental design (refer to 5.4)

5.5.2.5.2 Collecting and analysing data (also refer to phase one 5.5.2.1.4)

In **phase two** of this research project, quantitative data was collected from respondents with a self-administered questionnaire before (pre-test) and after (post-test) the intervention. Babbie (2007:246) defines a questionnaire as a document containing questions and other types of items designed to solicit information appropriate for analysis. He also makes it clear that although the term “questionnaire” suggests a collection of questions, a typical questionnaire will probably contain as many statements as questions. It is important to note that respondents were given an **information leaflet** and **informed consent form** (**Appendix 5.3**) before they completed the **questionnaires** (**Appendix 5.4**) and before they participated in the programme that was presented.

Reliability and validity, specifically as far as the research instruments are concerned, are crucial aspects in quantitative research (Nieuwenhuis, 2007a:80). Bless et al. (2006:149) emphasize that reliability is the extent to which the observable measures that represent a theoretical concept are accurate and stable when used for the concept in several studies. Validity is concerned with just how accurately the observable measures actually represent the concept in question or whether, in fact, they represent something else. Important aspects to consider are content validity, face validity, criterion validity and construct validity (Delport & Roestenburg, 2011:172-177).

The quantitative data obtained in this research project from the questionnaires in the pre-test and post-test, were processed by making use of a statistical consultant from the Department of Statistics, University of Pretoria (Chapter 8 refers). Kruger, De Vos, Fouché and Venter (2005:218) point out that analysis means the categorising, ordering, manipulating and summarising of data to obtain answers to research questions. Graphic presentations might include, among others, bar graphs, doughnut graphs and histograms. Data analysis (in the quantitative paradigm) does not in itself provide the answers to research questions. Answers are found by way of interpreting the data and the results. To interpret is to explain and to find meaning (Fouché & Bartley, 2011:249).

5.5.2.5.3 Replicating the intervention under field conditions

As De Vos and Strydom (2011:486) and Fawcett et al. (1994:39) indicate, that a primary goal of intervention research is to develop interventions that are effective in a variety of real-life contexts for those who actually experience the problem. Replication helps to assess the generality of the effects of the intervention. This was exactly the researcher's goal: she intended the intervention, which will be developed, to be of use in different contexts in future, but it was not part of this study as such.

5.5.2.5.4 Refining the intervention

The researcher was critical of the intervention and made adaptations where necessary after the first pilot implementation. The feedback given by respondents in the post-test and verbal evaluation of the programme assisted in this process.

5.5.2.6 Phase Six: Dissemination

This is the last phase of the intervention research process and was not implemented in this study.

Once an intervention has been field tested and evaluated, it is ready to be disseminated (De Vos & Strydom, 2011:487). Several operations assist in making the process of dissemination and adaptation more successful: preparing the product for dissemination, identifying potential markets for the intervention, creating a demand for the intervention, encouraging appropriate adaptation and providing technical support for adopters (Fawcett et al., 1994:39).

Although this phase was not part of the research process itself, a seminar was presented to professionals in this field of psychiatry including the members of the MPT, after completion of the research. This seminar was utilised to test/prepare the product (programme) for dissemination and to identify potential markets for this programme. The feedback of this will be provided in Chapter 9. The results of the study were written up, in the form of a thesis. Two article manuscripts from the thesis, co-authored by the supervisor, will be submitted to a peer-reviewed scientific journal, for publication. A paper will be presented at an appropriate conference, nationally or internationally. The researcher might also publish a booklet reflecting the psychosocial educational programme that she developed.

In conclusion, Fawcett et al. (1994:50) mention that intervention researchers must address several challenges; for instance: the process takes a long time, it is complex and it demands a variety of research and interpersonal skills. The researcher however also did experience that it is also rewarding to develop something new that might identify and aid a certain disadvantaged group in the future.

5.6 TRUSTWORTHINESS

Qualitative research should, as closely as possible, reflect the thoughts, feelings and experiences of those who participate in research. In other words, trustworthiness is established when findings as closely as possible reflect the meanings as described by the participants. The research results should reflect that we as researchers are hearing what our participants are saying (Lietz, Langer & Furman, 2006:444, 456).

Nieuwenhuis (2007a:80) is of the opinion that in qualitative research the researcher is the data-gathering instrument. Thus, it seems when qualitative researchers speak of research “validity and reliability”, they are usually referring to research that is credible and trustworthy. Lincoln and Guba (1985, cited in Nieuwenhuis, 2007a:80) also include applicability, dependability and confirmability as key criteria of trustworthiness.

To expand this point, an aspect that must be emphasized when **analysing** qualitative data is trustworthiness. According to Nieuwenhuis (2007b:113) assessing trustworthiness is the acid test of data analysis, its findings and conclusions. Researchers need to constantly keep in mind the procedures that should be used for assessing trustworthiness of the data analysis. These procedures include consistency checks and credibility checks. Important aspects mentioned by Nieuwenhuis (2007a:80, 2007b:113-115) and Johnson (1997, cited in Thiart, 2012:68-69) that were applicable to the researcher’s study included:

- **Using multiple data sources**: It is generally accepted that engaging multiple methods of data collection, such as interviews and document analyses (such as patients’ files to confirm the diagnosis of BD), will lead to research trustworthiness. In this study, referrals for the participants were made by reliable resources: the private psychiatrist, the psychiatric hospital and the bipolar support group. Experts in the field were also consulted. All the participants had been caregivers for a number of years and spoke from a position of experience.

- **Stakeholder checks**: People who have a specific interest in the research (members of the MDT) were asked to comment on the research findings, interpretations and conclusions.
- **Controlling for bias**: Prior to the research, the researcher was not known to the participants. This aspect made it easier for them to see her in the role of researcher rather than social worker.
- **Avoiding generalisation**: Although the researcher does know the profile of caregivers of bipolar people well in general, they were still perceived as unique individuals and the researcher tried to seek insight into participants' perspectives, experiences, attitudes and behaviours. It was realized that different cultural groups might have different perspectives on mental illness and thus participants of different races were involved in participating in the research.
- **Using quotes carefully**: Each quote used in the research findings chapter was chosen deliberately and carefully and there was an effort to reproduce enough of the text to allow the reader to decide what the participant was trying to convey.
- **Maintaining confidentiality and anonymity**: The researcher did respect these aspects.
- **Theoretical validity**: All quotations, as transcribed from the verbatim interviews, were substantiated by literature.
- **Extended fieldwork**: The researcher has twenty-four years' experience in psychiatric social work that gave her a very good understanding of the field.

Lietz, Langer and Furman (2006:441, 447) mention aspects such as utilising reflexivity, an audit trail, triangulation by the observer and prolonged engagement in order to manage the threats to trustworthiness. Reflexivity is active acknowledgement by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation. The researcher consequently did make field notes during the interviews and also afterwards reflected upon the impact which a specific interview and contact with a participant had on her; and subsequently debriefed the participants.

On the basis of the above explanations, the researcher is confident that trustworthiness was ensured.

5.7 PILOT STUDY

5.7.1 Feasibility of the study

Strydom (2005a:208) emphasizes that it is necessary to obtain an overview of the actual, practical situation where the prospective investigation will be executed. The feasibility study is therefore especially important with a view to the practical planning of the research project and is an important aspect of the pilot study.

The feasibility of the study took into consideration **aspects** such as venue, cost, time, duration of the study and the caregiver's willingness to take part in the research.

- **Venue**: The researcher visited most of the respondents for **phase one** at their homes, but also conducted two interviews at the hospital where she works, while one respondent chose to come to the researcher's home. In each case, a private, quiet place was available to conduct the interviews. In **phase two** a suitable venue was made available at the University of Pretoria where the programme was presented. It was central and safe parking was available. The programme was presented to two different groups during the daytime, on two consecutive Saturdays.
- **Cost**: Telephonic contacts with participants were a cost consideration, because not everybody could be contacted via email. The researcher also incurred petrol expenses because home visits were carried out in phase one. Other costs that needed to be considered were: material used during the presentation, a workbook for participants and refreshments.
- **Time**: This was an important factor as research is not the first priority of the researcher's workplace and much of the work had to be performed after hours and during weekends. Most of the respondents indicated that a Saturday would best suit them for attending the programme.
- **Duration of the study**: Mixed methods research was utilized and this aspect prolonged the duration of the study. The development of the intervention (programme) was also very time consuming.
- **Willingness to take part in the research**: Caregivers were mostly willing to participate in the research because the researcher listened to their needs and they were offered a psychosocial educational programme that could help them in future to assist the patient in their care. It was however, necessary to contact the potential participants a few times to remind them of the programme and to communicate arrangements. There were a few people who said that they would come but then withdrew before they attended. There were people who were referred as potential participants whom the researcher did not

meet before the day of the programme, increasing the risk of withdrawal by them; nevertheless only two of these did not attend; while one participant was hospitalised.

5.7.2 Testing of the data collecting instruments

The pre-test of **phase one** of the study, using the interview schedule (phase four: **5.5.2.4**) was conducted with one caregiver; the changes recommended were made to the interview schedule. The researcher then became aware that a home visit and conducting the interview would take a few hours. She also realized the importance of confirming the appointment and making sure of the address.

The researcher did test the questionnaire (**phase two**) on two caregivers that were not part of the study. This helped her to realize that it would take a caregiver at least 30 minutes to complete the questionnaire and also that some questions were not clear.

The pilot test of **phase two** of the study was conducted during the first implementation of the programme and recommendations used to refine the programme before the second implementation.

5.8 ETHICAL ASPECTS

Bless et al. (2006:140) point out that the word “ethics” is derived from the Greek word “ethos”, meaning one’s character or disposition. It is related to the term “morality”, derived from the Latin term “*moralis*”, meaning one’s manners or character. The researcher concurs with their statement that “a moral issue is concerned with whether behaviour is right or wrong, whereas an ethical issue is concerned with whether the behaviour conforms to a code or a set of principles”. Strydom (2005c:57) concludes that ethics is a set of moral principles, which is suggested by an individual or group, is subsequently widely accepted and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.

From whatever angle ethics is approached, the fact remains that the researcher from the onset of this research comprehended that it was her responsibility to prevent any abuse during the course of the research project and that research participants had to be treated in a humane and sensitive way.

According to Strydom (2005c:56) researchers encounter two basic categories of ethical responsibility:

- To those who participate in a project; and
- To the discipline of science, to be accurate and honest in the reporting of their research.

Strydom's (2005c:58-66) classification of ethical issues was utilized and applied to this study as follows:

5.8.1 Avoidance of harm

Subjects can be harmed in a physical and/or emotional manner. Babbie (2007:63) agrees that psychological harm can be inflicted in the course of a social research study and stresses that the researcher must look for the subtlest dangers and guard subjects against them. Bless et al. (2006:141) emphasize that the most basic principle of research is that the participants not be harmed by participating in the research project (non-maleficence). They go further, saying that it is important that research not only does not harm but also potentially **contributes to the wellbeing** of others. This particular study focused on the possible needs and challenges of the caregivers and participation was on a voluntary basis. The researcher was, however, always aware of the possible embarrassment or discomfort that respondents might encounter. Then again, participants did benefit in terms of the knowledge and skills they acquired and the support they received from the programme. The researcher specifically undertook debriefing after the interviews and some of the respondents were referred to an appropriate colleague for counselling – not as a result of the interview, but for other issues that were picked up.

When the programme was presented, the researcher made sure that the participants felt safe enough to share experiences.

5.8.2 Informed consent

Babbie (2007:64) defines this norm by declaring that subjects must base their voluntary participation in research projects on a full understanding of the possible risks involved. Obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedures which will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher, be provided to potential subjects. Voluntary participation and adequate information are of the utmost importance. In this regard, Bless et al. (2006:142) highlight the principle of autonomy and make clear that it incorporates the freedom of individuals' action and choice to decide whether or not to participate in the research.

In the hospital where the researcher works, it is normal practice that the social worker contacts the caregiver. Consent was therefore not obtained from the patients before the particular caregivers were contacted; instead, various caregivers indicated an interest to take part in the study. The researcher was aware that it might be the case that a patient did not want the researcher to contact family members, because of previous family conflicts, but reasoned that it might be exactly those families who could benefit from the programme. In some cases, the researcher did not ever meet the patients. The researcher also gained permission to access clinical files at the hospital to verify the diagnosis and to gain access to the caregivers. After initial contact details of those caregivers interested in participating were provided to the researcher, they were contacted (via telephone and/or e-mail). The researcher made an appointment with the particular caregiver where the content of the **letter of informed consent** was first discussed; once the caregiver consented, the interview proceeded.

An information leaflet and letter of informed consent (**Appendix 5.2**) were used to explain the details of the study and to obtain the voluntary consent of the caregivers. The participants were informed of the content and the confidential nature of the study and told that they could withdraw from the study. Each was given a copy of the signed letter of informed consent while the researcher kept the original. They were also informed that the data would be tape recorded (in phase one) and transcribed. All participants were informed that the data would be stored at the university for 15 years, as prescribed, for archiving and possible future research.

Before the programme was presented (in phase two) the information leaflet and informed consent (**Appendix 5.3**) were handed out. Participants had a chance to read it and then sign it before commencing with the pre-test.

5.8.3 Violation of privacy, anonymity or confidentiality

Privacy implies the element of personal privacy (Strydom, 2005c:61) while Babbie (2007:64, 65) describes anonymity as only guaranteed in a research project when neither the researcher nor the readers of the findings can identify a given response with a given respondent. A research project guarantees confidentiality when the researcher can identify a particular person’s responses, but promises not to do so publicly or in such a way that the person could be identified by anyone other than the researcher.

In psychiatry, handling information in a confidential manner is very important, because of aspects such as social stigma and shame. It was important that the selected caregivers/participants were aware of the diagnosis, so as not to breach confidentiality, as far as the patients were concerned.

Information in this study's **first phase** was gained through semi-structured interviews, but it is only reflected in a general manner in the research report. In the **second phase**, respondents were part of a programme. A pre-test, intervention and post-test were performed and the programme was also evaluated by participants. The researcher specifically reminded respondents in phase two, during the implementation of the programme, about respecting the confidentiality of other respondents.

5.8.4 Deception of respondents

As Strydom (2005c:60) points out, deception of respondents may happen when information is withheld or incorrectly offered to ensure their participation when they would otherwise possibly have refused. Facts may be deliberately misrepresented in order to make another person believe what is not true. This occurs when the researcher intentionally misleads subjects by way of written or verbal instructions, the actions of other people, or certain aspects of the setting.

In this study, respect and honesty towards the respondents were essential. All correct information regarding the research was provided in the letter of informed consent and the information leaflet. It was also specifically because of this aspect that the researcher did not involve a control group. Caregivers who volunteered to participate in the research did so to receive the benefit of the programme, along with everybody else who volunteered. Respondents could not be expected to spend their time and petrol merely to come in to a venue to fill in a questionnaire, and to have to return again later for the post-test. It is furthermore very important to be professional and respectful towards people and to distinguish what would possibly work in theory and what would work in practice.

5.8.5 Actions and competence of researcher

It is necessary that the researcher should be constantly aware of her ethical responsibility (Strydom, 2005c:63). In this study, the research took place across cultural boundaries and it was important to refrain from any value judgments. Values and norms of other cultures were respected. Strydom (2005c:63) states that objectivity and restraint in making value judgments are part of a competent researcher's tools. In psychiatry, cultural differences must be considered; the clinician might be challenged by the fact that the respondents do not believe that western medication is able to make a patient function more adequately (Mabunda, 2004).

As previously mentioned, the researcher is an experienced psychiatric social worker who is knowledgeable in the practice of research and has conducted research for her MA studies. She was supervised by her promoter from the Department of Social Work and Criminology at the University of Pretoria. She has worked in an academic tertiary milieu for more than twenty-four years at a psychiatric hospital that is connected to the University of Pretoria. She has been a guest lecturer for social work students teaching the module on mental health at third year and fourth year undergraduate level as well as postgraduate level in the MSW (Health Care) programme on mental health. Throughout the years she has supervised many social work students studying at different universities.

5.8.6 Release or publication of the findings

Strydom (2005c:65) emphasizes that there is an ethical obligation upon the researcher to, at all times, ensure that the investigation proceeds correctly and that no one is deceived by the findings. The report will have to be accurate, objective, clear and unambiguous and contain all essential information. English and Van Tonder (2009:10) declare: “Your research is only as good as the words it’s written in”.

Results of the proposed study were compiled in a formal report, namely a thesis. The caregivers that had been involved in the training programme received feedback on the outcome of the programme. It was imperative to give them recognition for their participation and to express gratitude. They were made aware that they were being instrumental in helping to develop a programme that, in future, could empower many others in a position similar to theirs.

A hard copy and electronic version of the research will be made available in the library of the University of Pretoria and, as mentioned, two articles will be submitted for publication, with the promoter as co-author, to a scientific journal. A paper could also be presented at a conference.

5.8.7 Debriefing of participants

Debriefing entails interviews to discover any problems generated by the research experience so that problems can be corrected (Babbie, 2007:67). During some of the individual interviews participants did become emotional discussing some of their feelings, but the researcher was sensitive towards this aspect. As was mentioned, all participants were debriefed by the researcher after the interview. Participants requiring counselling were referred to a colleague.

Subjects may benefit from and become involved in the research to such an extent that they become dependent on it and may suffer on completion of the programme. This programme was however, only **one day** in extent and it served to empower respondents with knowledge and skills. Material in the form of a book and other hand-outs was also given to respondents to refer to in future.

Although this was not the purpose of the programme, it also provided participants with some form of support. They could identify with others in the programme and learn from each other.

5.9 SUMMARY

In this chapter research methodology was discussed - specifically the research approach, the type of research employed, the research design, the pilot study, as well as issues of trustworthiness and ethical considerations. A mixed methods approach was used in this study. Applied research, namely, intervention research, was utilized. The phases of intervention research were applied. An exploratory sequential mixed methods design was chosen. It was indicated that feasibility was investigated before the research was done. Trustworthiness in terms of the qualitative phase of the study received attention and lastly different ethical aspects were considered and discussed.

The biopsychosocial model enabled the researcher to have a broad perspective on the research process.

In chapter six, the empirical research findings of the qualitative phase of the study are discussed.

6. CHAPTER 6: EMPIRICAL RESEARCH FINDINGS OF THE QUALITATIVE PHASE

6.1 INTRODUCTION

> **Participant 7:** Yes I think it is like a little pebble you throw in and then it makes all those circles and it goes out and into a wider community but at the end it is only that first little ring around the pebble that truly understands it.
> **Participant 8:** I sometimes really think it is more difficult for us as caregivers than for the patient himself.
> **Participant 11:** BD has torn my family apart.

The research findings of phase one, the qualitative study, are provided by first furnishing **profiles** of the research participants and the patients and then offering a **presentation** of the categories, themes and sub-themes.

The theoretical framework of this study, the integrated biopsychosocial model, enabled the researcher to remember that a caregiver must be viewed as a person whose psyche and soma (mind and body) are being affected in his/her role of being a caregiver of somebody with BD.

6.2 PROFILE OF PARTICIPANTS AND PATIENTS

The research findings highlight the following aspects: the **demographics** of participants, **profiles** of participants (caregivers), **images** created of the particular patients **as well as observations and reflections** regarding the interviews.

6.2.1 Demographics of participants

Table 6.1: Demographics of participants

Name	Age Caregiver Patient Relationship to patient	Gender Marital status	Race	Qualifications and occupation
Participant 1 (pilot interview)	56 years 35 years Mother	Female Married for 23 years	White	National Diploma in Technology (Microbiology and Haematology) Works in a university laboratory
Participant 2	36 years 29 years Husband	Male Married for 4 years	White	Grade 12 Works at an electrical engineering firm

Name	**Age** **Caregiver** **Patient** **Relationship to patient**	**Gender** **Marital status**	**Race**	**Qualifications and occupation**
Participant 3	44 years 44 years Wife	Female Married for 21 years	White	Office administrative diploma System support consultant
Participant 4	54 years 24 years Mother	Female Widow	Black	PhD in Education Works at University of Technology
Participant 5	26 years 52 years Daughter	Female Engaged	Black	Medical doctor
Participant 6	58 years 60 years Wife	Female Married for 37 years	White	Grade 12 Administrative capacity at a medical scheme
Participant 7	58 years 29 years Daughter	Female Single	White	Currently working on MEd degree in Education Teacher
Participant 8	52 years 33 years Mother	Female Married	White	Grade eleven Self employed
Participant 9	50 years 59 years Wife	Female Married	Indian	Grade 12 Technical administrator
Participant 10	24 years 59 years Son	Male Single	Indian	B Com Degree Finance (Hons.) Accountant
Participant 11	57 years 55years Wife	Female Married for 32 years	White	B Com Degree Accountant (part time) Farmer

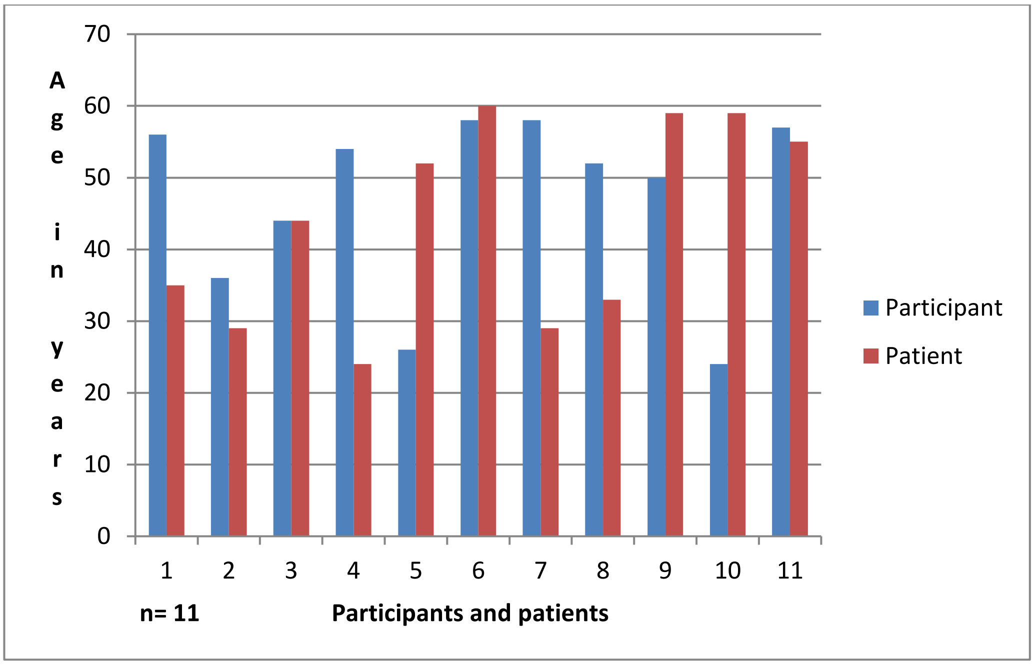


Figure 6.1: **Age of participants in relation to age of patients**

Discussion: Participants encompassed a wide spectrum of people (refer to **Table 6.1**). The caregivers' ages varied from 24 years to 58 years and those of the patients from 24 years to 60 years (refer to **Figure 6.1**). Nine females and two males were involved in the research. The participants represented nine patients - three females and six males. Diverse ethnic groups were involved. All the participants are well educated and hold good jobs.

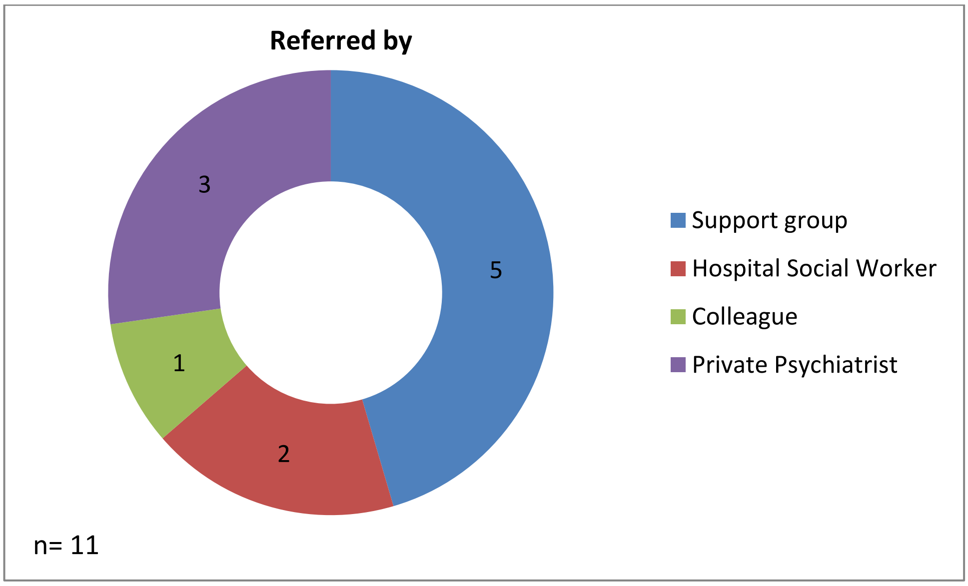


Figure 6.2: **Source of referral of participants**

Discussion: People from governmental mental health services as well as from the private sector participated in the research (refer to **Figure 6.2**). As mentioned, participants represented different spheres of the research population.

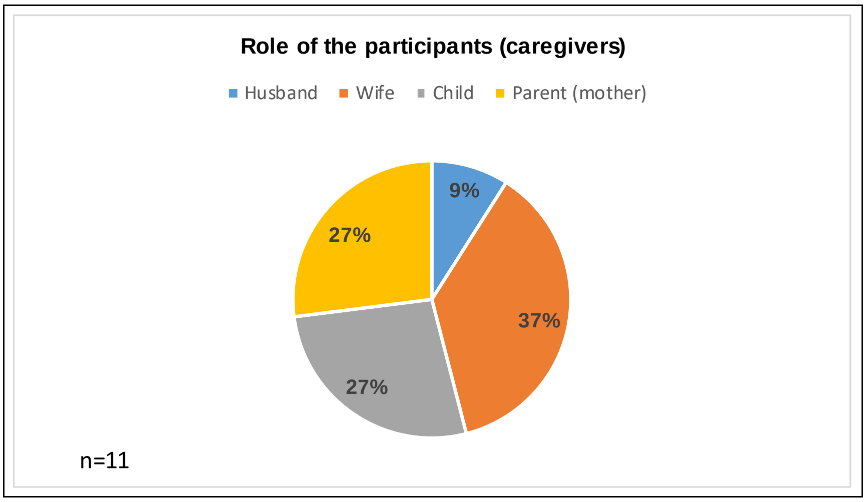


Figure 6.3: **Role of the participants (caregivers)**

Discussion: There was just one husband who participated in the research, while four wives volunteered to do so (**Figure 6.3**). It could perhaps be argued that women fit better in the role of caregiver, although this would be a generalisation. Children are severely affected by a mentally ill parent - even when they are adults. This was clear when the children reflected on their lives. The parent participants were all mothers and their unconditional love for their children was clear. There were two groups where the wife and child of the same patient were interviewed, which provided their different perspectives. In the first instance, the interviews took place separately while in the second they were interviewed together.

6.2.2 Profiles of participants (caregivers)

Table 6.2: **Profiles of participants (caregivers)**

Participant 1 (pilot): She is the mother of the patient, who is currently not staying with her, or talking to her. She divorced her first husband when her child, the patient, was 4 years old and remarried. They then had three teenagers in the house, which was not easy for her. Her husband is 65 years old. He had a stroke and has been retrenched. The researcher met him and he was concerned about the patient, but apparently he and the patient are not on good terms with each other ("she has got a problem with her stepdad"). He has two sons from a previous marriage who are respectively 36 and 32 years old, one of whom lives overseas and the other one lives in another province. A **protective factor** is that she wants to learn about the illness. She is very religious. **Risk factors** are that she blames herself for her daughter's problems, works very hard and in the process

overburdens herself. At the moment she works in three jobs (on Saturdays at Doggy Parlour and also runs her daughter’s pre-school, as well as being full time employed at a university laboratory). She is worried about her daughter (the patient) and also about her ten year old grandson (her daughter’s son). She does suffer from depression. Her husband is not religious and this is difficult for her.

Participant 2: The **primary caregiver** is the husband of the patient. He does however, think that he and his parents-in-law share the responsibility amongst themselves. He has a very good relationship with them. The patient’s parents stay close by and she has a good relationship with them. He describes himself as an analytical person who likes to understand.

It is his second marriage and they have one daughter of 2 years and several months. His first marriage lasted about 6 years and his present marriage was 4 years at the time of the interview. He works for an electrical engineering company that supplies protection equipment for high voltage substations throughout the world. He works and lives in Gauteng.

Protective factors are that the patient does have support from her extended family. Her husband is also very supportive and he wants to learn about the illness. **Risks** are that the patient is not always able to fulfil her roles as a wife and mother. The caregiver does feel his freedom is restricted and that there are financial constraints, because the patient is sometimes unable to work.

Participant 3: The **primary caregiver** (44 years old) is the wife of a patient (44 years old). They have been married for 21 years and have a 17 year old daughter who is still in school (Grade eleven). The caregiver and daughter are very close to each other. The caregiver previously experienced miscarriages before this daughter was born. She does administrative work. She is currently not very happy in her job. She is studying further in office administration to become a personal assistant. The caregiver describes herself as a very quiet person, somebody who does not like conflict or any confrontation. She would like to be in a work position that is more satisfying than her current one and she would like to ensure that her child can study further.

Protective factors are that the patient does have a job; neither he nor his wife abuse substances. He is compliant with his treatment. He is described as a responsible person and does not overspend. They are of the Christian religion and they both consider religion important in their lives. Both attend Bible study groups at their church. She is a good supporter, helper and loving person. **Risk factors** are that the marriage is not what the caregiver would have liked it to be; she has previously contemplated leaving him. He does not want to socialise and communication within the family is a problem. He works long hours. The family rents a house on a smallholding, outside of the city. This is very difficult for the caregiver, because it is far from work and school. The caregiver feels that the patient does not acknowledge her emotional needs and is not always available to support her. The fact that she is very sensitive towards other’s feelings affects her and she feels that there are times that she cannot cope with certain situations. She does sometimes feel frustrated and angry. She mentioned that she did not experience a good childhood – she was always rejected as a child. The caregiver is also using medication for depression. She suffers from hypertension and her thyroid is underactive. The daughter made a suicide attempt a year after her father was diagnosed with BD. She overdosed on her father's medication. It is clear that the father's illness impacted on the wife and the daughter (the whole system).

Participant 4: The **primary caregiver** is the **mother** (54 years old) of the patient (a 24 year old man). He does however, currently reside in a rehabilitation centre. At present she resides in a security estate in Gauteng. She was born in Limpopo. She was the first born, the only girl. Her father was an academic at a University. Her mother was a teacher, but is now retired. At the time of her husband's death (20 days after a motor vehicle accident) the patient was in a psychiatric hospital and he did not know that his father was ill in hospital. This made the burden on the mother even heavier. She has experienced losses and disappointments. She feels that she is able to understand the pain of others because of what she has gone through. She is interested in attending the programme and she does need support and knowledge.

Protective factors are that the caregiver has beneficial insight regarding the challenges of BD. She realizes that life has challenges. She realizes that boundaries are important. She can afford to place the patient in a good rehabilitation centre. She receives her strength from God. **Risk factors** are that the caregiver is a single parent. The patient tends to manipulate the caregiver. He has a substance abuse problem. The mother became depressed after the death of her husband. She used medication for the depression as well as sleeping tablets.

Participant 5: The current (at the time of the interview) **primary caregiver** is the husband of the patient. The participant is the daughter (26 years old) of the patient (52 years old). She is a medical doctor and qualified in 2010. She is living in Gauteng and her parents are in the Northern Cape. She is going to be married soon. She has a younger brother who is 22 years old and at University. Her parents are alone during the year – their son returns home during holidays. She has been one of her mother's caregivers for years, because her father used to be away from home for his work. He is however still the primary caregiver. This interview was about the daughter's experiences, but also about her perception of her father's experiences. They are both caregivers.

Protective factors are that she has useful insight regarding her mother's illness and this has helped her to deal with the situation. **Risk factors** are that she must also support other family members such as her father and brother, on an emotional level. She must keep up a 'front' and 'be strong' because others need her to be. She misses her mother's support. She was exposed to her mother's illness from a young age. Roles were reversed. Her parents are a constant worry to her, even though she lives far away. She still feels responsible for them.

Participant 6: The current (at the time of the interview) **primary caregiver** is the wife (58 years old) of the patient (60 years old). She considers herself and her 29 year old daughter (their only child) to be the main caregivers of the patient. The daughter has lived alone since November 2011. The patient's mental illness has worsened since 2002, but he has been sick for a long time; his wife was unaware that his behaviour was due to an illness. She just thought it was his personality. **Protective factors** are that the caregiver is able to provide support to the patient and her daughter and function in an independent manner. **Risk factors** are that the caregiver might be doing too much for the patient and making him dependant on her. The extended family is not supportive.

Participant 7: She is the daughter of Participant 6. She helps her mother to take care of the patient. She has only recently moved out of her parents' house and is now staying on her own – although still in the same town. She has her own friends. The daughter says that her parents' relationship reminds her of Romeo and Juliet because her dad was brought up as a Christian, but her mother was a Jehovah's Witness and then her mother's mother (the grandmother) did not want the two of them to get married. She does think of her future and the impact of the illness upon it. **Protective factors** are that she has valuable insight into her father's illness and the family dynamics. She was able to move out of her parents' house, although she feels guilty about it. She is able to persevere. She describes her mother as a Margaret Thatcher (Iron Lady) - someone that can cope with anything. **Risk factors** are that she has also become stressed and struggles to become totally independent. Her parents are a constant worry for her. It seems her mother is still making demands on her time and considers her to be her friend. She feels her parents sometimes position her in the middle between them. It is the daughter's perception that her father cannot live without her mother. The daughter is also in therapy for depression and pulls out her hair. She has a fear of the genetic component of the illness. She does not like conflict.
Participant 8: The **primary caregiver** at the time of the interview is the mother (52 years old) of the patient (33 years old). She helps her husband in their business and she works very hard. She had to sacrifice her own dreams - she wanted to be a singer. She worries about the patient's future. **Protective factors** are that she has perseverance and she is able to have seen the pattern of the illness. She does not take her son's behaviour personally. He does not abuse substances. **Risk factors** include that she does not have her husband's and family's support. She does seem to be overprotective towards her son. She avoids conflict and in the end this also affects her health. Her husband (patient's father) does help her but he does not accept their son to the degree that she does. The patient has had numerous admissions to hospital since approximately the age of 17 years.
Participant 9: The **primary caregiver** is the wife (50 years old) of the patient (59 years old). She works at a school. The couple have 3 children, age 28, 26 and 24 years old. The two older ones (daughters) are married and their son is still at home. He is still studying. They have one granddaughter as well. **Protective factors** are that she has the support of her children in coping with the illness of her husband and their father. She is a positive person. **Risk factors** include that the patient does not always comply with his treatment. The caregiver has also had depression.
Participant 10: He is 24 years old and recently completed his studies in networking. He stays with his parents and supports his mother in the caregiving role. He and his mother are of the Hindu religion. **Protective factors** are that he is a very proactive person who solves problems and is not afraid of confrontation. **Risk factors** are that he might feel responsible for his parents and his

independence might be restricted by the father's illness. He sometimes becomes impatient with his father and even aggressive towards him.
Participant 11: The **primary caregiver** is the wife (57 years old) of the patient (55 years old). They live on a farm and she does auditing for an extra income. They have 3 children, aged 31, 29 and 27 years old (two sons and a daughter). She views herself as a people- person. It took a long time for the patient to be diagnosed and it was a relief when it happened. **Protective factors** are that she describes herself as a very stable person and this helped her to cope with the patient's instability. The sons are still staying on the farm and they do also help with the caregiving. She is a planner and a financial person. She sees herself as the strong one in the marriage – the responsible one. She mentioned that the fact that she lost her father when she was still very young made her more independent and made her a stronger person. **Risk factors** include that she is someone that does not like any conflict; and it becomes very difficult when the patient is aggressive. She does suffer from depression. Their daughter has also been diagnosed with BD. She has a boyfriend from a different cultural group and this is difficult for her conservative family to accept. One of the sons also suffers from depression.

Discussion: Participants' profiles have been provided to offer a broad overview of each unique context (**Table 6.2**). The **protective** factors and **risk** factors in every situation were highlighted (Categories 5 and 6). In one case (Participant 2) there is a young child in the house and in another there is a teenager (Participant 3). Seven of the participants (Participant 2, Participant 3, Participant 6, Participant 8, Participant 9, Participant 10, and Participant 11) were still living with the patients. Others are adult children who have moved out of the house (Participant 5 and Participant 7). It is clear that although these children no longer reside with the patients, they still experience the impact of having a mentally ill parent. Although the son of Participant 4 is in a rehabilitation centre, she still has very close contact with him and fears the day that the centre might tell her to fetch him owing to his behaviour. Participant 1's daughter lives with her boyfriend, but her mother is emotionally and financially very involved with her daughter's life.

Some participants (Participant 1, Participant 2, Participant 4, and Participant 11), did indicate the importance of religion in their lives. Most of the participants are from Gauteng, but Participant 11 is from the Northern Cape (her husband consults a psychiatrist in Gauteng). It should be mentioned that some caregivers were also experiencing depression and/or anxiety (this may be genetic or due to the stressful circumstances of taking care of a mentally ill patient).

The researcher identified risk and protective factors regarding the caregiver scenario (**Table 6.3**). Parker and Ketter (2010:349) emphasize the need to address those **psychosocial**

factors that **risk** exacerbating the underlying condition and "unbalancing" the individual. The psychotherapist (social worker) needs, as in the case of the patient, to be aware of early warning signs and to introduce strategies that could minimize precipitating factors and ones that work towards relapse prevention. Miklowitz (2011:157) also refers to some of these factors, but it was clear that the researcher's participants did not realize the importance of the maintenance of regular daily and nightly routines nor that triggers and mood should be monitored.

Table 6.3: Risk and protective factors, evident from interviews, regarding participants

Risk factors	Protective factors
Denial of the illness.	Accepts the illness and wants to learn about it.
Burden and stress.	Able to handle stress and demands.
Caregiver (and other family members) having psychiatric problems (such as depression) as well as physical problems, such as hypertension.	Caregiver is a well-adjusted, healthy person.
Lack of support from family.	Support in all spheres.
Patient cannot fulfil roles (also role reversal).	Patient is still functional.
Feels that freedom is restricted and patient is demanding. Patient is dependent on the caregiver. Caregiver must be the buffer between the patient and others.	Patient is independent and takes responsibility for her/his life.
Financial constraints.	Financial resources.
Substance problems with patient and caregiver.	No substance problem or self-medicating.
Poor compliance with treatment.	Compliance with treatment and follow up.
Caregiver blames him/herself for the illness.	Caregiver understands that the illness is not her/his fault.
Caregiver and patient very sensitive to criticism. Become emotional (angry) and impatient.	Resilience and perseverance.
Enmeshment/overprotectiveness. Caregiver is very controlling.	Respect for boundaries and freedom.
Patient has comorbid personality problems (manipulates, self-centred).	Patient accepts and knows him/herself and does not blame others.
Caregiver and patient have poor insight.	Caregiver and patient have good insight.
Exposed to the illness from a young age.	Was already an adult when first confronted with the illness
Caregiver afraid of the genetic component of the illness.	
	Believes in a Higher Power.

6.2.3 Images created of the particular patients by the participants

Table 6.4: Images created by the participants of the particular patients

Participant 1 The patient is 35 years old and was diagnosed with BD in 2006. She is a private patient and has been hospitalized twice. She is a divorcee. She and her child of ten years old live with her boyfriend in another town. They have been in the relationship for three years, but it is a very unstable relationship. He has often threatened to leave her. She has put her mother into debt in excess of R700 000.00 and her mother might lose her house. The patient is described as being extremely aggressive and abusive - especially towards her mother and also her child. She is described as being manipulative, impulsive and irresponsible. The profile of this patient does seem to fit that of a **borderline personality traits/disorder**. She also has a substance abuse problem (alcohol and tablets). Her **main role** is that of being a mother.
Participant 2 The **patient** was diagnosed with BD II a year previously, but, according to the caregiver, she feels that she had been ill since she was 16 years old. She had a miscarriage at about five months and apparently she still refers to this baby as her daughter. She also named the baby. During this time she also witnessed somebody dying, after her boyfriend was obliged to attack this person to protect her. She still sometimes inadvertently sees this (previous) boyfriend which then brings back bad memories. She firmly believes that she was/is part of a twin and the researcher is not sure if it is a delusion. It was also reported that she has had self-mutilating behaviour in the past. It might be that she does have **borderline personality traits**. The patient was described as being extremely spiritual. She is also creative and artistic. It was reported that she can become irritable, angry, impatient and that she has an extremely strong personality. Three weeks prior to the interview the family underwent a crisis. The patient attempted suicide. It seems that the trigger was that because she could not do her job (she is a beautician) they told her she need not come back to work. She enjoyed her work and was very happy, but struggled to remember - it seemed that she could not concentrate well. Her **main roles** are wife and mother.
Participant 3 The patient has been mentally ill for about four years. He has been diagnosed with BD 1 and also had a stroke 14 years previously. This makes him forgetful and he seems slightly rigid in his way of thinking. His personality changed too. Work stress and the fact that the family were obliged to move several times seem to have contributed to him becoming ill. He is one of five children. His **main roles** are husband, father and provider. He works as a bookkeeper.
Participant 4 The patient is currently staying in a rehabilitation centre, but still maintains very regular contact with his mother. The patient has a younger sister and an older brother. His interest is computers. The patient suffers from a **substance** problem which complicates matters. His mother also experienced and experiences him as being manipulative (even before he became mentally ill, as

a teenager). Currently, his **main role** is the sick role and being a son, he makes no other contribution.

Participant 5

The patient has been mentally ill since 1990. She was diagnosed with BD 1. The patient is 52 years old and has university level education. Her husband is 60 years old and has also attained tertiary degrees. They have been married for 27 years (since 1985). They belong to the Christian religion. She is described as a very religious person. She does not abuse any substances. The patient's parents were opposed to the marriage, because the husband was from Zimbabwe and came from a poor socio-economic background. She has two sisters - the youngest works in England as a mental health care nurse. Her **main roles** are that of wife and mother.

Participant 6 and 7 (wife and daughter)

The patient is 60 years old and was boarded from his job after having worked for 40 years. He was one of eight children. His father who was a train driver was often away from home and is described as having been abusive towards the patient when the latter was a child. His parents were divorced and his brother was murdered. It was reported that the patient is not a very affective person. His diagnosis is BD II, with obsessive compulsive disorder. He was hospitalized during the course of his illness. His **main roles** are those of husband and a father.

Participant 8

He is 33 years old and has never been independent, having always lived with his parents. The patient sometimes helps them in the business. He has never married and does not have children. He spends all his time at home. He was in matric when he fell ill and needed to be admitted to a psychiatric hospital. The patient's mental illness started at a young age, but he was only admitted when he was 19 years old. His diagnosis is BD 1. When he was supposed to write his final exam he could not. He attempted doing a course in electronics, but he could not finish it either; about two years ago he attempted a scuba diving course, but he could not complete the theory.

He is the second son in a family of four children. The others are all working, married and have their own families. His siblings reject him. His father is described as having no tolerance for the illness and of being abusive towards the patient. The father blames the patient and his mother that he is ill (saying the illness is due to a bad spirit), although there is a very strong family history of illness in the father's family. The illness has also negatively affected the patient's parents' marriage.

In addition, he suffers from a physical illness, psoriasis, a skin disease which is very painful. He has frequently been hospitalized during the course of his illness. He becomes very aggressive when he is ill and has threatened to kill his mother. The police were required to take him to hospital. The patient is not functioning well. It does seem that his **main role** is just to be a child at home.

Participant 9 and Participant 10 (wife and son)

The patient has not been well for years (almost 10 years) and has been diagnosed with BD I. It was stated that he is very intelligent, very professional and that he is a perfectionist in everything he does. He goes the extra mile, trying to please people, but nonetheless those people do not

realise that he is not himself. He does not abuse alcohol; he only smokes. He is described as a very good husband and father, when he is in his "normal" state. He is also very caring.
Participant 11 The patient has been ill for about 25 years and has had more than 10 admissions to hospitals for psychiatric problems. He does not have a substance problem. He is very religious.

Discussion: The caregivers represented a wide variety of patients (**Table 6.4**). The common denominator was the fact that the patients had been diagnosed with BD (with or without comorbid conditions). Most patients have very caring families, but some have suffered rejection from family members or the community.

6.2.4 The researcher's observations and reflections with regard to the interviews

During the interviews the researcher made field notes as is recommended by Schurink, Fouché and De Vos (2011:406). After the interviews the researcher also reflected upon each interview that took place (**Table 6.5**).

Table 6.5: Observations and reflections of researcher with regard to the interviews

Participant 1 She was anxious and her mood was labile. It does seem that she is depressed and overwhelmed. She has lost weight and is also recovering from breast cancer. She still sees her oncologist. She is a very friendly and caring person. She described herself as a person who "can accept lots of things" and has "lots of patience". She wanted to verbalize her feelings.
Participant 2 He was very open and willing to share and express his feelings. He shared about his wife's recent suicide attempt: he feels that he was able to handle it well, although he was very shocked by the incident. During the interview it became clear that the caregiver had a need to talk about this event. He commented that the family learned from this incident and that **communication** in the family improved after this has happened. It was clear that he feels responsible for his wife's well-being, but is sometimes also frustrated by the situation. He does sometimes experience his wife as being demanding. The researcher referred him to the Federation of Mental Health for a follow up.
Participant 3 She was very open, friendly and willing to share and express her feelings. She has a need to learn more about the illness and how to manage it. She feels knowledge will empower her to cope better. She is trying her best, but is not obtaining the necessary support from her environment. The patient was at work and the caregiver could therefore talk freely. Her daughter was at home, but did not contribute to the interview.

Participant 4

Patient’s mother had to deal with her husband’s death and her child’s illness - thus putting stress on her. She is however a strong person and she does have skills to deal with problems. Her main concern is her child (the patient’s) future. She is an organized person and has high standards. She wants the best for her children. She often talked of her child in the third person (“they are very manipulating, these kids”).She was emotional during the interview (crying). She is somebody who thinks about problems, analyses them and looks for solutions. She does not deny the challenges of life.

Participant 5

She was very open and willing to share. She possesses good insight. She comes across as a very **responsible person**. Researcher was aware of her intense worry about her mother. Her profession has helped her to become more objective towards the situation.

As a young child growing up she was sometimes alone with her mother being manic and psychotic and it must have been very frightening. She had to hide the fact that her mother was ill.

Participant 6

She perceives Participant 7 as being well in control of the situation, although it is difficult. She depends on her daughter for advice. She manages to see that her husband still possesses positive characteristics. However, she does not feel appreciated.

Participant 7

She was open and willing to share. She has clear insight. She is caught between her parents – feeling **responsible**. This might be more difficult because she is an only child: “I am the only child and I lived for 28 years with my mom and dad”. The researcher was aware of her anxiety and her possible guilt feelings about having moved out of her parents’ house. Researcher thought that she wants to find her own identity, separate from her parents, but it might be that it is not allowed. Researcher was aware of her hurt and the loss of a relationship with her father, because he was not there for her.

Participant 8

Despite being anxious, she was friendly and open during the interview. She is deeply affected by her son’s prolonged illness. She was sometimes emotional. It was clear that she is trying very hard to maintain the equilibrium at home. She is blamed for everything that goes wrong. She is very worried about her future.

Participant 9 and Participant 10

This interview was planned with the wife of the patient, but when the researcher arrived at the home, the son was also there and wanted to participate. The researcher welcomed this, because it offered an opportunity to gain more insight. Although the patient was at home, the researcher talked to the family members alone. Afterwards the wife asked the researcher also to talk to the patient, so as not to cause him to feel left out. In some way it was challenging to talk to both family members together - to really attend to both of them simultaneously. They were very open and willing to share and express their feelings and views, although the researcher respects the fact

that it is not always easy to share personal details with a complete stranger. This family's culture is different to that of the researcher, but they were very accommodating.
Participant 11 She is a person that introspects and therefore knows herself very well. She presented as a person who is aware of her strengths and weaknesses and who can cope with demanding situations. The researcher could feel her pain and the struggle through which she is going.

Discussion: The duration of interviews was, on average, one and a half hours. Most of the interviews were at the homes of the participants and the fact that home visits occurred, meant that additional information about the participants' broader context was provided. They were all very cooperative and it is the researcher's opinion that they were open and honest. Participation in the research was voluntary and participants therefore wanted to share information and emotions. The researcher was struck by the level of their perseverance under very difficult circumstances and that they would not give up hope. In conclusion, it became evident that the profile of the participants and patients provided will contribute to a better understanding of the themes and categories that are to be discussed.

6.3 CATEGORIES, THEMES AND SUB-THEMES

This section presents the categories, themes and sub-themes derived from the transcribed interviews. Each theme and sub-theme contain narrative accounts from the interviews, using verbatim quotes from the transcriptions. These themes are each discussed and supported by literature. All names have been replaced by pseudonyms. The researcher attempted as far as possible to provide a true reflection of the data from interviews.

The researcher identified 12 **main categories** with related **themes** and **sub-themes**. The main categories are:

- Needs
- Burden
- Relationships
- Illness
- Protective factors
- Risk factors
- Emotions
- Participants' and other family members' response to mental illness
- Roles and qualities of a caregiver and roles of the patient
- Psychosocial challenges for caregiver

- Psychosocial challenges for patients
- Recommendations from participants' practical experience of what works for them

6.3.1 Category 1: Needs

Two themes were identified in this category: the needs of the **caregiver** (9 sub-themes) and those of the **patient** (3 sub-themes) (albeit communicated from the caregiver's perspective) (**Table 6.6**). As suggested by Ogilvie et al. (2005), there is a need to **understand caregivers**' views and perceptions of the stresses and demands arising from caring for someone with BD, in order to develop practical, appropriate, and acceptable interventions and to improve the training of professionals working with bipolar patients and their caregivers. It was very important for the researcher to establish the real needs of caregivers, because these formed the basic framework of the programme she developed.

Table 6.6: Category 1 - Needs

CATEGORY	THEMES	SUB - THEMES
Category 1: Needs	Needs of **caregivers**	• Acknowledgement • Sacrifices own needs • Support (emotional and financial) • Information/knowledge • Skills, tools and coping mechanisms • Space/freedom/day off • Order and stability • Programme • Future aspirations
	Needs of **patients**	• Need to be accepted • Need to be trusted • Need for friends

6.3.1.1 Theme 1: Needs of caregivers

This theme contains nine sub-themes.

- **Acknowledgement**

This sub-theme is reflected in the quote below.

Participant 7: "I think that is why I am so glad that you are doing this study because it sounds "egosentries" (egocentric), but it is like there is always such a lot of focus on this person with bipolar, always about helping him and how can you support your husband. But what about the person, do you think that is just superwoman or super husband standing there?" "There is always such a lot of focus on the person with the illness that people just tend to forget what about the people around them".

- **Sacrificing one's own needs**

The quotes below from the interviews reflect this sub-theme.

Participant 2: "That is it, I didn't care about myself. I don't, if it happens tomorrow, I will again not care about myself. I will just want her to be better and to be ok". "I have not bought a new pair of "tekkies" in four years. Her needs are more important than mine. Hers are much more intense than mine".

Participant 4: "I said to myself I also need to look after myself".

Participant 6: "Ja, I think about my needs". "Yes, he comes first".

- **Support (emotional and financial)**

The quotes below, from participants in the interviews, support this sub-theme.

Participant 3: "So sometimes I bottle it up and then it gets too bad. At times I feel just that I could go and talk to somebody who knows precisely how I am feeling who has got the same, who knows precisely how a person with BD or depression works, or who can give me practical advice on how to sort out my own feelings. I don't know and you sort of feel, o where am I going now?" "At that stage I just felt I had it. I just had enough of being the strong one all the time, being the mother and father of this child and know that I don't have any support at that stage of any emotional or yes the financial means of an income, but the emotional support I really needed more at that stage".

Participant 5: "There is definitely a need for support for family. Even just sometimes to speak to someone and get some advice, maybe the person is hypo manic and not feeling well and you just need to know what can you do to stabilize her during this period. So it is very difficult on the **family**".

Participant 6: "No there is not somebody. But as I say the family and friends and that and people at work and that, they don't understand this condition, so you can't get help from them. And also not people at his work".

Participant 7: "It is just like, there is no support for you to help. There is no one. My one friend is an occupational therapist and she also has the knowledge so she understands, but other people they don't understand".

Participant 11: *"Ek dink party keer veral omdat jy vrou is, wil jy doodgewoon terugsit en getroetel wees en versorg voel en nie voel die verantwoordelikheid is net myne nie* "(I sometimes think, especially because you are a woman, you want to sit back and be spoilt and feel that the responsibility is not mine alone).

- **Information/knowledge**

The following quotes reflect this sub-theme.

Participant 2: “Absolutely, anything that I could get or absorb to use and to make her quality of life better. Actually I will grab them with both hands for sure”. “It is just if I had a little black book in my pocket that’s got a couple of answers that I don’t have, maybe I will say things that will help her. The little book doesn’t exist but that would have been nice”. “There are things I don’t know that I don’t’ know that I don’t know them”.

Participant 3: “I really do feel that is my biggest need as a supporter is to know who else I can go and talk to, where can I get the right information. That session that you had - that was really for me an eye opener. A lot of things that you told us made a lot of sense to me. You know what I really feel would make life easier for all the caregivers is that knowledge, power, like the session we had with you at the support group. If I just had more knowledge”. “I feel really I would have done much better if I had all this type of things already that I knew, if I could just knew where I could get it. Maybe my eyes weren’t open, maybe it was available, but I didn’t see it. I didn’t know about programmes that was held for people to supporting people with bipolar or stroke victims or any of those things at that stage, so for me that I think is the integral thing that you need to just do”. “If I had the **knowledge** then already how to. Good advice and input where you can really say ok I know whom to talk to, I have got this specific problem, I know who I can go and call and say ok help me to think about a good solution or let’s just maybe you know of something else. Somebody else I can call, or on which **website** I can go in and will give me the correct advice”. “It is too high language for you. Yes to know what it means. So it must be like a **practical**. Like a person from the street can understand what they are saying”.

Participant 4: “But sometimes I become like very **confused** because they gave him this type of medication and then I took him to another doctor just for second opinion and the doctor said no stop this medication. Sometimes you really become **confused** as to whether is this the real thing, is this the right medication you know”.

Participant 5: “So that problem made me see that even in educated population groups, **psychoeducation is very important**“. “I think when the diagnosis is **first made**, that is when **you need really intensive psychoeducation for the family**. Because that is the time when relationships are broken and relationships are damaged the most is when the diagnoses is first made. When the patient is full on manic and full on psychotic. And often times it is very hard to pick up the pieces afterwards, cause now to try and mend broken relationships is very hard. So it would be good if people are educated, that this is what you can expect and also that you are gonna expect it for the rest of your life”.

Participant 6: "He is sick for a long time, but the way he acted I did not know it was due to a sickness condition. I just thought it was his personality"; "on the Internet, you go and look this, and that and you think your husband has got that and then you read this one and you think he has got that. I don't know, I ... "

Participant 7: "If people could be more enriched with knowledge you know, they will, we could have had a better life" "I think in a way the **media** can also be blamed because they sort of say this and this and these are symptoms and if you then go and look broader there is lots more of little underlying stuff as well". "But I think now it is sort of easier because I have more **knowledge** about it."

Participant 8: "I did not really have much knowledge about the mental illness when I married him. I was very young; I got married when I was 17 years. If I look back now, and I see, I could have seen the **symptoms** if I knew about them, but we did not realize it until he was much older". "I think there will always be areas that I could learn from because I only know what I have read and what I have been told over the years. That is it. I think there is much deeper, if I could maybe understand especially what the **medication** does and why they have to have certain medications and when they go on the high, if I have more knowledge to know what to do to prevent it. Because I can see when he goes, when he is starting to go on a high, if I could just do something to **prevent** him from going on a high".

- **Skills, tools and coping mechanisms**

The quotes below, from the interviews, support this sub-theme.

Participant 1: "I want some help to say to me **what I should do** in these circumstances. I need to have the correct way of **how to deal** with it and I think I will never have enough knowledge to see what am I supposed to do and not to do and to have the '*die sekerheid'*, the surety of what I am doing is all right. And I find that it is more practical for me if somebody tells me I did this and this".

Participant 2: "If we handle them wrong, there are things that we are going to regret".

Participant 3: "**You need to know** when **to do** certain things at what times. That guy or that person suffering from bipolar doesn't want to know, he doesn't care as long as he is taking his medication and everything is hunky dory, I am feeling ok, I am not too high and I am not too low, that is it". "That is precisely what I needed. I needed that tools. The more tools that you have got to know what you use, the better you become and the better situations for everybody around you. So you need to get a **coping mechanism** how to cope with this and go on and see how you are going to work around and do a method of getting better and this is what helped us". "Like I said knowledge is power and the tools, the more

tools you have knowledge about, the better you can handle situations that are noted, sort it out quicker and be it turned around in a positive way".

Participant 7: "I think my biggest need will be you know how to **cope** with it, how do you, what can you do not to be pulled down if you father is like that ".

Participant 8: "I don't really know the right way. I am just trying to do what I think is best".

- **Space/freedom/day off/respite**

The quotes below reflect this sub-theme.

Participant 2: "But I get my four to five hours on a Sunday. That is what our agreement is. I am very glad that she is offering me that time. I think if she wasn't offering me that time, it wouldn't have gone the way it is going now. It would have been a big issue because I can't be there 24/7. I can't. I have got my outlet, four hours on a Sunday that is a little bit of an **outlet**".

Participant 4: "Some days you will tolerate that, but some days you are human. But some days, this is just too much, but ja I must say some days when you are not stressed up too much it is just one of those days, but some days he will keep on nagging you on something, then it is like ai, ai, just give me my **space**, because I just need to relax a little bit. It is because you are also stressed up because I am working as well and so it is just like I can't take this. I just want to sit down and relax. I intend having a life now. Ja, I didn't have a life the past ever since 2010, but now I can go to friends, and even now I can do what I want. But I want my **freedom** if I want to go somewhere, it is normal. I would love to go there and not feel that you, he needs me I must go back home. It is like when you have a small baby you know, you go and you want to come back home quickly to see if things are still ok". **"**That is a need, like for instance, hmm, during December holidays maybe you want to go somewhere because you are working the whole year. You need to be able to phone to say can I have somebody to come and stay with my child here, so that I can at least have a week or so on my own - a **respite**".

Participant 8: "Yes I want some me time sometimes but it is very difficult to get".

- **Order and stability**

The following quotes reflected the participants' need for order and stability.

Participant 3: "When he is at home it should be an organized situation. Ok, at this stage it is not, so sometimes that frustrates him a lot."

Participant 6: "I must live with that, I want everything neat and that and it is not like that because he always got a few jobs running at the time".

Participant 7: "But we know we know what can trigger him and we tried to prevent **that trigger**, because we want to make life easier for us".

Participant 8: "I really don't know. If he just was stable. At the moment the only way I see that stability will come is when he is not around. But where does he go?"

- **Need for programme**

This sub-theme is reflected in the quotes below.

Participant 2: "If it is available I will do it, because I might just learn something or I might be able to share something with somebody and they would learn something".

Participant 3: "So yes, I feel the programme that you want to do is going to be a wonderful thing for us who are the supporters. I think that it is a wonderful idea. I mean it is not just your husband who has got bipolar or depression per se, you feel it is not the people that work with you, they are in the street, I mean the person behind the till might also be a sufferer at that and it will make you so much more better to handle that person with grace and really handle them so that they know they are also very important".

- **The future**

This sub-theme is substantiated by the following quotes.

Participant 4: "My hope is I want him to be better one day as a mother".

Participant 7: "I think for me it is like I am scared that I might also have it, I think because you sort of I know a while back it was it is *oorerflik en dit is geneties* (it is inherited and it is genetic) so I think that thing is always there with me. What if I have it? I think if a mother has it it is much worse. I think *sy is maar die dryfkrag agter die huishouding* (she is the driving force in the household).

Discussion of theme 1.1: Participants felt that the patient always receives all the attention and that the caregiver is often ignored. They put the patient's interest above their own. Caregivers must remember their **own** needs, should share responsibilities with others and stop BD from taking over family life (CAMH, 2000:39). This effect of this illness may lead to the carer losing his/her social life, which in turn may make him/her feel extremely lonely and isolated. Supporting a person with BD who is very ill may prove exhausting, often to the point where a person might neglect their **own needs** (Aiken, 2010:121).

It is evident from the quotes that caregivers need support on different levels. Families need opportunities to relate to persons with similar experiences. How well families do in the face of a severe mental illness may depend to a significant degree on how well their needs for support are met (Hatfield, 1987a:21, 1987b:191). The "terrible sense of isolation" described by one parent, for many relatives is overcome upon **meeting others** performing similar roles in other families. That "sense of being a pariah…a creature to be pitied" is reduced by being with other caregivers and hearing that others have experienced the same unpleasantness, the same despair, anger, and anxiety. The capacity to endure in the face of a tenacious problem depends on the existence of a **community of fellow sufferers** who affirm and protect one's sense of worth, even when the evidence of the moment is ambiguous or contrary, who share and keep alive a common interest in the midst of a wider society that does not care, who provide counsel and concrete assistance, and who foster a belief in the future when all others fail to do so (Terkelsen, 1987a:148, 149).

Participants' need for initial and ongoing psychoeducation on a practical, understandable level was indicated. They also need to know how to access information. Families need to **know** about their relative's illness if they are to be informed consumers and expected to help the recovering individual (McElroy, 1987:227). Family members of people with BD are usually hungry for **information** about the disorder, particularly during or after a manic or depressive episode, whether or not the episode involves hospitalization. Relatives may harbour many **misconceptions** about the illness. Well-meaning relatives who do not understand the disorder may view drug treatment or psychotherapy as crutches. They should understand that at least a portion of the patient's behaviour is biologically and chemically determined (Miklowitz, 2011:5, 283, 284, 286). It is important that everyone in the family learns as much about the illness as possible in order to know what they are dealing with (Aiken, 2010:121).

Participants were unsure of what to do - sometimes not realizing that there is no recipe. Caregivers do have a need for skills, such as how to communicate with the ill BD patient, what to do if the patient becomes suicidal as well as other coping skills. Participants indicated that they wanted to be part of a psychosocial educational programme meme. Family members do not always know what to do when the relative with BD reacts negatively to their attempts to help (Miklowitz, 2011:97, 281).

It became clear that caregivers need some time away from the caring situation and that they long for stability in their lives.

CAMH (2000:38) refers to the caregiver's fear about what the future holds. The **uncertainty** of the future thus may create anxiety with relatives (Miklowitz, 2011:283). Caregivers may also be concerned about the future because bipolar illness is a largely **genetic disorder** and might affect the couple's children. The **unpredictable** nature of this illness can be a huge obstacle to making plans. Uncertainty about the future may cause a caregiver to feel as if they are in **limbo** (unable to move forward owing to the fear that the illness will spring up) (Last, 2009:3, 31). On occasion, it can prove impossible to **plan ahead** of time due to the varying episodes of the sufferer's mood (Aiken, 2010:121).

6.3.1.2 Theme 1.2: Needs of patients

The following theme consists of three sub-themes.

- **Need to be accepted**

The following quote reflects this sub-theme.

Participant 2: "You know what these people they are just warm people and they also need to be loved and kissed and hugged and they are also pretty damn normal".

- **Need to be trusted**

The quotes below support this sub-theme.

Participant 2: "Everything was ok and we stuck next to her, we did not move for the next three days. She was not allowed to be alone at all and then she told us that look, this and this and that sorry I am feeling a lot better. You can start trusting me now, it is ok".
Participant 3: "Hm, when it comes to my husband being his caregiver is that he likes to be not bothered with, or that is what I think ".

- **Need for friends**

Participant 2: "She didn't realize that there were friends and other people and they talked to her and they say they love her and she actually does make a big difference in their lives and she says, I was not aware of it".
Participant 5: "He would feel that he needs a break from her very often so after work instead of coming home, he will go off and have a drink with his friends because he needs that. He is tired, then she feels lonely because he is running away from her, she doesn't have any friends, so it is just a vicious circle". "She becomes very hostile and argumentative and literally mean when she is manic and as a result of it she doesn't have a lot of friends because **people don't understand** that this person is going to be rude to me sometimes, doesn't have a lot of friends, she is almost socializing isolated".
Participant 8: "He has got no friends. The friends he had all deserted him because of this illness".

Discussion of theme 1.2: Participants were aware that the patients also have needs. It is a sad fact that patients may lose contact with their peer group and become very isolated. Michalak et al. (2006:27-36) conducted a qualitative study in which they asked people with BD what they **need** to have a good quality of life and some of the aspects that were mentioned included routine, independence, **social support** and the need to restore their sense of self-worth and identity.

Discussion of category 1: In summary, the key findings of this category demonstrated that both caregivers and patients have needs that the other often ignores. The needs of the patients were reported through the eyes of the caregivers and it is possible that they were ignorant of some of the patients' needs. Caregivers presented with a strong need for knowledge and skills to be able to handle the patient when he/she is ill and consequently, the need for a psychosocial educational programme. Another strong need that was evident among the caregivers is the need for support.

6.3.2 Category 2: Burden

Two **themes** were identified in this category: **objective** burden (2 sub-themes) and **subjective** burden (6 sub-themes) (**Table 6.7** refers). Living with and loving somebody who has BD is a daunting task (Last, 2009:9). Taylor (2006:12) refers to the fact that the **burden** that a disease causes is estimated by calculating the severity of pain, suffering, disability and deaths attributed to the disorder. In addition to disabilities, bipolar illness ends in **suicide** for many patients. Available data suggest that the caregiver burden is high and largely neglected in BD - it is a matter of increasing clinical concern. Patients living with an "over-burdened" caregiver may have an increased risk of relapse (Ogilvie et al., 2005:25, 29).

Table 6.7: Category 2 - Burden

CATEGORY	THEME	SUB-THEME
Category 2: Burden	Objective	Financial burden Effect on health (physically and mentally)
	Subjective	Stigma Embarrassment Replacement for incapable patient Burnout Unpredictability Effect on the family system

6.3.2.1 Theme 2.1: Objective burden

Hoenig and Hamilton (1966) in Hatfield (1987a:16) applied the concept of “objective burden” to describe the adverse effects on the household of such factors as heavy financial costs, the effect on health, and the intrusion and disruption of the lives of family members. Perlick et al. (2008:484) also used these terms, but referred to objective burdens as increased expenditure of time and money.

The following quotes reflect participants’ objective burden.

- **Financial burden**

This sub-theme is reflected in the quotes below.

Participant 1: “I have got terrible financial problems in the past two to three years. I literally gave all my money and those that I should still get from my pension, I borrowed to her, and there is no way that I am going to get it back. My future plans were actually to retire last year to be with my husband that has already been, he has been retrenched in 1992, but I will not be able to retire now at this moment and be with him. I will have to work at least another five years to get out of all this debt. I never had debt, I never ever had debt, and I always saved and was conservative with my money. If something happens to the money that I have borrowed to my daughter that was invested in a school, then we will lose our house. I have no money left. I am in so much debt everywhere that I have borrowed money from my family, from my husband, and on the house that I will not be able to help her and I don’t know what is going to happen”.
Participant 11: “Ja, especially on the financial side of things is that you get very stressed and because you know there is nothing, and still you have your expenses to deal with”.

- **Effect on health (physically and mentally)**

It was evident from the quotes that caregivers’ physical and mental health is affected by caring for a person diagnosed with BD.

Participant 1: “I suddenly realized I can’t talk without starting to cry. I can’t go to work without crying the whole way to work and come back. When I am on my own, then I realized I need help because I am so totally devastated now after the situation”. “Like it is **depression** because I can just cry for no reason and I can cry my heart out by myself in the car of wherever I go, but it is only because I can’t help it. Sometimes I will say to myself, but you must stop crying. Ok, you must let out some of your feelings, but don’t let it carry on so that you feel totally you are not in control of how I cry, because then I know that must be depression". "I am sure I am depressed because you don't cry 'sommer net' for nothing".

Participant 3: "I am sensitive to people how they feel, how they react so I see that quickly and am also affected by it very quickly, so I tend to be, like my husband when he is down, I become also like very down". "I sometimes tend to go also into a depressed mode and not coping with things". "So I think I have been on my… it is the Prozac, but it is the generic, I think now for 6 or 7 years already. If I don't drink it I know, I know I am not coping. But I just don't, I just get very down and I can't see the positive side of life, but so sometimes that medication is not enough. I sometimes drink just one extra to cope through the day".

Participant 4: "I was depressed and I think these days I am much better now".

Participant 5: "By the time she gets admitted, he is so exhausted because he also has two weeks of no sleep and two weeks of intense emotions. So and then she gets booked off and he doesn't".

Participant 6: "Sometimes you do get **depressed**".

Participant 7: "I think you know what scares me is that now I must also take medication because I am very anxious. I get very stressed and anxious". If he is down, I will also just feel down".

Participant 10 and participant 9: "Ja, my Mother…. She would have attempted to a suicide episode. Did you become depressed? Yes, a lot". (Researcher asked a question).

Participant 11: "*Ek gebruik antidepressante en dan sien ek 'n sielkundige"* (I use anti-depressants and see a psychologist).

Discussion of theme 2.1: BD definitely has a financial impact on the lives of caregivers. The manifestation of **mental illness** in a family member is invariably a **disaster** for the whole family, a disaster in which all are victims of the event and its sequelae. No one and no part of the emotional life of the family is unaffected. The illness touches everyone, affecting attitudes toward self and toward life, producing **symptoms** in other members, altering the family structure, influencing life choices, and more (Terkelsen, 1987a:128).

6.3.2.2 Theme 2.2: Subjective burden

It was clear from the interviews that caregivers experienced a subjective burden on an on-going basis.

- **Stigma**

The following quotes reflect this sub-theme.

Participant 4: "O well I didn't really tell many many people, you know, the close relatives, my mother, my brother ....and very few friends I must say at this stage".

Participant 5: "I remember what it did to me it made me somewhat a nervous person because what I will do is when we are in the house together I will lock all the doors because I did not want her to run in the street, dressed inappropriately or whatever and then I will sit watching TV but with the other ear I am listening for her bedroom or for the front door and if somebody arrives at the front door, somebody rings the doorbell, then I have to run to the door before she does and tell the person to go away for whatever reason so that they don't see my mother, because in those days I thought she was mad, I did not know any better".

Participant 7: "I don't want to get friends over because you don't know how your father is going to be or if you have friends over, you must tell them listen don't mind my dad today or they want to know where is your dad, no he is in the room and he sleeps, no what's wrong, no he is tired and then you would sort of always tell a sort of little white lie" "I think at the end it is also difficult for you because then your family members they don't want to come to you anymore because of this person and it is like, but if my dad had cancer, then you would have come. If he had some kind of other illness, then you would have come, but you were not educated about this, you just assume it is his personality and I think that is also why there is sort of a disruption within the family, is because they think he is a difficult man".

Participant 8: "The community out there cannot understand that this is an illness, this is not the normal behaviour of this person. Because the normal behaviour of this person is a kind, loving person".

Participant 9: "In the beginning you know it was, we were afraid to talk about it because we were in a denial ourselves". "Hmm, now it, we found that it is better to be open and honest about it, to everyone, family, friends, whoever. Because at the end of the day it is everyone that gets affected. So everyone should know exactly when my Father is sick, when he is well, when he is doing different things, so at the end of the day there is no miscommunication from any party. And everyone understands that the patient is definitely not well".

- **Embarrassment**

The following quote is indicative of the embarrassment experienced by the caregiver.

Participant 5: "I followed her into the street and I asked her to come back into the house and she refused. She said no she is not coming back into the house and we literally had a bit of a scuffle in the street, and I remember the neighbours looking out their windows and watching me physically like grabbing my mother and forcing her back into the house and the embarrassment and wondering what did the neighbours think what is going on. So it was a very **stressful time** for me and I also started making excuses for my friends why they can't come to our house because I don't want them to see her like that. So I would now say you can't come to my house for whatever reason but also it was very bad, I couldn't go visit, because somebody had to be home with her. I couldn't leave my mother at home".

- **Replacement for incapable patient**

The quote from the interview below reflects this sub-theme.

Participant 11: "*Ek was hoofsaaklik die versorger en die opvoeder, want pa het in depressive tye in die bed bly lê en hy het hom totaal onttrek en ma moes aangaan, ons moes bly leef, ons moes aangaan. So die kinders het altyd geweet ma is daar, maar pa was afwesig*". I was the carer and the educator, because dad stayed in bed when he was depressed and he withdrew himself and mom had to carry on, we had to live, we had to carry on. So the children always knew mom is there, but dad was absent. "*Ja, ek kan eerlik vir jou sê die eerste keer toe hy gediagnoseer is, toe sê hy hy dink dit is die lekkerste siekte om te hê want nou gaan hy doodgewoon 'n bordjie om sy nek hang en sê ek is 'n verkwister niemand kan my aanvat daaroor nie. Dit is so, ek gaan dit in al die koerante laat publiseer, ek gaan koop wat ek wil, ek gaan doen wat ek wil, want ek het hierdie siekte, ek het is nou vrygespreek. So ek het geen verantwoordelikheid nie"*. Yes, I can honestly tell you that the first time when he was diagnosed he said he thinks this is the nicest illness to have, because now he can put a label around his neck and say that he is a squanderer and nobody can challenge him. He said he was going to publish it in the newspapers - he was going to buy what he wants to, do what he wants to, because he has this illness and he is now acquitted - he does not have any responsibility.

- **Burnout**

This sub-theme is reflected in the quotes below.

Participant 2: "You can get tired and you can get tired very quickly if you busy with helping or assisting at home, I think if you are a normal couple it is a little bit easier, I think so. I don't know, because I have not had a normal relationship. This a lot of work".
Participant 3: "In the meantime you are not coping, because you don't look after yourself properly".
Participant 4: "With the father gone it is very tough. I am on my own I must say most of the time". "You know they are also very demanding these kids and there were times that I felt that I couldn't cope with those demands with the job as well and you know other live

challenges as well. So, it was very difficult". "When he was staying with me here, I must say it was really tuff, it was a bit difficult. Because my mind would always be at home what's happening when I am at work". "It is not as easy because I have, especially my last child is a daughter, she is in matric so that it was very difficult for me this year in particular because I also had to give her the support that she needs or needed in order to be able to write her matric. So ja, it is not as easy as ABC". "It is just too much. Then you try to sleep, then you can't sleep because then you are thinking".

Participant 5: "When she first became ill I was about 15 years old. I would be left alone with her". It was a lot for me to carry on my own and I remember at that stage my father, he was in Namibia, so we couldn't even contact him on the phone and I knew she was beyond, and at that stage I was never expose to mental illness".

Participant 7: "I think a lot of times you are **burnt out** because it is like you know he won't' make coffee or he won't help with this, he won't help with that and you must sort of do that and I think what the worse for me was when he is in D (private hospital), I think it is because then you must do the swimming pool, you must do the birds, you must do the garden, it is driving all the way there it is driving all the way back. I mean, and I know the first time he was admitted I had to take him and in a way I blame my mother for that. I think to expect a child to take her father and to drive up and see him in a psychiatric hospital that was a shock. I think if anyone ever must ask me what was the worse day in your life it would have been to take your dad to be submitted [admitted] the first time. That was horrible for me". "I will see my mom and then she will go about my dad did this and he did that and, and I will be like I am the daughter, I don't want to hear that, I still have my life ahead of me to live and I cannot live my life because I am hearing all of these negative things as well".

Participant 8: "I sometimes really think it is more difficult for us as caregivers than for the patient himself". "So I thought when I got married it is about 20 years and then my children would be out of the house. Then me and my husband will be alone and we can enjoy each other. But now it is 33 years later, 35 years later and still I have got this child in my home and it doesn't seem that he will ever go anywhere else".

Participant 10: "I think it was very much more difficult when we were younger because over and above, **the burden** of making sure things were fine. My Mom had to see that we were fine as well, you know? In a situation where you have to make a choice of moving out, my Mother needed to think, ok, I have 3 little kids with me. So I need to make sure they are fine".

Participant 11: "You just get beyond exhaustion, physically as well as mentally".

- **Unpredictability**

The following quotes from the interviews support the fact that caregivers experience BD patients as very unpredictable.

Participant 6: "If T comes home from school, if she was home before me or I was home before her, we would always ask how is dada, because you don't know. If she picks something up, she will ask, how is dad, but she always asked if she sees him first or I see him first, because we never knew how he is going to be". "And like, you know family they do know how he is they have to handle him with gloves on".

Participant 7: "You cannot just say what you want to say. You must always first think what you want to say because he can get quite angry. You must just be careful what you say because you don't know what his reaction will be towards it." "I remember growing up as well if I do something wrong, I will not go and tell him, because I am scared of what he can say". "*My ma sê altyd jy stap op eiers* "(my mother always say that you walk on eggs).

Participant 8: "We were too worried to leave him at home alone. So we rather took him with and he made the holiday absolutely hell for everybody because he didn't want to go anywhere. He just want to lay there in the caravan all the time and if we wanted to do something or anything, he would complain about it. So it was very, very difficult".

Participant 9: "Yes, and then he tried to burn the place (hospital ward). Ja, the other children don't know about it. I think he was only rebellious".

- **Effect on the family system**

BD not only affects the patient - it affects the whole system, as was made evident by the quotes below.

Participant 1: "If she loses her temper, the whole family gathering is up in flames and it is terrible."

Participant 2: "Our daughter will benefit, her mom, everybody will just benefit if she is let's call it **stable** for a better term. So we will indirectly benefit from her having stability. Absolutely".

Participant 5: "And every night she was waking up at 3 or 4 and putting on the light and doing this, and reading a book and eating things, so I was also sleep deprived. A full week I was waking up at 3 in the morning, so I was also tired and irritable and then on top of that, we are trying to help her and she is busy snapping at me. So you do become very **tired** and my father was saying the same thing that when she is about to be ill, and when she is not sleeping, they sleep in the same bedroom. He gets to the office at 8 and he just wants to sleep on his desk. Because he has been up since 4 with her. So it is very difficult on the

family". "For family living with someone like bipolar, that is **one of the hardest things**. The fact that you can't rely on this person for emotional support, you … the **basic thing** in life is to have someone **to share** joy with, to share sorrow, to share expressions. I mean that is the point of any relationship. Everything else is second, the clothing and the housing. So when you take that away, that really puts a strain on a relationship".

Participant 8: "It is not so much the patient, I think that goes through so much pain, it is the family". "That is very difficult, it is very very difficult for us as a family". "It is actually **heart-breaking** for us as parents". "That is where the tension in the house comes from concerning this child. It has been since he was born. Then I will have a fight with my husband and it is always that **tension** in the house". We nearly separated at one stage. He has quite a few times; my husband just said he is leaving, took his things and went off".

Participant 9: "O, your whole family is gonna be destroyed". "Yes, because, bipolar patients are very difficult you know, they will walk in here and tell you, talk all the good things about everybody and the next minute you become the bad one, completely different. You know, in their eyes, I don't know why it is with them, it is like, their immediate family becomes their enemy". "And it is so sad, every time my husband gets sick, the children wrote their exams". **"**It is a big problem. It wasn't easy to go through a situation. It affects everyone in the house. Everyone gets affected. You know the studying, the concentration, even if just being at home and having the patient. A patient is the one time fine and the next minute the opposite, like two split personalities. And I don't know whether it is normal, but this is how it goes and we have to monitor the medication. It affects everybody in the house; it is difficult, very, very difficult. Yes, it is not an easy situation; I must say it is difficult".

Participant 10: "I think also why it is so difficult to deal with is because of the pressure. On the **family** in the sense that there is lots of fighting, there is lots of arguing, there is a lot of disagreements amongst the people in the family. It also takes a big toll on your life outside this house in terms of work, study. It takes a big toll on that, I mean it is difficult to go to work every day and concentrate and be yourself, knowing that your Dad is ill with bipolar. You know what I am saying?" "They attempt to turn against immediate family". "So yes, I do become very protective all over my Mother and now that my sisters, if they were still staying with us, I would also be protective over them. It is just now, it is myself and my Mom that is staying in this house. So yes, I do become very protective and as I say, this is nonsense….'let's take our things and get out of here'. The normal things that a grown-up man will say".

Discussion of theme 2.2: Stigmatization of individuals diagnosed as having serious mental illnesses has been globally observed, and the family members who help care for them report feeling stigmatized as a result of their association with the loved one (Gonzalez et al., 2007:41). The participants also reported a level of stigmatization in their lives and even within their own families and communities. When a parent is mentally ill it may have a profound effect on a child's life.

Identifying and modifying burdensome aspects might reduce the level of burden and their negative effects on both caregivers and patients' outcomes. Most studies evaluate acutely ill patients, whereas the most relevant problems may be related to **sub-threshold symptoms** and long-term outcome. In a study undertaken, the highest levels of distress were reported regarding the patient's behaviour; the most distressing behaviours were hyperactivity, irritability, sadness and withdrawal (Reinares et al., 2006:157). As may be understood from the participants' responses, the behaviour emanating from the illness was also very difficult for them.

No one welcomes a **diagnosis** of BD. It is a serious illness that has the potential to devastate individuals and wreak havoc in families (Last, 2009:9). The level of disruption caused in the families of the participants became evident during the interviews where phrases were used such as: "gathering us up in flames", "**heart breaking** for us as parents", "your whole family is gonna be destroyed".

Discussion of category 2: In summary, the key findings of category 2 were that the participants did communicate that they are exposed to different burdens. The patient's illness is a very demanding situation and it is clear that their (the caretaker's) health may be severely affected. Society also does not always understand mental illness and this contributes to the burden that caregivers must bear. As with many chronic illnesses, BD **afflicts** one but **affects** many in the family. It is important that all those affected receive the help, support, and encouragement they need (Mondimore, 2006:258).

6.3.3 Category 3: Relationships

In this category 4 **themes** were identified, type of relationship (4 sub-themes), characteristics of the relationship (3 sub-themes), communication and family-staff relationships (**Table 6.8** refers). It has been the researcher's experience that **relationships** are the backbone of strength when one is confronted with a difficult situation or crisis (such as living with BD). In this regard, relationships are seriously affected and it is necessary that the caregiver, patient and professionals act in such a way as to minimize the effect preventatively. The researcher will draw attention to different relevant relationships that became evident.

Table 6.8: Category 3 - Relationships

CATEGORY	THEMES	SUB - THEMES
Category 3: Relationships	**Type**	Parent - child (parent is caregiver) Child - parent (child is caregiver) Marital Family
	Characteristics	Co-dependency and dependency Boundaries
	Communication	
	Family-Healthcare	

6.3.3.1 Theme 3.1: Type

The following sub-themes reflect the types of relationships.

- **Parent - child (parent is caregiver)**

Of the participants, three are parents of children who have been diagnosed with BD. The following quotes offer a glimpse into their relationships.

Participant 1 (abusive relationship): “I always thought have you totally lost your mind, because how can you ever talk to anybody like that. I am your mother. She once told me that *ja* but you are the closest to me so I have to do it to you. And I just said how do you come out at that and she just said no that is how it works in life”. “Even if I am really a total wreck and totally emotional and heart sore she will just say ja just stop crying, I don’t want to see you like that and she will leave the house in anger. “She said, I don’t want to have contact with you, **I don’t want to see you again**, I don’t want to speak to you again, because you are treating me like a child and I am not going to stand for that anymore”. “She is my daughter and my only child, she was also my friend, oh she is not anymore, she does not want to have to do anything with me because she is just telling me I am bad, I am bad”. “So it is like a vendetta against me and why me?”

Participant 4: “He is not that bad, but it is up to him (expectation of mother to son). Sometimes I thought of going away and work abroad and then I realize but hey, I have got him. When the father died, he was in hospital. He did not even know that the father was in hospital. He just kept on saying why is dad not coming to pay me a visit?”

Participant 8: “He (Father) is very hard to tolerate especially concerning this illness. But what I have observed is, where his mother is concerned, he was tolerant, but where his brothers and my son is concerned, he is absolutely intolerant. He said it is just laziness, they must just go on and do something and stop it”. “I don’t know if my husband did not want this child to be there, if that is the feeling I got from it. Because even the day he was born, my husband was upset with me and everything that this child did wrong, he was always upset with me. Always, he is always **blaming me** for everything this child is doing wrong". "It is **very, very difficult** for him" (father). "He (father) tolerates quite a lot but sometimes he just snaps and if he snaps he doesn't really count his words, he says very, very hurtful things. To me it is all the time like he is breaking down especially with this son of mine. He is always breaking him down and something out of the past, things that happened and always throwing it at him. It is not forgive and forget that part. It is always coming up, saying the same things over and over and over". "I can be as kind and loving as I want, but he doesn't want my love and acceptance, he wants his father's love and acceptance".

- **Child - parent (child is caregiver)**

The child-parent relationship emerged as a prominent sub-theme of relationships; various relationships were described as indicated in the quotes below: mother-daughter, father-daughter and father-son.

Mother - daughter

Participant 5: "I was really hurt. I was hurt because I phoned her to share something that I was joyful about and she completely went off on a tangent and upset me about something else. It is so pointless, I was so upset. I actually had to just calm myself down and accept that, ag there is no point".

Father - daughter

Participant 7: "I think you are scared and, jy begin twyfel in jouself' (doubt yourself) and the other day we also had a talk and I think maybe go off a bit of the topic, but I mean my father would never say yes I am proud of you or you look pretty and I think for a daughter that worthless information is important, so I think growing up with my father, it was difficult and I mean even for myself today in **relationships** it is difficult because you will always sort of think you are not worthy enough, but I think when you will get those reactions, you know you become scared. I think it is that thing again that your words hurt the most". "I think you always, you know I always thought I am not worthy enough. I think that is why I will always pressure myself just to hear form my father that I am good enough, but it doesn't happen. It is lately now that he will say o you look nice, or you look cute and I just think, sjoe, I wish I could have heard that when I was at school. Now he will sort of start to say things like that and I think you know you will know that he loves you and you know he is proud, but you want to hear those words actually".

Participant 11: "*My dogter het op 'n stadium gesê my pa is nie vir my 'n pa nie".* There was a stage when my daughter said my father is not a father to me.

Father - son

Participant 10: "We have been, are facing this for almost 10 years now. So in a different way said, if you look at 10 years ago, I was 13 years old and now am 23. Hmm, so you are looking at two perspectives from a child's point of view and also from a grown-up's point of view. I would see him doing something and I would ask him 'why are you doing that'? And I will very clearly point out what you are doing is very wrong and it is very irrational. It looks very stupid, and then he realise it, that I think that what he is doing is very wrong, and he also, it will register what he is doing. 'Ok, what I am doing is not rational' and then he would become rebellious. He would **shout at me** or tell me why are you worried that I am doing it? Then I walk away, so we would clash a lot".

- **Marital relationship**

The sub-theme of marital relationships was obvious because five participants were married to patients. The following quotes from the interviews with participants are provided to support this sub-theme.

Participant 2: "So what she would really want, I wouldn't really want. But we compromise between the two of us. It is just put a little bit of more effort in that is the way I think. You have to, you are there and that is why you have been put together, it is the road you are walking together".

Participant 3: "Then it is the physical side, he will then just not touch me at all which is, that is my love language. I mean, I prefer that to anything else when it comes to even just holding my hand is precious to me, but then there is no physical contact, there is no, you know for me that is a bad thing because then I feel more withdrawn. I don't deal well with **rejections**. It is like we have got a king size bed, you lay that side and I lay that side. It is like this big space in between. I don't have a husband per se, that is how it feels at times. I don't have that support of a husband, I don't know where I stand with him. Because then I am totally "deurmekaar" (confused). So I don't have something I can count on, to say that person or that thing is going to be like a rock. Just after my child's incident, I really wanted to leave, because I really was mad at him".

Participant 5: "My father is now the only person she socializes with. On top of that she is mean and rude to him as well. So there is **tension** in their relationship. He has told me in private before that one of our family friends once told him years back that he is still young, he can still find himself another women, why is he still with this crazy woman. Why does he put up with this? So it is a sacrifice for him to be with her, he decided that I married her and I am going to stick with you. But when she becomes manic, she throws that back in his face. **She was really mean**, she says things like ja I am just a crazy woman why don't you divorce me and you want to divorce me anyway, you know, and maybe I must beat you or maybe I must just make your like miserable. I will file for a divorce, she says things like that and then once she is no longer manic, I don't know if she doesn't remember that she said that or if to protect herself to pretend that she doesn't remember that she said those things. Then she is fine and now he is sitting with all that hurt and that resentment".

Participant 9: "Yes and I know of a lot of people and families that got separated, that got divorced".

Participant 11: "We have come to a point now in our marriage that we are very very good friends, a very happy couple. '*So ja, ek is baie dankbaar daarvoor'* I am very thankful for that. "*Ja, veral ek was verskeie kere op die punt van 'n egskeiding. Waar ek vir myself gesê het ek gaan nie toelaat dat ek emosioneel verder afgebreek word nie. Dit is veral in die high tye wat hy ongelooflik aggressief was, ongelooflik krities, niks is reg nie, niks is goed nie, jy as mens is nooit goed genoeg nie*". Yes, I did many times contemplate divorce. I told myself I am not going to allow that I am broken down any further. It is especially in the high times that he became very aggressive, very critical, nothing is right, you as a person are never good enough.*"Ek is doodeerlik, ek het baie keer gesê ek wens hy skiet homself dat dit oor en verby is dan weet ons dit is klaar, dit is afgehandel*". I am very honest, I said many times I wish he would shoot himself so that it is over and done with, then we shall know that it is finished.

- **Family relationships**

Problematic family relationships constituted a prominent sub-theme for some of the participants. This is important, because if these relationships are affected, the level of support given will also be affected.

Participant 1: "She has got a grandmother and grandfather and my mother and father that loves her so much and I can see that they are also going through a terrible time, the same with the brothers and sisters. They are so concerned about her, but she has no contact with them. She doesn't even answer calls from them". "I know now that her divorce was because of being ill". "The friend that she is staying for three years now also wanted to move out, he couldn't take her moods anymore and I begged him to please stay." "He is very hard, he is somebody like he will also swear back at her and just tells her, get off my back, or I will take my things and I will go and then she and the little boy stay at home all by themselves. What is going on then there if she is totally devastating and he is just always telling her I am going to leave you? And she is like always telling him you should not leave me; she is so scared of him leaving her".

Participant 2: "She spends quite a lot of time with her mom and then obviously after hours with her dad and so on".

Participant 8: "He (father) is blaming him (patient) for everything that is going wrong in our life. Everything. It doesn't matter if it is financial or him being there too much, but I do understand my husband. I do understand that he cannot really take it anymore. He is getting old now, he just doesn't have the energy". "He has set him an ultimatum if he doesn't get his life right then he is just going to chuck him out". "It really feels like my husband hates him".

Participant 11: "*Hy aanvaar ander mense as sy familie en sê dit is nou my familie, julle is nie meer my familie nie, julle is nie meer my gesin nie"*. He accepts other people as his family and he says that is now his family. You are no longer my family.

Discussion of theme 3.1: Parents may provide decades of extended caregiving for their adult son or daughter with BD during those times when debilitating symptoms are obstacles to social and occupational functioning and independent living. Parents of adults with serious mental illness are at an increased **risk** for poorer health and mental health and marital disruption (Aschbrenner, Greenberg & Seltzer, 2009:298, 303). According to Aiken (2010:83, 88, 90), **children** can feel an overwhelming sense of **responsibility**, even **blaming themselves** for the parent's disorder. Sometimes the child might experience feelings of anger, sadness, fear, insecurity, worry, confusion, loneliness, pain, stress, helplessness and frustration. The researcher definitely identified this tendency - participants reported their fears and insecurity growing up with a mentally ill parent. These did continue, even in adulthood. The child might also develop a **psychiatric condition** (Aiken, 2010:107). This was also the case in the current research.

As may be seen in the quotes extracted from the interviews, the issue of the marital relationship and how it is affected, emerged strongly. The marriage where a partner is bipolar may come under severe pressure and often ends in **divorce** (or one partner may even commit suicide). Relationships, even for couples who do not have to contend with mental health problems, are demanding and bipolar illness increases that level of difficulty, particularly when it is untreated or inadequately treated (Last, 2009:277). Withdrawing from one's spouse or partner and considering divorce may seem the only way out of an intolerable situation (CAMH, 2000:33). The researcher did encounter this trend during the interviews.

It is difficult to conduct a loving and intimate relationship when one partner is a caretaker and the other is a patient. It is important that they should talk **about what both want** and need from the relationship (Fast & Preston, 2004:175, 12). This is an important aspect when providing marital counselling where one (or both) partner has/have BD. Partners will have to compromise. The sensitive area of sexuality was mentioned during the interviews. Issues may include the patient's **low libido** when depressed, **hyper sexuality** when manic and a general lack of affection towards the partner when too ill to have a fulfilling and intimate relationship, as well as the side effects of medications (Fast & Preston, 2004:163, 174). It is clear from the quotes provided that the BD marriage takes hard work and demands sacrifices.

People who do not have BD have no idea how terrible it is to live with, while those with the illness have no idea how terrible it can be to live with someone who has BD (Fast & Preston, 2004: 112, 113). Antai-Otong (2003:243) agrees, stating that the marked changes in mood, personality, thinking and behaviour that are part of the disorder often have significant effects on **interpersonal** relationships across the life span. It may therefore influence not just the nuclear family, but also the extended family.

6.3.3.2 Theme 3.2: Characteristics

Two sub-themes emerged under this theme that described the essence of the particular relationships.

- **Dependency and co-dependency**

The researcher has found that dependency and co-dependency is a common theme when observing the patient - caregiver relationship. It is important to establish if it is present and whether it is in the interest of the different parties and if it possibly hampers recovery. This phenomenon became evident in the quotes of a few participants.

Participant 4: "You know when they go and stay at their own places, then they realize that life is not that easy, so I am thinking ok maybe he needs a place to go and stay there. I want to say that flat it is yours; you are going to stay there".

Participant 7: "I think if something might happen to my dad, my mom will be able to survive and go on. I mean she is the one, paying the electricity, paying the accounts, paying everything, running the household, getting his medication, making his appointments so for her it will just be he is not there in my life anymore, but **for him** it will be she is not there anymore and all that responsibility".

Participant 9: "Whenever he goes into this phase, we got financial problems. So if we have to move, he will survive but not the way, his lifestyle will change. He would not be able to manage".

- **Respect for boundaries, autonomy and independence (caregiver and patient)**

This sub-theme is closely linked to the above mentioned sub-theme. Some people become **overinvolved in their role as caregivers** and feel the need to step in and **take over**, even when their loved one is relatively well. One might expect that if a relative were very protective, involved and self-sacrificing in response to a loved one's BD, the result would be good rates of adherence to prescribed medication regimes and better health outcomes. On the contrary, however, people whose caregivers tend to be **overinvolved** have poorer adherence to medication and are more likely to develop further episodes of illness (Berk et al*.,* 2008:271-272). The following quotes support this sub-theme.

Participant 1: "She said to me I don't want to see or hear anything from you and that is the last because you are treating me as a child and I am sick of that and you are trying to rule my life and I cannot take it anymore". "Why don't she want to love me anymore and I know I have no control. You can't tell somebody you must love your mother". "You always will do the best for your child and always give too much, but the fault that I did made in my life is that I gave her **too much** where I should have withhold a little bit just for the sake of not giving her everything I could afford and could do and do with her". "You have to keep a little bit of distance. Don't ask that. I am trying to do it, I am really doing it at the end". "I am her mother, I am the closest to her. Why does she deliberately cut me out, **she know I can't be without her** and **she cannot be without me**". "He just said, you must leave her alone because she is so angry towards you for everything you did and that is not fair. She should not treat you like that and I said to him, what else can I do? She is my daughter, we were always together, we did things, so I cannot not do it".

Participant 2: "I have got four hours in a week that is my time. That I spend with myself, alone with just or two or three friends and I will take my four hours in a week. I do not care what happens, and she knows it. She knows that is what I will do. On a Sunday morning I get on my motor cycle and I come home at 11h00. That is the way it works, finish and klaar. That is my four hours a week. The rest of the week is hers with the daughter. It is an unspoken rule that we have got, maybe not a rule but it is just an unspoken agreement. Don't tell me you want to do something else on a Sunday morning because it ain't gonna happen. She understands that. It is my four or five hours and she is happy with it and the rest of the time I am there. I don't go out with mates on booze cruises in the week or on a Friday or on a Saturday we have a big fat braai at the chommies house and we drink. I don't do that. I am at home every evening". "That is the way she is. I am not going to try and change it because I am happy with the way she feels".

Participant 3: "You tend to carry those people's sadness or their load as well on top of your own, so you feel responsible for their happiness". "I tend to take on the responsibility to make him happy, to make sure he is always happy **which is not my job**".

Participant 4: "It is only up to a person who says now I am deciding I am stopping (using substances), but me I can scream, I can cry, I can pray, I can do whatever, I can talk". "I want you to know something my son, I love you very much, but if you are going to do that to yourself, and you think that you are coming back here, it is not going to work because it is either on the streets or there and there you know you get good food, we pay a lot of money there a month".

Participant 7: "I recently moved out of home because I realized that it would be the best thing for me so that I can start to have my own life because I will worry a lot about my mom how she will be coping". "If he is down, I will also just feel down". "I think it is better staying on my own now". "But I think sometimes she (wife) must also learn a bit to let go a bit".

Participant 8: "We do stuff, that we will normally say no if he lands in trouble next time, leave him there, but when you get to the point where he is in trouble, we always go and bail him out. We always go and fetch him. We always try and fix all his, all this stuff that he makes wrong, we try and fix. Sometimes I think we are doing **too much, but we don't know better**."

Participant 10: "It is difficult because I wouldn't really leave because maybe in my state of mind when I am extremely angry. There was a time when I packed my bags and I now leave. There were times, look I can't deal with it. And then I will tell my Mother, no, she should come with me. And she would have because I don't know why. I wouldn't go because in the back of my mind I think, ok, is my Mother gonna be ok? Is she gonna be fine? No, I wouldn't".

Participant 11: "*Gaan ek sê ek het 'n snypunt en beskerm ek myself en daarop is ek baie gesteld* ". I have a limit and I am adamant about it.

Discussion of theme 3.2: Co-dependency refers to both the excessive neediness of the caregiver to be needed and the insatiable neediness of the care recipient, as well as the **unproductive role** these two forces can play in a relationship (Last, 2009:139). In the case of Participant 7, his wife does everything for him and he would struggle to survive without her. It might also be that this role results in a payoff for the caregiver who wants to feel needed. The patient can therefore become dependent on the caregiver, but also vice versa.

Some of the participants were aware of the importance of the patient‘s and their own boundaries, but others seemed to overstep these and were then surprised by the reaction that they created. With one of the participants, the mother wanted to regain control over her daughter’s life, but the daughter seemed to become very frustrated in the process. Boundaries between the patient and caregiver were not clear. The caregiver also stepped in by handling problems at the patient’s work and grandchild’s school. The caregivers’ and patients’ boundaries must be respected (Last, 2009:124). **Parents** tend to be more emotionally overinvolved than **spouses** while emotional over-involvement among mothers is the best predictor of patient relapse (Perlick et al., 2004:1034). This was also the researcher’s finding.

6.3.3.3 Theme 3.3: Communication

All relationships are built on communication (verbal and non-verbal) and it is inevitable that either good or bad communication will influence any relationship. The following quotes will show that the participants value this aspect.

Participant 2: “I am sharing to her the way I feel. It makes a difference - the way we say something or ask something, it makes a big difference. This has helped a lot just with the little bit of extra **communication** or telling what we are feeling inside, that actually makes a big difference because those people can keep everything bottled up, they can, I know, she has done it for years and after four months it will explodes”.

Participant 3: “My husband, he also doesn’t want to connect or tell about bad things”. ”Me and my child would say ok, we will check how the **mood** is when he comes in, before we will discuss anything and that is limiting. Because you don’t always want to check what a person’s mood is. You also got something that you would like to discuss and it is for you important and then you see ok the mood is not good and then you have to subside and say just keep quiet. Let’s just handle this on our own way if we can, if possible and then when he later find out we handled it, then he is mad because we did not tell him. But at that stage we didn’t feel comfortable to tell him because you know it is going to end either in a quiet war that is going to happen in the household or he is going to be so mad it is going to be like a screaming and shouting. So what no”. “It is like spilled milk, you can get it back into the bottle. And it is like your words, if it is negative words you can’t go and fetched them and put them back. It has already done the damage in somebody’s heart. I use to **never say anything**, but I think at this stage, I am nearly there. I am nearly **communicating** my feelings. So it will take bit of time you know. It is also a thing that I need to learn. To tell them when I am not happy. To tell them when everything is not good inside me. That I need some help, you know”. “Then you have to really read that mood very carefully before you go on. It is like walking on eggs. So you need to determine if the egg is going to hold you or not". "I don't feel like I can just say, you know when you are mad you just tell him you are mad. You are always thinking **what consequences there are** going to be with this word order and then you tend to just leave it, just keep quiet and go on".

"With bipolar I understand that there is high time and then I know everything is sort of nicely in line and then the physical contact and everything. He **talks** and he is very good and then there is the low time. Then there is no physical contact there is no really good conversation of good, like emotional quality between us and uplifting and everything and then it goes and you think ok, I must know, when is this high time when is this nice time, I must go keep all these things in my heart and keep it safe and remember there is going to be a bad time coming now soon. So that is limiting for me in a lot of ways because you never know how long this good time is going to keep and you never can say ok, it is ok to be like that".

Participant 5: "He **can't talk to her** because he feels that when he talks to her, often times she will be hypomanic and the few times that he tried to reach out to her, she said it is not my problem that you don't know how to manage your finances. I don't want to know those particulars; you spent your money on other women that is why you don't have money. That is why you are in debt, things like that. So now **he doesn't talk to her anymore**, he either talks to me or like I am saying he is with his friends. So that has affected their marriage and then when she is not ill, she will say to me that she is lonely because my father never talks to her".

"He is always out and even when he is at home, he will watch TV, he will watch the news, and he will go to sleep. So it is **really a bad relationship**."

"She would also like to be treated like a woman and be asked how is work, how is this how is that, do you need help in the kitchen and not feel that the only time you **communicate** with me is when you worry about my medicine."

Participant 7: "I think he is also not a very affective person. He will not just hug you and I think being one of eight children. What can burn one out is that you always try to, I **will try to talk to him, but he doesn't respond**. It is hard to talk and you don't get any response and then it is like why are you bothering …, it is not going to help him".

Participant 9: "Every time he goes into this manic phases, then we become his enemy. You know he never wants to speak to us, to have anything to do with us".

Participant 10: "I think that is where the misunderstanding between the patient and the family comes into play with where the patient does irrational things that we see and he, according to the patient, he is never wrong. They are right and they never want to hear anything else from anybody else".

Discussion of theme 3.3: Stable relationships, as emphasized, are based on good communication. BD often takes away a person's ability to reason, so that the person with the illness often says and does things that are not part of their real behaviour or an honest reflection of their true and deeper feelings (Fast & Preston, 2004:115). When a person is psychotic, communication becomes even more of a challenge (Miklowitz, 2011:283, 287). Mondimore (2006:252) emphasizes the importance of honest and open communication. Some participants struggled to be open in their communication because they were afraid of the reaction. They found it difficult either just to be quiet or never say what they really mean. Nonverbal communication also played a role, for example the lack of affection, the ignoring of each other or the aggressive reactions.

6.3.3.4 Theme 3.4: Family-Healthcare

An area that is sometimes ignored is the family-healthcare relationship. Caregivers feel that staff are in a controlling position and can indeed add to an already difficult situation, as the quotes will indicate.

Participant 1: (Psychologist to mother) "She can see I am an *"inmengerige" ma*. Ja, I am an interfering type of mother. I am trying to rule my daughter ".

Participant 5: "We never had any family sessions whatsoever, I am only now aware that there is such thing as a multi disciplinary team. We were never exposed to a **social worker**, never exposed to a psychologist and I guess in private because the **doctors are all about time and making money**. Even the psychiatrist himself never made himself available to speak to the family. He would speak to my mother for the same time that he is in consultation. Even now this year when she needed to be admitted, my father said phone the psychiatrist and he said I think she is about to lose it, she is not sleeping, etc., etc., can I please come and speak to you and the psychiatrist said sorry I am fully booked for the next two months and two months is too long".

Participant 8: "I just think that sometimes we need more support from, you know as I felt through this whole thing, it felt like I was telling some people what I want to happen, but as I say **you get nowhere**. I speak to the doctor and then he just goes ahead with what he thinks is right. It is as if he is **not really concerned** about what we feel. That is the feeling I got. In the end, I thought they discharged him too quickly".

Discussion of theme 3.4: From the quotes it became clear that families are often very frustrated that they cannot reach team members, are not considered and also are not given answers. Not being understood by professionals can exacerbate the distress of families and unnecessarily increase their burden. Too often, professionals view the family as

unidentified patients needing treatment rather than as **adult learners** attempting to deal with a major mental illness (McElroy, 1987:227, 228).

Discussion of category 3: It can be exhausting to live with a hypomanic person and frustrating to deal with a seriously depressed person day after day. The changes and unpredictability of the moods of someone with BD intrude into home life and can be the source of severe stress in relationships, straining them to breaking point (Mondimore, 2006:256, 257).

The key findings of category 3 were that relationships across a wide spectrum are very important in the world of the BD patient and caregiver. They may be dynamic, supportive, but may be very painful. Once relationships break down it can have a negative ripple effect causing other problems within the family system.

6.3.4 Category 4: Illness

Six themes and numerous sub-themes were identified in this category (**Table 9** refers).

Table 6.9: Category 4 - Illness

CATEGORY	THEMES	SUB-THEMES
Category 4 Illness	**Symptoms of being ill**	Depression Mania/hypomania Irritability and aggression Instability Changes in personality when becoming ill Psychosis Lack of functioning Continuousness pattern
	Triggers	
	Diagnosis	
	Hospitalization	Admission Discharge
	Treatment	
	Belief system of patient and family members	

6.3.4.1 Theme 4.1: Symptoms of being ill (Chapter 2, where symptoms of BD were discussed, refers)

The researcher identified 8 sub-themes here.

- **Depression**

Depression is a very real part of BD; the following quotes refer to participants mentioning it.

Participant 3: "Because in the beginning he would just sleep the whole day, he would not do a thing".

Participant 6: "He start coming home a bit earlier, he would tell his boss he has got something on. He will take leave and that and then you know the problems are starting now, he doesn't want to go to work".

Participant 7: "If he is depressed he will just leave. He will just get home after work and he will shower and he will stay in bed. He will not even eat. And then he has this CD of I think it is Gert van Wyk, 'Beautiful in Beaufort Wes'. And if he puts that on then you know he is so deep in that black hole".

Participant 8: "If I don't give him food, he does not eat and further he just lies in his bedroom doing nothing. If I want him to do something, I literately have to force him to do it". "Because he just doesn't want to get out of bed". "Most of the times he doesn't go with us because he doesn't want to go out. He just stays at home".

- **Mania/hypomania**

The other side of depression is mania or hypomania which is necessary for a diagnosis of BD I or II. The quotes below support this sub-theme.

Participant 1: "I know that they really **can't work with money**, but I mean this is really astronomical. She does have no sense of working with money and I did not really recognize that when she was younger, definitely not".

Participant 3: "Every time we would come there, you don't know what is going on. He is like everywhere. Because the man I married was a quiet man, always happy and ok, and now he is like **forever talking, hyper active**". "Then he just **didn't sleep**. For two weeks, I think he slept one hour and he kept me awake all the time. Because he will come into the room and say I thought about this, and his brain would never switch off. And then at one stage I had to call my brother-in-law to come and assist, because I didn't know how to handle the situation, because he didn't want to listen to any reason at that stage".

Participant 5: "She was **fully manic**, she didn't sleep, she kept me awake through the night, she would come into my room and get into bed with me and **talk fast** continuously through the night by the morning none of us had slept and then she would insist that we must get up and go do shopping and we must do this and we must do that". "We had to physically restrain her in the street to drag her back into my Aunt's house, telling her that 'we can't let you go, we don't have cell phones, we are in another country. Cause if we get lost, what is going to happen? All the while she is busy shouting 'you people are abusing me'. So it was that bad on our last day in England. Eventually we made it to South Africa in one piece". "So she has never had hyper-sexuality, she has had **excessive spending**. There was one year when she decided that she was going to start a soap making business and she was going **to make millions for her family**. And she bought with **her last savings**, this huge soap making machine for like R25, 000.00. That was all her savings, that machine **has never been used** to this day, it sits in the outside room at home".

Participant 8: "The normal behaviour of this person is a kind, loving person. But when he goes on the rampage or when he goes into this **manic** state, then he is this **arrogant aggressive** person. They do things that they normally won't do. He is not a drinker, he is not a smoker, and he is not a person that would go out to a club or anything like that, but when he gets into the manic stage, that is where he goes. He is **always in trouble**, then he will be in trouble with the Police and it is just normally for doing stupid things. It is not really criminal, but it is disruptive".

Participant 9: "Oh yes that is the biggest problem. When he goes into this phase, money becomes an issue. He insisted that he wanted like in R 30,000.00. And how he insisted and how he devoted to pay them and eventually I had to pay it". "Yes, then he goes into this manic phase, even ballistic buying stuff".

Participant 10: **"**Money becomes an issue. As a result of this phase, they can do, spend irrationally and **thinking they have a lot of money**, and they don't. There was an instance where he set us back financially. And within a week that money was blowing". "He spent a lot, unwisely obviously, and also they attempt to have **a lot of energy**, and they will do all sort of things. They will get up at 5:00 in the morning and go to bed at 12:00 at night". "Their **minds are racing all the time**. You even, you are able to sense it, their minds are racing the way they will be, maybe busy with one thing and then they will go and come back and then they wouldn't remember what they are busy with and then they go and work with something else".

Participant 11: "*Jy weet nooit, hy het byvoorbeeld 'n slaghuis begin, alles op skuld hy het vyf voertuie in 'n jaar se tyd gekoop. Twee groot vragmotors. Hy het sy boerdery totaal gelos, hy het net, kom ons sê regtig mal gegaan*".You never know. He did for instance start a butchery, on debt; he bought five vehicles in one year – two big lorries. He left farming, let's say, he went 'mad'.

- **Irritability and aggression**

BD patients also become irritable and aggressive, as is evident from the following quotes.

Participant 1: “Relapse was quite like a bomb explosion”; “screaming and swearing”; “my daughter was so rude to them”; “she can’t cope and she made such a bad mishap of her life and that is for her bad”; “she was furious”.

Participant 2: “She will say you know I am extremely irritable. I will just say ok cool, I understand”.

Participant 5: “With my mom when she is manic, she is very **irritable** and by nature she is a very sweet soft person, but she can actually be very cold and very mean and very harsh, the **things that she can say to you when she is manic**, so if you don’t remind yourself that this is not who she is, she is unwell, you can yourself getting very hurt by the things that she says”.

Participant 7: “But for me you know it is more like throwing things and our garage door has this bump in it where he did kick it once and you know tearing up of papers and stuff like that. That is how he will get”.

Participant 8: “Like this last time, he even threatened to kill me. Ja, and I know it is just in his manic state, I understand it, but it must come from somewhere. Why does he say things like that if he doesn’t mean it? Because I know he doesn’t mean it. I had the strength to just ignore what he says”.

- **Instability**

Instability in mood and behaviour are often a major challenge for caregivers; the quotes offered below support this sub-theme.

Participant 1: “She can’t do anger management for herself at all. For the littlest thing you always have to be aware to **walk sort of on eggs**, all the time, because I am so scared to say the wrong thing too, even to have the wrong body language or to have the wrong voice tone that she would pick it up and then she explodes again. That is why this three years she seldom visited me, or us here at home, but every time she did, it was with screaming and shouting and how bad we are and the vibe of this house and she left”. “But they must know about the problem because she has **physically attacked** the grandchild’s rugby coach.

Participant 3: “That is why I said you never know, you have to watch the mood when he comes in”.

Participant 6: “Within seconds he can be another person”.

Participant 7: "I rather take it like this than take it up and down and up and down and up and down, so I think I am satisfied with him just being on one level. I think that is easier to cope with".
Participant 8: "The problem does not go away because with him in a few days he will be or **in jail** or **in hospital** and actually it makes the problem worse".

- **Changes in personality when becoming ill**

When a patient starts relapsing, he/she does change in their personality and participants also experienced this, as indicated in the following quotes.

Participant 8: "Somehow he cannot realize that his whole personality changes, it is this arrogant person and nobody can be with him for more than 10 minutes without being angry with him".
Participant 11: "*So ja, dit word 'n mens of soos ek dit beleef het wat jy glad nie, jy is met een mens getroud en hier is daai mens in dieselfde liggaam, maar dit is heeltemal 'n ander gees, 'n heeltemal ander siel. Ek gaan sover gaan om vir jou te sê dit voel of hy sy eie god word".* You are married to one person, but here is this person in the same body, but with a different spirit. It is as if he becomes his own God.

- **Psychosis**

BD patients may present with psychosis, and participants did report this in the interviews.

Possible delusion
Participant 2: "Something, I don't know if it is important that might help, she believes that she is one of twins and that the other one either died when they were born or was stolen in the hospital. She believes it and you can't change her mind".

Hallucinations/psychosis
Participant 4: "He just started doing funny things and then we took him back to the doctor. They said no he is psychotic we would have to go back to the psychiatric hospital".
Participant 5: "There are times that she did not go to work for two months, she would wear the same dress for three days and she would sit in the garden. I remember her sitting on the grass and cutting the grass with a small tiny nail scissors, cutting the grass with that, I mean really. And talking to herself and smiling with herself, really hallucinating but she would be at home throughout this time because there was no facility where she could be hospitalized for two months". "I can remember the day as if it was yesterday, I can picture her running down the corridor of the Mediclinic and screaming and she was seeing

butterflies, she said she was running and chasing butterflies and the male nurses, that sight of her fighting with the nurses and them having to forcefully inject sedatives into her, I can remember it like it was yesterday".

Participant 6: "Hmm, but as I say the depression was there often and then also this, what do they call it, you feel stuff walking on you" "No not voices, no, no". "Then he has got the torch on the bed looking at the *goggas* that are coming through the ceiling and then I must also sleep in his bed with all these *goggas* and then he will take the bed down and he puts towels on the cushion and he sleeps at the end side of the bed because it is *goggas*"."That was why he was in D (private hospital) now last, and then he rubs on his forehead and he goes like that, because the *gogga i*s on him".

- **Lack of functioning**

When a person has been ill for a period of time, his/her functioning starts to deteriorate and it is also compromised, as indicated by the following quotes.

Participant 6: "I tell him the braai area would be nice if we extend it. When you get home then he started working there and he has got 5 jobs at a time, nothing gets finished. He will order steel and corrugated iron and then, it lies there, five months, he doesn't start working. He starts to paint, don't worry I will finish, but it never gets there".

Participant 8: "In his case, he also never finishes a project. He would start off going full steam and halfway through he would lose interest completely and then he just go down". "He has never thought like a normal person. Even when he was small. He never had, he always had these big dreams, he is going to be this rich man and have **his own island**, but he doesn't realize that nothing comes to you, it is not just handed to you, you have to work to get there and I think he is **just a broken sole**".

- **Continuousness pattern**

If a caregiver is able to begin to see a pattern that is positive, they are then able to start to put measures in place to prevent the illness from becoming out of control. This sub-theme is substantiated by the following quotes.

Participant 7: "It is like a never ending **cycle**".

Participant 8: "The **pattern** is repeating itself again, because he was on this high admitted and now he is sent home, and now he is in the low again. So it is actually for me it is the same as the previous times. It repeats itself, everything repeats itself. It is when I think he is starting to get better; I start to get anxious because I know this, now trouble is coming again". "It is also like a pattern. When he, he spends all his money when he is on a high, everything then he has nothing and then he comes back and we start him off again and his dad gets soft again and he says come we are going on again. It goes quite ok for a while". "I really wish I could just cut October out of the calendar. I don't' know why but October always October it is a problem. Then the trouble is worse. My husband is intolerant he doesn't know what to do it is like he is intolerant with everything. I don't know if it is something with his moods or what, but every year it is October. I means it makes the tension just much worse".

Participant 10: "So it is very, it plays a very difficult role in our lives because it is not, we don't live a constant life throughout, so we have a 3 year stage where he is fine and then after the 1 year, he goes into an episode when he gets sick and then we are not the normal happy family and then after another year, we are happy let's say for 2 years, and then he gets sick again. So it brings in a lot of chance in our lives".

Discussion of sub-theme 4.1: It is clear that the caregivers could identify when different **episodes** were occurring. The researcher found that participants mentioned **different symptoms** of the illness during the interviews. Some were able to report on a definite **pattern** that they had observed over time; some could distinguish between the well and the ill personality and the lack of functioning. When patients experience a manic episode, the family are frequently unable to control the situation. Their on-going energy, overspending and aggressive behaviour becomes unbearable to live with. Every episode of the illness is a stressful life event for all the family members and, even when the illness is stabilized, the fear of new relapses is often present (Reinares et al., 2006:157-158).

The experience of aggression and psychosis were the aspects that were especially difficult to handle. It must never be forgotten that BD can occasionally precipitate truly **dangerous** behaviour (Mondimore, 2006:255). The reasons to acquaint caregivers with the symptoms of BD include that when learning about the illness, they are enabled to identify the prodromal symptoms of new episodes and are able to intervene more aggressively (Miklowitz, 2010c:111).

6.3.4.2 Theme 4.2: Triggers

Caregivers have, over time, learned to identify triggers of the illness and could report on it as follows:

Participant 2: "But I think she was depressed and which leads up to it because of her not being able to grasp what she was supposed to do, and so on and so on and it just escalated and escalated and because she lost her job, it must have been heavy on her". "That (miscarriage) and another incident when she was 16. Her boyfriend at that time killed somebody else, so that also made a big impression on, I think her personality and the way she thinks and the way she feels. Because he killed a person to, what is the word I am looking for, ‘*om haar te beskerm’* (to protect her)”.

Participant 3: “It can be a small thing that is going to rock the boat which is going to make it stop immediately and then you feel, ok what happened now. I don’t know. Sort of everything was quite ok until a few seconds ago and then ok. It is not like he wakes up the morning like that. It could be a small incident you know that would just **trigger** something”. “He was like on duty 24 hours at that stage”.

Participant 5: “So for four weeks, she did not work, she took one month leave, two weeks travelled to Zimbabwe. Then straight from that two weeks later we flew to England, and then it is a twelve hour flight even if you sleep, you are not sleeping properly and then we got to England and we were visiting all different family and friends so when we came back, that was immediately when she had to be admitted”.

Participant 7: “We know what can **trigger** him and we tried to **prevent that trigger**, because we want to make life easier for us”.

Participant 8: “Ja, sometimes but this last time, there was **really nothing** that could have triggered it. Everything was going absolutely well”.

Participant 10: “I think that, I personally think that it is nothing specifically that triggered it, well one thing that could really is not taking his medication”.

Discussion of theme 4.2: Participants were able to recognize that triggers are warning signs that an episode of illness may follow. In some cases, patients still became ill without triggers. In CAMH’s Information Guide (2000:11), it is stated that too much stress or difficult family relationships do not cause BD. However, these factors may “trigger” an episode in someone who already has the illness.

6.3.4.3 Theme 4.3: Diagnosis

It became clear from the interviews that participants experience difficulty until the correct diagnosis has been made, as indicated in the quotes below:

Participant 3: “So then the doctor said that it is bipolar, he had a very bad high, so they calmed him down and then they diagnosed, and said yes, he has got bipolar”.

Participant 4: “Is the diagnosis the exact correct one? Because remember you see this doctor then the next time it is another doctor, and the next time it is another doctor, so follow ups were a bit difficult”. “And it is not like I say that those people don’t know what they are doing, but as a concerned **mother**, you sometimes ask yourself, if something is not working, then you start asking but is this thing maybe, something else". "As a mother you will have those questions that you will ask yourself I am not the psychiatrist so I cannot say much about that, but as a person who is concerned, you do sometimes you know ask yourself and worry".

Participant 11: "*Ek dink omdat die siekte aanvanklik nie reg gediagnoseer was nie het daar 'n geweldige lang tyd verloop wat baie beter tye kon wees met hulp as jy weet*" I think because the illness was not diagnosed correctly in the beginning a long time passed that could have been better with help if you know. "The first diagnosis was a Reverent and he said he was obsessive compulsive and that is it. There was no medication, no referring to someone else, nothing and then after years, years and years he go to a psychiatrist and it well, the psychiatrist said that he is just a very selfish person he will have to deal with that and then after a very manic period when he spends probably all of our money then diagnosis was made that he is bipolar and then the treatment started and I would say the best deal of twelve years was lost".

Discussion of theme 4.3: It has been the researcher's experience that a diagnosis gives relief to caregivers, because there is something definite that they can study and they can empower themselves. They can start to accept it. They then know why the patient is behaving in a certain way and that it is not their fault. It can take years for the right diagnosis to be made and it is usually a very difficult road for the caregivers (and the patient). Miklowitz (2010c:31) states that the differential diagnosis of BD is very difficult to make. The boundaries between bipolar and other disorders have been debated for years - it is still unclear where this disorder ends and other disorders begin. The diagnosis is often of great concern to patients and family members.

6.3.4.4 Theme 4.4: Hospitalization

- **Admission**

The quotes below from the interviewed participants support this sub-theme.

Participant 2: "She got extremely irritated, she does not like hospitals, *Pa ek wil nou huis toe gaan* (Dad, I want to go home). Me and her dad stayed by her side all the time".

Participant 3: "They got him to be admitted to V Clinic. They first had to calm him down. So they had him on very big doses of seroquel, because he is a big man and that took about a week. That was nerve wrecking".

Participant 4: "Ja it was tough also to take him to the hospital. You can't just take him to (psychiatric state hospital) straight as you know then I had to go to that other hospital, Tshwane, then the queue, sjou it was so frustrating. **That day I will never forget**. The queue and everything and you know they did not really care about us until I stood up and said guys we have been here for many hours and I think I came back home around 1h00 that day".

Participant 5: "Even now this year when she needed to be admitted, my father phone the psychiatrist and he said I think she is about to lose it, she is not sleeping, etc., etc., can I please come and speak to you and the psychiatrist said sorry I am fully booked for the next two months and two months is too long. "I could definitely see that she was ill. I did not know of any mental illnesses, I just know in my mind she was being mad, that is how I could put it and I did not want anyone else to see that. I didn't want her to be taken away. It was very difficult. It was a very very difficult time for me". "So that night **she was admitted**, but even then we have to fight her, to get her into the car and even though we got to the hospital, she ran and I remember her running down the corridor and the male nurses chasing her and she was screaming and she had to be sedated in front of me, her fighting and them injecting her with sedatives and that is how she eventually became admitted and that night one of our family friends slept at home with my brother and I until my father could come back from Namibia".

Participant 7: "The worse for me was when he is in hospital, I think it is because then you must do the swimming pool, you must do the birds, you must do the garden, it is driving all the way there it is driving all the way back. I mean, and I know the first time he was admitted I had to take him and in a way I blame my mother for that I think to expect a child to take her father and to drive up and see him in a psychiatric hospital that was a shock. I think if anyone ever must ask me what was the worse day in your life it would have been to take your dad to be admitted the first time. Filling in those questions, that was very hard and I think that was just the worse day of my life. That was horrible for me".

Participant 8: "We as caregivers need to know how to handle situations like that and especially to have such a person admitted at the hospitals systems is also very difficult".

Participant 10: "That is why he was forcefully taken to (psychiatric state hospital), he went into this manic phase and then apart from that having so much of energy … he was also aggressive, very aggressive. So we were left with no choice to forcefully take him there. It causes a lot of damage and emotional …and I mean the trauma of forcefully taking the patient to W (psychiatric state hospital)…"

- **Discharge**

Participants find it challenging when the patient is placed back in their care, as is indicated by the quotes below.

Participant 4: "I remember especially December last year, at the hospital they said no we are discharging him. I just felt like dying because I wanted to take leave and to rest a little bit and now they are saying but no we can't keep him here and I was like o, what am I going to do and you can't go anywhere by the way".

Participant 5: "She would still be hypomanic or still slightly psychotic, but they sent her home for us to deal with". "She would be at home throughout this time because there was no facility where she could be hospitalized for two months. So it became our problem. They were just admitted for ten days, during this acute psychosis and mania and then discharged to us for the rest of the time". "Because I think it is too expensive in private so she would be admitted for maybe a week, at most ten days but then that is not long enough for her to fully stabilize".

Discussion of theme 4.4: Participants revealed that it is difficult to **admit** a person to a government hospital - the lengthy process can be very stressful for the caregiver. One of the adult children discussed in Aiken (2010:103) states how she felt she betrayed her dad by leaving him in hospital, because every time the family visited him he begged them not to leave him there. A participant also shared how difficult it was for her to take her father to the hospital and to leave him there. Other participants had to request the help of the police and initiate involuntary treatment. Treatment is given to persons against their will if clouded judgement prevents them from making good decisions about their treatment (Mondimore, 2006:253). Given the fact that hospitalization can be a scary proposition it can however, amongst other things, provide a person with a much-needed rest or break from the stresses of day-to-day life (Miklowitz, 2011:207). Participants seemed to feel a sense of relief once a patient is admitted, because then they know that all the responsibility is not placed on them.

Surdat (1998:443) states that for many patients, being **discharged** from hospital is just as stressful as an admission, as one has been in a protective, structured environment. Caregivers did indicate that it is difficult to take the patient back home again. Challenges regarding private hospitalization were mentioned.

6.3.4.5 Theme 4.5: Treatment

The treatment regimen is another unknown factor for caregivers with which they are confronted. The quotes below indicate participants' concerns in this regard.

Participant 4: "So as a parent you start asking yourself as to whether what is **the correct** medication?" "So, I think from my side I am just worried sometimes as to whether he gets the right medication".
Participant 6: "Now it is going much better with him since he is on the right medication and he is with the right psychiatrist and psychologist, he is a different person now". "Then it was this tablet, then that tablet".

Discussion of theme 4.5: Participants ask questions about treatment - especially if they do not see an improvement. They may be expected to monitor treatment at home, but when it is not discussed with them it becomes very difficult. This does demonstrate how important it is to discuss treatment options with the caregiver.

6.3.4.6 Theme 4.6: Belief system of patient and family members

Patients are part of a certain context; therefore the belief system in this context impacts on everybody in the context, as can be seen from the quotes below.

Participant 5: "There have been instances when she **went to church** and we prayed for her and she believed she was healed and she flushed her whole month of supply down the toilet. It has happened, not even once, numerous times".
Participant 8: "Yes, he is denying that it is an illness at all. He says it is the **influence of the devil** that does that. Yes, I think it is like he thinks that my son must have done something at some time in his life to let the bad souls come into his live and control him because the first time that it happened, before he was admitted, my husband sat with him and he phoned one of our pastors".

Discussion of theme 4.6: Caregivers' previous experiences of health services may influence their beliefs about the illness (Ogilvie et al., 2005:25). The **illness beliefs** of the caregiver have been found to strongly relate to the degree of experienced burden: to the extent that the caregiver believes that the patient can influence his or her symptoms but is not making an effort to do this, the higher the degree of this burden (Van der Voort et al., 2007:686). Sometimes caregivers (and the patients) think that God is punishing them by giving them this illness and that if they believe "enough" they will be healed. Alternatively the devil is given the blame for the illness and in the process the patient is also blamed for something beyond his/her control.

Discussion of category 4: The category of illness was a prominent aspect discussed by the caregivers, from which it became clear that the illness has exercised a vast influence on all their lives in the past, is still influential and will also have an influence in the future. They live with the illness on a daily basis and without the necessary knowledge it is even more difficult to manage. Every episode of the illness is a stressful life event for all the family members and, even when the illness is stabilized, the fear of new relapses is often present (Reinares et al., 2006:157-158). BD has been called “a confusing and life-changing” disorder (Aiken, 2010:15).

6.3.5 Category 5: Protective factors

In this category, three themes were identified (**Table 6.10** refers).

Table 6.10: Category 5 - Protective factors

CATEGORY	THEMES	SUB-THEMES
Category 5 Protective factors	**Insight**	
	Concordance with treatment	
	Resources and support	

6.3.5.1 Theme: Insight

The following quotes reflect factors relating to insight (of caregivers and also patients).

Participant 1: “She said there is something wrong, she can’t keep it in and the next day she phoned me and said would you help me mother”.

Participant 5: “She has got insight but it was taking a very long time. That is another thing, the insight takes a long time to build and that is what we need to be aware of. It has been 22 years now. So I think the insight is something that is so difficult for the mind to grasp that this thing is forever”. “It has taken years for us to get to a point where she is compliant on her own”.

Participant 10: “We would find him doing that, whatever he is doing, we will find that it is irrational and unreasonable and then maybe someone else could find him to be ok and normal, but we know that it is not ok and normal. So that’s how we would say, ok, **he is not fine**”. “You are gonna experience all those emotions but in the end after the patient has recovered, **you need to understand** the patient’s **illness**. It is just something you can’t hold on to it until like when the patient is recovered, you can’t hold on to it anymore because **it wasn’t the patient’s real self**”.

Discussion of theme 5.1: The interviews highlighted that not all caregivers/family members have gained insight. They also provided evidence that there are fewer relapses among patients who understand their illness and their treatment (Mondimore, 2006:146).

6.3.5.2 Theme 5.2: Concordance with treatment

Concordance with treatment emerged as an important theme; the quotes below indicate that conflict may arise between the patient and caregiver if there is no concordance in this regard.

Participant 2: "You know what, I forgot to take my pills last night, sorry I forget".

Participant 3: "He drinks a pill in the morning, in the afternoon and one in the evening".

Participant 5: "So as soon as there is a change in her **routine** that is when, I think not purposefully, but she becomes non-compliant". "So as soon as her routine has changed, she loses it". "She says that he doesn't treat her like a wife, he treats her **like a patient**. Because he will every evening try and remind her, have you taken your medicine or if he sees that she is a bit more energetic than normal, then he will pick up that something is wrong and he will say have you taken your medicine and then she will snap and say I am not a crazy woman don't you have anything else to talk to me about. You haven't asked me how was my day at work, you haven't asked me how am I feeling today, all you can do is ask me about my medicine".

Participant 9: "He feels why must he take these tablets. Then he loses it completely and that is when he goes psychotic".

Discussion of theme 5.2: People with BD often discontinue their medication. It is not possible for anyone to *force* a person to take responsibility for his or her treatment. Unless the patient makes the commitment to do so, no amount of love and support or even threats are able to make someone take this step (Mondimore, 2006:257). Estimates vary, but the consensus seems to be that **more than half** of those with BD abandon taking their medications at some point in their lives. Accepting a programme of pharmacotherapy to treat BD is a long-term commitment and thus a very important personal decision (Miklowitz, 2011:135, 138). Findings indicate that patients whose caregivers were more emotionally **overinvolved** were less compliant with their medication regime (Perlick, et al*.,* 2004:1033). The researcher also found that the caregivers realized that the patients need to take responsibility for their own lives and for their treatment. If approached in the wrong way, some patients would resist taking their medication.

6.3.5.3 Theme 5.3: Resources and support

Participants realized that in the struggle with this illness, they (and the patients) do need support as is indicated in the quotes below.

Participant 2: “She didn’t realize that there is like 20–30 odd people that love her to bits. She didn’t see, just thought that she was completely on her own. She didn’t realize that there was friends and other people and they talked to her and they say they love her and she actually does make a big difference in their lives and she says I was not aware of it The people are talking to you over the phone, they are sending messages and she saw that people are at least caring about her and she thought that no, nobody give a crap about it and we actually do”.
Participant 3: “Like **God** is to us, he is a rock we always can trust on”.
Participant 6: “The **support groups** help a lot because if it wasn’t for them, I don’t think that my husband would have gone to other psychiatrists and psychologists which diagnosed him correctly. Because for 7 years he was diagnosed with major depression”. “So I did not know that there is bipolar 1 and bipolar 2. I didn’t realize that. So you know I would like people with children or husbands if they have got a problem **to come together and talk**. You know, how do they find the person, are they doing what my husband is, ok, you can read the books and all that, but how do they deal with it, what do they do?”
Participant 9: “That is what we do. If there is a problem I phone them immediately and then they come”.

Discussion of theme 5.3: Some participants experienced their religion as a resource while others mentioned the importance of the support group. Utilization of community resources to develop a network of trusted people and to join a support organization is an important aspect (Aiken, 2010:144, 157). It is clear that support from others functions as a buffer and helps to keep the system more stable. It is therefore very important that caregivers should seek support and that they do not isolate themselves. According to the researcher, there were also other important protective factors present amongst the group of participants, such as: **intelligence, good education, coping skills, resilience, balance, stable personalities, financial stability, responsibility and caring**.

Discussion of category 5: Building a social support network is one way to lower the risk of caregiver burnout (Haycock, 2010:193). The importance of protective factors was discussed above and it was evident that insight, concordance to treatment and support contributed towards a better outcome to handle the illness.

6.3.6 Category 6 Risk factors

Some of the factors in this category are the opposite of the protective factors discussed above. Instances would be lack of insight and lack of resources. Six different themes were identified in addition to some sub-themes (**Table 6.11** refers). There are certain factors that pose a risk for both the patient and the caregiver; the aim should be to minimize these factors.

Table 6.11: Category 6 - Risk factors

CATEGORY	THEMES	SUB-THEMES
Category 6 Risk factors	**Lack of caregiver insight**	
	Suicide/Homicide	
	Comorbid conditions	Personality Substance abuse Anxiety Medical problems
	Lack of treatment, resources and support	Police Cultural aspects
	Mental illness in family	
	High expressed emotion	

6.3.5.4 Theme 6.1: Lack of insight by caregiver

It does happen that the caregiver may also lack insight, as revealed by the following quotes.

Participant 5: “My Mom’s mother even to this day struggles with it. She doesn’t understand what is going on with her”.

Participant 8: “He doesn’t even agree with him taking the medication”. “His father doesn’t really believe in medication I don’t really know why because if he has a pain he takes a tablet and he drinks it but he cannot see that this medication can do anything for him”.

Discussion of theme 6.1: For many years psychiatrists and the therapists who work with them in treating patients with BD, have developed a type of intuition that there are fewer relapses among patients who understand their illness and their treatment better, who make an effort to learn to cope better with the stresses and difficulties that everybody faces, and whose family members are also **informed** and supportive. Psychiatrists have also observed that factors such as **life stresses** and difficult relationships at home, seem to precipitate symptoms and to affect the course of the illness (Mondimore, 2006:146).

6.3.5.5 Theme 6.2: Suicide/Homicide

Caregivers reported on the theme of suicide and also the reaction it provoked in them, as is reflected in the quotes below.

Participant 1: “It was the very first time that she would say that she wants to commit suicide but that she will take everybody with”; “She knows that they don’t have any weapon or something that she can use, but one day she will be able to relieve everybody of her and her problems”.

Participant 2: “That brings us back to the incident three weeks ago. A lot has changed in the way we do things.” “Wondering what is going on, what is going on. That is what went through my mind. What is going on? I did not even closely imagine what I found at home would be at home, not even close. I did not expect to find what I got. I found her wedding dress, all her favourite shoes, her favourite makeup all her favourite jewellery all on the couch and a little letter saying please give this to our daughter when she is big and strong and to understand, she broken all our wine glasses, all over the floors, took some medication, basically some strong headache tablets and disprin and she had about 2 litres of wine and I found her on the bed and she has cut all her forearms from here to there, both of them to shreds with a steak knife. I think she was just seriously intoxicated”.

Participant 6: “You know they say they want to do something to their live and then you think do it, do it, and I am beneath all of this nonsense. There were no attempts, but he talked about it”.

Participant 7: “No he would talk a lot, he would say like *hy wens hy kan die goed kry met wat hulle, hulle het die een hond uitgesit en hy het gesê hy wens hy kan die goed kry met wat hulle die hond uitgesit het, dat hy dit ook kan gebruik* (he wanted to get the stuff that was used to euthanize the dog) of and my mom she would talk she just wish she can get something and **kill all three of us** because then we will be rid of all our misery and Researcher: Did that happen often? Not that often, but I think it was two years back or so when she said it, and I will tell her I think you must go and see someone. She says no, I am tired, I am tired of all of this”.

Participant 8: “Yes, I worry about that all the time. He has tried it a few times unsuccessful, but he has said to me Mom I will never do it again after the last time. He said he will never do it again because I know it is not the way to go, but I always worry about it because if somebody wore me down and broke me down like that, I don’t think I will even want to live with it”.

Discussion of theme 6.2: The researcher observed that suicide attempts or ideation were experienced as very disturbing by participants. Chessick et al. (2007:482) report that the suicide attempt of a spouse or family member is an experience that has an enduring effect on the caregiver, even years after the event. Their study also found that caregivers of those with BD who were currently experiencing suicidal ideation or who have made a suicide attempt, report significant health difficulties. There were also participants who threatened to harm family members. One of the risk factors for suicide is present if a person is **isolated** from friends and family members (Miklowitz, 2011:241, 242). Some of the patients in the research study did tend to isolate themselves from the caregivers, either through their unacceptable behaviour or because of their withdrawal.

6.3.5.6 Theme 6.3: Comorbid conditions

A number of patients also had comorbid conditions as indicated in the following quotes.

Participant 1: "She blames me for everything"; terribly lying that I was not used to. I just believed her, everything that she always told me, but I know now that that is not the truth"; "manipulates"; "no empathy"; "My child doesn't tell the truth as well with the psychiatrist or the psychologist, not with anyone of them". "Her friend told me that he came home and then like half a bottle of whiskey or half a bottle of brandy would have disappeared. She was always sleeping and that she took lots of pain tablets. With me as well, when she did visited me then, she always had a headache and always said her back is so sore, she can't live and then I always gave her some tablets, but I did not know that she already had took quite a lot at home".

Participant 3: "What also was worse when T was 30 he had a stroke, his whole personality changed with the stroke".

Participant 4: "It sometimes makes me angry to say if you stop, your life can be ok again, but you continue and you taking us with you. You are destroying the entire family". "Yes, it was there the substance abuse. I wouldn't know really it is marijuana but he said he used other stuff as well. I can't say he is clean". "If he continues smoking this things then it means they will not trust him because it is an issue of trust. They will not trust him to go outside or maybe at the end they will say no we cannot keep this person he is too problematic".

Participant 6: "Ja, they don't understand that. I mean I think this is now more with my husband's **OCD** you know that people will talk to him and then you have to tell him Piet is still talking with you, then he will say I must check why is it so skew there, why is the palisade so skew. I mean if they don't know his condition, they would think he is rude".

Participant 7: "…who is diagnosed with bipolar and OCD".

Discussion of theme 6.3: Some of the patients did have a **substance** problem, others an **anxiety** problem or a medical problem while yet others' **personality** traits made it more difficult for the caregivers to handle them. It has been the researcher's experience that caregivers do not always understand the difference between BD and personality disorders; therefore they believe that all the patient's psychiatric behaviours are due to the BD. The most frequently reported comorbidities reported by people with BD were ADHD, anxiety disorders and alcohol or drug abuse disorders (Miklowitz, 2010c:51). In this study no patients were diagnosed with adult ADHD. She has also found that in the psychiatric hospital in which she works, this diagnosis is seldom made concurrently with (adult) BD.

6.3.5.7 Theme 6.4: Lack of treatment, resources and support

Caregivers are challenged by the inadequate availability of treatment as indicated below.

Participant 4: "What if they say no we cannot keep this person, he is problematic. What am I going to do?" "The thing is if they say come and fetch him now, where will I take him to?" "Ok I know he will never be happy anywhere, because of the manipulative way". "But you see, something again that I wanted to talk to you about is that I have realized one thing, this country doesn't have facilities for such people. He will suffer alone in silence. That is also something that I have realized and I even said to myself, if I can have money I will built something. Because I know what parents are going **through**". **"**So that's what I wanted for him, somewhere where he will be able to live a normal life, not just sleep the whole day". "So I have looked at this type of disease and I said where are the facilities? It is not as easy as ABC".

Participant 5: "I think that is why often a lot of our patients receiving mental care, they are fully crazy they are psychotic because the family does not have any avenue to interview before them and the family can pick it up a few weeks before that, this person is waking up at 3h00 every morning. This person is irritable, this person is shouting at me for no reason, but there is **nothing you can do, you must just sit and wait until they are fully psychotic and fully manic then only** does the healthcare system accommodate them".

- **Police**

Caregivers desperately need police support as is reflected below.

Participant 8: "Especially if the community could understand, like the Police, it has been many a time that the police arrest him, they beat them, they really treat them inhumane and these people have got an illness, they are not criminals. Even though sometimes they do criminal acts, they are not criminals. Even when we went to get him at the B Police Station in this last time, the inspector that there with him, I could see how he gets aggravated with this person and I said to him, listen this person is ill. That is why, just ignore what he says, but they just cannot do that".

- **Cultural aspects**

It should be remembered that mental illness affects all cultures, but sometimes in different ways.

Participant 4: "I think with us blacks it is even more difficult these days because we don't have the support that we used to have in the past. My relatives are very far from here. I am from Limpopo". "The support system that they used to have were your mommy, your granny, your extended family, in the townships there is nothing like that. You must go to work, who is going to be looking after the sick person. So it means you must stop working and then you stop working, who is going to pay for the electricity, who is going to pay for food. So those are just some of the things that I am looking at, I am saying you know what, it is not easy. Bottom line is, it is tough ".

Discussion of theme 6.4: Participants emphasized the serious **lack of** resources - especially affordable rehabilitation centres. It was mentioned that the police need education to understand how to deal with the mentally ill person. In earlier times there was more family support in times of illness. In modern times and especially in urban areas, support for others seems to have diminished. Social and cultural backgrounds may most certainly play a role in the burden of caregiving and caregiver perceptions of this (Van der Voort et al., 2007:685).

6.3.5.8 Theme 6.5: Mental illness in a family

BD is a disease with a genetic component, as these quotes also confirmed.

Participant 1: "The family always complained about the **grandma** that was very depressed most of times"; "the **grandfather** was a very impulsive man"; "her **child** is ADHD diagnosed two years ago": "he was in a terrible state, because he was like hallucinating at night, getting nightmares, could not take the dark, he will not go from one room to another".
Participant 2: "We believe that it is genetic".
Participant 3: "That is how her thoughts (daughter) were at that stage. That was one of the main reasons why she did what she did, but it is all these things coming together and that was the last straw and it was a small straw, but it broke her will to go on". "I sometimes tend to go also into a depressed mode and not coping with things". "Three years ago also she

(teenage daughter) tried to commit suicide with his medication". "Yes, I definitely think she might have, because the way, the signs I see that it can also just be teenagers as well because they also not always stable, because they also still have to find themselves. I will keep my eye open and make sure that when she is older to make sure she goes for tests to see if it is not, that she can get the medication in time".

Participant 6: "His one brother tried to gassed himself, they got him in time, but his short term memory has been affected, his mom actually was that type of person she locked herself in a room and for three days she did not come out and I am sure looking back, I am sure she has got bipolar, she is on antidepressants now. Two of his sisters are on tablets, I am sure it runs in the family"; "She (daughter) also has problems. She went to psychologists and that when she was small. She had problems".

Participant 8: "Yes, it is, on my husband's side, his mother and three of his brothers. It has been an influence on my family since we have been married. Even before I was married to him it started. I had to do with his mother before we were married as well". "And you know when I had children, I just believed my children wouldn't, I didn't think it could be passed on to my children and also we did not realize it until he was much older".

Participant 9: "We are aware bipolar - it seems like some doctor says it pass on from one generation to one generation. But we don't have any family members". "I hope it stops here and don't continue. I don't want for any of my children to have that".

Participant 11: "His uncle has four sons, three of the four is diagnosed with bipolar and then other of his family as well as bipolar. My daughter also diagnosed with bipolar".

Discussion of theme 6.5: More than half of the participants reported that other family members were also diagnosed with a mental illness. In participant 8's case, there is a very strong history of mental illness in the patient's family; his grandmother and three of his uncles have been thus diagnosed. Some participants were worried about the genetic component. BD runs in families and people with BD tend to find mates who themselves have mood disorders (called *assortative mating*) (Miklowitz, 2011:61, 77). It has long been recognized that BD exists in clusters within families and seems to be inherited in some individuals (Mondimore, 2006:198).

6.3.5.9 Theme 6.6: High Expressed Emotion (EE)

BD can cause chaos in families, because they sometimes become very emotional themselves, and as a result every aspect of the situation becomes worse, as indicated by the quotes below.

Participant 5: “We went to visit my aunt earlier this year in June, and my mother was manic in England and one thing with sister being very irritable, very impossible, refusing to do certain things and my aunt, instead of understanding with her training that she had that my mother is actually being unwell, would argue with her and make it worse”. “And the thing is the emotions that living with someone that is bipolar evokes, because at some stage my mother was crying my aunt was crying”.
Participant 8: “Keeping the peace is the most difficult”.
Participant 10: “I hear what is happening and I will fight and then it will be like a three way, so that is basically the things that were a bit challenging for me.”

Discussion of theme 6.6: EE studies focus on the discovery that psychiatric patients who returned to live with families who expressed a high level of criticism and emotional over-involvement, tend to relapse and need more frequent hospitalisation than those families displaying low EE (Lefley, 1987a:30). **Family and interpersonal conflicts** may be **risk factors** in the course of BD (Miklowitz, 2011:96, 97).

Discussion of category 6: The key findings of category 6 were that caregivers and patients are exposed to risk factors. It is clear that if these factors are acknowledged and minimized then the patient’s prognosis improves. Both patients and caregivers would therefore be able to handle the situation more adequately.

6.3.6 Category 7: Emotions of participants and patients

Category seven highlights emotions that participants shared during the interviews. It is evident that their emotional responses cover a broad spectrum (**Table 6.12** refers).

Table 6.12: Category 7 - Emotions of participants and patients

CATEGORY	THEME	SUB-THEME
Category 7 Emotions	**Emotions of participants** Anger/Aggression Apathy Desperation Fear Feeling trapped Frustration Feelings of guilt Hopelessness Hurt	

CATEGORY	THEME	SUB-THEME
	Jealousy Loneliness Overwhelmed Rejection Self-blame Uncertain Worry	
	Emotions of Patients	

6.3.6.1 Theme 7.1: Emotions of participants

Attention is drawn to specific emotions experienced by participants, as evidenced by the quotes below.

Anger/Aggression

Participant 7: "I get sort of angry because I then know that at the end of the day the **financial burden** is going to be on my mom. I mean it is not going to be like R50 000 but I mean say like just a R1 000 and then I would just get angry at him because I know that impulsivity is going to be on her".

Participant 10: "No, no. Hmm, it is different in the sense of 10 years ago, I was very soft and emotional and I wasn't grown up so, 10 years later, as we sit today, it is completely different. You can ask my Mom. There will be times that I get very **aggressive**, I will be angry all the time. And it is just in my nature, because I am a grown-up guy and obviously I am gonna flash what I think is wrong. I have feelings, if I feel something is wrong, I feel it is wrong. Because I am guy and I am gonna stand for it. But 10 years ago it wasn't like that at all. I would be like, I would rather withdraw myself and I wouldn't even speak about it. I maybe tell my Mother 'No that is wrong', but I just wouldn't really act. And this time around I can get very much aggressive. Very much aggressive and there is times where I do feel sorry for my Mother, but there is lots of times I am just angry all the time, and I tell my Mom "No this is nonsense". I tell her she needs to open her eyes, to just listen to me. You know because I am seeing from this point of view where I see all the wrong. And my Mother, I don't know what is it that she can't see. So that just **frustrates** me a lot". "You know my Mother used to get upset with me, she will tell me "no I must have respect, I must just keep quiet, keep calm'. But it is difficult for me to keep quiet and keep calm when I am seeing what is happening. So ja, but I think my Mother would be able to elaborate a bit more on my emotions because she knows how I get also, when I experience, when he goes through a phase like that".

Apathy

Participant 9: “No, I don’t feel anymore.”

Desperation

Participant 8: “*Ja*, because now I as a caregiver cannot make him do anything, so like today, he doesn’t want to come, I cannot make him to come. I cannot make him to take part in further treatment even if he comes to me and said he is not going to drink his tablets anymore; I cannot really do anything about it. I cannot force him to”. “That is why me and my husband we are really at woods end, we want help for this child”.

Fear

Participant 2: “I had the scare of my life, let me tell you. I, when I got home and I picked her up, I told her we need to go to the hospital, dammit”.

Participant 3: “Sometimes you **feel** like about a bipolar or that person’s is like a can of coke that has been shaken, just don’t tick on it, you might just have big explosion on your hand so. Coke makes it very “taai” (sticky). I mean they can see that I am **mad**, but it’s not that frequent, I am always **scared** about what the consequences of that might be, my child tends to see my madness more than my husband would. Then he will not know that I am **furious** at that stage”.

Participant 5: “Even the first time when I became fully aware of the fact that she has a mental illness, he was away on a week long trip to Namibia and I was alone at home with my mother and my brother and that weekend she sent him away for a sleepover at his friends, so it was me and her alone together for the whole weekend. I was scared, I was shocked, initially I was worried for her, ja I was very worried”.

Participant 7: “I am **scared** of what he can say. My ma ‘*sê altyd jy stap op eiers’* (my mother always says that you walk on eggs).

Participant 9: “I think I got a **fear** in me, and I am a very frightening person. The fear will never go away”.

Feeling trapped

Participant 8: “I feel so trapped. I can’t even go and buy bread because he always wants to know where are you going and I can’t go and visit my friends any more, my sisters”.

Frustration

Participant 1: “Totally frustrated and I think *baie moedeloos, want ek sien nie lig nie” (*very hopeless because I do not see light).

Participant 2: “Frustration yes because I feel I don’t have all the means to help her to the best care that she could probably get”. **“**Sometimes I will say what’s wrong, no we do that as people, what is wrong, nothing, that is wrong. Just say what is wrong instead of saying nothing. That is the worse word to respond to somebody if they ask what is wrong or how do you feel about it. That is very very bad".

Participant 5: "I was frustrated and I was fed-up and I was tired".

Participant 7: "Yes like I just want to shake him and say come out of it. Count all the blessings that you have, you have me, you have your wife and I mean you still have all your limbs, I mean".

Feelings of guilt

Participant 1: "I know I have done everything, but I know I have done too much. I think I have done too much for her".

Participant 2: "I don't really feel guilty because I think it is my fault that she is like she is, it is not". "I would buy six beers and take them home and then I feel guilty because I bought something for me and not for her and I, maybe I am just a softy, I don't know".

Participant 3: "I really took this of what my child did on myself I felt really I was the one responsible for what she did, I felt like I wasn't a good enough mother. I really had to fight myself and get help to put it into the right perspective".

Participant 5: "With my father I think there is guilt. Because of, like I told you, that our family believes that he is cheating just before my brother was born, precipitated the illness. So I think he also, cause he knows that she became ill when she found out that he was cheating. So I think he has some guilt issues that he has never spoken to anybody about, that he might have caused her to be ill".

Participant 7: "He doesn't have a clue that I am going to worry and then I feel bad because I am living on my own". You know, yes you sort of has to tie the strings a little bit, but I still have money to do things so I am like maybe I must move back home and support them financially and then it is like a thing but no you have your own life to live, so even with me it is like this tug of war going on". "I remember I was overseas when it happened and I came back in October for my cousins wedding and my grandfather said that he cannot believe that I went away and left my father alone and that felt then that it was my fault that my father was like that and then I felt ashamed because now my mother must suffer alone with it".

Participant 8: "It makes me sometimes think that I lacked in some departments. Maybe I should have forced him to do stuff more, but I don't think it will make a difference. Because if he did not want to do a thing, he just did not want to do a thing. Yes, I do feel sometimes guilty I suppose because sometimes you have to be very harsh on them, but then I was harsh with the other children as well sometimes and nothing happened to them".

Participant 10: "The only **guilt feeling** that I think we did feel was, when we put him in (state psychiatric hospital) after seeing the conditions he was surrounded, we felt a bit sorry, that we took him there. That was the only sort of guilt, but other than that we knew what we were doing. It was for the right course and we knew that we had no choice”.

Hopelessness

Participant 3: ”I will cry, I will cry in the car or I will go to the bathroom at work and just cry my heart out and get it over with and just get it out of my system.

Participant 7: “What can burn one out is that you always try to, I will try to talk to him, but he doesn’t respond. It is hard to talk and you don’t get any response and then it is like why are you bothering”.

Participant 8: “So the hopelessness is of such an extreme extent that I sometimes just give up”. “I cannot help him, it doesn’t matter how hard I try, I cannot help him and it seems to me that he just doesn’t have a future”. “I wonder is there a God because I asked so many times but still it just goes on. Even with his mother, I saw many times how his father prayed about it, and it made no difference. It is just the situation just carried on”. “Yes absolutely hopeless”.

Hurt

Participant 5: “He is very hurt because he sacrificed a lot to be with my mom”.

Jealousy

Participant 7: “I think jealousy is a big thing that also comes because look how I must suffer and look how my mom must suffer and they just have it easy in life. No that is a big thing, the jealousy, for family and your peers.

Loneliness:

Participant 4: “So all in all it is like, sometimes you feel alone”. “Very lonely and very stressful”.

Participant 6: “Yes, I don’t like being alone, but I mean with a person being depressed and that then you know he is there, but you are **still alone**. You know I mean half past five he will go to bed and then I will take his lunch or supper to the bedroom and that and then I stopped doing that. He must get out of bed and come and eat”.

Participant 7: “It is a very lonely thing”.

Participant 8: “I cannot share this with my husband”. “So, I feel like I am always **alone** and I just had to take him to be admitted now. It was me that has to do it”.

Overwhelmed

Participant 2: “I have sometimes felt that I have just to get on my motor cycle and not come back. I have felt like that and I think if there is a lot of people that feel like that to, but I feel like that for two minutes and then I get back and would look into her eyes and my daughter's eyes and then the feeling goes away. So there is it, I am not arguing about it".

Participant 4: "I think I was just tired and from the past two years it was very difficult for me I didn't even think I was going to survive. It was just too much". "Sometimes of course you know you feel like wow it is the end of the world, why me, I cannot do this, but you **have to be strong** as a mother and be there for your child". "Yes, you are right. There were times that I was overwhelmed and you know you don't know what to do. You want to do something but you don't know what it is what you want to do".

Rejection

Participant 1: "Terribly, really, totally rejected". Other phrases used by Participant 1: "Hopeless case"; "Uncertainty"; "Very tense"; "feels alone"; "scared". "I really feel I can't go on like this anymore. I think it is the depressing thing of my daughter that she doesn't want anything to do with me".

Self-blame

Participant 6: "I was stupid. You see, it should have come from my side, you must go and see another psychiatrist, you must got to a psychiatrist, you must see another psychologist and I did not believe it. Because I do everything, you see. I should not have been so stupid. I should have realized 7 years, nothing is happening. If only I have found out about this therapy. I said we must go to a support group. I could have had a much better life. Yes, my daughter could have had a better life. I could have had a better life".

Uncertain

Participant 1: "*Ja*, very uncertain."

Worry

Participant 1: "*Ja*, at this moment I feel really like I am so down and it is just because I don't know how to go on every day, ever knowing I don't know if my daughter will get better".

Participant 2: "All I was worried about was to get her to hospital. I couldn't care about anything else. I would have run somebody over in the street, I couldn't be bothered. All I had to do is to get her to be better".

Participant 4: "I was so worried". "I can't get peace, you worry as a parent. What if he does something bad to himself, because he doesn't like it there?"

Participant 6: "I can't get hold of him and then **I am in a state**, where, he is not answering the phone number and you are wondering if he had done something to himself"; "a lot of stress".

Discussion of theme 7.1: It is clear that caregivers reported a wide range of emotions regarding their interaction with the patients. It has been the researcher's experience that patients frequently focus just on their own emotions and are surprised that the caregiver might also be frustrated or hurt. Reinares et al. (2006:161) report that, regarding adverse effects on others, nearly 70 % of caregivers were distressed by the way the illness (BD) had affected their **emotional health** and their life in general. Family members and friends can experience a **number of conflicting emotions** when someone they love is diagnosed with BD; for example, shock, grief and even shame for having judged the patient for their erratic behaviour (Fast & Preston, 2006:1). It is possible that a caregiver might feel **pressured**, when having to look after the patient (often without support). He or she might even feel trapped ("I feel so responsible for him and yet I'm dying in this relationship. It's all about him. I feel like I am in a jail") (Fast & Preston, 2004:137, 139). CAMH (2000:38) states that caregivers should **acknowledge** and **accept** their own feelings and also the fact that experiencing conflicting emotions when a loved one is diagnosed with BD, is normal. Caregivers should be afforded the opportunity to work through their thought processes and emotional reactions through guidance dialogues (Tranvag & Kristoffersen, 2008:15). **Negative emotions** of family members are often at their peak during the **recovery period**, following an episode (Miklowitz, 2011:281, 282).

6.3.6.2 Theme 7.2: Patients' emotions

Participants provided their view of the emotions that they had observed in the patients and which the patients had reported to them. Although these observations are "through the eyes" of the participants, it is important for caregivers to recognize their emotions.

Participant 2: "She says I feel **down**, I feel **irritable** if she feels good, you can see that then you don't ask, but if you see something is not *lekker,* (nice) you ask her and she will just say she is irritable". "The only thing that will help me is that she does not get angry, that is the only thing. She gets just a little bit too **angry** for me".
Participant 4: "Say but mommy I don't want to be here" (unhappy).
Participant 5: "And with her, she has **guilt issues**, because what she would do is, when we were young and then … after she got very ill, she was fine. She would **over compensate**. My brother and I, we are not a rich family but the little my Mom had, she would always, she didn't really spoil herself a lot. So once she was better, she would buy us clothes, if we wanted to go there, she would buy me that". "My mother, because now she has been manic and now she is bipolar, she loses touch with other people's emotions because she is so caught up in her own world, she didn't realize that my aunt was sad, she said to my aunt why do you care, why was I so important to you".

Participant 6: “He **got cross** very easily, he broke stuff, if the car did not want to start, he would kick it, threw stuff against the wall, when a shirt is not ironed properly he would rip it open with the buttons falling off”. “But previously he got, very **depressed**”; but you always have to be, you watch what you talk. He gets cross very easily. He gets upset, he is upset”; “he gets **rude** just verbally”; “So you can’t predict”.
Participant 7: “I think it will be a lot of words like yes I am useless, or yes I am not good enough, or no one worries or sometimes a lot of self-pity“.

Discussion of theme 7.2: **BD** is an illness of the mood (affect), but one must be careful not to ignore the patient’s emotions. Emotion is a state of arousal that can be experienced as pleasant or unpleasant (*Oxford Concise Medical Dictionary*, 2010:240). Affective disorder is any psychiatric disorder featuring abnormalities of mood or emotions (“affect”) (*Oxford Concise Medical Dictionary*, 2010:15). One also needs to be careful of the other extreme: interpreting *every* strong emotion in a person with a mood disorder, as a symptom. One should recognize the person’s capabilities and potential. Just because a person has a psychiatric illness does not invalidate him/her (Mondimore, 2006:249).

As indicated by the quotes, a patient may also become angry, have guilt feelings and feel “useless”. It is important that this should be interpreted to the caregiver. Patients’ feelings may include **worthlessness**, **guilt, failure, anger, shame, frustration, resentment** and **loss of control** related to having a psychiatric illness (Mondimore, 2006:228, 249, 251, and 252). CAMH (2000:32) mentions that the depressed person may feel very **lonely** and **isolated**. A patient may also be self-pitying (Fast & Preston, 2004:144). Aiken (2010:39) says that there was a time when she felt that she would rather have a terminal illness than bipolar illness, because she would know what to expect of the end result. Other emotions to which Aiken (2010) refers include **fear** and **anger** (76), **jealousy** towards her sister who could offer her daughter stability (125) and **grief** (159) for the life before BD.

Discussion of category 7: The key findings of this category are that both the caregiver and patient experience a variety of emotions when confronted with BD. The importance of recognizing this and processing the emotions cannot be emphasized enough.

6.3.7 Category 8: Participants’ and other family members’ responses to mental illness

In this category, the participants’ and other family members’ responses to mental illness are revealed through examining the different quotes. Each participant is unique; hence it cannot be expected that responses will be the same. Six different responses by the participants were identified (**Table 6.13** refers).

Table 6.13: Category 8 - Participants' and other family members' responses to mental illness

CATEGORY	THEME	SUB-THEME
Category 8 Participants' and other family members' responses to mental illness	**Participants**	Acceptance Adapt Denial "Fed-up" Hiding Suppressing/avoiding feelings
	Other family members	Acceptance and rejection

6.3.7.1 Theme 8.1: Participants' responses

The following quotes reflect participants' responses to mental illness.

Acceptance

Participant 3: "There is always a blessing somewhere I must count. So this is, I must actually just be getting over myself, that is all".

Participant 4: "So that is life, sometimes some things work well."

Participant 7: "I think if you grow up you get used to it and you think that is life, so for me it is like I can't say there, I don't know if I can say that there was a loss because for me that is life. Yes, exactly I did not know better, that is life. You know I did grow up I thought it is normal. I come from school on a Friday and play with your dolls until Sunday, but now if I hear what other people did when they were children, I am like my goodness gracious me, but I did not know that, so yes, like you said there is nothing better, I did not know better".

Adapt

Participant 2: "I just said, ok, it is ok, I will sort it out and I have learned to **adapt** to the way she reacts. Where it might be there that other husbands won't do that, they will pak (pack) their tas (suitcase) and they will be out of the door. So I have learnt to adapt and I wouldn't change for the world. If somebody gives me R20 million tomorrow I would probably not take it to stay with her".

Participant 10: "It is one of two things, it can make you or break you and you need to just be firm on how you handle the situation because if you take this negative effect, it is gonna really bring you down".

Denial

Participant 4: "*Ag sometimes* I just felt like maybe I should just get a job somewhere abroad, just run away. Somewhere I will just sit and not think about all this problems".

Participant 8: "Yes, yes, I have many thoughts about it, but my, it doesn't make sense to run away from your problems. You must deal with it". "I just try and carry on with my work and try to ignore everything around me, but sometimes you just can't carry on like that".

"**Fed-up**"

Participant 6: *"Gatvol"*; ("Fed-up"). "I can live with everything, but the depression is terrible. I can't take that ". "My daughter, that time when his brother was murdered, she said they should rather have murdered him. He get ugly, He did ugly things".

Hiding

Participant 6: "I always say we all walk **with masks on our face**. No at work and that, I mean they think everything is honky donky in your life, other people don't know what is going on in your life. I mean family can't understand but why don't you talk to each other, but they don't know what the consequences are. They don't understand it, this condition".

Participant 7: "Yes, I think you suffer, you seem to be strong from the outside".

Suppressing/avoiding feelings

Participant 4: "You become harsh on the phone and then you switch off the phone at work you are busy, busy and then you would go back in your car and you think of your child".

Discussion of theme 8.1: Some of the participants used defence mechanisms such as denial or the suppressing of their reactions, but others tried to adapt and adjust to the circumstances. Reactions of caregivers in the midst of BD are very **individual**. It may be easy to **rationalize** some BD behaviour. **Denial** is one of the most daunting obstacles to treatment. Denial on the part of family members is especially high during calm periods **between** bipolar episodes. It is then that the last episode may more easily be dismissed as an aberration; something that, although unpleasant, will not happen again (Haycock, 2010:115).

6.3.7.2 Theme 8.2: Extended family members' responses to mental illness

In the midst of a serious mental illness such as BD, there are bound to be responses from other family members as well, as indicated in the quotes below.

Participant 2: "I think myself and my mother in law and my father in law shared it between the three of us because they are great people and if I can't help, they help". "It's almost as if there is a little bit of a silent communication between the three of us, we do understand. And my mom will always, o she had a bad day or if the wife was a little bit irritable or so on she will tell me".

Participant 4: "Ag not really and I don't want to **burden** my children with this part, they are still young and I think they need their lives. They know the other one is sick".

Participant 5: "So the family really needs to **understand** that because of lack of understanding, you end up all fighting with each other which does not help".

Participant 7: "I remember the one night my dad was in (private psychiatric hospital) and we went to watch Buddy Holly and we actually booked the tickets because he wanted to go and see it, so he couldn't and we stood there and we were sort of talking and I just started to burst out of tears and the whole story of the live of my dad came out and my aunt said, but I never knew it was like that". "Even with family members, you know they will always sort of say that "*julle maak hom toe in watte"* (you overprotect him) and it is like, but we know we know what can trigger him and we tried to prevent **that trigger**, because we want to make life easier for us." "I think it is difficult, I think you can try and try, but if you are in that big black whole, you cannot do anything".

Participant 8: "It is only me and my husband that still cares for this child. His sister doesn't even want to speak to him. The one brother had tolerated but they really, he is pushed away all the time". "My **daughter**, she is very intolerant. She is very much like her father. She has got her father's temperament as well. She is very intolerant towards him. He embarrassed her".

Participant 10: "Ja, I know they are very supportive and understanding (sons in law of patient). They are also very well aware of the symptoms and effects of this illness, so they are very supportive in a sense that they support my sisters and obviously ourselves as well and whenever there is a situation, if there is a need for them to be here, then they will be here. Ja, so they do understand".

Discussion of theme 8.2: Other family members displayed a variety of responses. It was clear that some of them accept the patient, while others reject him or her. In the case of participant 10, the extended family was supportive. In her report, Cara Aiken's **sister** (2010:132) comments that although she knows it sounds awful, she always feels the need to distance herself when Cara is ill. She adds she never knows what to say to her and she cannot listen to the same symptoms over and over again. She wishes she could do something that would cure her of her mental illness, but she cannot. All she can do is be there for her and try to ease the burden.

Discussion of category 8: In this category it was clear that participants and extended family members have certain **responses** in relation to the patient's mental illness. Participants reported that they would typically first deny, hide or suppress their reaction, also reacting in a "fed-up" manner, before coming to a place of acceptance of, and adapting to, the situation. From this it may be understood that it is clearly a process. Other family members were more at a distance and showed less intense reactions (as reported by the participants). The problem of lack of understanding from the extended family and their embarrassment were reported. In some instances, the extended family were supportive.

6.3.8 Category 9: Roles and qualities of a caregiver and roles of the patient

Different roles that caregivers and patients play were identified in this category by analysing the quotes. Qualities of caregivers also came to the fore (**Table 6.14** refers).

Table 6.14: Category 9 - Roles and qualities of a caregiver and roles of the patient

CATEGORY	THEME	SUB - THEME
Roles and qualities of a caregiver and roles of the patient	**Roles of caregiver**	Supporter Wife Mother Child having caregiver role Mediator Protector Peacemaker Leader Financial provider Survivor Enabler Helper to patient and others
	Qualities of a caregiver	
	Roles of patient	Parent Patient Husband Father Mother Breadwinner

6.3.8.1 Theme 9.1: Roles of caregiver

- **Specific roles**

By analysing the quotes, twelve caregiver roles were identified.

Supporter

Participant 1: "So don't worry about that, because I know your child needs it".

Participant 2: "I would not be happy to leave her alone with someone and I am not saying that and staying there because of our daughter, I am staying there because I want to be there, because of us as a family. I don't want to find a new family. I am very happy with what we got". "We carrying on boosting her that it is going to be good and you are going to enjoy it". "Ja I don't want the wife just go on her own, because I am there to support her that is why I go with her".

Participant 3: "When he comes and he wants to talk that I am available to talk and yes that is what I feel my **role** is and if he, because he tends to forget things very quickly, to be always very helpful with that". "I am really a very good supporter, I would like to always help somebody as good as possible. It is just giving him the calm environment that he needs".

Participant 7: "If I know he is down, then I will just stay at home with my mom. I don't want her to be alone. I think sometimes for me and everyone is always why did you not move out earlier. I am like, who is going to be there to support my mom? Who is just going to be there to help her, because I mean it was always my dad did not want to go and do that, because I think he knew I am there to do it with her and I think now he sort of is being stretched to also go and do those, do the activities with her and stuff like that. So I don't know I always say you feel like a, like a, *soos 'n kruk"* (like a crutch).

Wife of patient

Participant 3: "He is like always at work. I feel that it limits our marriage in that way because then we can't like have that special time once a week which is just our time which we can built on our relationship. Because if he comes home 09h00 at night I am tired. "So then there is really no time to really hear what was his day like and how can I assist or support or anything and then, or maybe talk to him and say ok my day was crappy and I would like just to load it off my chest".

Participant 6: "I am actually like the strong person. If I wasn't like this, what would have happened? If I was like my husband. What would have happened with our family life?"; "**because I am use to doing everything**".

Mother

Participant 1: "It does not matter how bad you telling me I am, I am still your mother. Unfortunately I will always love you, it will stay the same. I will never stop loving you"; "It makes it very difficult for me because I will, ja you know you will never let your child just stay in the dumps or without a roof over her head"; "she is my daughter".

Participant 4: "And ja, that is me. I am a mother. My role I think is there of **supporter** and **mother** and **the motivator**". "We as parents we did our best, we gave them all the good values, the wonderful values that would make them become good citizens but as I said as a parent you can do up to this level beyond other levels it is very difficult".

Participant 8: "It is still my child, I brought him into this world and I still love him". "Just a normal mother taking care of this child that has a problem". "This son of mine".

Participant 9: "So that is why as a **Mother** you wanted to keep the family together as well. And that is what I said, I said to them 'we must put everything aside, forget about the past and come back. Pick up the pieces and just move on".

Child having caregiver role

Participant 5: "I will go to school in the morning and leave her at home knowing that she is unwell and come home from school and look after her in the afternoon"."So it wasn't that continuing I had the **burden** of assuming the mother's role, but when she was ill, that burden was there".

Participant 7: "Yes I think I see myself as a caregiver because I will also ask him did he take his medicine or sometimes I must go and get his medicine".

Mediator

Participant 1: "I don't want to have trouble".

Participant 6: "My daughter she picks up very easily something is not, there is something wrong with her dad. Then she wants to know, you know now that she has moved out since November last year, I tried to hide it from her, because it upsets her. You must keep a front, there is nothing wrong".

Participant 7: "And I think it is sort of like also to sort of knowing my mom she will say something and then I will sort of "tree in" (intervene) and give her an eye so that she can know she must not say that". "I am in the middle".

Participant 8: "Yes I am always in the middle". "I have learnt just to keep quiet because the moment I say something in defence of anything, then I am the bad guy and I will hear him that I am always on these people's side".

Participant 9: "Definitely, it feels like everything is left upon me, doing things and thinking for yourself, ja everything. And then also the biggest problem is you're caught between the children and your husband. Now, your children feel that he is wrong and if you say no, you, give him a chance. Maybe tomorrow he will be better, things like that. But they don't, still get worst and worst. And then you are stuck in a situation you don't know how to get out of it".

Protector

Participant 2: "We will definitely have to ask, we check, we understand, it is our responsibility whether we like it or not, it is ours, we have got it and we shouldn't worry about it".

Participant 5: "So I would now say you can't come to my house for whatever reason but also it was very bad, I couldn't go visit, because somebody had to be home with her. I couldn't leave my mother at home". "I believed that if anyone found out that my mother was behaving the way she was, they would take her straight to this hospital and lock her up. So for that reason I did not tell anyone, I tried to deal with it on my own". "I had to always be on guard".

Participant 6: "I should have told her about his got his good parts as well. I mean he really do anything for us, he tries his utmost best, so other people always just see the bad side, the bad stuff he is doing".

Participant 7: "Even like we censor certain reading stuff".

Participant 8: "I tried to stop him, I tried to tell him you are making a mistake again because he said to me previously mom if I do it again try to convince me that I am doing the wrong thing. But he just doesn't listen to anybody so I tried and then the worry comes back because now I know he has to take meds and I know he is not going to and I have no control over it. It is like I still want to have control over it, I don't want the problem, but I still want control over, I still want my child with me". "I would always try to **protect** this child. I don't know if it is right or wrong, but I am always protecting this child in one way or another and when I just say something to protect him, then my husband gets angry".

Participant 10: "If we leave him, and not support my Father, I personally think that everything will just fall apart. Everything will just completely fall apart".

Peacemaker

Participant 1: "I will rather keep quiet, with not arguing with her, but be a peacemaker then to say listen I have also got rights to be your mother or anything like that, I am not that type of person".

Participant 3: "I don't want to have any confrontation of any sort it is like even in my house, and I am very loving".

Participant 7: "You will always sort of looking and watching out and you know try to do the right thing and I think I a way also with, '*ek probeer konflik vermy*' (I try to avoid conflict) I will rather say no it was my mistake. I don’t like conflict at all. I will rather take the blame, *nee konflik vermy ek so ver as moontlik*” (Conflict I try to avoid as far as possible).

Leader

Participant 3: “You have to be the strong one and sometimes it just gets too much to be the strong one all the time”.

Participant 11: “*Ek dink binne ‘n huwelik met ‘n bipolêre persoon is dit, rolle het omgedraai. Ek het die versorger geword en moet die sterk een wees en moet die leiding neem en die besluite neem en binne gesinsverband definitief ook, binne familie, ja as ‘n nie net man-vrou nie, maar man, vrou en kinders”* I think in the marriage with a bipolar person roles are reversed. I became the carer and must be the strong one and must take the lead and make decisions - also within the family, not only as husband and wife.

Financial provider

Participant 1: “I am looking after them financially. I am doing all their medical aid, I am doing the grandchild’s school funds, I am really doing everything. Because if I don’t do it, my daughter is on the street. Because if the friend leaves her, he told her, he can’t afford to pay that house all by himself”.

Participant 2: “I carry that part of the stress in the household because I bring in 90 % of our income. So it is a big fat piece of sleeper wood on my shoulder”.

Participant 3: “So when he got out of this, he did not have a work at that stage but I was working at the company that I am working now”.

Participant 11: “Ja, they are doing the farming (sons of patient), they took over the farming *as ‘n geheel, ek is aan die finansiële kant, so ek gee die finansiële advies en ek gee die morele en geestelike ondersteuning”*.(I give the financial advice and moral and spiritual support). “*Waar dit kom by die bestuur van ons boerdery byvoorbeeld wat ‘n besigheid is, val die verantwoordelikheid terug op my”* (Concerning the management of the farm it is my responsibility).

Survivor

Participant 3: “We need to, we don’t make the time, we actually are just going day by day and just o God, thank God I got through this day, without losing my temper, without rocking the boat too much or whatever. So you sort of need to get that little bit step better and say ok, what, how did I managed through the day, what can I help other people with, you know in that sense”.

Participant 4: “I must say, it was very hard. Sometimes I ask myself how I survived that period. It was a test and a half of my life. I have never been tested like that”.

Participant 8: “But that is a life I chose and I live with it and I make the best of it”.

Enabler
Participant 4: “I want him to go back to school. I want him to have a normal life and that is what I am working towards right now and I won’t stop. I will keep on trying”.

Participant 6: “He won’t survive. He can’t do anything for himself. He phones me about everything, he can’t make his own decisions, I must decide. Hmm, he is actually difficult to satisfy, I mean I get his tablets, I must make sure he drinks his tablets, he won’t’ go to the chemist to get the medicine. He tell tonight is his last tablet he is drinking. **He is 100 % dependent on me**”.

Helper to patient
Participant 1: “I immediately took leave and I paid because she didn’t, she lied to me and she didn’t have a medical aid yet and still, so I had to pay cash to get her into a hospital and the longest I could keep her there was ten days. I took leave to look after her ten year old boy. I just felt, I feel still responsible for her wellbeing, for her health and for everything, because it is my child and I will always do that. “I want to help her; I want to help her only if she can be happy and feeling that life is worthwhile for her”.

Helper to others
Participant 8: “If I can help anybody else to cope with this situation there is nobody out there that knows what it is to live in this situation”.

Discussion of theme 9.1: The variety of roles played by caregivers is illustrated in the above quotes. When a person initially married, it is possible that neither had any illness and this relationship was entered into as a partnership, but as the one partner became ill, the other one ended up in the **caretaker-type** role (Last, 2009:267). The caregiving role is very demanding, frequently distressing, and harmful to health and quality of life (Reinares et al., 2006:158).

One of the challenges for the caregiver of the person being diagnosed with BD is being part of his/her loved one’s “**treatment team**” - the group of individuals who share the common goal of promoting the patient’s mental health (Last, 2009:127; Fast & Preston, 2004:1, 2). None of the participants mentioned that they saw themselves in this role, indicating that they are not always invited to become part of the team. Mondimore (2006:236) refers to the fact that an astute friend or family member who knows how to communicate observations in a caring, non-provocative way, upon noticing sustained changes in mood, is one of the best **supports** a patient can have. Caregivers should be made aware that they are in a good position to fulfil this role.

The role of the family includes **support**, understanding and encouragement of the person who is ill (Mondimore, 2006:248, 252). CAMH (2000:39) warns that the caregiver should try to do things **with** their relative rather than **for** him or her. Last (2009:267) agrees, saying it will be important not to extend the level of assistance beyond what is necessary. It did seem that some of the participants were doing too much for the patients.

The caretaker role does not have to be permanent. In fact, it needs to end at some point. This is especially true when the caretaker is the partner. The goal is to learn to leave the caretaking role while still being an important part of the patient's treatment plan. Once the patient and his/her partner create a treatment plan and learn how to manage BD, the partner will **not** have to play the caretaker role anymore. He/she can revert to being a partner, a friend and a lover again, once the illness is properly managed. The partner that was once the caretaker might have a difficult time adjusting to the fact that the ill partner now has strength, a self, and a life. The relationship will change when the patient starts to get well. Some relationships do better when one partner is ill - the roles are clearly defined and there is a caretaking system in place that is familiar and safe. When the ill partner gets better, everything changes. There will be new roles to play. Joyous recovery can be short-lived when people are **stuck** in their old roles (Fast & Preston, 2004:181, 186, 200).

6.3.8.2 Theme 9.2: Qualities of a caregiver

Participants were asked what qualities they see as necessary for a caregiver.

Participant 4: "**Understanding** and then of course understanding the disease". "And the treatment and *ja* you know, and also to be assertive to question certain things. In terms of your child's treatment, in terms of the sickness, you know". "I have done my own research, I have talked to the psychologists, I talked to social workers, medical doctors, friends, and I am still continuing to doing that. You know just to beef up my knowledge and that".
Participant 5: "You have to be **patient**, very, very patient and you have to be someone who can **separate** your own emotions from the situation, not to be able to look at the situation objectively and you have to understand that this is an illness and it's not worthwhile for making, get angry, and **you have to forgive**. Because that person will upset you, that child will take your money and spent it, that child will smash your car or you know, there is going to be instances that this person really lets you down and you have to forgive".
Participant 6: "Have patience. Yes, it just makes you stronger".
Participant 7: "*Deursettingsvermoë,* (**perseverance**) I think when I start something, I will complete it and I always say I don't know if it is a strength or a weakness, but I will also give 110 %".

Participant 9: “But like I say, it is a very difficult situation and it takes a lot of **courage** to deal with that”. “Oh, lot of **patience** with him, it is number 1 in this world with patients because they always tell you they always tell me I am a sucker for punishment. “I don’t know when it is gonna run out but I have a lot of patience and I think I can deal with the situation better now”.

Participant 10: “In terms of personality, characteristics, I would say one very important thing is, if you let all of these things … can make you feel negative, can make you feel sort of give-up and then you are gonna lose, so you need to have a lot of **patience**. You must be very assertive if you sit back and you accept everything what the patient’s says, it come over you for the rest of your life. So you need to be asserted, you need to stand your ground. At the same time, you also need to be **caring**, because if you are assertive and you are uncaring it makes you seem like a very bad person. So you need to be caring towards the family as well, you need to be supportive towards your family”.

Discussion of theme 9.2: A number of participants noted that it is important to be patient and caring, but also to be assertive and set boundaries. This showed that the participants possessed insight into the caring situation.

6.3.8.3 Theme 9.3: Roles of patient

- **Specific roles**

In analysing the quotes, six caregiver roles were identified.

Role as Parent

Participant 1: “I heard that the mother is screaming on him almost the whole day, she can’t get at the end of screaming and shouting at him, only when her friend is with her, he stops her doing that”.

Participant 2: “When she got home, obviously she had bandages on and I said to her that mom has got eina and she said it twice and she has not referred to it again”.

Participant 5: “Now that I look back, I realize that it was her over compensating for putting a strain on us. For the times when she was hospitalized”.

Role as Patient

Participant 3: “He looks after himself when it comes to his medication, I don’t have to remind him to take his medication. So he is a very good patient when it comes to that”. “We got luckily past that part when it was very bad, when it was just self focused and everything. So when it comes to this he really has become much better”. “But at least that’s for me a light in the tunnel, because he didn't do that previously but now he sees when his actions is gonna be not good for us as a family or for me as his wife. So that for me is very positive".

Participant 4: "So he came for the funeral and he said no he don't want to go back and I said no but **you are sick** you have to go back (to hospital). But they sedated him heavily when he came for the funeral".

Participant 8: "It is always a problem because he is doing nothing. I think the doing nothing is more harmful than working".

Participant 9: "And rebellious and you know, he refused to listen to us, he was forcefully taken to W (state psychiatric hospital)".

Participant 11: "*Op die ou end het hy besef bipolêr vra van 'n mens samewerking. Dit is nie net ek gebruik pille ek dit is nou ek het my deel gedoen nie. Die psigoterapie wat ek moet kry, moet ek na luister en ek moet aan myself werk. Ek is dit nie net aan myself verskuldig nie, ek is dit aan my gesin verskuldig en toe daai draai in sy lewe kom, het die draai in ons huwelik gekom". *In the end he realized that bipolar ask your cooperation. It is not only to drink pills. I have to listen to my therapist and work on myself. I owe that to myself and my family. Then things started to improve in our marriage.

Role as Husband

Participant 3: "Then I called him, and asked him please come and help me, to get her to hospital and at that stage he just said now he has got all this cash on hand, he can't come. To me I felt like all the money in the world isn't important as important as my child's life. So I had to call other people".

Participant 7: "I think if something might happen to my dad, my mom will be able to survive and go on. I mean she is the one, paying the electricity, paying the accounts, paying everything, running the household, getting his medication, making his appointments so for her it will just be he is not there in my life anymore, but for him it will be she is not there anymore and all that responsibility".

Role as Father

Participant 3: "The same with my child. I know she would like to have nice new clothes and then he will say o she must go and get three quotations which is, how can you say that to a teenager. You can't". "With the teenagers it doesn't work that way and to explain that to him, it is a total different story. It is not that easy".

Participant 7: "I want a husband who has all the qualities of my father". "It always feels bad to talk about my father, because he is a wonderful man, if I call him now and I tell him hoor hier dad the 'pot het geval, kom maak hom gou reg', (dad, the vase fell. Please come and mend it) he will be here now". "I mean that, he will do everything for me and my mom, any,

any anything. I mean he will probably do more for me than for my mom". "He always want to help me".

Role as Mother
Participant 2: "She might get irritated with our daughter and I said 'nou wag 'n bietjie' (just wait), hold on, wait, two seconds and then it is better."

Role as Breadwinner
Participant 7: "I don't think he has a clue about what is going on with the finances".

Discussion of theme 9.3: Some of the patients (in the view of the participants) were not able to fulfil their roles of parenthood, spouse and breadwinner. It was also clear that some roles overlapped. Some of the patients were not happy to be obliged to go to hospital, but others did show some insight into their role as a patient.

Discussion of category 9: In this category, roles of the caregiver and patient, as well as qualities a caregiver needs, were highlighted. The key findings were that many roles are played in this scenario, but each situation is unique. There are no rights or wrongs, and roles are played according to the ability to face certain situations.

6.3.9 Category 10: Psychosocial challenges for caregiver

This category highlighted different themes resulting from challenging situations (**Table 6.15** refers). BD often leads to chaos when it is out of control and this inevitably affects the caregiver. The risk for relapse may then be heightened. As **Participant 7 stated**: "So it (the illness) impacts on so many different levels".

Table 6.15: Category 10 - Psychosocial challenges for caregiver

CATEGORY	THEMES	SUB - THEMES
Psychosocial challenges for caregivers	**Fear of being spontaneous and of the unexpected - creating uncertainty**	
	Expectations of the caregiver	
	Dealing with stress	
	Losses and limitations	Losses and limitations in general Specific losses and limitations • Freedom as a young child • Loss of friends

CATEGORY	THEMES	SUB - THEMES
	The challenge of seeing the positive in a difficult situation	• Loss of life • Loss of self • Limitations on caregiver's life • Loss of daughter

6.3.9.1 Theme 10.1: Fear of being spontaneous and of the unexpected - creating uncertainty

Some participants shared that the patient creates a certain milieu where other family members, as a result, become afraid to be themselves. Things might happen that are not expected and caregivers are exposed to uncertainty, as is indicated by the quotes.

Participant 2: "I will phone her mom and ask how C was today, was she ok, was she a bit upset, was she a bit depressed and they would normally give me a little feedback so that I know sort of what I am getting myself into when I get home at 5. I have got a little bit of background of the day or she was extremely happy, they had a very good time together so that I know she would be a little bit more relaxed when I got home and then I know how to handle the situation".

Participant 3: "With my daughter also you know, when she was smaller, I would also tell her, don't tell dada, don't tell dada about it. I mean if she bumped a glass over, and it was an accident, he was furious about it".

Participant 4: "Ja the thing is you don't know what he will do. He didn't do anything, but you don't know. That is stress enough, you know something that you don't know but something that you think it might happen. Then that is what kills you more than anything else. The unknown, yes". "You end up really not knowing whether it is true he doesn't like the place or he is just, you know, playing with your emotions".

Participant 6: "Felt you had to watch what you are doing, you couldn't be yourself. I think my personality has also changed when I am with him. You can't actually always be yourself".

Participant 7: "I think it is because you like to need to handle him with gloves. I think you must, you cannot just say what you want to say. You must always first think what you want to say because he can get quite angry or you cannot just sort of, you must just be careful what you say because you don't know what his reaction will be towards it". "I think now that I am in a relationship with someone and I think it is now just nice to know that I can **be who I am, I don't have to watch my words**, you know if you want to be funny, you can be funny he don't say anything to me and I mean I also told him about my father, because I think it is important that he also knows you know that this is my father and this is why I am like I am, that I am still very careful about what I say. I mean, sometimes I would just want to say something and it would think no I cannot say it".

Participant 9: "Like, it is difficult, you don't know when they are gonna change. You don't know what to expect. Ja that is how it is". "Everyone becomes so tensed, and become so emotional, you feel like there is no answers. You feel that the patient's on treatment and it is not helping. The patient, at times they are so good and the next minute they are like a walking bomb. So anytime they can explode. It is just like you don't know when is the next, the way the patient reacts. It is frightening actually. So I really hope this is the last one, I don't want any of my children to become like this."

Participant 11: "*Jy weet nooit as jy vanaand gaan slaap wat kry jy more oggend nie. Jy gaan of 'n persoon kry wat gisteraand in 'n high was en hy het verskriklik baie rapids cycling periodes gehad, vanaand is hy in 'n high, môre oggend is hy so depressief dat jy hom nie uit die bed kan kry nie en hy wil nie lewe nie en hy het deur die dag ook het hy tot vier, tot vier verskillende siklusse gegaan, so die mens wat by die deur uitstap is nie die mens wat by die deur terugstap nie. Jy weet nie wie kry jy volgende nie"* You never know, when you go to bed tonight what you will get tomorrow morning. You will either get a person that was on a high last night and he has had numerous rapid cycling episodes, tonight he is on a high, tomorrow morning he is so depressed that you cannot get him out of the bed and he does not want to live and he also went through up to four different cycles in the day. So the person that leaves through the door is not the same one that enters through the door. You do not know who you are getting next.

Discussion of theme 10.1: Participants reported that patients would react in a manner that was unexpected in response to something relatively small that happened. This would therefore also impact particularly on the children in the family. Participants felt they were obliged to adapt to the patient's needs and could not be themselves. People in the midst of a manic or depressive episode may say insulting, dismissive, and hurtful things (Haycock, 2010:227).

6.3.9.2 Theme 10.2: Expectations placed on the caregiver

Participants indicated that they experience expectations from various angles, as reflected in the quotes below.

Participant 2: "You know if somebody else is going to tell me I don't feel like running away, they are talking nonsense, because it does happen".

Participant 4: “If people that are **professionals** feel that, what about you if you are not a professional here, if you are just somebody and then you are exposed to this, you are faced with this problems”.

Participant 6: “I must jump for him and I mean what he wants me to do, I must do it, otherwise he is annoyed, what he expects me to do, I must do”.

Participant 7: “I think for me challenges is not with my father, it is more like other people. Like my **aunt** was here and she would also say that we must use words building up my father and I would **like you don’t have an idea, you have any idea so don’t come and tell me how I must handle my father**. I think that is challenges. I think they can be very judgmental over other people, they are trying to help. I think my biggest challenge will be just that. Just too maybe accept that this is going to be a lifelong, it is not just going to be happy go lucky now for the rest of his life, there is still going to be times when he is down in the dumps”. “I think the whole illness is a challenge because there is such a lot of little things”.

Participant 8: “Everything that goes wrong is my fault. I am so used to it, that it doesn’t bother me anymore”.

Discussion of theme 10.2: The caregiver should have realistic expectations of him/herself, of the patient and also of the “treatment team” (Last, 2009:138, 143), while respecting everyone’s limitations and boundaries. CAMH (2000:34) states that the caregiver should not become caught up in the patient’s euphoria, or with their unrealistic expectations. Do not try to convince the patient that his/her plans are unrealistic. It is clear that expectations (coming from the patient as well as other sources) can sometimes become overwhelming to caregivers.

6.3.9.3 Theme 10.3: Dealing with stress

Challenges create stress; the quotes below clearly indicate that the participants were sometimes overwhelmed by this.

Participant 4: “No I think I was just going through, it was emotional, you know you have the son sick here and the father dead, trying to cope. It was not as easy, it was very difficult, very, very difficult”. “I think I was just tired and from the past two years it was very difficult for me I didn’t even think I was going to survive. It was just too much”.

Participant 5: “It did because like I am saying I couldn’t even relax at home even if she was sleeping I would watch TV with one ear, with the other ear I was listening for her bedroom door or listening for the front door or listening for the doorbell, because I had to always be on guard and it was quite bad. There was one afternoon where I was watching TV and now

I relaxed for a little bit and she actually went out into our street and then I asked her to come back because she would sometimes just walk off and you will not know where she has gone to, how we are going to find her and it was just me and her home, and I followed her into the street and I asked her to come back into the house and she refused. She said no she is not coming back into the house and we literally had a bit of a scuffle in the street, and I remember the neighbours looking out their windows and watching me physically like grabbing my mother and forcing her back into the house and the embarrassment and wondering what did the neighbours think what is going on. So it was a **very stressful time for me** and I also started making excuses for my friends why they can't come to our house because I don't want them to see her like that. So I would now say you can't come to my house for whatever reason but also it was very bad, I couldn't go visit, because somebody had to be home with her. I couldn't leave my mother at home".

Participant 11: *"'n Boerdery is 'n voortdurende besigheid, op hierdie stadium is ons nog verskriklike droogte, so die beeste moet versorg word en as gevolg van maniese tye se optrede, sit jy nou sonder geld om daai beeste te versorg. So dit plaas geweldig* ***druk*** *op jou"*. (To farm is an on-going business. We are also having a terrible drought, the animals must be taken care of and because of his behaviour during manic times, you are stuck without money to take care of the cattle. It puts tremendous pressure on one). "*Ja, ja daar is geen sekuriteit nie, niks nie".* (Yes there is no security, nothing).

Discussion of theme 10.3: Participants indicated that there were times when they did not think they would be able to carry on. A person with BD might ask for financial assistance to get out of trouble that could be traced to the illness. Many people find that being close to someone with untreated BD is expensive (Haycock, 2010:107). Financial issues and lack of security was experienced on different levels by the various participants.

6.3.9.4 Theme 10.4: Losses and limitations

Losses and limitations are discussed in general first, followed by the specific losses and limitations applicable.

- **Losses and limitations in general**

Participant 2: "I want to be there, if I am not there, my daughter of two years old can't help mom, who is going to help mom. I will be there and I will be the proverbial policeman to help. If she feels bad and she wants to go and have a dose, she can go to bed at 7 and I can look after our daughter. If I am not there gallivanting with the boys, who is going to look after her. So those things I have given up, I just don't do it anymore".

Participant 3: “That is my sacrifice, my time”. “Then it is a lot of things that he doesn’t like to go to crowded places or functions of that sort, so I would like to go to concerts and I know it is not going to be nice for him. So we don’t do it. So that is also a bit limiting. Sometimes that type of thing is uplifting”.

Participant 4: “I think in a way yes it did like in a way I would like to go somewhere and I would just say *eish* I am not going because I have got this child of mine”. “Yes, yes. I did like go on holidays and then you really have to think how you are going to deal with this matter, you want to go somewhere”. “*Ja* I can say that with the father passing away, *jo* **it was very very difficult**. Now I don’t know if it was him or the passing of the father, but I was like very sick. Ja, it was not easy. Ja, the losses were there”.

Participant 5: “I think it is the fact that we can’t really rely on the person **for emotional support**. Because I think that is one of the most important things in a family. I mean, even if you are in a poor family where you can’t get financial support from a family member but the emotional support is based at human needs. Being in family you don’t have that, for me, that is the hardest part”.

- **Specific Losses and Limitations**

Freedom as a young child

Participant 5: “Like I am saying I couldn’t even relax at home even if she was sleeping I would watch TV with one ear, with the other ear I was listening for her bedroom door or listening for the front door or listening for the doorbell”.

Participant 7: “I also went to a psychologist and she said you know that I never had the chance to be a child. I was born a grown up because it was from you are little, you are conditioned to, if you play you must play quite, don’t say that, don’t do that, say I was never allowed to play and yell and just be a normal child. You know always be prim and proper and sit on your place and be careful of what you say”. “You know it is just like, jy is oud voor jou tyd. Jy is oud voor jou tyd”. You are old before your time.

Loss of friends

Participant 5: “So it was a very stressful time for me and I also started making excuses for my friends why they can’t come to our house because I don’t want them to see her like that”.

Participant 6: “He doesn’t want to visit other people”.

Loss of life

Participant 7: “That I can start to have my own life”.

Participant 8: “Yes it is out of control. I have prayed about it, I have done everything I now can think of, but it seems that nothing helps. Sometimes I really think that I am losing life because of his illness”.

Loss of self

Participant 7: "I realized that I must tell him some things you know and I will say that do you remember that the first year at Hartenbos I did something and you said stopped acting and it is like no I never said that and I am like he doesn't remember that but that stays with me and that is sort of keeping me back from showing who I really am".

Participant 11: *"Ek weet nou nog nie hoe ek daardeur gekom het nie. Maar ja, ek het toe op 'n punt gekom waar ek gesê het, nou is ek eerste prioriteit en net ek bly eerste prioriteit want ek gaan nog leef, maar ek weier om sonder 'n siel te leef. Ek weier om 'n leë mens te wees, want binne my huwelik kry ek niks en is ek leeg getap".* I still do not know how I got through it, but I got to a point where I said that I am now first priority and only me stays first priority because I am going to live, but I refuse to live without a soul. I refuse to be an empty person, because in my marriage I receive nothing and I am drained.

Limitation on caregiver's life

Participant 8: "Because you always have to be there. You always thinking about, even if he is not with you, say you are going to a braai to somebody somewhere then you always thinking about this one person that is at home, that also has to have a meal, even though he is actually grownup, he just doesn't take something to eat for himself. But you are always thinking of him being there at home."

Loss of daughter

Participant 1: "I will have to see my daughter happy again like she was before, because she is now a total different person", "I am the one that phones every second day or second night and to speak to my grandchild as well, because he really needs care"; "Terribly hopelessness because to wait six months to three years to see if the medicine will really make her like who she was before. It seems like an eternity to me".

Discussion of theme 10.4: Participants experienced losses of different kinds. A caregiver might experience that the person is "absent" when being ill and the relationship is "temporarily suspended" (Last, 2009:227). CAMH (2000:38) confirms this, pointing out that it is normal to experience a deep sense of loss when a person's relative is behaving in ways that you do not recognize. Clinicians need to be sensitive to help parents through the process of **grieving the loss** of their healthy child, especially in the acute onset of BD (Kowatch et al., 2005:3). If someone spends a great deal of his life caring for or worrying about someone with this illness, he might find his own accomplishments and sense of satisfaction limited. The goals and plans of the caregiver may fade as he instead tries to save or protect the person he looks after. A person with BD can take over a caregiver's life if the caregiver does not protect himself (Haycock, 2010:108).

6.3.9.5 Theme 10.5: The challenge of acknowledging the positive in a difficult situation

Some participants were able to reflect on the positive results of having a family member with BD.

Participant 4: "That is why it makes me understand her, no it does. You know when you have gone through tires you, you know you don't laugh you listen and you understand what they are going through. So I think that, that's me now". "Yes, I know what I am talking about, yes. Ja, maybe God knows why, that one day you can talk to other people, one day you can sit down and say ja, God exist. This and that happened to me and I have survived".

Participant 7: "I think sometimes people who have problems are more open to come and talk to me". "Maybe it is because through my father I learned to listen and maybe just more open and compassionate towards people".

Discussion of theme 10.5: The caregiver should not be so consumed with the illness that he/she ends up losing her/himself (Last, 2009:260). Hatfield (1987b:201) furthermore mentions that families are rarely seen in a positive light, their strengths recognized, or their heroic efforts, to support a deeply disturbed relative, acknowledged. Caregivers should be challenged to see the positive in the midst of a very difficult situation, because that will empower them.

Discussion of category 10: BD poses many challenges that are hard for anyone, except those suffering from it, to understand (Miklowitz, 2011:313). Assaulting another person, stealing, speeding, creating a public disturbance, and lewd conduct are among the more common ways a person might break the law during a bipolar episode (Haycock, 2010:198).

The researcher found that most of the participants reported on the challenges they face. Some even felt that their own well-being is threatened and the expectations and stresses they are exposed to can become unbearable. Caregivers are faced with a wide variety of challenges and demands on a daily basis. Even when they are not experiencing mood episodes, bipolar individuals can be, in a way, very "**high maintenance**" - they repeatedly impose both large and small **demands** on their spouses (Last, 2009:141). Last (2009:2, 260) refers to both the patient and spouse/partner when she mentions that: "Whether it's meeting expectations at work, keeping up with friends and family, pursuing hobbies and interest, and, at times, even just taking care of the basics of sleeping, eating, and grooming - BD makes day-to-day life a challenge". The researcher noticed that participants did not report much on the challenge of patients not taking their treatment.

6.3.10 Category 11: Psychosocial challenges for patient

Making peace with the illness and the idea of staying in treatment is much more difficult than healthy people realize (Mondimore, 2006:257). It is the researcher's opinion that it must always be remembered that the patient also faces challenges. During the interviews it was reported that the issue of work is a concern. It was also mentioned that patients experience losses. Six sub-themes of loss are highlighted (**Table 6.16** refers).

Table 6.16: Category 11 - Psychosocial challenges for patient

CATEGORY	THEME	SUB-THEME
Psychosocial challenges for patient	**Work**	
	Losses	Loss of self Miscarriage Loss of job Loss of friends Loss of life Loss of home environment

6.3.10.1 Theme: Work

The following quotes from the interviews reflected this theme.

Participant 1: "She cannot actually work with people and I realized that from her first job, now that I look back, she, every job she was very close with her boss and then it was for maybe 6 months going good and then suddenly, and then it was at the end like a firing cession and CCMA and all the problems and terrible".

Participant 2: "The pressure of trying to understand and getting to do the job the way she was supposed to do it, it was a lot of hard work and a lot of stress, so just trying to learn, but she can't learn it, she forgets and so all of that builds up and builds up and now that she doesn't have a job and all it is just a big fat snowball and then the firing happened". "So it was extremely difficult because it is a high placed, it is a medical industry, you can't make mistakes, it is a lot of forms, you can't do this wrong, so it's a lot of protocol that you have to follow and she was just not getting it under the knee, so the doctor said it's not going to work, you don't have to come back to work tomorrow, it is fine, we will pay you a salary until the end of the month which is now, but there is no need because you are just not grasping the concept as quickly as we would want you to".

Discussion of theme 11.1: People with BD face significant challenges in the **workplace**. Some of these challenges arise from the stigma of BD and the reaction of others. The bigger challenge, however, is finding a job that is satisfying but also helps keep a person from mood cycling (e.g. a shift job is not conducive). It is difficult to balance severely fluctuating moods with a stable work life. Maintaining a stable mood is essential to functioning well at a job (Miklowitz, 2011:300). Participant 2 did attempt suicide because she lost her job.

6.3.10.2 Theme: Losses

The theme of loss in the lives of patients was reported by the participants.

- **Loss of Self**

Participant 10: “He is a completely different person, it is like two completely opposite people, completely different. The thing is, even once he sort of going to this episode, and eventually he came out of it, he don’t remember, all sort of stuff that we used to do. So that already tells you that it is two different personalities”.

- **Miscarriage**

Participant 2: “Absolutely, it had an effect of her since she was 16 and still does. She wouldn’t say it, but I believe that some days she just misses it because she would have been 10 years old and running through the house and we are taking care of our new little one and sometimes it is there, you can see it in her eyes, she misses it, she doesn’t know, she believes what she looks like and she is with Jesus and all that type of stuff, so she believes it and I am not going to take that away from her because it makes her feel comfortable because she knows where she is and she is playing in the flowers and all that type of stuff, I am not going to take that away from her or complain because it means something to her”.

- **Loss of Job**

Participant 2: “So she has lost her job”.
Participant 5: “Sometimes she wouldn’t go to work for two, three months at a time”.

- **Loss of Friends**

Participant 1: “She does not have the friends anymore she had like two three years ago”.
Participant 7: “I think he also lost with his illness a lot of friends, you know colleagues at the work who also does not understand it, I think he is a very lonely person due to his illness because people will think, o dit is ‘n ongeskikte man daai”. This is a very rude man.

- **Loss of Life**

Participant 8: "Yes, yes, I feel very bad for him because he sees all his brothers and sister getting married, having children and he also wants that but he doesn't even know a friend because they all have thrown him away. He had a girlfriend she is also bipolar, but I don't think it is going to carry on, because when she is too, it is going to be too difficult for him to cope with his own illness and the illness of the girl as well. But I think, I really think he loves her but then I don't think he will pursue it".

- **Loss of Home environment**

Participant 4: "Where he is right now, he is not happy to be there and I think it is because there is order there. So they punish them if he does something wrong then they will just say no mommy will not come and see you".
Participant 8: "Every time that this happen my husband says he is not coming back to this house. I will not allow him to come back to this house ".

Discussion of theme 11. 2: People with BD were often very energetic, popular, bright, and creative before they became ill. Subsequently, once their illness is diagnosed and people around them start treating them like a "mental patient", they become resentful and start yearning for who they used to be. They experience deep feelings of loss over the dramatic changes the illness has brought. A patient can also lose status, work and money, or compromise relationships (Miklowitz, 2011:60). The losses that were reported in the lives of patients indicated the severe impact of the illness on their lives.

Discussion of category 11: The key findings of category 11 were that patients are faced with challenges. A patient wrote to Aiken (2010:51): "being bipolar is **challenging**, even frustrating at times, but I don't think I'd wish to live without it. I've learned to embrace it as a part of myself. I am me. I don't want to be anyone or anything else". A patient with such an attitude will undoubtedly be able to face challenges in a more positive way that somebody who cannot accept the disease.

6.3.11 Category 12: Recommendations from participants' practical experience of what works for them

During the interviews participants also reviewed what they find helpful in dealing with this difficult situation. It was clear that the participants also had **strengths** that they can utilize. Different **strategies** were reported by the participants. The researcher will also be able to use these recommendations in future with other caregivers, because they were made by people in their difficult situation on a daily basis. Other caregivers might benefit from these.

Table 6.17: Category 12 - Recommendations from participants' practical experience of what works for them

CATEGORY	THEMES	SUB-THEMES
Recommendations from participants' practical experience of what works for them		
	Different strategies: Perseverance Development of insight Sense of humour Exercise Relax together Give each other space/time out Support from friends More knowledge from website and books Creating a calm environment Support group Patient must have own interests Counselling Support when patient consults with the doctor Alternative placement Order, structure and routine Better communication Read, being creative Support from God Inner strength Focus Positive self-talk and self-knowledge Treat yourself by doing what you like Keep a diary Avoid negative input Educate the public Adequate sleep Routine Do not argue	

6.3.11.1 Theme: Different strategies

The strategies that were reported came from the practical experience of participants (**Table 6.17** refers). They are reflected in the quotes below, in no particular order of importance.

- **Perseverance**

Participants with perseverance have a better chance of conquering the effects of this disease.

Participant 3: “Then his mother died and then I felt, ok, let me just try again. And here I am 21 years later. So I am not sorry that I didn’t go through the fact that I did not leave him at that stage. I feel still there is a purpose behind what happened. It is not that easy always”.
Participant 4: “I want him to go back to school. I want him to have a normal life and that is what I am working towards right now and I won’t stop. I will keep on trying”. “So that is why I have to find a way of dealing with this matter **on my own**”.

- **Development of insight**

A participant who tries to understand the patient also shows respect.

Participant 2: “If you live with these people you must know that this person is not stupid. They are still as intelligent as they always were it is just the way they feel inside, that is different. So you must not underestimate a person with bipolar, don’t worry, it is just the way she feels, she will be all right tomorrow. Be really, really very careful. It is not that simple”.

- **Sense of humour**

A few participants mentioned the importance of a sense of humour.

Participant 2: “Thank goodness for a good wine that she was intoxicated that she couldn’t take any more medication and I then rushed her to the W (hospital) emergency room”.
Participant 6: “He has got a very good sense of humour”; “when my husband is on a high, you know he is the nicest guy. Like my daughter will also say, she doesn’t think there is a family that laughs such a lot like us because we make a lot of jokes”.
Participant 7: “We used to laugh a lot”.

- **Exercise**

This participant realized the importance of exercise for relaxing.

Participant 6: “Perhaps that also helped because they say exercise is good”.

- **Relax together**

Participants acknowledged doing things together with the patient.

Participant 2: "So I said look just me and my wife will go away for three days. She really wants to do that, just to get away". "I think that would be almost like retail therapy because it will be going away therapy for both of us, because I think both of us need a time". "She is going to just relax, she can paint because she is extremely artistic so I said you know what write poems, and write poems from here, if you depressed, write a depressing poem, it is ok. Or if you want to paint a picture, do it, because that will be a little bit of an outlet".
Participant 3: "What is also very good of him, he likes to read. So he reads a lot about in books and stuff and it takes time for him to connect and see what he has read he can actually apply, but I think he is gonna get there".
Participant 6: "Go out and for coffee and that he likes to do that with me. We will go to coffee shops, he likes that".

- **Give each other space/time out**

This participant mentioned that he also needed his own time.

Participant 2: "Or just talk about something else, or talk about a friend that did something during the week, and just have a beer and just chill have a cigarette and talk nonsense. When I get home, cool get off my horse, now I am at home again now I attend to my priorities and my responsibilities".

- **Support from friends**

Participants did report that friends support them.

Participant 3: "I do have friends at work. I have got a good friendship and support structure at my work place". "Also I go to bible study, women bible study groups do courses and then helps me also to get focused a bit more in a balance. Not to just see my own self and how bad am I feeling and then you can see everything in a different light which is better". "Or my manager, I will go to her office and say I am having a very bad day and these I can't really handle, any conflict today".
Participant 4: "People say ag you know what we are driving to Mpumalanga because my friends do that just to console me".

- **More knowledge from website and books**

The particular participant used websites, but people do not always know which websites are safe to use.

Participant 3: "You must at least know which **website** is a trusted website that you will get the correct advice because you can like I said, internet is vast, you can go to a website get the wrong advice due to taking it in the wrong way. So to have always a list of trusted websites that you know that whatever is said in there has been tested and has been proven". "A lot of things that you told us made a lot of sense to me at that stage and the books that you advised us. I did get that book. Luckily no incident happened. Yes I did not need to go to the book to go and see what to do yet, but it is a book that is going to be in my house that is going to be helpful for me and my child to handle certain things and even my husband because he loves reading. So it will help him also understand himself".

- **Creating a calm environment**

It was mentioned that it is important to contribute to a calm environment.

Participant 3: "For me it is just to make sure it is a calming environment when my husband comes home. Not to be putting more stress on him that he doesn't need".

- **Support group**

Participants mentioned the need for a support group for caregivers.

Participant 3: "It is like just the support group. **Just for the supporters**, you know if you can have once a week if you can say ok this week I have this issue that I don't have any idea how to sort this out or any of that and it would be nice just to have a little, like a place where you can go and deal with that. I don't have that".
Participant 6: "You know, I always said I wish the support group, **they only have the caregivers**, people living with people like this. I would like to speak and find out what does a person do in their live that has the problem". "So you know I would like people with children or husbands if they have got a problem to come together and talk". "You know it would be nice to speak to people living with people having mental disorders, how do they cope with that".

- **Patient must have own interests**

If a patient can be encouraged to have his/her own interests the participant felt it might take some pressure off the caregiver.

Participant 3: "But he is involved in a men study, bible study groups at our church and he did a course now for men, so when he is doing these type of things, he is much better for me".

- **Counselling**

Caregivers should also seek counselling when needed.

Participant 3: “Sometimes I go to maybe a counsellor when it is just too much for me and then I tend to see things a little bit more in a positive light”.

- **Support when patient consults with the doctor**

Participants mentioned that it does help when the caregiver is present during consultations.

Participant 3: “What he would like me to do, but is not always possible for me, when he goes to the psychiatrist he would always like me to go with, because I see things differently and I can explain to the psychiatrist this is what I see, how do we handle it. Because he will not see it that way or he will not pick it up at all”.

Participant 6: “I never went with my husband to the psychologist and I don’t go with every time, but I find it going with, should go with sometimes. That helps a lot. Because I don’t think they always tell them everything”.

- **Alternative placement**

Sometimes alternative placement for the patient becomes the only option.

Participant 4: “But now I am feeling much better. I think it is now because at least he is somewhere else, it is easy. He is in another residence yes. And I know that they are looking well after him”.

- **Order, structure and routine**

Participants reported better results when order, structure and routine were introduced.

Participant 1: “Her friend is very, very hard, he is not a soft type and it looks to me that that works wonders on her. He says no. You are in this house, you will abide to my rules and if you don’t like it, then go out”.

Participant 4: “That is why it is said the best thing is to take him to somewhere there is order. You wake up in the morning, you make your bed, breakfast, on Sundays they cook themselves. You know there is order”.

Participant 5: “So as soon as there is a change in her **routine** that is when, I think not purposefully, but she becomes non-compliant”.

- **Better communication**

Caregivers and patients should communicate about their needs and feelings.

Participant 7: "More verbalizing what we are thinking, we are verbalizing our thoughts and he can also realized and I think my mom will always say but just do a mind shift".

- **Reading, being creative**

Reading and creativeness helped this participant.

Participant 11: "*Ek lees baie en ek is baie kreatief, ek doen skilder, en ek probeer die lewe vir myself lekker maak want ek het die filosofie as 'n mens nie die lewe vir jouself kan lekker maak nie, het jy ook nie die vermoë om dit vir ander te kan lekker maak nie".* I read a lot and I am creative, I paint and I try to make my life enjoyable, because I have the philosophy that if you cannot make life nice for yourself, you also cannot make it nice for others.

- **Support from God**

A number of participants reported that their belief in God is their strength.

Participant 2: "Religious, very, very religious and understands heaven and hell and demons and all that type of stuff. She understands it extremely, extremely well. She has actually completed a couple of courses".

Participant 3: "God will not give you something you cannot handle".

Participant 4: "I ended up saying you know God says I have got plans for you, plans to prosper you and not to destroy you and I am like saying God you know this is the tile from 2010 and I hope one day I will stand there and say it is over. It is just time for that, this is not easy". "*Ja* my faith is my support and I got this friend of mine, actually she is the one I tell everything".

Participant 7: "I think for me what kept me grounded was my faith and religion". She (her mother, Participant 6) was just crying one morning. I asked what is going on because I have hardly ever see her crying, she said she heard God telling her that she can't live without her husband. I think those words were her anchor that keeps her in that difficult times. You know that even though he has this illness and even though we are going through all of the difficult times, she still loves him".

Participant 11: "*En ek gaan soek my vrede by my Hemelse Vader. Ek bid geweldig baie en ek het baie intieme vriende".* I look for peace at my Heavenly Father. I pray often and I have many intimate friends.

- **Inner strength**

Participants with inner strength might be more able to handle difficult situations.

Participant 4: "I am very understanding, very, very understanding. I was like that in the past, but now it is more and I am very observant now. I talk to people, people have got different problems, but I talk to them. I am very sympathetic".
Participant 7: "Yes, I am sometimes I think too responsible."

- **Focus**

Participants will sometimes have to be very focussed to reach their own goals.

Participant 5: "So I learnt just to separate things in life. To separate home and to separate school. I think I was a bit young in high school, so I was in grade 10 or grade 11 that year and we had exams coming up, and I just had to continue and go and write my exams".

- **Positive self-talk and self-knowledge**

It is important that participants motivate themselves but also know themselves.

Participant 7: "So I think it is also a lot of positive self-talk to one self as well".
Participant 11: "I know myself very well and I have to learn to deal with my own moods".

- **Treat yourself by doing what you like**

Participants should be good to themselves.

Participant 11: "*So ek probeer regtig vir myself goed wees, myself net 'n bietjie treat, al is dit 'n dood gewone kuier by 'n vriendin, al is dit doodgewoon onder 'n boom sit met 'n meerkat"* (I try to be good to myself, treat myself even if it is to visit a friend or to sit under a tree with a meercat)." *Ek gaan soek my vrede in die natuur*" (I look for peace in nature).

- **Keep a diary/journal**

One of the participants reported that it could help to write down the patterns of the illness.

Participant 8: "I can see the mood changes, it forms a pattern. If I could have held a diary, I would have written there say in March or whatever, he would go into depression and the depression would come and go deeper and deeper. I see the signs and then suddenly, it just turns over. Then you think ag he is coming right now, then for a week and then he goes haywire".

- **Avoid negative input**

This participant decided to avoid people who do not understand the situation.

Participant 11: "*Ek het besluit mense wat nie verstaan nie, mense wat het kritiek lewer het ek nie in my lewe nodig nie. Ek het nie bykomende seer in my lewe nodig nie".* I have decided that I do not need people that do not understand, people that criticize I do not need. I do not need more sorrow in my life.

- **Educate the public**

The participant identified that if the public could become better informed about mental illness this could also benefit the individual.

Participant 7: "So I think that people they don't understand the illness, they think this is a moody person, this is a horrible person '*met 'n aardige persoonlikheid'*, (strange personality) but they don't understand it".

- **Adequate sleep**

This participant reported on the importance of sleep - perhaps because she is a medical doctor.

Participant 5: "It is so important, it is really, really important".

- **Do not argue**

The participant realized that arguing with a person who is mentally ill will not achieve anything.

Participant 5: "I know what to say, I know if she starts to argue, there is just no point arguing back with her. You just keep quiet and you let her be".

Discussion of category 12: Participants were very resourceful and were able to offer practical ideas about what works for them. If they were to share these ideas with others this would also empower them. The researcher is intending to use these ideas in the programme that she is going to present to caregivers in phase two of the research.

6.4 SUMMARY

The following categories, themes and sub-themes emerged from this research:

Category one assessed the **needs** of the caregivers and the patients (participants' perception). It was very necessary for the researcher to establish the **real** needs of the participants because the psycho social educational programme that will follow, will be based on these needs. Participants are sometimes so focussed on the needs of the patients that they neglect their own. It was evident that they have a need for acknowledgement and support, but also for knowledge about BD and the skills to handle difficult situations.

In **category two** participants' **objective and subjective burdens** came to the fore. It was clear that they did not always realize that caring for a psychiatric patient brings a burden with it. In these modern times there is still a stigma attached to psychiatric illness. Sometimes the participants expected the impossible of themselves.

The significant aspect of the wide spectrum of **relationships** was highlighted in **category three**. Participants were in different relationships with the patients (parent, child, and spouse), each of which has its own difficulties. It was clear that although communication is an important activity, it is sometimes troublesome. Participants also sometimes struggle with their relationships with the MDT.

Illness was a central factor that all the participants had in common and this was discussed in **category four**. Participants shared their personal experiences on a broad level in terms of the different manifestations of BD and treatment options.

In the management of BD it is very important to take note of **risk factors** (**category five**) and **protective factors (category six)**. Participants are not automatically aware of these factors and that if they are adequately managed, relapses can be minimized. This will therefore also be emphasized in the researcher's programme.

Caregivers frequently react on an emotional level when confronted with BD. It is important to be sensitive regarding emotions. Participants did report a range of **emotions**, as captured in **category seven**.

Category eight highlighted the **responses of participants and other family members** in regard to BD. It included aspects such as denial, but also acceptance.

When a family system is confronted with an illness as serious as BD, each member in the system will adapt to certain roles. **Category nine** captured the **roles** that are being played by the participants but also those that the participants thought are being performed by the patients. It became clear that functional roles often have to be taken over and sometimes this may cause role confusion.

Nobody will deny that BD challenges those whose lives are confronted by it. **Category ten** focused on different **psycho social challenges** that were reported by the participants. Losses experienced because of this illness were also an important theme.

Challenges for the patients were also noted by the participants, especially those concerning work and losses. This demonstrated the participants' concern for the patients. These were discussed in **category eleven**.

The needs and challenges of the caregivers were on a biological, psychological and social level. That made the biopsychosocial model very relevant in this study.

Lastly, participants often had to find their own **ways of coping** in the past; the information that they shared regarding **what works** for them is addressed in **category twelve**. These items ranged from a sense of humour to better communication and just persevering. Utilizing this list, the researcher in future will also be able to provide other caregivers with some ideas.

The following chapter provides a short overview of psycho-educational programmes, after which the psycho-social educational programme (SEE-SAW programme) developed by this researcher to address the needs of the caregivers of BD, will be presented too.

7. CHAPTER 7: PSYCHOSOCIAL EDUCATIONAL PROGRAMMES FOR CAREGIVERS AND THE SEE-SAW PROGRAMME

7.1 INTRODUCTION

> Managing your BD is part of the larger journey of living your life (Berk et al., 2008:xiv).

The great majority of illnesses are influenced by psychological and social factors. A biopsychosocial model places emphasis on prevention and rehabilitation (Baumann, 1998:11). The biopsychosocial approach is appropriate in the management of psychiatric pathology. This includes the use of medication, psychological support and counselling, education and social intervention where necessary. Failure to adopt this holistic approach to management will result in inadequate management or frequent relapses (Daubenton, 1998:8).

More than perhaps for virtually any other mental illness, there is a need for a comprehensive and **integrated** approach to the management of bipolar disorders. The **limited view** that treatment of bipolar disorders consists only of finding the “right” pharmacotherapy has largely been dispelled.

In the last decade, four main models of psychological interventions have evolved for bipolar disorders – cognitive behaviour therapy, interpersonal social rhythms therapy and family - focused therapy and the fourth model that was developed *de novo* by the **Barcelona** group, a psychoeducational programme. One of this group’s key principles in their approach is that interventions have to emphasize a psycho-bio-social model of bipolar disorder (Colom & Vieta, 2006:xii).

The incidence of bipolar disorders amounts to approximately 4 % of the adult population, but may reach 6, 5 % of the population at large if minor and atypical forms are included. The consequences of the disorder and its subsequent relapses for the individual and for family members, combined with the high risk of mortality by suicide suggest that a multiple therapeutic effort must be made, **going beyond** while at the same time supportive of drug therapy (Colom & Vieta, 2006:3).

It has become clear to the researcher’s that there is an abundant amount of knowledge available on BD, but perhaps the challenge is to **reduce** this knowledge to make it **simple** and digestible for patients and caregivers. This overflow of information is especially true for the international arena, but not necessarily for the South African situation.

It is the researcher’s opinion that each and every patient as well as their caregiver/s has the right to know more about his/her disorder. Psychoeducation meets a fundamental right of the patient and of any human being: **the right to know** (Colom & Vieta, 2006:28). Recognition of the family as a valuable **asset** in the care of persons with mental illness has brought to the attention of mental health providers the need to support family caregivers in this demanding task (Hatfield 1987a:60).

In **chapter three** psychoeducational therapy has been discussed. In **this** chapter the emphasis will be on specific programmes available and how it can be developed for the **needs** of a specific target group (the caregivers of people being diagnosed with BD). McElroy (1987:225, 240) alludes to the fact that there is much to suggest that families of the seriously mentally ill and the professionals who treat them march to the beat of a different drummer. Findings from several studies indicate that each group holds different views about the needs of the families. It is imperative that professionals be aware of the family perspective on the meaning of mental illness. Successful programmes for these families must articulate the expressed needs and approaches deemed to have merit by the targeted population. It is important to view the family as adult learners as opposed to unidentified patients.

Approaches that seamlessly integrate pharmacological and psychological approaches to bipolar disorders are few and far between, yet it is exactly these types of strategies that are urgently needed if we are to achieve better outcomes for our patients (Colom & Vieta, 2006:xiii).

The researcher has found from the literature especially **two groups** that have been developing programmes - Colom and Vieta (Barcelona, Spain) and also Miklowitz (Los Angeles, USA). This chapter will be referring to these authors’ work, but it will also include material from other experts. It will provide a theoretical background while the **SEE-SAW** programme of the researcher will focus on relevant practical aspects.

Most programmes however still focus on the patients, but the researcher’s focus was the **caregiver**, because the caregiver’s acquired knowledge is of equal importance in the recovery of the patient. The researcher’s programme was only **one day** with most other programmes’ covering a period of months. The researcher’s programme therefore had to cover the most critical aspects and each respondent received documentation to use for future reference. The researcher followed a biopsychosocial approach with her programme, because the emphasis was more on prevention and rehabilitative aspects than on cure.

7.2 EDUCATIONAL AND SUPPORTIVE MODELS OF FAMILY INTERVENTION

Phase 2 of **intervention research** is information gathering and synthesis. When the researcher was developing her own programme, Zipple and Spaniol (1987:261) provided a good starting point. They mention:

- **Informational** approaches that are designed primarily to provide information
- **Skills-training** approaches that are designed primarily to develop skills
- **Supportive** approaches that are designed primarily to enhance the family's emotional capacity to cope with stress
- **Comprehensive** approaches that incorporate information, skill training, and support in a single intervention.

Zipple and Spaniol (1987:271-274) also make suggestions for **enhancing** educational and supportive approaches. The researcher will mention some:

- **Clarify mutual goals**: what professionals believe families want and what families want is often different. Assuming what families need without adequately checking out underlying assumptions usually leads to families feeling discounted, devalued, and disenfranchised by professional intervention. In phase one of this research the researcher assessed the needs and challenges of caregivers of people being diagnosed with BD.
- **Point out family strengths**: It is important to focus on family strengths as well as areas in need of change. Professionals should give ample time to acknowledging what families are doing what is defective and help them to acknowledge it to themselves. The researcher has found that it is easy to criticize families instead of embracing them.
- **Learn to respond to intense feelings**: Professionals need to learn to deal with the intense feelings of family members. Some families report a long history of frustration and abuse by the mental health system. This can be especially true in South Africa with very limited resources for mental health care. Families may also have been rejected or abused by the patients.
- **Encourage family enrichment**: Families may need permission to put greater time and energy into themselves. Professionals can encourage families to create a greater balance within their **own lives**. This balance can be encouraged by helping families to

refocus their energies on their own needs and wants. Positive options can include activities such as spending time with old friends, going to the theatre, re-involving themselves in activities that have nothing to do with mental illness and doing other things that they enjoy individually and as a family.

- **Provide information about psychiatric illness and medications**: Families report that their need for information about mental illness and concerns about problems associated with drug management are very high priorities. Understanding mental illness is complicated and especially if treatment and even diagnoses change over a period of time – this does happen.
- **Provide practical advice**: It is very important to give special attention to the practical management strategies families say they need and how to teach them. One way to enhance these strategies is to **include experienced family members as co-trainers**. Many families have learned useful coping skills and **can teach professionals** and other family members what they have learned. The researcher is of the opinion that a professional should also be able to learn from the patient and his/her family.
- **Provide information about community resources**: Professionals should provide information about the resources in the community. It is important for professionals to become familiar with the quantity as well as the quality of these resources and to learn to link resources together for the benefit of their clients and their client’s families. Families and members of the MDT look to the social worker for resources and it is therefore the duty of the social worker to be knowledgeable about resources.
- **Encourage involvement in local family support and advocacy groups**: It is essential that professionals get to know the family groups in their area by attending some of their meetings and finding out what their concerns are. In South Africa there are support groups for people and their families with BD run by SADAG (South African Depression and Anxiety Group), SABDA (mental health support/advocacy group for caregivers and clients affected by schizophrenia and bipolar and other mental illnesses) and various church groups.

Although Zipple and Spaniol made the above mentioned suggestions in 1987, the researcher has the opinion that their suggestions are still relevant today.

7.3 INTERNATIONAL PROGRAMMES

In the next section five programmes will briefly be discussed. Although these programmes were primarily for the patients (and not the caregivers), the researcher still decided to mention what programmes are available:

7.3.1 Psychoeducation Manual for Bipolar Disorder (Colom and Vieta - Barcelona, Spain)

The unique aspects of the Barcelona approach are that it is based on the philosophy of psychoeducation, but uses an adult-learning model to achieve its goals, and it provides patients with a group approach which not only offers them peer support but also allows them to learn from each other. Many clinicians are cynical about psychoeducation because everyone claims to offer it to patients, but few clinicians apply a systematic and comprehensive multifaceted model that helps individuals actually modify their actions or learns new coping or problem-solving skills (Colom & Vieta, 2006:xii).

The psychoeducation programme of this group emphasises the following aspects which is covered in 21 sessions:

- **Awareness of the disorder**: (what is BD?, aetiology and triggering factors, symptoms of mania, hypomania, depression and mixed episodes, evolution and prognosis).
- **Drug adherence**: (mood stabilizers, antimanic drugs, antidepressants, plasma levels of mood stabilizers, pregnancy and genetic counselling, psycho-pharmacology vs. alternative therapies, risks associated with treatment withdrawal).
- **Avoiding substance abuse**: (psychoactive substances: risks in BD).
- **Early detection of new episodes**: (information - frequent relapse signals, Individualization - identification of one’s own warnings or operational warnings, specialization - prodomes of prodomes, or early warning signs, early detection of mania and hypomania episodes, early detection of depressive and mixed episodes, what to do when a new phase is detected?).
- **Regular habits and stress management**: (regularity of habits, stress-control techniques, problem-solving strategies).

7.3.1.1 Evaluation of this programme

The researcher can report that there were certain **similarities**, as well as **differences**, between her programme and this programme. The themes that were discussed do correspond being the important issues that the researcher also felt should receive attention. The respondents were also at least 18 years old. In both cases sessions were interactive.

The Barcelona programme was developed for the patients and not the caregivers. The Barcelona Group did however also set up a parallel programme designed specifically for the family members of the patients. The programme lasted over 21 sessions (90 minutes each) on a weekly basis while the researcher developed a one day programme. The programme was directed by more than one therapist while the researcher was the only presenter. In the case of the researcher's programme an occupational therapy colleague was present during the presentations and helped to facilitate the day.

The researcher is not a medical doctor (like in the case of the Barcelona programme), but the content of the programme was discussed with medical colleagues. Not being a medical doctor gave the advantage of being on the same "level" as the caregivers and to be able to "understand" their language.

South Africa is a third world country with little resources and it would be difficult for patient's families to attend sessions on a long term basis.

The researcher's programme is **psychosocial educational**, including social aspects such as relationships, the burden to the caregiver and introduction to community resources.

The most helpful aspects of the Barcelona programme are that it has been written in a language that is simple and accessible to anyone with no training in psychiatry or psychology (Colom & Vieta, 2006:48). The programme is practical and offers good suggestions. The authors share "useful tips" after each session with the reader.

7.3.2 Bipolar Disorder: A Family-Focused Treatment Approach (FFT) (Miklowitz - Los Angeles, USA)

Clearly treatment for BD **must go beyond** medication maintenance to include consideration of the familial and social-interpersonal aspects of this illness (Miklowitz, 2010c:vii).

Miklowitz (2010c:7-12) state that the six **objectives** of FFT are to assist the patient and relatives in the following areas: **integrating** the experiences associated with episodes of BD, **accepting** the notion of a vulnerability to future episodes (bipolar is real), accepting a dependency on mood-stabilizing **medication** for symptoms control, distinguishing between the patient's **personality** and his or her bipolar, recognizing and learning **to cope** with stressful life events **that trigger** recurrences of BD and to re-establish functional **relationships** after the episode.

7.3.2.1 Evaluation of this programme

The researcher did find this programme to be very user friendly. The direct quotes given for the group leader to use is handy. It is her opinion that another publication by the same author (The Bipolar Disorder Survival Guide, Miklowitz, 2011) is also very accessible for the reader and contains pragmatic ideas.

The similarities to the researcher's programme are that both are based on psychoeducation, emphasises the importance of adherence to treatment, respect the patient's personality, acknowledge triggers and nurture relationships. Miklowitz (2010c:104) mentions that family members are allies in the treatment/recovery process and the researcher shares this view. Miklowitz (2010c:107, 108) refers to the offering of concrete suggestions about what family members can do to make their situation better. The researcher also tried to offer suggestions, e.g. how to approach the MDT or the police.

The more material that comes from the participants, the better (Miklowitz, 2010c:110). There was not so much time for **interaction** during the researcher's programme and that is something that can be improved in future.

The researcher's programme gave the caregivers the opportunity to meet in the **absence of the patients**, because caregivers cannot always be open and honest if the patients are present. In the researcher's programme not so much emphasis was put on communication enhancement (CET) and problem-solving skills which are core modules of FFT (Miklowitz, 2010c:27). FFT has also been used for adolescents and parents (Miklowitz, 2010c:x) while the researcher's respondents were adults. The researcher's focus was not the exploration of emotions while Miklowitz (2010c:105) does include that aspect as well. The researcher's programme is for any **caregiver** and not only for family members. FFT sessions are delivered in 21 sessions lasting 9 months on an outpatient basis, while the researcher only conducted a one day programme. Much less content was therefore covered, but a manual and other hand outs were provided for self-study. The FFT programme is directed by more than one therapist while the researcher was the only presenter (an occupational therapist helped her during the presentation to keep to the time limits and also with the completing of the questionnaires). The researcher presented the programme to a group, while the Miklowitz programme is presented to a family or a couple (Miklowitz, 2010c:100). The researcher's programme can be presented even when the patient is still in hospital while the Miklowitz (2010c:102, 103) programme is presented after the patient has been discharged.

An aspect that the researcher found most helpful was the clinical case examples that are offered throughout the book and that are hands-on.

The researcher agrees with general aspects contributing to the therapeutic stance e.g. to use humour, to create dialogue, to encourage participants to offer input or personal experiences, to depart from the agenda if more pressing issues present themselves (e.g. emotional aspects), to avoid technical jargon and to be optimistic about what is to come (Miklowitz, 2010c:100).

7.3.3 Take charge of Bipolar Disorder: A 4-step plan for you and your loved ones to manage the illness and create lasting stability (Fast and Preston - New York)

In this publication (Fast & Preston, 2006) four distinctive steps are described - medication and supplements, lifestyle changes (sleep, diet, exercise, light, work and money), behavioural changes (knowing triggers) and asking for help (choosing a supportive health care team, teaching family and friends how to help you stay stable and insurance).

7.3.3.1 Evaluation of this programme

Its **target group** is the patient, but it does also contain very valuable information for the caregivers. This book is written in an easy, understandable way. If it is read and the information is applied, it will lead to a better quality life for both the patient and the caregiver. It is emphasized that people who have been very ill with BD can stay healthy and stable when they use a holistic treatment plan.

The same authors have also written a book "*Loving someone with bipolar disorder: Understanding & helping your partner*" (2004) covering aspects like BD triggers, work and money, sex and the hard truths about BD.

The goal of their programme is to help the **caregiver** to find the correct **balance** between understanding and helping the patient so that the caregiver is still able to pursue his own goals and dreams. It focuses on **prevention** instead of crisis control and the provision of **tools** the caregiver needs to be a resource and support for the partner inside of crisis manager and constant caretaker. The programme focusses on a **holistic** treatment plan and practical strategies (Fast & Preston, 2004:1, 2, 4).

This book is for **self-study**. It is written by a patient and a professor of psychology. The patient was diagnosed with bipolar II and her partner was diagnosed with bipolar I. This is a programme that the patient and caregiver (couple) study together to create stability. They journey through it together (Fast & Preston, 2004:12, 18).

7.3.4 The STEP-BD (Systematic Treatment Enhancement Programme for Bipolar Disorder) Research Project

In one of the largest studies done on the treatment of BD, called the STEP-BD Research Project, fifty eight present of **patients** achieved full remission during the research programme using state-of-the-art medical treatments (NIMH, 2011). It is also very important to note that the 58 % who did well were treated aggressively using strategies such as sleep monitoring, strict adherence to medications with the least side effects, and a nonstressful and very structured environment (Fast & Preston, 2012:37).

7.3.4.1 Evaluation of this programme

This study demonstrated that patients who received medication and nine months of either family-focused, cognitive behaviour, or interpersonal and social rhythm therapy were more likely to recover from episodes sooner and remain healthy longer. Furthermore, the results showed that participants stuck to their treatment plans better, had fewer relapses, and required fewer hospitalizations than medicated patients who had just three sessions of psychoeducation (Haycock, 2010:93).

The researcher's programme was for caregivers and only a one day programme. Although the patients might have benefit by the caregivers' acquired level of knowledge that was not tested during the researcher's programme.

7.3.5 Wellness Recovery Action Plan (Mary Ellen Copeland)

In conclusion the researcher would just like to mention **The Wellness Recovery Action Plan (WRAP)** which is an evidence based practice used world-wide by people who are dealing with mental health challenges as well as medical conditions (http://www.mentalhealthrecovery.com). Diabetes, weight gain, pain management, addictions and trauma are just some of the many life challenges that can benefit from WRAP. It can also be used as a framework to guide relationships in peer support, recovery groups, agencies and organizations. It is being used in schools, prisons and hospitals – with people of all ages who want to attain the highest possible level of wellness. It was originally developed by a group of people who lived with mental health difficulties and were searching for ways to resolve their wellness issues - WRAP was their answer. It can be used by anyone looking to develop a plan to manage a path to wellness.

WRAP includes aspects like triggers and early warning signs, a crisis plan and a toolbox that are also important aspects of the researcher's programme.

It is clear that different programmes have been developed all over the world for BP patients and their families. The researcher tried to apply the relevant aspects to her programme taking into consideration that it was only a one day programme and just for caregivers.

7.4 SOUTH AFRICAN NATIONAL PROGRAMMES

It was not part of the original protocol of this study to investigate the South African situation. In the hospital that the researcher has been working for more than twenty four years psycho-education is mostly done by all the members of the MDT although in an informal way. It is sometimes implemented before the final diagnosis is made and may thus lead to misinformation and confusion. There might be a period where the diagnosis is not final and the patient has a differential diagnosis. During this period psychoeducation should be approached cautiously. There is no formal psychoeducation programme for the caregivers in this facility.

The researcher did attend a seminar (Deconstructing Bipolar Disorder, 2013) where a psychologist from a private psychiatric hospital in Gauteng gave feedback on the psycho-educational programme that they present. It is mostly based on the Vieta model.

It was already mentioned in **chapter one** that the researcher contacted social work colleagues in other psychiatric hospitals and that none of them have formal psychosocial educational programmes. It is possible that the researcher can still disseminate her programme nationally.

7.5 OVERVIEW OF THE RESEARCHER'S SEE-SAW PROGRAMME for caregivers of people living with bipolar disorder, a psychosocial educational programme

After the qualitative phase of this research where the participant's needs and challenges were identified, the researcher designed and developed a one day **psychosocial educational programme** for the caregivers of BD people which she called the SEE-SAW programme. This programme was presented to two different groups of caregivers on two consecutive Saturdays (see **Appendix 7.1** for the programme for the day - SEE-SAW programme). The researcher is presenting her detailed programme in this chapter. **Please take note that it was written for the benefit of the caregiver and as such the style was adapted for the caregiver**. The researcher has also mostly written the programme in the first person and the numbering was adapted to make it more userfriendly. The programme must be considered as an entity on its own in this research report. Some of the material that was used in the programme is a repetition of material in previous chapters, because it was part of the researcher's literature study when the programme was developed. The researcher used a power point presentation and other hand-outs (See **Appendices 7.2-7.9**) to summarize the contents of the programme. Information was also compiled in a booklet for the benefit of the caregivers to use as a reference in future.

7.5.1 The SEE-SAW programme

An episode of bipolar disorder (BD) is a very stressful life event for a patient and his or her family, an event that significantly disrupts the family's **equilibrium**. Even with the best drug treatment, patients frequently relapse, function poorly at the interpersonal and work levels and in turn, the families are left to pick up the pieces (Mkilowitz, 2010c:12, 22).

It is therefore a privilege to **welcome** you to this one-day programme. It is hoped that you will enjoy it and that it will better equip you in your **role as caregiver**. As one, you have the potential to make an enormous difference in the life of your loved one. The more you know about the illness, the better chance you have of helping your loved one to find **stability** and to have quality of life.

As with those who suffer from depression, close **friends and relatives** are able to be important allies in the patient's efforts to **prevent** hypo-manic or manic relapses. They may also be able to **protect** the patient from some of the consequences of the illness. (Berk et al., 2008:193).

We shall all learn from each other today. You are already **experts** in your own way. This is not a therapy group; the emphasis will be on **psychosocial education about bipolar illness**. We shall laugh together, hopefully not cry, but if we do, it will be nothing of which to be ashamed. If feelings should surface during the discussions, please share them. I am not only interested in facts; I would like to know how this material applies to you and your own experiences.

Once family members are able to understand the patient's experiences of the illness and develop better ways to cope with the cyclic nature of the disorder, their caretaking burden lightens correspondingly (Miklowitz, 2010c:26).

Ice breaker

Round of introductions

I would like to tell you a story (adapted from the story of the "Strooihalm, vuurkool en boontjie", Bamberger, 1967:60-62).

Once upon a time, there was a woman who had three sons: a coal, a bean and a straw. **The bean** was the clever, creative one, but also vulnerable and sometimes lived in his own world. One day the three of them decided to go on a journey. They came to a stream that they could not cross and the straw said he would lie down for the others to cross over. When the coal crossed over, the straw set alight and broke. They both fell in the water and drowned.

When the bean saw this **(stressor)**, he became very depressed and wanted to kill himself. He decided however to rather smoke dagga to ease the pain **(self-medicating)**. He withdrew all his savings and bought a very expensive car **(impulsive)**. He thought that he was a millionaire and a very important person **(inflated self-esteem)**. While racing in his car, he became very aggressive and assaulted someone and then he was arrested. In the cells, he was not able to obtain any substances, but now he could not **sleep**. He was talking non-stop and had too much energy **(manic symptoms)**. He said that he felt very happy, in spite of his stressful circumstances. At other times he became extremely irritable. He lost contact with reality, becoming paranoid and hearing voices talking to him **(became psychotic)**. The police took him to a general hospital that then, after 72 hours of observation, referred him to a specialized psychiatric hospital. He was admitted as an *involuntary mental health care user,* because he did not think that he was ill or that he needed treatment **(lack of insight)**.

The social worker in this hospital contacted his mother who was very worried and shocked to hear what had happened. The bean gave permission for the doctor to give the mother the diagnosis that was Bipolar 1 disorder, because by this time the symptoms had already been present for a **week**. The illness was explained to her and she then reported that her mother had also been a psychiatric patient **(genetic component)**.

The mother wanted to know what she could do and it was explained that her support would be very important to her son. She could empower herself with knowledge and skills to be able to coach him upon discharge and to be aware of **risk factors, triggers** and signs of **relapse**. It was emphasized that he should always stay on his medication, follow up monthly at the outpatients' department and not use any substances. He should however become as independent as possible, work again and carry on with his life. They could both attend support groups. If anything should worry her after discharge, she could contact members of the multi-disciplinary team (MDT) whom she met during his admission.

7.5.2 Expectations of programme

7.5.2.1 Of participants by facilitator

It will be important that you do **participate** as much as you want to. A given is **confidentiality** in the group as well as **respect** for each other. Remind yourself to focus on the **solution**, not the problem. You must have an open mind and the **willingness** to try new ideas to treat an old problem. You must have the courage to **grieve the loss** of some of the hopes and dreams you had for your relationship, while simultaneously taking decisive action to improve the relationship.

7.5.2.2 Of facilitator by participants

Group needs to voice expectations.

7.5.3 Explanation of the programme

This programme was developed based on the **needs of the caregivers** that were obtained during individual interviews, literature research, as well as from the 24 years of experience, which the researcher has had while working with psychiatric patients and their families. An **acronym (SEE-SAW)** has been developed to represent different important aspects. It is a practical programme, involving sharing basic information and resources. Bipolar disorder is a complex, debilitating illness and it is clear that not everything can be covered in a single day’s programme, but it is hoped that the **areas of priority** will be addressed and that this programme will help you in your journey with the patient in your care. It is equally important that you learn what **not** to do or say as what to do or say (Fast & Preston, 2006:xxiv).

The researcher has identified particular important aspects that will go into the **SEE SAW SURVIVAL SUITCASE (S4)** and if you always keep it ready, it might help you to cope better. The following table, **Table 7.1**, gives an overview of the SEE-SAW programme.

Question to the group: what would you put in your survival suitcase?

Table 7.1: Overview of SEE SAW programme

SEE SAW STABILITY

SITUATION (part one)		**SURVIVAL STRATEGIES (part two)**	
S1.1	SPECIFIC INDIVIDUAL WITHIN A SPECIFIC SITUATION	S2.1	STAGES OF TREATMENT
S1.2	SYNDROME OF BIPOLAR AND RELATED DISORDERS (DSM 5)	S2.2	STEPS OF INTERVENTION

SITUATION (part one)		**SURVIVAL STRATEGIES (part two)**	
S1.3	SNOWBALL OF EPISODES	S2.3	STRATEGIES OF MANAGEMENT by the multi-disciplinary team in conjunction with the patient and caregiver
		S2.3.1	BIOLOGICAL • Pharmacological • ECT
		S2.3.2	PSYCHOSOCIAL • Psycho education • Cognitive-behavioural Therapy (CBT): • Interpersonal and Social Rhythm Therapy (IPSRT) • Family-focused Therapy (FFT) • Genetic Counselling/Education • Substance Abuse Treatment • Crisis intervention
S1.4	STIGMA, SECRECY IN THE STORM	S2.4	SELF-MANAGEMENT OF BIPOLAR DISORDER TO REACH STABILITY
		S2.4.1	Warning signs of relapse that caregiver and patient must become aware of and steps that can be taken:
		S2.4.1.1	Specific mania guidelines
		S2.4.1.2	Specific depression guidelines
		S2.4.2	Identifying and managing triggers
		S2.4.3	Know the risk factors and protective factors
		S2.4.4	Healthy balanced lifestyle
		S2.4.5	Stress management
		S2.4.6	Clearing out chaos
		S2.4.7	Learning to problem solve
		S2.4.8	Support network available for patient and family

SITUATION (part one)		**SURVIVAL STRATEGIES (part two)**	
		S2.4.9	Journal
		S2.4.10	Maintaining boundaries and setting limits
		S2.4.11	Create laughter and joy in your relationship
		S2.4.12	Spirituality
		S2.4.13	Self-education
		S2.5	STUMBLING BLOCKS
		S2.6	SUPPORTING THE PERSON WHEN HE/SHE IS ILL
		S2.7	SURVIVAL PLANS
		S2.7.1	• Psychiatric emergency
		S2.7.2	• Relapse prevention (minimising relapse)
		S2.7.3	• Suicide
		S2.7.4	• Well-being or wellness plans
		S2.7.5	• Treatment contracts
		S2.7.6	• Social Rhythm Metric (SRM)
E1	ETIOLOGY	A1	AID
E2.1	EVOLUTION AND PROGNOSIS OF THE ILLNESS	A2	ANIMAL: Ostrich
E2.2	THE EVOLUTION OF FAMILY RESPONSES TO MENTAL ILLNESS THROUGH TIME	A3	ASK for help and information - it is AVAILABLE.
E2.3	EXTRAORDINARY DEMANDS upon caregivers	A4	ASSESSMENT
E2.4	EXPECTATIONS MUST BE REALISTIC	A5	AWARENESS of personality
E2.5	EFFECT ON RELATIONSHIPS	A6	ADMISSION to hospital (Mental Health Care ACT 17 of 2002)
E2.6	EFFECT OF CULTURE	A7	Team APPROACH
		A8	ACCEPTANCE (hard work for both)
		A9	ADHERENCE to treatment
		A10	ALTERNATIVE treatment
		A11	ADMINISTRATION of property
		W1	WELLBEING OF THE CAREGIVER
		W2	WORK and finance
		W3	WELL KNOWN people

SITUATION (part one)		**SURVIVAL STRATEGIES (part two)**	
		W4	WHAT WORKS?
		W5	WAYS of keeping WELL
		W6	WAY forward (post episode period)
		W7	Make mental health system WORK for you

PART ONE: SITUATION

S1.1: SPECIFIC INDIVIDUALS WITHIN A SPECIFIC SITUATION

Your family member suffering from BD is a **specific individual within a specific situation**. Even the way a patient relapses is unique. It might be your husband, wife, parent, child or sibling. Each one of you is in a specific relationship to a patient and each relationship has unique **challenges**. You might also find that **roles** have changed in your relationships, which is very demanding. This illness affects the dynamics within a family system.

Alert: While treatment of BD is costly to society, not treating it costs even more due to lost wages and compensation, lost productivity and suicide. It can also take a toll on family members who act or try to act as caregivers (Haycock, 2010:22).

You are also a specific, special individual and it is important that you know **yourself** to be able to cope with the situation of being a caregiver. You should know your **strengths and weaknesses**.

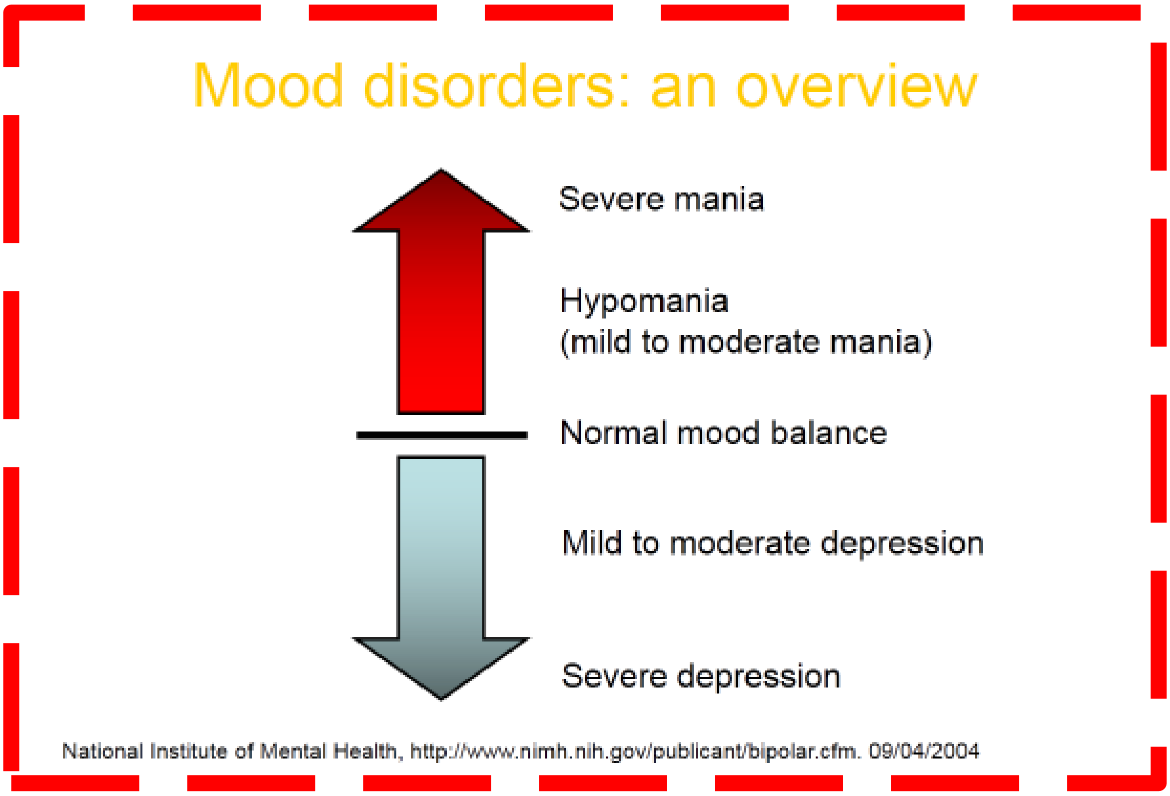
Question to the group: How do you understand bipolar disorder?

S1.2: SYNDROME OF BIPOLAR AND RELATED DISORDERS (DSM 5)

Fast and Preston (2006:xxi) state that bipolar disorder (BD) is **simply** an illness that affects parts of the **brain** that regulate emotions. Colom & Vieta, (2006:76) agree that it is a brain disorder. It affects the limbic system, neurotransmitters, and the endocrine system. Bipolar disorder is not your (the patient's) fault; it is a brain disorder that is influenced by many factors, including interactions between your biology and your environment. It must however be viewed as a serious condition requiring treatment because when it is out of control, it can destroy lives (Haycock, 2010:19, 23).

Before we can discuss bipolar disorder any further, we need to understand the role of the **DSM**. The American Psychiatric Association’s **Diagnostic and Statistical Manual of Mental Disorders** (DSM) is a classification of mental disorders with associated criteria designed to facilitate more reliable diagnoses of these disorders (DSM 5, 2013:xii). This classification is also used in South Africa.

The diagnosis of bipolar disorder is covered in the chapter of the DSM 5 which discusses **bipolar and related disorders** (DSM 5, 2013:123). For the purpose of today’s programme, only the most common diagnoses will be discussed.



National Institute of Mental Health, http://www.nimh.nih.gov/publicant/bipolar.cfm. 09/04/2004

Figure 7.1: **Mood disorders an overview**

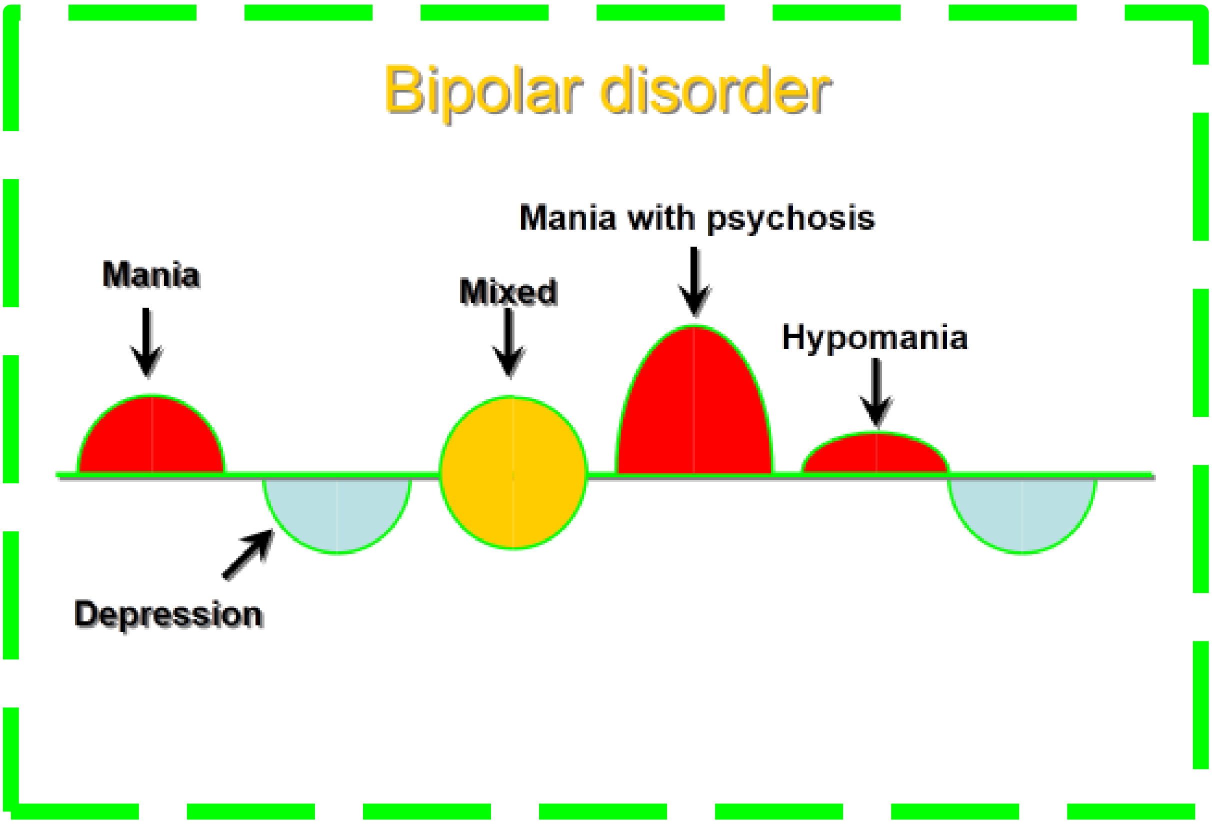


Figure 7.2: **Bipolar disorder**

- **Bipolar I disorder**

For a diagnosis of Bipolar I disorder, it is necessary to meet the criteria for a **manic** episode (DSM 5, 2013:123). The above figure depicts the hypomania, manic and mixed state over time and thus, in which way the sufferer's mood fluctuates. As was stated, a depressive episode is not necessary for the diagnosis of Bipolar I disorder, but a person may have had depressive episodes as well. Mixed features in the DSM 5 (2013:127) are referred to as being a specifier.

Simple truth: Mania is an abnormal, persistently high or irritable state of mood.

- **Bipolar II disorder**

For a diagnosis of Bipolar II disorder, it is necessary to meet the criteria for a current or past **hypomanic** episode *and* criteria for a current or past major **depressive** episode (DSM 5, 2013:132).

Difference between mania and hypomania: Mania is present in Bipolar I, while hypomania is part of Bipolar II. The difference is that hypomania, which shares the same symptoms as full-blown mania, is not as serious, although it still causes significant problems in the lives of people with BD. Both mania and hypomania have progressive symptoms (Fast & Preston, 2006:20).

Depression is a biological illness and it does not necessarily require triggering factors to appear. Bipolar depression is characterized by alterations that are more behavioural (apathy, anergy, hypersomnia) than cognitive. The essential characteristic of a depressive episode is that it involves a period of at least **2 weeks** during which there is a state of depressed mood or a loss of interest or pleasure for almost all activities (Colom & Vieta, 2006:85, 86, 89). Remember, depression is not something you are, it is something you have (Berk et. al., 2008:18).

Table 7.2: Symptoms of Bipolar disorder (Miklowitz, 2011:112)

Symptoms of mania	
	High (euphoric or elated) mood or irritable mood
	Decreased need for sleep
	Increased activity level
	Increased sexuality
	Pressure, fast speech
	Racing thoughts
	Appetite disturbance
	“Grandiose” or unrealistic beliefs
	Distractibility
	Loss of self-control and judgement
Symptoms of depression	
	Low mood or sadness
	Increased or decreased appetite and weight changes
	Sleeping too much or too little
	Loss of energy: excessive fatigue or tiredness
	Loss of interest or pleasure activities
	Changes in activity level
	Suicidal thoughts or actions
	Decreased ability to think or concentrate
	Feelings of worthlessness or excessive guilt
	Decreased sex drive
	Tearfulness
Symptoms of psychosis	
	Unusual or unrealistic beliefs
	Hallucinations
	Speech that is difficult to understand
	Impulsive, dangerous, or irrational behaviours
	Slowness, apathy, lack of emotional responsiveness

Symptoms tend to occur in clusters that comprise a syndrome. Several symptoms must occur together before the diagnosis of bipolar disorder is made (Miklowitz, 2010c:113).

Role of Caregiver: If you know the symptoms, you can act.

Recognising and monitoring symptoms

Ghaemi, Saggese and Goodwin (2006:6) present a useful acronym for **mania: DIGFAST**

Distractibility:	An inability to maintain one's concentration.
Insomnia:	A decreased *need* for sleep.
Grandiosity:	Inflated self-esteem.
Flight of ideas:	A subjective experience of racing thoughts.
Activities:	An increase in **goal-directed** activities (social, sexual, work, home)
Speech:	Pressured or increased talkativeness.
Thoughtlessness:	Commonly called *risk-taking behaviour*, for example sexual indiscretions, spending sprees, impulsive travelling and reckless driving*.* Ghaemi, Saggese and Goodwin (2006:7) conclude that mania is diagnosed when **euphoric mood** is present for **one week** with three of the DIGFAST symptoms, or **irritable mood** with four symptoms, and there is significant social or occupational dysfunction.

Another **tip** when looking at symptoms is the word **"FIND" - frequency, intensity, number and duration**.

Simple truth: One feature of manic episodes is accelerated **psychomotor activity**. This means there is an increase in bodily activity: pacing, walking, fidgeting, gesturing. In contrast, depressive episodes are typified by **psychomotor retardation**. Body movement is less rapid and active, due to diminished mental activity (Haycock, 2010:6).

- **Cyclothymic disorder**

The essential feature of cyclothymic disorder is a **chronic**, fluctuating mood disturbance involving numerous periods of hypomanic symptoms and periods of depressive symptoms. Full criteria for a hypomanic or major depressive episode are not met (DSM 5, 2013:140).

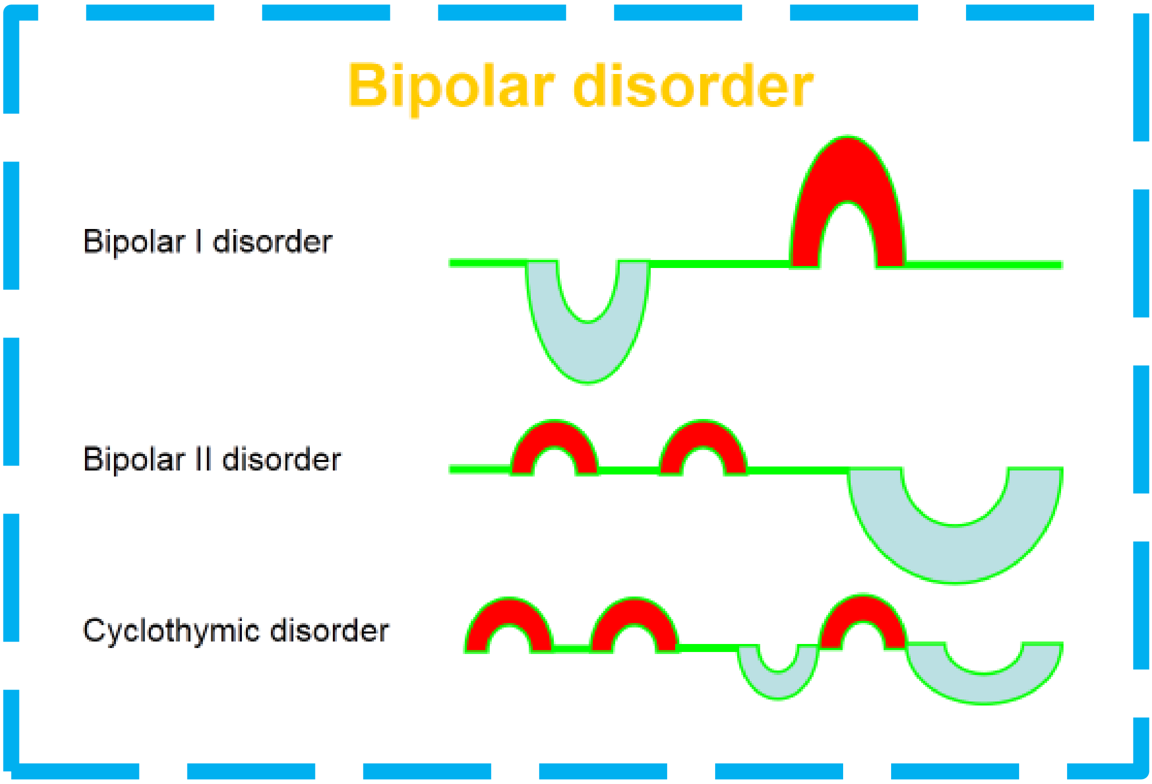


Figure 7.3: **Bipolar I disorder, bipolar II disorder and cyclothymic disorder**

National Institute of Mental Health, http://www.nimh.nih.gov/publicant/bipolar.cfm. 09/04/2004

From the figure above, it is clear that while **depression** is the important aspect of Bipolar II disorder, hypomanic episodes also occur.

- **Substance/medication-induced bipolar and related disorder**

The diagnostic features of substance/medication-induced bipolar and related disorder are essentially the same as those for mania, hypomania, or depression. A key exception to this diagnosis is the case of hypomania or mania that occurs after antidepressant medication use or other treatments and persists beyond the physiological effects of the medication (DSM 5, 2013:140).

- **Bipolar and related disorder due to another medical condition**

The essential features of bipolar and related disorder due to another medical condition are presence of a prominent and persistent period of abnormally elevated, expansive, or irritable mood and abnormally increased activity or energy predominating in the clinical picture that is attributable to another medical condition (DSM 5, 2013:146).

Different from schizophrenia: BD and schizophrenia are two different disorders that share certain kinds of symptoms, psychotic symptoms, just as the flu and an infection might also share symptoms such as a fever, but they continue to be two clearly separate illnesses (Colom & Vieta, 2006:82).

Correct diagnosis is important

Simple truth: For most people struggling with this condition, it takes at least **10 years** between the onset of symptoms and a correct diagnosis (Haycock, 2010:28).

Role of Caregiver: Family members play an important role in helping their loved one receive a correct **diagnosis**. Family members can describe prior episodes of mania, hypomania, or depression that the patient may have forgotten (Miklowitz, 2010c:32).

The only way to determine for certain if a patient has bipolar disorder is to consider past and present medical and mental health **history** with the help of a specialist qualified to diagnose mental disorders. A doctor will look for specific criteria that point to the presence of bipolar disorder and eliminate other medical conditions that produce similar symptoms (Haycock, 2010:18).

Essential: Sometimes symptoms attributed to bipolar disorder are caused by another serious condition. Patients with bipolar symptoms should receive a complete **physical exam** to exclude metabolic diseases or ailments such as Huntington's disease, brain tumours, or other medical conditions (Haycock, 2010:67).

For family and friends: When your loved one is first diagnosed with BD, it helps if you have a **list of questions** ready for his or her health care professionals. You can ask, "What **role** will I have to play in helping my loved one find stability? What are my **rights** as a family member?" Write down what you want to say and ask before you see a health care professional. Remember however that the patient also has rights and he/she must usually first give permission before the doctor may give the diagnosis to anybody else.

Bipolar disorder is frightening if it is untreated. **Recognizing and naming** the patient's major symptoms is the first step to take in understanding and beginning to **take control** over bipolar disorder. When you know what to expect, the illness can't throw you a curved ball anymore. This will help you to predict the future with some accuracy and also help you feel safer (Fast & Preston, 2004:35). This is true for the patient as well as the caregiver.

Warning: to receive an accurate diagnosis of bipolar disorder is to receive one of the most serious diagnoses in the field of psychiatry. If the patient ignores it, if the symptoms remain untreated, the patient could end up in a prison, a psychiatric hospital, or in a situation that increases the patient's risk of suicide. The patient can find him/herself broke and in debt, jobless with little chance of future employment, and isolated from other people because he/she cannot sustain healthy relationships (Haycock, 2010:252).

For the patient

- Give your doctor an honest self-report; it is the only way to obtain an accurate diagnosis.
- Being treated for bipolar disorder is a lifetime proposition, so you owe it to yourself to seek out a second opinion.
- Find out all you can about the medication you are taking.
- Ask questions (Haycock, 2010:29, 30).

S1.3: SNOWBALL OF EPISODES

At the beginning, **mania** is just like a little snowball sliding smoothly down a slope, not apparently dangerous and you can stop it with your hand. As it rolls down the mountain, there comes a point where it cannot be stopped without heroic measures and it may do a great deal of damage (Colom & Vieta, 2006:164). Episodes of bipolar disorder are **major life events**, not only for the patient, but also for all who **care** about him or her (Miklowitz, 2010c:6).

- **Mania**

Mania progresses in stages (Miklowitz, 2010c:24, 28).

Stage 1 *(prodromal period of escalation, hypomania)*. Family members may not notice anything unusual, except perhaps that he/she seems "weird", irritable, doing too many things at once.

During an *active or acute period* of illness (stages 2 and 3) the patient becomes severely ill.

During **stage 2**, he or she may be extremely elated and grandiose, making foolish decisions (e.g. regarding sexual indiscretions, risky or impulsive financial transactions), become more motorically hyperactive, and sleep little or not at all.
As **stage 3** sets in, the patient may have delusions and hallucinations, speak rapidly and nonsensically, and experience a dysphoric or panicky state in addition to mania euphoria or irritability. Family members know something is quite wrong at this stage and the

alternative of hospitalization is considered; they experience a great deal of **anxiety, worry, and feelings of helplessness** (also refer to evolution of family responses to mental illness). The manic person, however, loses insight, does not believe that anything is wrong and may fight attempts to have his or her behaviour constrained. Family members are perhaps most disturbed and frightened by **manic episodes**. Sometimes patients **disappear** at this stage, and family members do not hear from them again until they have been picked up by the police and admitted to a hospital.

For information: Not all patients show this progression of stages; some never become psychotic. Bipolar II patients never move beyond stage 1. There is no definite duration of these stages.

As the patient gradually begins to decelerate from a manic episode (the *recovery* or *residual* phase), he or she may re-experience stages 2 and 1 or alternatively may cycle into a severe depressive episode (Miklowitz, 2010c:28, 29).

- **Depression**

The **stages of a depressive episode** are less clear-cut. Often, the patient has been mildly or moderately depressed over a relatively long period (dysthymia) and the acute depressive episode reflects a worsening of this on-going state (Miklowitz, 2010c:30).

Symptoms leading up to the acute episode: (Miklowitz, 2010c:113-114).

Clinician: So, you couldn't **sleep**?
Peter: Yeah, I was staying up later and later. It didn't happen all at once, kind of gradually.
Mother: And I spoke to him on the phone and he was coherent, but **talking too fast** for me to follow. Something about cell biology.
Peter: I started reading all the time. I couldn't put down my biology book, which is weird 'cause I had thought before that biology was super boring.
Clinician: So sleep disturbance and this sudden interest in biology were your first signs?
Peter: Yeah.
Clinician: and then you started having **more energy** for work?
Peter: Yeah, but I also had this sense that I had **gained a few IQ points**, I felt I understood things like never before.

Question to the group: What manic/hypomanic symptoms can be identified?
Note that BD might be accompanied by symptoms of other conditions like anxiety or substance abuse and these are known as **co-morbid** conditions.

Roles of caregiver when episode is acute: **Not colluding** with the patient's developing episode by, for example, condoning or participating in risky behaviour, drug taking or drinking. You might have to be a **crisis manager**. Call the doctor or appropriate hospital emergency department or the police on behalf of the patient if he/she becomes worse or is in danger of hurting him/herself or others (Berk et al., 2008:194).

Roles of caregiver post manic or post depressive phase of illness: During a post manic or post-depressive phase family members must adapt to an ill relative who was once functional but now may be unable to interact with them constructively. When a man who is the primary wage earner becomes ill with bipolar disorder, his **spouse** may suddenly have to provide for the children and her ill husband. Likewise, the aging **parents** of an ill bipolar adult may find themselves in the unwelcome position of having to care for their offspring again, only now in the form of running to and from hospitals, answering late night calls from police, bailing him or her out of jail, and paying enormous medical bills (Miklowitz, 2010c:27). Give time to recover and talk things through and problem solve around difficult consequences rather than to criticise (Berk et al., 2008:194). The caregiver has an **extremely important role** to help the patient to obtain equilibrium.

It is important to keep track of the **pattern** of the illness. Most people with BD experience recurrent episodes with differing degrees of wellness between them (Berk, Jorm, Kelly, Berk & Dodd, 2008:10).

S1.4: STIGMA, SECRECY IN THE STORM

Question to the group: Can you think of any **prejudices** that society applies to psychiatric disorders?

- **Relevant audio type presented** (e.g. tape of "Whackhead" Simpson - a radio show where a presenter plays pranks on people. In this tape he refers to BD and clearly his ignorance is showed. It can lead to discussion in the group).

During the first confrontation with BD, you might feel that **secrecy** is important because of the **stigma**, social scorn and shame associated with mental illness and psychiatric hospitals. An added burden is that it carries the stigma of "mental illness", which makes it harder for many people to accept (Berk et al., 2008:xiv). In 12 step programmes, it is often explained that folks are "…only as sick as the secrets they keep". Sometimes the symptoms of BD also lead to keeping secrets and holding back important information (Freeman, 2011:17).

Stigma involves stereotyped beliefs about the negative qualities of a particular group (e.g. people with mental illness) (Berk et al., 2008:47*).*

Alert: Caregivers who are concerned about stigma sometimes isolate themselves from social contact and become depressed. Consequently, they may miss valuable sources of support and enjoyment (Berk et al*.*, 2008:47*).*

Accepting a psychiatric diagnosis means accepting **being different**. This is a very real issue for many patients, who usually feel uncomfortable telling friends, lovers, bosses, or co-workers about their symptoms or hospitalization. They believe, often realistically, that others will reject or avoid them and no longer desire their companionship. They fear they will be fired or demoted from their jobs (Miklowitz, 2010c:188, 189). They and their family need to consider:

- Whom do you tell about the disorder?
- How much do you tell them?
- What is the likelihood that these persons will actually respond with rejection?
- How can you de-stigmatize the disorder for these people, so they will not be afraid?

Question to the group: What would you say the causes of bipolar disorder are?

E1: ETIOLOGY

Genetic vulnerabilities, biological vulnerabilities, and socio environmental stressors interact in bringing about episodes of mood disorder or in protecting against their occurrence. Bipolar disorder is caused by multiple factors that interact with each other. No one person, event, or experience makes this disorder occur (Miklowitz, 2010c:49, 63, 129).

- **Genetic**: Although BD is a genetic illness, parents should not think they have done something wrong and that they caused their child to become ill (Fast & Preston, 2006:xxi). The disorder might not manifest itself until adulthood. In order for certain illnesses with a hereditary component to manifest themselves; certain environmental factors need to occur that are just as important as or more important than genetics, which is why the disorder does not manifest itself from birth. Oftentimes, the first episode is preceded by an environmentally **stressful** situation (Colom & Vieta, 2006:76).
- **Biological**: These mood swings are *not* character flaws. They result from biological changes in areas of the brain that control mood. These biological changes respond to

medication. It is a recurrent illness that may be compared to, for instance, asthma (Berk et al., 2008:xii).

A person's ability to adaptively control strong emotions relies on a very complex interaction of **brain chemicals** operating to regulate the millions of nerve cells in a part of the brain called the **limbic system**. The limbic system and a closely related brain structure, the **hypothalamus**, are responsible for igniting appropriate emotional reactions, for maintaining some degree of control, and for getting the brain and body back into a **state of homeostasis**. In addition, these **brain structures** also influence a number of biological functions such as sleep, appetite, sex drive, physical and mental energy and activity levels. To carry out these necessary functions, the brain must maintain a delicate **balance** of neurochemicals, most notably serotonin, norepinephrine, glutamate, GABA, and dopamine (Fast & Preston, 2006:36).

There are several **physiological mechanisms** involved in BD, most of them at the **neurotransmitter** level. Neurotransmitters are the substances in charge of carrying information in the brain. There is empirical evidence that some neurotransmitters (dopamine, serotonin, noradrenalin, acetylcholine) work abnormally in BD. There are also abnormalities in hormonal functioning, most of all in the **thyroid** hormone.

For information: We can currently say that without doubt, BD has a **biological base and is genetically transmitted**. Theories indicate that different psychological or social factors that were presumed to cause BD are no longer considered valid. We now know that all these factors may bring on the disorder or make it worse, but are never the cause of it (Colom & Vieta, 2006:71).

Bipolar disorder results from a **change in the mechanisms** that regulate mood. It appears that the **limbic system** is the area in the brain in charge of acting as an authentic "**mood-o-meter**", similar to the **thermostat** in an air conditioner: it keeps the temperature steady and activates the structures needed to **maintain equilibrium**. Likewise, the limbic system may be seen as a "mood thermostat" - in charge of keeping moods stable, constant and to react the right way to its surroundings (Colom & Vieta, 2006:67).

In the case of the thermostat, when it detects a temperature higher than the one it has been set at, it activates the cooling unit and it, in turn, activates the heater if the temperature is excessively low. A person's mood tends to be regular and dependent on their environment. When people are suffering from bipolar disorder due to their "mood-o-meter" not working properly, their mood becomes unstable, variable, and independent from their environment (Colom & Vieta, 2006:71).

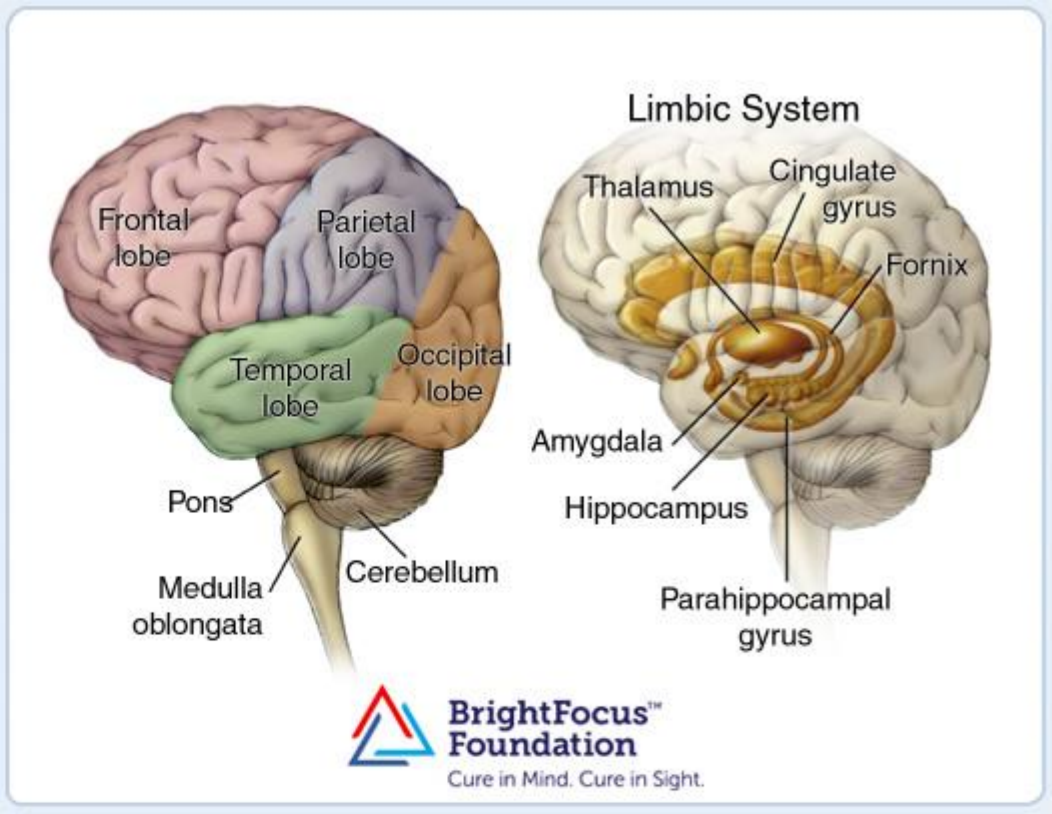


Figure 7.4: Sketch of the brain

We must distinguish between **causes** (biological) and **triggers** (either biological or environmental). It is important to make it clear that episodes can appear **without there being any trigger** (Colom & Vieta, 2006:73, 75).

We have to keep in mind, on the one hand the **genetic factors** that are responsible for a person being **vulnerable** to a particular disorder and, on the other hand, the factors implied in **stress** response (Colom & Vieta, 2006:76).

- **Stressors**: Miklowitz (2010c:11, 49, 121) focus on the **vulnerability-stress model**. The model emphasizes the **interaction** of genetic and biological factors that define the vulnerability to the disorder, and environmental stress factors that activate the underlying vulnerability. These two classes of factors interact with one another. No one event causes the disorder, but rather collections of events create cumulative levels of stress that would be upsetting to anybody.

Simple truth: Although the underlying foundation for bipolar disorder must have been present, some people report that their episodes began when they were under great stress. These stressful events may include childbirth, divorce or breakup of a relationship, loss of a job, death of a loved one, and serious financial difficulties (Haycock, 2010:63).

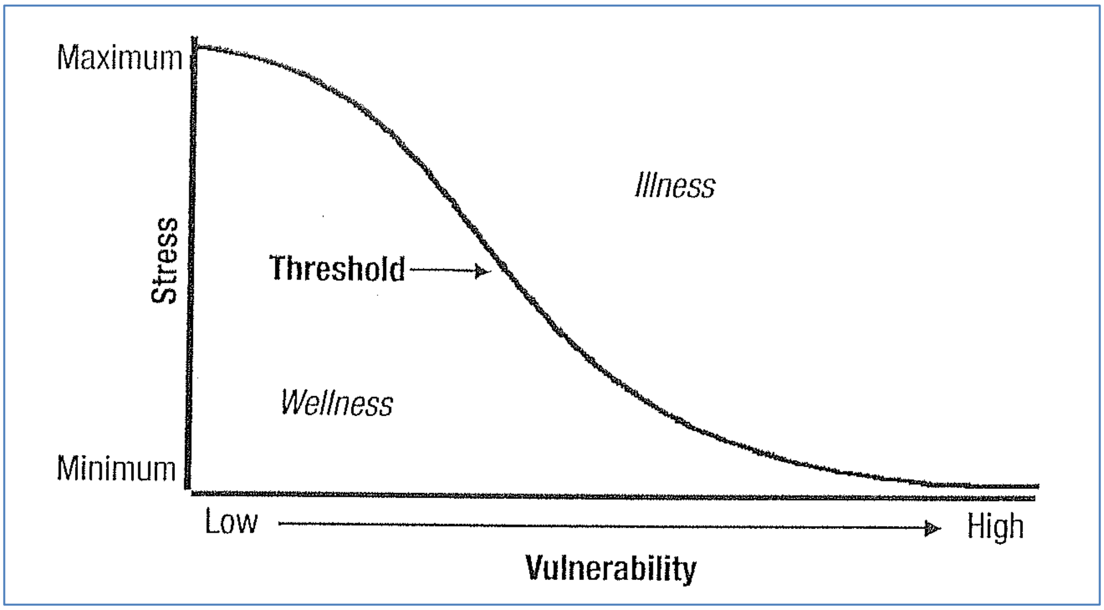


Figure 7.5: **The vulnerability-stress model for understanding periods of illness and wellness (Miklowitz, 2011:77)**

In summary: How do people come to display the symptoms of bipolar disorder? (Miklowitz, 2010c:132).

- People are born with a **genetic or biological predisposition** to develop bipolar disorder.
- The environment may become more **stressful** and interact with a genetic or biological vulnerability.
- **Coping skills** may be inadequate for dealing with environmental stress.
- **Drug abuse** can set off an existing biological vulnerability.
- **Sleep deprivation** and changes in **daily schedules** can set off an existing biological vulnerability.

Question to the group: Can I have children if I have bipolar disorder?

When one parent has bipolar disorder, there is a 15 to 30 % chance that your child will develop the illness. It's so easy to think, *it won't happen to me,* but it has already happened to your partner's parents, (their child, your spouse), so do not be naïve. This makes it also very important to watch for any early warning signs of mood swings in your children (Fast & Preston, 2012:206).

E2.1: EVOLUTION AND PROGNOSIS OF THE ILLNESS

Generally speaking, although there are exceptions, the disorder begins to become just barely noticeable **during adolescence**, reaching its peak in adulthood, when it manifests itself as a depressive or manic phase. A person is at the highest risk of having his or her first episode when he or she is under the age of 50. With every relapse, the affected person becomes more **vulnerable** to stress. The more episodes the patient experiences the more probable it is that he/she will suffer subsequent relapses. In addition the time interval between one episode and the next becomes shorter and the duration of the episode increases (Colom & Vieta, 2006:76, 100).

After the first episode, years may pass without any symptoms being felt by the patient (euthymic), but we must take into account that bipolar disorder is a **recurrent disorder** which means that many who suffer from it will present with future episodes.

Simple truth: Even though most persons who suffer from bipolar disorder return to total normalcy in the periods between episodes, some (20-30 %) continue showing affective liability or instability and interpersonal or work difficulties (Colom & Vieta, 2006:99).

Questions considered by relatives after a manic or depressive episode (Miklowitz, 2010c:174). Perhaps you have also wondered:

- Will he/she ever get better?
- Will he/she be able to work and be productive, and live independently?
- Will I always have to take care of him or her? What will happen to him or her when I die?
- Should I leave this relationship? Did I marry the wrong person?

E2.2: EVOLUTION OF FAMILY RESPONSES TO MENTAL ILLNESS THROUGH TIME

“The way in which **families** respond to mental illness varies as a function of time, undergoing its own patterned temporal development, a pattern that transcends individual differences in response disposition” (Terkelsen, 1987b:151).

Terkelsen (1987b:152-164) mentions the following stages:

- Ignoring what is coming
- The first shock of recognition
- Stalemate
- Containing the implications of illness
- Transformation to official patient-hood
- The search for causes
- The search for treatment
- The collapse of optimism
- Surrendering the dream
- Picking up the pieces

The researcher is of the opinion that caregivers of people diagnosed with BD go through a **process** of different emotions when first confronted with the illness and that they also **need time** before they come to accept and adjust to the illness. The material for this table is derived from personal and clinical longitudinal experience with families (more than 24 years) and adapting the above model (Terkelsen:1987b:152-164). There is however, great variation in the **pace** at which the **individual** members of **families** move along this path.

Table 7.3: The evolution of family responses to mental illness through time

STAGE	CONTEXT	EMOTIONS and responses of CAREGIVERS
1. Unaware of mental illness (may last for years)	Patient starting to behave in a strange way. Experiencing problems at work, in the family and society (neighbours may complain).	Ignoring, minimizing changes, providing assistance, concerned, are becoming anxious. Naiveté about mental illness.
2. Becoming slowly aware	Something serious happens: patient might commit a crime, spend family's money or act "crazy" in public. Recognition of possible mental illness.	Tell the affected person to "pull himself together", denial (emotional distance) and shock, bewildered, disruption in family, intensified anxiety and panic. Experience stress. Taking all the responsibility.
3. Aware of illness	Behaviour due to the illness (e.g. aggression, psychosis, withdrawal) can no longer be ignored. The patient may not	Start to seek help e.g. traditional healer or Western medicine. Fear of the unknown.

STAGE	CONTEXT	EMOTIONS and responses of CAREGIVERS
	be aware that he/she is ill. Conflict between family members might happen.	Feeling ashamed because of stigma and having judged. Embarrassment. Uncertainty. Overwhelmed. Sense of helplessness, unable to act effectively. May however, still be optimistic and hopeful. Unrealistic expectations and lack of insight. Want a “quick fix”.
4. Social status transformed to psychiatric “Patient”.	The patient becomes out of control. His/her life or someone else’s is threatened. Hospitalization might follow. Eventually a **diagnosis** is made, although it might still change.	Overprotective (visit every day). Anxiety and fear. Relief that a diagnosis is made. Emotional pain. Grief of losing the “well” personality.
5. Search for causes and treatment	Pre-existing belief system of family about the nature of mental illness. Challenge to family‘s capacity to cope with ambiguity, controversy, and unanticipated outcomes of treatment. Challenge of the institutional policies and practices within the mental health system. Demands on family to take patient home.	Guilt feelings. Blame the health system, the patient and also themselves. Loss of internal cohesiveness in family. Search for information on mental illness. In chaos, regarding what action is to be taken. Flight into health (minimizing the effect of the illness). Some caregivers may become depressed. Marital strain, disrupted social life, hardships for siblings. Unrealistic expectations of the patient may continue.
6. Collapse of optimism (months to years)	Family start to realize that the illness is chronic in nature and although patient might get better, he/she suffers relapses and does not return to previous level of functioning. Total remission	Over-concern Avoidance: family might start to withdraw and might also reject the patient. Hopelessness Resentment Frustration Anger

STAGE	CONTEXT	EMOTIONS and responses of CAREGIVERS
	is unlikely. Family must cope with the burden of the illness.	Mourning the loss of idealized internal images of the affected member. Grief reaction. Letting go of dreams. Family members restructure their lives to reduce contact with the patient.
7. Restoring equilibrium	Seeing the illness in perspective. Compartmentalize the illness so that it is seen as one of an array of challenges in the life of the family, rather than the central problem. Sought-after balance is hard to discover and harder to maintain. Letting go can be very difficult.	Adjust to the realities of long-term caregiving. Becoming realistic. Understanding, acceptance. Loneliness and isolation. Tolerance. Call attention to the inadequacy of currently available social supports and clinical services. Some caregivers might still reject the patient or might adapt a "don't care" attitude. The caregiver should talk about "issues"; if these are ignored, they will become bigger and resentment will grow exponentially, still affecting relationships years later.

Challenge to the group: share some emotions. Do you sometimes feel **overwhelmed** with your loved one's **needs**?

Simple truth: **Family members and friends** can experience a number of **conflicting emotions** when someone they love is diagnosed with bipolar disorder like **fear, worry**, **denial, anxiety, hopelessness, anger** and even **irritability**. You may be **shocked**. There can also be **grief and shame** at your own behaviour if you have judged someone for erratic behaviour. This is normal, because bipolar disorder can be very **frustrating** (Fast & Preston, 2006:1).

Family members often undergo a **grieving process** of their own. This is especially true if the patient has had more than one episode, and the reality of the illness now seems unavoidable. To close relatives, the person they used to know, who may have been talented, popular, energetic, and seemingly destined for success, is now dull, sedated, and unmotivated, or alternatively, grandiose and unrealistic.

It is easy to be **angry** at your partner when he/she is sick. Rest assured that you're not alone if you want to blame bipolar disorder for what it has done to your life or done to the person you love. Bipolar disorder is not a nice illness (Fast & Preston, 2004:136). This diagnosis is **a loss**, a major loss. The brain the patient thought would be there when needed, often malfunctions and is able to destroy the patient's life (Fast & Preston, 2006:259).

Sometimes you may feel **guilty**. You might feel like you want to run away. Your partner is needy and vulnerable and you wonder how you can only think of yourself in a time like this. You do not have to feel guilty about wanting to be in a healthy relationship. You have needs and dreams, and bipolar disorder is affecting this (Fast & Preston, 2004:138).

Words are often inadequate to describe the **fear** you feel when your partner has serious bipolar disorder symptoms. How can you explain to anyone what it feels like when the person you love literally changes overnight and starts to hear and see things you cannot hear or see? How can you explain what it is like when you realize your partner is missing, and you have no idea where they are? The ultimate fear presents itself when your partner says they want to die or when your partner actually attempts suicide (Fast & Preston, 2004:134).

Caregivers may also feel like they want to **withdraw** from the person or **leave** (Berk et al., 2008:36).

Alert: **Denial** on the part of family members is especially high during calm periods between bipolar episodes. It is then that the last episode may more easily be dismissed as an aberration, something that, although unpleasant, will not happen again. Such wishful thinking may have a negative effect on the ultimate fate of a person with bipolar disorder. Getting a professional opinion may help offset errors in self-diagnosis (Haycock, 2010:115).

E2.3: EXTRAORDINARY DEMANDS upon family caregivers that leave them exhausted.

Question to the group: what have you found the most demanding aspect concerning this illness?
Lefley (1987b:114-119) mentions certain **categories of behaviours** among the mentally ill that evoke differential response in significant others. These behaviours can intrude on the lives of others and make **extraordinary demands** upon family caregivers. Among them are:

- **Hostile, abusive or assaultive behaviours**: Typically reflecting poor impulse control, these behaviours are often related to inadequate or inappropriate medication. Hostility may be directed at other family members.
- **Mood swings and unpredictability**: Many family members find it difficult to contend with this type of inconsistency.
- **Socially offensive or embarrassing behaviour**: In addition to personal abuse, family members must often contend with the patient's acting out toward others. Neighbours may not want the patient living in the neighbourhood and may begin to ostracize the family.
- **Amotivation, refusal to take responsibility for self**: Family are constantly frustrated by the self-imposed isolation of the mentally ill family member, who seems willing to spend a lifetime doing nothing in a world in which activity is valued.
- **Self-destructive behaviours**: Rejection of a functional role is one way of being self-destructive. More overt behaviours include refusal to take psychotropic medications, which almost inevitably results in de-compensation and the revolving-door syndrome, or conversely, substance abuse, with similar sequelae.
- **Behaviours disturbing to household living**: Poor handling of money and poor personal hygiene are common complaints among family members. Sleep reversal is another difficulty encountered by family members who have the usual diurnal cycle. Property damage, both deliberate and inadvertent, may be a constant irritant.

These household disruptions often generate a cycle of events. Family members, few of whom are able to show the saint-like behaviour of constant low **expressed emotion (EE)**, register protest and complaint regarding intrusions on their daily equilibrium. Patients, fragile at best, respond with withdrawal, depression or come full cycle to the assaultive aggression, indicated at the beginning of this section. On the other side, the depression, fear, and anxiety experienced by patients who are beginning to return to the world of reality are empathetically felt by their parents, wives, siblings and sometimes, their children as well.

Burden

Another aspect that can be very demanding is the burden of being a caregiver. If you are the loved one of a person with bipolar disorder, perhaps you are hard on yourself for not figuring out sooner what the problem was. You might wish you could do more to help the person - or maybe worry that you are too protective and do more than you should. When you have to deal with the needs of a person with bipolar disorder and look out for other family members plus your own needs, you might feel as if there is no way for you to do it all. As a **caregiver**, you need to remember that you cannot do everything for everyone.

Simple truth: Your first priority should be making sure you take care of yourself as best you can. You will not be able to help someone else or yourself if you burn yourself out or suffer a mental or physical health crisis. You are not responsible for anyone's mental illness. You cannot heal anyone; you can only help (Haycock, 2010:189).

It is more the exception than the rule that the mental health service has developed routines for taking care of the family, who often **feel overlooked and forgotten**. When the support system contributes to humiliating, invasive and devaluating experiences for the next of kin, their burdens are amplified (Tranvag & Kristoffersen, 2008:5).

The behavioural and emotional experiences of the person with bipolar disorder **affect everyone**: the patient's parents, spouse, siblings, and children. In fact, as hospitalizations have become shorter and shorter, and as patients are discharged in quite unstable clinical states, the **burden** on the family has become considerable. It is easy to understand how the kind of stress and burden they experience can make them angry or resentful of the patient. In other cases, they may become overprotective or "enmeshed" with the ill family member (Miklowitz, 2010c:5, 26).

Essential: Did you know that it is completely normal and fine if you don't want to be one of the people your loved one asks for help? Not everyone is cut out for caretaking. You need to let your loved one know what you can and are willing to do. You have a life and you have the right to be true to yourself (Fast & Preston, 2006:177).

E2.4: EXPECTATIONS MUST BE REALISTIC

It is almost always best for the patient and family to reduce their expectations for the patient's social and occupational performance during the immediate **post episode** period. The patient and family must set **realistic goals**. If the patient is still hypomanic, he or she may try to resume the work habits of the pre-illness period, but may be cognitively and/or emotionally unable to handle the demands of these tasks. Likewise, if the patient is depressed, he or she may not have the motivation, energy, or mental stamina for these renewed responsibilities (Miklowitz, 2010c:27, 153).

E2.5: EFFECT ON RELATIONSHIPS

Bipolar disorder makes enormous demands on relationships. From neediness to unreliability, paranoia, insensitivity, acting moody, and feeling terribly lonely, BD can make the patient a difficult person to be near. One of the best ways for a patient to keep his/her relationships strong, even when undergoing mood swings, is to learn to recognize the **signs** that he/she is getting sick. The illness can then be treated, instead of the patient taking out his/her problems on the people around him/her (Fast & Preston, 2006:220).

Simple truth: It may be very difficult to remain friends with someone who has a lot of mood swings. It is difficult to have a loving and intimate relationship when one partner is a caretaker and the other is a patient (Fast & Preston, 2012:220, 184).

Haycock (2010:206-214) addresses different relationships:

- **Spouse with BD**

Disagreements about money is a common source of conflict for many couples, but when the one spouse is diagnosed with BD, the problem may be complicated by the lingering effects of a serious mood disorder. If there are children, their needs will have to be balance with the **partner's needs**.

Sexual problems are common with BD. From the lack of sexual drive when the patient is depressed to hyper sexuality when the patient is manic, BD can make a person's sex life really miserable. Then there are the medication side effects to complicate the problem. Treating bipolar disorder **first** so that you can find some stability is the best way to deal with sexual problems caused by the illness (Fast & Preston, 2006:234).

Alert: The often high rate of risky sexual activity among people with bipolar disorder makes them more likely to acquire sexually transmitted diseases or experience unwanted pregnancy than the general population (Haycock, 2010:198).

- **Parent with BD**

A child of someone with bipolar disorder might experience a **role reversal** that leaves the child feeling more like the parent than the child. Children may feel responsible for events involving family life such as marital strife, divorce, illness and tragedy that are, in fact, out of their control. If a parent could benefit from medication and chooses not to take it, his competency to parent is questionable.

- **Living with a sibling with BD**

Having a brother or sister with bipolar disorder can be a source of tension, depending on the relationships in the nuclear family.

E2.6: EFFECT OF CULTURE

Were you raised in a **culture** where mental illness was seen as a weakness? Is there a chance that you have passed this attitude on to your loved one? This illness is serious enough without worrying about the cultural pressure that many family members, often older ones, place on the person with BD (Fast & Preston, 2006:247). Cultural issues must be taken into account when devising psychotherapeutic strategies.

Important **roles** of the **caregiver** are those of **encourager** and being an **expert.**

PART TWO: SURVIVAL STRATEGIES

S2.1: STAGES OF TREATMENT

Treatment of bipolar disorder may be thought of as a **phasic process**: the **acute treatment** phase during which the goal is to treat an existing illness episode; the **stabilization** phase with the goal of remission and the **maintenance** phase when the goal is to prevent future episodes (Miklowitz, 2010c:42, Miklowitz, 2011:100 and Vieta, 2009:50, 52).

Table 7.4: Critical challenges in the stages of pharmacological and psychosocial treatment (Miklowitz, 2010c:42, Miklowitz, 2011:100 and Vieta, 2009:50, 52)

Stage	Goals of treatment	Issues for patient/family
Acute	Gain control over severe symptoms.	Trauma and shock, dealing with police and/or hospitalization (in some cases), making sense of what has happened.
Stabilization	Hasten recovery from the acute episode, address residual symptoms/impairment, encourage medication adherence.	Adapting to post episode symptoms and social-occupational deficits, financial stress, accepting a regular medical regimen, uncomfortable discussions about medication and illness, denial about realities of the disorder.
Maintenance	Prevent recurrences, alleviate residual affective symptoms,	Fears about the future, accepting the illness and the vulnerability to future

Stage	Goals of treatment	Issues for patient/family
	continue to encourage medication adherence.	episodes, coping with on-going deficits in social-occupational functioning, issues surrounding long-term medication adherence.

S2.2: STEPS OF INTERVENTION

First, the patient's **safety** must be guaranteed. It is important to alleviate symptoms and allow a return to usual levels of psychosocial functioning. Achieving rapid control of agitation, aggression, poor judgement, and impulsivity is particularly important to ensure the safety of patients and those around them and to allow the establishment of a therapeutic alliance (Vieta, 2009:77, 49).

Warning: A person in the midst of mania or depression may not understand what is happening to him or her. He/she has no power to **turn off** the episode and avoid its effects (Haycock, 2010:197).

Second, a complete **diagnostic evaluation** of the patient must be carried out.

Third, a **treatment plan** that addresses not only the immediate symptoms but also the patient's prospective well-being, must be initiated. Although current treatment emphasizes pharmacotherapy and psychotherapy addressed to the individual patient, stressful life events are also associated with increases in relapse rates among patients with mood disorders. Thus, treatment must reduce the number and severity of **stressors** in patients' lives. Mood disorders are chronic and the patient and the family must be advised about future treatment strategies. According to Vieta (2009:49), **subsequent goals** include establishing and maintaining a therapeutic alliance, monitoring the patient's psychiatric status and response to treatment, providing education about bipolar disorder to the patient and family, enhancing treatment compliance, promoting regular patterns of activity and sleep, anticipating stressors, identifying new episodes early, and minimizing functional impairments.

TIP: The patient should come to the appointment with the doctor **planning** to gain some information about diagnosis, treatment and medication (Zetin, Hoepner & Kurth, 2010:121).

S2.3: STRATEGIES of MANAGEMENT by the multi-disciplinary team (MDT) in conjunction with the patient and caregiver

It is important to recognise what the patient can do to help **him/herself** (i.e. to take medication and to develop skills for self-managing the disorder) and what the **family** can do to help (i.e. to participate in and facilitate the patient's treatment, keep the environment low in stress, and keep performance expectations to a minimum).

Paralleling the vulnerability-stress model, the treatment of BD consists of two primary components:

- A **biological (pharmacological and ECT)** management approach for correcting underlying biological vulnerabilities associated with the disorder and
- A **psychosocial** management approach to mitigate the effects of stress triggers (Miklowitz, 2010c:143). Psycho-education, cognitive behavioural therapy, interpersonal and social rhythm therapy, family focused therapy, genetic counselling and substance abuse treatment will be discussed.

Simple truth: If treatment is working, **stick with it**. Successful treatment requires sticking to a regimen (Haycock, 2010:149, 183).

Vieta (2009:49, 52, 53) refers to the fact that bipolar disorder is a chronic recurrent illness that requires a **comprehensive** and **long-term programme** of medical care to help patients overcome the symptoms and functional impairment associated with the condition. Although there is **no cure** for bipolar disorder, effective treatment can decrease the associated morbidity and mortality. A long-term **preventive strategy**, that combines medication and psychosocial treatments, is optimal for managing the disorder over time. The illness may result in negative consequences for the patient as well as for their family, friends, and the wider society. The extremes in mood swings of bipolar disorder, unless treated, can seriously affect well-being by damaging relationships, sabotaging education and careers as well as threatening financial security and personal safety (Haycock, 2010:1, 2). According to NIMH (2010:8) BD is best controlled when treatment is **continuous**, rather than intermittent. With adequate containment of their condition, patients with BD can improve their social and occupational functioning, sustain high work productivity, and achieve acceptable **HRQoL** (health-related quality of life), which in turn should reduce service utilization and lifetime healthcare costs (Vieta , 2009:13).

Simple truth: Miklowitz (2011:100, 128) states that regular contact with a caring mental health professional who collaborates with the patient on his/her health care will increase his/her feelings of hopefulness. Almost all therapy goes better if a patient is with a therapist he/she respects and trusts, with whom he/she has a good **relationship**, and who he/she feels genuinely cares about him/her. NIMH (2010:8) strengthens this view, when stating that treatment may become more effective when people work closely with a doctor and talk openly about their concerns and choices.

Essential: **Effective treatment** requires a well-informed patient, a supportive family and an understanding social network (Haycock, 2010:66).

There is an **anecdote** about bipolar disorders that shows that, even though its treatment is certainly modern, its history is lengthy. This is the **story** of the treatments received by Ferdinand VI (1713-1759), the Spanish King who suffered from bipolar disorder and who underwent a great variety of therapies including broth with turtles, frogs, veal and vipers; enemas; head baths; gelatin of deer antler and young viper and donkey's milk (Colom & Vieta, 2006:114).

S2.3.1 BIOLOGICAL

PHARMACOLOGICAL management (Medication)

- The single largest contributor to remaining free of mood disturbance is taking medication prophylactically. In order to stay well this means, among other things, taking **medication exactly as prescribed, every day of your life**. Most people with BD take multiple medications to keep their illness in check (Last, 2009:33, 95).
- Medication is the first-line treatment for bipolar disorder and according to Miklowitz (2011:98) and Taylor (2006:15) treatment without **appropriate medication** is doomed.
- According to NIMH (2010:6) it is important that before starting a new medication, people with BD should talk to their doctor about the possible **risks** and **benefits**. If the person with BD develops any **severe side effects** from medication, he or she should talk to the doctor who prescribed it as soon as possible. The doctor may change the dose or prescribe a different medication.

Question: Do you know **what** medication your loved one is using and the rationale for each prescription?

As a partner (caregiver) you need to know as much about medications as the person with the illness. You are the one who will be there when the side effects are difficult to tolerate, when the medications take a long time to work, and possibly when your partner goes off medication or refuses to take them (Fast & Preston, 2012:34).

For caregiver: It is important for **patients and family** members to become fully educated about the pharmacological treatments available to them (Miklowitz, 2010c:143). If you know WHY the patient is taking certain medications, it might be easier to motivate him/her to take it as prescribed. Never adapt the medication without the psychiatrist's permission. Suddenly stopping a medication may lead to "rebound" or worsening of BMD symptoms (NIMH, 2010:6).

Miklowitz (2011:103) states that in the best-case scenario, a medication regimen should do three things for a patient:

- Control and help resolve an episode that has already developed.
- Delay future episodes and minimize the severity of those that do occur.
- Reduce the severity of the symptoms a patient experiences between episodes.

The most widely used medications in the acute setting are **lithium**, some anticonvulsants (**mood stabilizers**), **standard antipsychotics, atypical antipsychotics and benzodiazepines** (Miklowitz, 2010c:143). Whenever possible, **oral therapy** should be offered first, but intramuscular injections are an alternative if oral therapy cannot be reliably administered (Vieta, 2009:77). Antai-Otong (2003:244, 245) refers to the fact that pharmacologic treatment of bipolar disorder often requires a **combined pharmacologic approach**. This often involves an antidepressant and a mood stabilizer.

1. Mood stabilizers

For decades mood stabilizers have been the **mainstay** of pharmacological treatment for bipolar disorder. They are used both in the treatment of **acute** mood episodes and as **maintenance** medication (preventatively) (Last, 2009:96). NIMH (2010:5) agrees that mood stabilizing medications are usually the first choice to treat BD. In general, people with BD continue treatment with mood stabilizers for years. Except for **lithium**, many of these medications are **anticonvulsants**, which are usually used to treat seizures, but also help control moods.

Miklowitz (2011:103, 104) mentions that to be **defined** as a mood stabilizer, a medication has to be effective in:

- treating acute manic, mixed, and/or depressive episodes of bipolar disorder without causing a switch to the opposite pole of the illness or rapid cycling and
- preventing future episodes from occurring.

Mood stabilizers can help to reduce symptoms of acute episodes and keep mood stable, preventing recurrence if taken in an on-going way. Certain mood stabilizers help to reduce suicide risk. It can take months before the person experiences the full benefits of the mood stabilizer (Berk, Jorm, Kelly, Berk, Dodd, 2008:10).

Simple truth: Fortunately, mood-stabilizing medications are not addictive.

The **main** mood stabilizers today are **lithium carbonate** and the **anti-convulsants**, typically, divalproex sodium or valproate, lamotrigine (Lamictal), or the older agent carbamazepine (Tegretol). Certain of the atypical antipsychotic medications, such as quetiapine (Seroquel), aripiprazole (Abilify), and olanzapine (Zyprexa), also qualify as mood stabilizers.

Lithium Carbonate

- The most well-known mood stabilizer is lithium. This psychotropic agent is still the first choice for Bipolar 1 **depressive** or **manic** episodes (Miklowitz (2011:104, 106). It was the **first** medication proven to **stabilize** mood in bipolar disorder and also to **prevent manic** or **depressive** episodes from returning.
- There is substantial data to suggest a role for lithium in the **prevention of suicides** in bipolar and other mood disorders (Levine & Chengappa, 2009:283).
- Last (2009:96) mentions that lithium has a **prophylactic** effect - it reduces the frequency, duration, and severity of future episodes of mania and depression.
- Another advantage of lithium is that it **may reduce dementia**. That is the **conclusion** of a 2010 Danish study, which found that people who took lithium had lower rates of dementia than people who took antipsychotics, antidepressants, or anticonvulsants (Haycock, 2010:52).
- AACAP (2007:119) emphasize that before the initiation of lithium therapy, **baseline** laboratory assessments should include complete blood cell counts, thyroid function tests, blood urea, nitrogen, creatinine and serum calcium levels as well as a pregnancy test in female adolescents.
- Last (2009:96), indicates that lithium can take anywhere from **10 days to 3 weeks** to work. Doctors will determine whether the **dose of lithium** is in the “therapeutic range” by measuring the level of the substance in the bloodstream. Early on in the treatment,

these blood tests are performed frequently to ensure that the level is at a point where it will be effective and not too high, since lithium at **high** doses can be toxic.

Patient Alert: Having your blood tested regularly helps prevent **lithium toxicity**. Miklowitz (2011:109) indicates that this state is extremely dangerous and even potentially **deadly** and it is therefore important to know the signs of toxicity so that you can get in to see your doctor as soon as possible. Some signs are problems with balance and coordination, blurry vision and disorientation. Last (2009:97) ads that **warning signs** can include **gastrointestinal symptoms** (like severe nausea, diarrhoea), **muscle coordination problems** (like severe tremor, slurred speech) and **altered consciousness** (like confusion or seizure). If lithium toxicity is suspected, the patient must go to the emergency room to get the proper treatment for this condition.

- NIMH (2010:6) indicates that when treated with lithium, it is important to make regular visits to the treating doctor.
- Common **side effects** of Lithium Carbonate according to Miklowitz (2011:115), NIMH (2010:6) and Last (2009:98) include weight gain, fatigue, sedation, stomach irritation, bloating, indigestion, or diarrhoea, joint or muscle pain, increased thirst, dry mouth, frequent urination, metallic taste in the mouth, hand tremor, thyroid dysfunction, acne or psoriasis, mental sluggishness or memory problems, kidney clearance problems, restlessness, brittle nails and/or hair. The dosage can vary from 300-2,400 mg per day and the blood level from 0, 8-1, 2 mEq/L.
- The sudden withdrawal of lithium may precipitate a relapse, so discontinuation, when decided on by the psychiatrist, should always be gradual (Colom & Vieta, 2006:114).

It is clear that in spite of all the **advantages** of lithium carbonate, it can also be **challenging** to have to take this medication. The patient and the caregiver will therefore have to be well informed about the rationale for the medication and his/her relationship with the MDT must be based on transparency and trust to ensure compliance.

Anti-convulsants

- For over two decades, **anti-epileptic drugs** (AEDs) have been integral to the treatment of bipolar illness (El-Mallakh, 2006:147). Last (2009:98), Miklowitz (2011:109) and Antai-Otong (2003:245) mention that although anticonvulsant medications were not initially developed for bipolar disorder, they were first approved for use in treating epilepsy; many of them were discovered to have mood-stabilizing effects properties effective in the treatment of bipolar disorder.

- **Divalproex sodium** (valproate) and **olanzapine** (Zyprexa) are standard treatments for the manic phase of bipolar disorder, but **carbamazepine** is also a well-established treatment. **Topamax** is another anticonvulsant showing benefit in bipolar patients. The most frequently used are **valproic acid** and carbamazepine (Tegretol) (Sadock & Sadock, 2003:570).
- Pre-treatment **workup** includes a complete blood cell count and liver function tests.

Patient Alert: A **pregnancy** test is needed because this drug can cause neural tube defects in developing foetuses. NIMH (2010:7) states that women with BD who are pregnant or may become pregnant face special challenges. Lippi (2009) highlights the fact that these medications can cause harm to the babies of pregnant patients, so if someone becomes pregnant while on these medications she should see the doctor as soon as possible to review the treatment. Stopping medications, either suddenly or gradually greatly increases the risk that bipolar symptoms will recur during pregnancy.

Consensus and practical guidelines concerning the treatment of bipolar disorders indicate the efficacy of **newer agents** such as **lamotrigine** (Lamictal) and **topiramate** (Topamax). Sadock and Sadock (2003:571) mention lamotrigine does not require blood monitoring and topiramate has the unique property of causing **weight loss**. There are some concerns about lamictal, because 5-10 % of people who use it develop a skin rash within 2 to 8 weeks of beginning treatment. This typically mild rash can, in rare instances, lead to more serious skin conditions such as **Stevens-Johnson** syndrome, a potentially life-threatening condition (Miklowitz, 2011:112).

Common **side effects** of mood-stabilizing medications may include:

- Fatigue, sedation, nausea, stomach pain, mild memory impairment, rash, problems with physical coordination, unsteadiness, constipation, dizziness, light-headedness, blurred vision and elevated liver enzymes. The most serious side effect of Carbamazepine, although quite rare, is a bone marrow reaction called **agranulocytosis**, which involves a dramatic drop in white blood cells (Miklowitz, 2011:115 and NIMH, 2010:6).
- Regular blood tests will indicate to the doctor if the patient is getting the proper dosage.

2. Antipsychotics

According to El-Mallakh (2006:185) antipsychotics are among the most frequently used medications in bipolar illness. Antai-Otong (2003:245) mentions that antipsychotics are frequently used as an **adjunct** to antidepressant therapy to treat psychotic symptoms of either acute mania or depression in the client with bipolar disorder until the mood stabilizer becomes effective. Vieta (2009:85, 86) states that **psychotic symptoms** (hallucinations, delusions or formal thought disorder) are present in more than half of all episodes of mania and are clear indications for aggressive treatment. Clinical guidelines vary in their recommendations for first-line treatment of psychotic mania. Some favour anticonvulsants over lithium when psychotic symptoms are present, while others recommend the combination of a mood stabilizer plus antipsychotic.

- There are **two kinds of antipsychotics** used today: the “older” or “conventional” types and the “newer” or “atypical” types:

Conventional antipsychotics (first-generation)

Serious problems can occur with the use of conventional antipsychotics, such as the potential to develop **tardive dyskinesia** (TD). NIMH (2010:12) states that this condition causes muscle movements that commonly occur around the mouth. A person with TD cannot control these movements. TD can range from mild to severe, and it cannot always be cured. According to Lippi (2009) the most **common side-effects** are tremors, dystonia, slow movements, restlessness, loss of facial expression, tiredness, dry mouth, urinary retention and constipation.

Atypical antipsychotics (second-generation)

Clozapine (Closzaril) was the first in this category. Hailed as a breakthrough in the early 1990s, it remains a potentially good option for people who do not respond to other mood stabilizers or antipsychotic medications. A potentially severe side effect of clozapine is that it can lower the levels of cells in the blood, which is why it is important that all patients on it have their blood taken regularly for testing, as scheduled (Haycock, 2010:75).

Today the **atypical antipsychotics** are usually the **first choice** for clinicians. Miklowitz (2011:114) states that increasingly, people are being treated with atypical (“second-generation”) anti-psychotics instead of, or in addition to, mood stabilizers. Many of these atypical antipsychotics **qualify as mood stabilizers**; they control acute episodes, decrease the vulnerability to future episodes and do not worsen the course of the illness. Atypical antipsychotics are evolving into the new standard for long-term treatment of bipolar disorder, even in individuals with no history of psychosis (Last, 2009:101).

According to NIMH (2010:5) **Olanzapine** (Zyprexa), when given with an antidepressant medication, may help relieve symptoms of severe mania or psychosis. Some studies show that people taking olanzapine may gain weight and experience other **side effects** that can increase their risk for diabetes and heart disease. **Aripiprazole** (Abilify) is approved for treatment of a manic or mixed episode. **Quetiapine** (Seroquel) relieves the symptoms of severe and sudden manic episodes. Miklowitz (2011:117) mentions that some doctors believe that quetiapine has the best record of *any* medication for treating both depression and mania in bipolar disorder. Two other atypicals - **Risperidone** (Risperdal) and **Aripiprazole** - clearly have antimanic properties and are often recommended as adjuncts to mood stabilizers if a person has manic or psychotic symptoms that do not resolve with a single medication. NIMH (2010:5) also mentions Ziprasidone (Geodon) as another atypical antipsychotic that may be prescribed for controlling manic or mixed episodes.

NIMH (2010:7) reports on **side effects**, which may include: drowsiness, dizziness when changing positions, blurred vision, rapid heartbeat, sensitivity to the sun and skin rashes. Atypical antipsychotic medication can cause major weight gain and changes in a person's metabolism. This may increase a person's risk for diabetes and high cholesterol. While taking these medications, a person's weight, glucose levels and lipid levels should be monitored regularly by a doctor. Clozaril, Seroquel and Zyprexa are known for their tendency to increase weight gain in patients as well as causing metabolic syndrome (Last, 2009:102).

Alert: Neuroleptic malignant syndrome is a very rare but extremely serious complication of nearly all antipsychotic drugs. The symptoms include rigid muscles that prevent movement, racing heartbeat, difficulty in breathing, fever, and confusion. It is crucial that the patient is immediately taken to a hospital so these life-threatening symptoms can be treated (Haycock, 2010:82).

3. Antidepressants

The **SSRI's** (selective serotonin reuptake inhibitors) are the most widely used antidepressants in the United States. They are the agents of choice because of their effectiveness, ease of use and relative lack of adverse effects, even in high dosages (Sadock & Sadock, 2003:566). According to Lippi (2009), they may also be used for **anxiety**.

Alert: There has been some alarmism about the use of antidepressants for individuals with bipolar depression. Antidepressants are usually recommended only **in combination with mood stabilizers** or **atypical antipsychotic** medications, not by themselves. In recent years there has been considerable controversy about whether antidepressants should be used at all in bipolar disorder. Nonetheless, given the **suffering** and impairment caused by bipolar depressions, most clinicians believe they should be kept as an option, especially if a patient has not responded to mood stabilizers or atypicals such as lithium, lamotrigine, or quetiapine (Miklowitz, 2011:118-120).

Floxetine (Prozac), Sertraline (Zoloft) and Bupropion (Wellbutrin) are examples of antidepressants that may be prescribed to treat symptoms of bipolar depression. Bupropion has a lower incidence of sexual side effects and weight gain than some other agents (NIMH, 2010:6).

One of the most serious concerns about anti-depressants is that they can cause people to become **suicidal** (their lethality when taken in **overdose**) and another is that they can bring on **hypomanic**, **manic**, or **mixed** states and cause rapid cycling. The **risk** of **suicide** in patients with mood disorder must always be considered. Most antidepressants are lethal if taken in large amounts. It is unwise to give large prescriptions to most patients with mood disorder when they are discharged from the hospital unless another person monitors the drug's administration. Sadock and Sadock (2003:566) are of the opinion that adequate **patient education** about the use of **antidepressants** is as critical to treatment success as is choosing the most appropriate drug and dosage. Patients with Bipolar 1 disorder, who are being treated with conventional antidepressants must be carefully observed for the emergence of **manic symptoms**. Patients are often concurrently maintained on therapeutic levels of a mood stabilizer.

Simple truth: It should be stressed that the patient will not become addicted to antidepressants, because the drugs do not give immediate gratification. Further, it will probably take 3 to 4 weeks for the effects of the antidepressant to be felt.

According to Sadock and Sadock (2003:566) the most common clinical mistake leading to an unsuccessful trial of an antidepressant drug is the use of too low a dosage for too short a time. Antidepressant treatment **should be maintained** for at least **6 months** or the length of a previous episode, whichever is greater. In this regard Vieta (2009:72) states that the goals of treatment in bipolar depression are to resolve depressive symptoms and establish a stable mood. In general, **what makes a patient well is likely to keep them well too**. Most guidelines recommend that antidepressants should be discontinued within 3-6 months of remission. The rationale for this approach is influenced by a concern that continued antidepressant treatment might induce switches into mania or cycle acceleration. Kowatch et al. (2005:9) say that it is recommended that antidepressant medication should be continued for at least 8 weeks after there is a depression remission.

Side effects may include:

- Headache, nausea, sleep problems (sleeplessness or drowsiness), agitation and sexual problems (including reduced sex drive and problems having and enjoying sex) (NIMH, 2010:7).

In conclusion, the treatment and prevention of bipolar **depression** is a major challenge in the long-term treatment of bipolar illness. While about one-third of patients may experience adequate prophylaxis with lithium or valproate, the majority of patients continue to be symptomatic. Antidepressants can play a role in the treatment of bipolar disorder, but special caution needs to be used to discover that minority of patients in whom antidepressants can be helpful, and to avoid that minority in whom they can be harmful (El-Mallakh et al., 2006:167, 180).

4. Benzodiazepines

Benzodiazepines are anti-anxiety agents that are often used in the acute phase of mania or to treat the accompanying symptoms of overwhelming **anxiety** and **panic** in the client experiencing bipolar symptoms (Antai-Otong (2003:245). Vieta (2009:84) and Miklowitz (2011:121) add that benzodiazepines are often used as adjuncts to lithium, anticonvulsants, or antipsychotics for the treatment of symptoms such as agitation, anxiety, or insomnia.

These medications are used for a brief time, until long-term medications become therapeutic.

Alert: **Potential disadvantages** of the use of benzodiazepines include the risk of **dependence** and the possible induction of either dysphoria or disinhibition. People may need higher and higher dosages over time to experience the same effects (develop tolerance) and can have withdrawal symptoms when stopping them, including seizures. Lippi (2009) also mentions that these medications are addictive and should not be prescribed for longer than 2 weeks, unless otherwise prescribed by a psychiatrist.

Common **benzodiazepines** include **lorazapam (Ativan), alprazolam (Xanax), diazepam (Valium) and oxazepam (Serepax)** (Kowatch et al., 2005:11). Lippi (2009) mentions that the following scenarios should be treated as **emergencies**:

- Patient has a convulsion and does not suffer from epilepsy.
- When patient suffers neuroleptic malignant syndrome or serotonin syndrome.
- An overdose was taken.

5. Anticholinergics

These are used to treat the tremors and muscle stiffness caused by antipsychotics. The most common side-effects are dry mouth, constipation and inability to urinate (Lippi, 2009). AACAP (2007:118-119) refers to the fact that the clinician must balance the potential deleterious impact of symptom reoccurrence versus that of the **side effects** of the medications. Any attempts to discontinue prophylactic therapy should be done gradually, while closely monitoring the patient for relapse.

6. Thyroid supplements

Miklowitz (2011:121) and Haycock (2010:80) point out that people with bipolar disorder often have **hypothyroidism**, and certain mood stabilizers, such as lithium, tend to suppress thyroid hormones. It is therefore not unusual for doctors to recommend thyroid medications - a thyroid supplement may help bring a patient back to a normal energy level. Research indicates that 30 to 50 % of people who do not have a complete alleviation of their depressions from traditional psychiatric drugs benefit from increasing their levels of T3 (the active form of thyroid hormone) with the prescription medication Cytomel, even if they do not test positive for hypothyroidism. Rapid cyclers and women are most likely to benefit from thyroid augmentation (Last, 2009:114).

It is the view of the researcher that **maintenance medication** is very important and she will therefore report on the opinions of a few **experts**:

Vieta (2009:87) states that maintenance medication is generally recommended following a single acute manic episode, in view of the 95 % lifetime risk of recurrence. The choice of pharmacological prophylaxis will be determined by the patient's history and response to prior trails. The **goals** of maintenance treatment include:

- Relapse prevention
- Reduction of suicide risk
- Reduction of sub-threshold symptoms
- Improvement in overall function

Kowatch et al. (2005:13) state that current research supports the efficacy of lithium, lamotrigine and olanzapine as **maintenance treatments**. The APA Practice Guideline for the treatment of patients with BD recommends that treatment with a maintenance agent should continue for a minimum of 18 months after stabilization of a manic episode. However, there are no clear answers to definitely inform clinicians regarding how long treatment should be continued.

Sadock and Sadock's (2003:571) opinion re maintenance is that the decision to maintain a patient on lithium (or other drug) prophylaxis is based on the severity of the patient's disorder, the risk of adverse effects from the particular drug, and the quality of the patient's support systems. Maintenance treatment is generally indicated for the prophylaxis of Bipolar 1 disorder in any patient who has had more than one episode. The rationale for this practice is the relative safety of the available drugs, their demonstrated efficacy, and the significant potential for psychosocial problems, if another bipolar I disorder episode occurs. During long-term treatment, laboratory monitoring is required for lithium, valproic acid, and carbamazepine.

In conclusion, AACAP's (2007:118-119) opinion is that patients and families must be **thoroughly educated** as to the **early signs and symptoms of mood episodes** so that, if necessary, resumption of treatment occurs as soon as possible. Diagnostic status should be reviewed over time to ensure that the course of medication therapy is justified.

Essential: NIMH (2010:8) warns that people with bipolar disorder should tell their doctor about **all** prescription drugs, over-the-counter medications or supplements they are taking. Certain medications and supplements taken together may cause unwanted or dangerous effects. Haycock (2010:78) states that there is a need to treat as many symptoms as possible with the **minimum** use of medications. Doses should also be as **low** as possible to minimize side effects and drug interaction.

Question: Can you share any **side effects** of the medication discussed that you are aware of with the rest of the group as well as methods to combat these side effects?

There is no way anyone can *force* a person to take responsibility for his or her treatment. Unless the patient makes the commitment to do so, no amount of love and support or even threats can make someone take this step (Mondimore, 2006:257). Patients whose caregivers were more emotionally **over-involved** were less adherent to medication (Perlick, et al., 2004:1033).

General: What is in a name?

Illman (2004:155) explains that drugs have **generic** (chemical) and **brand** names. The **generic** name is the name of the active chemical ingredient of the drug and is usually longer than the **brand** name. For example, Prozac is the brand name for Fluoxetine.

Drug checklist

Important questions for the patient to ask his/her doctor before starting a course of drug treatment:

Table 7.5: Drug checklist (Illman, 2004:155)

- What is the name of the drug being prescribed?
- What is it for?
- Will it interact with any other drugs I'm taking?
- Will I be able to drive while taking it?
- Will it make me drowsy or sleepy?
- What are the most common side effects and how long do they last?
- What should I do if I experience side effects?
- What is the right time to take it?
- How long will it take to work?
- How long am I likely to have to take it?

The patient depends on the doctor for the right medication, but should know the **rationale** for the different medications and should expect to have questions answered.

The reality of side effects: All medications have side effects and, unfortunately, the drugs used to treat BD are known to produce side effects in the majority of people taking it (Fast & Preston, 2006:51, 60). Once a patient can accept that he/she has an illness that needs medical treatment, taking the necessary medications may become easier.

TIPS not to forget the medication: (Colom & Vieta, 2006:142-143).

- Taking the medication at the same time with a daily routine act (when brushing teeth)
- Using “pill reminder boxes”
- Using some type of warning, such as the alarm or the clock
- Using “did you take your medication?” in the screensaver of the computer

When new medication is being introduced, it is imperative to keep a record of what is taken (dosage and time taken). The pathway to recovery, more often than not, is complicated.

The rule is trying several medications in the search for the right combination (Fast & Preston, 2006:47).

The following table, **Table 7.6** gives an overview of the relevant medication for the person diagnosed with BD.

Table 7.6: Overview of medication used to treat bipolar disorder (Fast & Preston, 2006:40-43, Fast & Preston, 2012:219-233, Kruger, 2013)

Mood stabilizers	Lithium	Eskalith, Lithonate, Camcolit
Other Mood Stabilizers	divalproex	Depakote
	carbamazepine	Tegretol
	oxcarbazepine	Trileptal
	lamotrigine	Lamictal
	topiramate	Topamax
	gabapentin	Neurontin
	sodium valproate	Epilim
	valproic acid	Convulex
Antipsychotics (first generation)	haloperidol	Serenace
	chlorpromazine	Largactil
	zuclopenthixol	Clopixol
	flupenthixol	Fluanxol
	trifluoperazine	Stelazine
Atypical antipsychotics (newly developed antipsychotic medications that treat psychotic symptoms and appear to have antimanic effects)	olanzapine	Zyprexa
	risperidone	Risperdal
	ziprasidone	Geodon
	aripiprazole	Abilify
	quetiapine	Seroquel
	clozapine	Leponex, Clozaril
Depot antipsychotics – preferably not for Bipolar Disorder	Clopixol depot	
	Clopixol acuphase	
	Fluanxol depot	
	Modecate	
	Risperdal Consta	
Antidepressants (used with caution)	fluoxetine	Prozac, Sarafem Lorien
	bupropion	Wellbutrin
	sertraline	Zoloft
	paroxetine	Paxil, Aropax

	venlafaxine	Effexor
	nefazodone	Serzone
	mirtazapine	Remeron
	citalopram	Celexa (Cipramil)
	escitalopram	Lexapro
	duloxetine	Cymbalta
	amitriptyline	Tryptanol, Tripiline
	clomipramine	Anafranil
	imipramine	Tofranil
	trazodone	Molipaxin
Calcium channel blockers*	verapamil	Calan, Isoptin
Benzodiazepines (also referred to as minor tranquilizers or antianxiety drugs)	diazepam	Valium
	clonazepam	Klonopin
	lorazepam	Ativan
	alprazolam	Xanax
	oxazepam	Serepax
Benzodiazepine sleeping pills	Temazepam	Restoril
	triazolam	Halcion
	zolpidem	Ambien
	zaleplon	Sonata
	eszopiclone	Lunesta

Alert: If a patient does not want to become **pregnant**, she should ask her doctor about the contraceptives that would be best, since some bipolar disorder medications can interfere with their effectiveness. If she does want to become pregnant, she should talk to her doctor to work out an appropriate treatment plan (Haycock, 2010:54). Tegretol, Trileptal, Topamax, and the herb, St.John’s Wort, can interfere with the actions of birth control pills (Fast & Preston, 2006:43).

Advantage: Fast and Preston (2006:35) state that not only do many of the medications used to treat BD reduce symptoms and help people maintain emotional stability, but some also have **neuroprotective properties**: they are able to protect the brain from being damaged by the illness, and may actually activate natural mechanisms for the growth of new nerve cells.

Warning about stimulants: It is well established that illicit stimulants such as cocaine and methamphetamine are notorious for causing manic episodes. Given this, for a number of years there has been some concern about the use of prescription stimulants to treat attention deficit/hyperactivity disorder (ADHD) in people who have both bipolar disorder and ADHD. It turns out that up to 35 percent of people with bipolar disorder also have ADHD. The most recent consensus is that stimulants such as Ritalin, Adderall, Dexedrine, and Concerta can be safely given to people who have bipolar disorder, but it is important to first be stabilized on bipolar medications before starting a stimulant (Fast & Preston, 2012:37).

For the patient: Once you have found a medication or combination of medications that works for you, **stay on it**. Your moods are stable because of medication, so if you stop taking it, the extreme mood swings are likely to return (Haycock, 2010:31).

In conclusion: According to Fast and Preston (2006:xii) it is normal for a patient to experience a love-hate relationship with their medication. Extensive research does, however, show that medications are the first line of defence against bipolar disorder mood swings. Finding the right medications can be very difficult. It can take a long time and the **side effects** can range from mild to very severe.

WARNING: Please note that it is very dangerous for you to encourage your loved one to get off medication and learn to manage the illness alone (Fast & Preston, 2006:49). Medication should be taken even when the patient feels well. Medication treatments are far from perfect, but they offer the kind of effectiveness that can substantially reduce suffering, keep families together, avoid catastrophes, and save lives

ELECTROCONVULSIVE THERAPY (ECT)

Keck, McElroy and Hawkins (2010:289) argue that ECT remains an important non-pharmacological treatment option for patients who do not respond well to or tolerate pharmacotherapy, or those who have severe, psychotic or catatonic symptoms. Miklowitz (2011:123) states that ECT is one of the more powerful treatment options available for people with bipolar disorder and other severe forms of depression. ECT works quickly and efficiently. It is mainly an acute treatment.

The researcher have observed that patients are frequently afraid of this procedure as they do not know what to expect. When this treatment is considered, it is therefore very important that the procedure and its possible side effects are properly explained to the patient and the caregivers.

Criticism against ECT

Because of the difficult and turbulent history of ECT, people with bipolar disorder and their family members frequently do not want to consider it, even in the direst circumstances. This is unfortunate, because in many cases, ECT is **lifesaving**. Many physicians recommend ECT very reluctantly as one of its **side effects** is a loss of memory. It appears that about two-thirds of people who receive ECT experience problems in memory functioning, but these seem to be temporary and usually disappear with time (Miklowitz, 2011:123). Other potential side effects include anxiety reactions, disinhibition, headaches and altered seizure threshold (AACAP, 2007:119 & Antai-Otong, 2003:246).

Clients receiving ECT are anaesthetized in a closely monitored medical setting and typically receive 6 to 10 treatments over a few weeks. According to NIMH (2010:8), ECT treatments on average, last from 30-90 seconds; patients usually recover after 5-15 minutes, and are discharged the same day. AACAP (2007:119) states that ECT is safe, as long as modern methods are used.

Candidates for ECT

In adults, ECT is an effective treatment for mania, but it is generally offered only for patients who have not responded to standard medication treatment (AACAP, 2007:119; Vieta, 2009:91, 92; Sadock & Sadock, 2003:571). ECT may be considered in patients with severe or treatment-resistant (refractory) mania or treatment-resistant mixed episodes. The treatment of acute, treatment-refractory bipolar depression is complex and poorly evidence-based. When first and second options fail, the most effective alternative is, again, ECT.

According to AACAP (2007:119) ECT is generally considered the treatment of choice for bipolar disorder in the following **clinical situations**:

1. Pregnancy - Miklowitz (2011:124) agrees, saying that although it may sound surprising, it is considered a safe option for women who are pregnant and severely depressed or manic. Most mood stabilizers and antidepressants carry some risk of harm to the unborn baby, but ECT does not, when administered under standard medical conditions.
2. Catatonia
3. Neuroleptic malignant syndrome
4. Any other medical condition, in which more standard medication regiments are contraindicated.

Lam et al. (2009:413) also include these **indications**: acute suicidality; psychotic features and rapidly deteriorating physical status due to complications from depression, such as: poor oral intake, history of poor response to medications, history of good response to ECT, patient preference, manic delirium, acute mania, unresponsive to medications, mixed states and rapid cycling, unresponsiveness to medications. Lam et al. *(*2009:417) mention the use of **maintenance ECT** (in which a single treatment is given every 1-8 weeks or longer) for selected patients to maintain response.

S2.3.2 PSYCHOSOCIAL Management

- Psychoeducation
- Cognitive – behavioural Therapy (CBT)
- Interpersonal and Social Rhythm Therapy (IPSRT)
- Family-focused Therapy (FFT)
- Genetic Counselling/Education
- Substance Abuse Treatment
- Crisis intervention

Essential fact: Colom and Berk (2010:412) allude to the fact that despite advances in pharmacological treatment, bipolar disorder (a biological illness) has **psychosocial consequences** both for the **patient and the family**. These factors, together with the huge gap existing between treatment efficacy and effectiveness and adherence problems, point to an urgent need to complement the available treatments for bipolar disorder with certain clinically based, **psychological approaches**.

Psychotherapies that address psychosocial difficulties and enhance illness management such as medication adherence and detection of warning signs of relapse, may play an important role in bridging the gap between symptom improvement, brought about by medications and a full recovery from illness (Swartz, Frank, Zajac and Kupfer, 2010:430). There is a growing body of evidence that supports the use of psychological interventions **in conjunction** with medication in the treatment of bipolar disorder (Berk et al., 2008:93).

Psychosocial interventions are needed to address the myriad of disruptions that emerge in the wake of the disorder. Efforts to enhance family and social relationships, including therapies, directed at communication and problem-solving skills, are likely to be helpful in bipolar disorder (AACAP, 2007:120; Ogilvie, Morant & Goodwin, 2005:30). **Psychosocial treatments**, which currently receive the greatest supportive evidence, are: **psycho-**

education, cognitive-behavioural therapy, interpersonal and social-rhythm therapy as well as family-focused therapy (FFT) (Vieta, 2009:64). This researcher would like to add: genetic counselling, substance abuse treatment and crisis management.

Role of caregiver: The patient and caregiver can/should also be **actively involved** - you are **not** a passive observer and have the right to be an informed participant in treatment. These treatment options can be delivered by the psychiatrist, psychologist, social worker or other trained therapists.

- **Psychoeducation**

Historically, minimal information of any type was given to caregiving relatives when the patient was discharged from hospital. Families have a burning **desire to know** all that they can about the strange disorder called "mental illness" (Hatfield, 1987b:201). Colom and Berk (2010:413) state that psychoeducation should be aimed at caregivers, as they are crucial in reinforcing the patient's positive behaviour towards the illness. This approach views the individual as interacting in a **dynamic ecological system**, and recognizes that the illness affects more than the patient alone.

Essential: The **burden of illness extends to the family**. There is evidence that stressful events within the family environment are often related to exacerbations of bipolar disorder; strongly **expressed emotion** has been described as an important predictor of relapse. Thus, bipolar disorder affects family relationships, and family relationships affect bipolar disorder (Colom & Berk, 2010:413).

Swann (2010:309) emphasizes the fact that if the **family** or those close to the patient do not understand the illness and its need for treatment, successful treatment is difficult, if not impossible. He also states that perhaps the most cost-effective approach is caregiver group psycho-education, educating and supporting caregivers, thereby reducing caregiver burden in bipolar disorder households. Van der Voort, Goossens and Van der Bijl (2007:686) stress the importance of assessing the illness-related **beliefs of the caregiver**, as the psychoeducationwhich is provided should match these beliefs.

- **Cognitive – Behavioural Therapy (CBT)**

CBT is a mode of treatment based on the idea that certain unhelpful types of **thoughts** and **behaviours** can trigger, escalate, and lengthen mood episodes. CBT focuses on the interplay among thoughts, behaviours, and emotions. Last (2009:116, 117) furthermore adds that the **cognitive** component helps people learn how to identify and then challenge their unhelpful, distorted thoughts and beliefs. The **behavioural** component of CBT contains a number of techniques that may be useful to those with bipolar disorder. Education about bipolar illness is offered and people monitor their moods every day, learning to be **vigilant** for their own, idiosyncratic, early warning signs of mood episodes. Other important components of the behavioural aspects of treatment include making lifestyle modifications, such as maintaining **good sleep hygiene** and keeping a **regular routine or daily schedule** for identifying and controlling cues and triggers of mood episodes. CBT is recommended for people who are relatively stable, following an episode of illness (Last, 2009:115). Parikh and Scott (2010:422) state that research studies **do not recommend** the application of CBT during **acute mania** and add that data on the utility of CBT during acute bipolar depression is only now beginning to emerge.

Other experts who recommend CBT for people with BD include NIMH (2010:7), Haycock (2010:89) and Berk et al. (2008:96), who mention that the cornerstone of this approach is to alter particular thought patterns and beliefs that is able to negatively change behaviour and increase the risk of developing or worsening a patient’s mood. CBT can help the patient recognize and manage potential mood-episode **triggers**. NIMH (2010:7) points out that the number, frequency and type of sessions should be based on the treatment **needs** of each person.

- **Interpersonal and Social Rhythm Therapy (IPSRT)**

Diverse authors, such as Miklowitz (2011:130), Berk et al. (2008:100), Haycock (2010:89, 90), NIMH (2010:7) and Colom and Vieta (2006:14-21) mention the use of Interpersonal and Social Rhythm Therapy (IPSRT) for bipolar patients.

Simple truth: **Regular habits and stress management** are extremely important in bipolar disorder and constitute the foundational ingredient of IPSRT. Moreover, developing regular habits and **routines** by means of IPSRT is efficacious in preventing recurrence of episodes in bipolar patients. Sleeping and social-rhythm disruptions have mood-destabilizing effects (Colom & Berk, 2010:418, NIMH, 2010:7).

Miklowitz (2011:130) explains that IPSRT is a form of interpersonal therapy that includes monitoring sleep-wake rhythms, patterns of daily activity and levels of daily social stimulation. This therapy has demonstrated delayed recurrences of bipolar disorder and increased the stability of daily routines and sleep-wake cycles. Swartz et al, (2010:430, 431) state that IPSRT is a tool to facilitate a full recovery from illness and promote long-term wellness. It integrates psychoeducational, interpersonal, and behavioural strategies in order to reduce symptoms, improve functioning and prevent recurrence of episodes. IPSRT fuses three distinct interventions: psycho-education, social rhythm therapy and interpersonal therapy, into a single psychosocial treatment.

Interpersonal and social rhythm therapy (IPSRT) was **specifically** developed to treat bipolar disorder. It concentrates on improving relationships with others and organizing or managing daily routines, including sleep schedules. Since lack of sleep and disrupted daily rhythms may trigger or worsen the severity of mood episodes, IPSRT encourages patients to establish and maintain **regular** eating, sleeping, working and relaxing routines, while improving skills for **interacting** with others (Haycock, 2010:89, 90).

According to Berk et al. (2008:100), IPSRT emphasises the role of interpersonal **relationships** in mental wellbeing. It recognises the role of loss and grief in dealing with bipolar disorder and offers clients the opportunity to express this and develop personal ways of adjusting. The other key element of IPSRT in dealing with bipolar disorder relates to the patterns of daily life, our *social rhythms.* This approach emphasises how disruption to regular social rhythms **can trigger** an episode of illness. There is evidence that regular day-night (circadian) rhythms are important in maintaining stable moods in bipolar disorder. The patterns of daily life includes such things as the time we get up and go to bed, and our usual activities, such as going to work or a regular morning meeting with friends. People involved in this therapy are encouraged to monitor their sleep/wake cycle (circadian rhythm), patterns of daily activity and levels of daily stimulation, like the number of people with whom they come into contact. This allows them to regulate their daily patterns so that their mood is not disrupted.

Essential: **One** of the techniques this individual therapy relies on is **self-monitoring**. Its value lies in preventing episodes more than in speeding recovery from them. To help stabilize their daily routines, people are asked to record their mood states, events and activities and level of social stimulation each day on a “**social rhythm**” chart (Haycock, 2010:90 & Last, 2009:120).

Swartz et al. (2010:440) report that the current research suggests that IPSRT successfully promotes rhythm stability and, when used as an acute treatment, leads to decreased likelihood of affective episode recurrence, increased occupational functioning and quality of life, when compared to clinical management interventions.

Role of patients and caregivers: Monitoring the patient's rhythms and patterns of daily activity. If any disturbance to the pattern is noticed, it should be reported to the MDT. The "social rhythm" chart can be a valuable tool; it is something concrete with which to assist discussion of a complex situation.

Family-focused Therapy (FFT): Miklowitz (2008:7-11) states the objectives of FFT as follows; to:

- Assist the patient and relatives in **integrating** the experiences associated with episodes of bipolar disorder.
- Assist the patient and patient's relatives in accepting the notion of a **vulnerability** to future episodes.
- Assist the patient and relatives in accepting a dependency on mood-stabilizing **medication** for symptom control.
- Assist the patient and close relatives in **distinguishing** between the patient's personality and his/her bipolar disorder.
- Assist the patient and family in recognizing and learning to **cope** with stressful life events that trigger recurrences of bipolar disorder.
- Assist the family in re-establishing **functional relationships** after the episode. (Please note that it has also been mentioned in this chapter when different programmes were discussed).

Miklowitz (2010b:443) points to the importance of considering the family or marital context when understanding the symptomatic fluctuations and functional consequences of BD. If nothing else, BD **creates havoc and emotional pain** for family members, to the point where they develop health and mood problems themselves.

Essential: The compromised emotional state of some caregivers may have a negative influence on the patient's course of illness. On the flip side, a spouse or parent who develops an understanding of the nature, course, triggers and treatment of the disorder may help to create a milieu which helps protect the patient against recurrences (Miklowitz, 2010b: 443).

Miklowitz (2010b:444) states that FFT consists of three stages: **psychoeducation** about the nature, aetiology, treatment and self-management of BD; **communication enhancement** training in which patients and caregivers rehearse effective speaking and listening skills; and **problem-solving** skills training, in which patients and caregivers define problems, generate and evaluate solutions and implement solutions to specific conflicts in the family. FFT is considered adjunctive to pharmacotherapy, not as a substitute for it.

Other authors have also commented on FFT. Vieta (2009:98) states that FFT is similar to psychoeducation, but places greater emphasis on achieving the support and cooperation of family and caregivers as integral components of successful treatment. According to Last (2009:121), FFT was originally designed to strengthen social support and reduce "**expressed emotion**" that is critical, hostile, or over-involved attitudes and behaviours that family members may exhibit toward the ill individual. The heart of the therapy is educational.

Berk et al. (2008:99) refers to the fact that FFT therapy is an inclusive approach that involves the person with bipolar disorder, as well as members of their family. The **aim** is to strengthen **healthy interaction and support between family members** and to help resolve any existing conflict in the family. The family works together to prevent relapse. Family-focused therapy helps enhance family coping strategies, such as recognizing new episodes early and helping their loved one (NIMH, 2010:7).

According to Last (2009:122), recent results from a large-scale, multi-site investigation of the treatment of BD, showed that FFT was as effective as other skills-oriented therapies, including CBT and IPSRT. Miklowitz (2010b:447, 448), states that FFT is effective in stabilizing bipolar mood symptoms and delaying recurrences and rehospitalisation. It also appears to benefit family relationship functioning. FFT should be considered whenever patients have access to family members and especially when levels of criticism, hostility or over involvement characterize family or marital relationships.

Essential for caregivers: Caregivers should be included in the treatment of bipolar patients. Combining family psycho education with pharmacotherapy has broad effects on patient' symptoms (time to recovery, time to recurrence, symptom severity) and psychosocial functioning (Miklowitz, 2010b:448).

- **Genetic Counselling/Education**

There is substantial evidence that supports the role of genetic factors in major psychiatric disorders. Clinicians are increasingly confronted with questions from patients and families regarding **risks** of disorders for themselves or their children. Genetic counselling has been **defined** as "…a communication process which deals with the human problems associated with the occurrence or the risk of occurrence, of a genetic disorder in a family" (Finn & Smoller, 2006:109).

Peay, Veach, Palmer, Rosen-Seidley, Gettig and Austin (2008:7, 8, 16) mention that psychiatric disorders are complex, fraught with diagnostic ambiguity and phenotypic variability and they engender feelings of stigma. The **uncertainty** associated with psychiatric disorders poses challenges for genetic counsellors because the current state of science does not allow the provision of conclusive information regarding aetiology, risk, or consequences of the disorder for any given individual or family. Despite the many sources of uncertainty, it is important not to underestimate the potential importance of genetic counselling for families affected by mental illnesses. An understanding of the cause of the illness may be an important component of successful adaptation to that illness, or to the risk of the illness. **Genetic counsellors can**:

- Help clients better understand the **cause** of the mental illness in their family.
- Provide a **safe forum** for clients to discuss their experiences of living with mental illness in the family, and concerns for others in the family.
- Help to **recognize** when psychiatric disorders within a particular family may in fact be syndromic.
- Discuss the range of disorder phenotypes, especially related to signs to watch for in Help clients better understand the **cause** of the mental illness in their family.
- Provide a **safe forum** for clients to discuss their experiences of living with mental illness in the family, and concerns for others in the family.
- Help to **recognize** when psychiatric disorders within a particular family may in fact be syndromic.
- Discuss the range of disorder phenotypes, especially related to signs to watch for in young people in the family, and the importance of **early intervention**.
- Help clients managing the uncertainty surrounding **risk** in offspring.
- Co-counsel with a mental health professional who can suggest appropriate **follow up**.

In conclusion, sometimes people who have a parent or a sibling with bipolar disorder wonder if there is some chance that they might also develop this disorder. Unfortunately, there are currently very few genetic counsellors or mental health professionals who specialize in this type of service provision. Psychiatric genetic research is progressing rapidly, and our understanding of the contributions of genes to the development of major psychiatric illness is ongoing. For the time being, the single greatest known risk factor for developing a psychiatric disorder is having a positive family history (Austin, Palmer, Rosen-Seidley, Veach, Gettig and Peay, 2008:28). See **figure 7.6** for an example of a family pedigree.

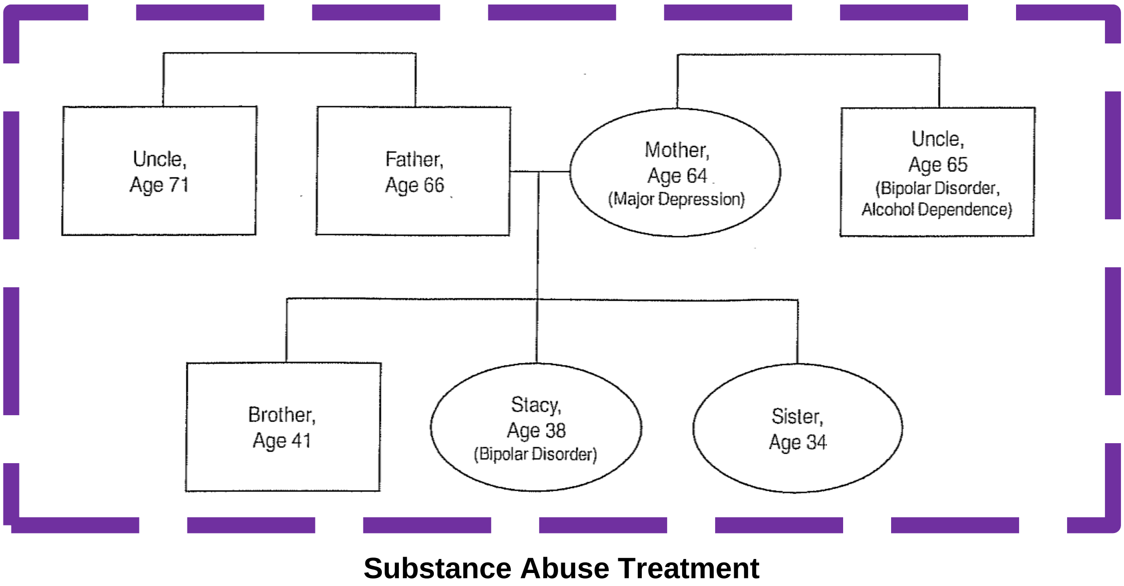


Figure 7.6: **An example of a family pedigree (Miklowitz, 2011:78)**

Warning: **Substance abuse** is extremely prevalent among people who have bipolar disorder, appearing at some time during the course of the illness in at least 60 % of individuals who have the diagnosis (Last, 2009:188 & Haycock, 2010:106). One out of every three bipolar patients presents with a substance abuse problem as **co-morbidity** (Colom & Vieta, 2006:147).

Alcohol affects BD in **two ways**: it causes depression and it interferes with sleep. Alcohol undermines sleep by significantly reducing the time spent in slow-wave sleep (deep-sleep) and this affects a sufferer's moods adversely by making the person more depressed (Fast & Preston, 2006:77).

Haycock (2010:67) emphasizes that substance abuse **treatment** will be necessary if a person is addicted to or abuses drugs or alcohol. Treatment may happen while a patient is hospitalized for BD if the unit treats **dual diagnosis** patients, or in a **rehabilitation centre** or on an **outpatient** basis. A patient and the caregiver can also attend support group meetings. Last (2009:191) refers to the fact that those who have a dual diagnosis (bipolar disorder and substance abuse or dependence) can attend a 12-step programme such as Alcoholics Anonymous or receive individual therapy.

Simple truth: **Alcohol** is commonly used by bipolar people to **self-medicate**, both in manic and depressive episodes, although research indicates it's more commonly used during manic or mixed states. Alcohol compromises the efficacy of pharmacological treatments, dramatically increases the risk of **suicide** and may promote bipolar symptoms. In addition to alcohol, bipolar people may use **street drugs** or abuse **prescription drugs** to self-medicate and "manage" their moods (Last, 2009:188, 192). These substances prevent the medications from working properly (Haycock, 2010:67). The abuse may mask the affective symptoms and "pollute" their presentation, leading to confusion in diagnosis (Colom & Vieta, 2006:147).

If a patient uses alcohol and drugs, the patient is likely to become inconsistent as regards his/her medication regimen and will have more trouble stabilizing as a result (Miklowitz, 2011:177). Alcohol causes depression in the medium term, increases anxiety, destructures sleep, reduces impulse control, causes cognitive deterioration, increases aggressiveness, and may cause the appearance of psychotic symptoms and mania.

Simple truth: Alcohol always makes BD worse. To avoid alcohol altogether is the best defence (Fast & Preston, 2006:77).

Psychoactive Substances and the effect they have on the bipolar patient

Simple truth: Recreational drug use and abuse often result in symptoms **similar** to those of BD. Recreational drugs fall into three main categories: **stimulants**, including powder cocaine, crack cocaine, and amphetamines; **depressants**, such as alcohol, tranquilizers, and barbiturates; and **hallucinogens**, which can be considered minor, such as marijuana, or major, such as LSD (Haycock, 2010:43).

The mere consumption of alcohol, cannabis and other toxics, even without reaching abuse quantities, can act as a **trigger** for a new episode. Patients must also be warned about the misuse of **coffee (caffeine)**, because many of them tend to drink it in excess, which might have an impact on the **quality** of **sleep** structure; it is also a potential inducer of hypomania and anxiety. Even cola drinks and stimulating beverages (such as Red Bull) are toxic substances with abuse and dependency potential and are accordingly inadvisable for a person suffering from bipolar disorder. In summary: consumption of **toxic agents** worsens the psychiatric symptomatology (Colom & Vieta, 2006:32, 147, 150, 153).

Marijuana: Creates an amotivational syndrome characterized by great apathy, it depresses, can trigger mania, interfere with sleep, increase anxiety and may cause psychosis.

Myth: Marijuana does not have harmful effects on mental health (Colom & Vieta, 2006:150).

Cocaine: Can trigger any type of episode – rapid cycling, anxiety, aggressiveness and psychotic symptoms.
Hallucinogens: Bring on psychotic symptoms. In a person with bipolar disorder, this might cause mania or anxiety.

Important: The only problem with bipolar patients smoking occurs when they stop smoking (probably because it will make the person irritable). Important tips include not trying to stop smoking during decompensation, rather in periods of greater stability. Do not try to stop suddenly (Colom & Vieta, 2006:154).

Role of caregiver: Go to support group like AA or NA.

- **Crisis intervention**

Crisis intervention may sometimes be necessary, for, instance when a patient starts to threaten **suicide**, becomes very **aggressive** or **psychotic**. It is important that you (the caregiver) communicate with the person clearly and calmly. Do not give a lot of instructions, argue, criticize or behave in a threatening way towards the patient. If appropriate, give the person choices to reassure them that they have some control over the situation (Berk et al*.,* 2008:19*).* If the patient or family should call the therapist, the situation must be assessed and an appropriate plan should be implemented. In the case of a **manic relapse** arrange hospitalization or emergency outpatient evaluation (Miklowitz, 2010c:289).

Suicide is an example of a crisis that may happen.

WARNING: Fast and Preston (2006:xxi) mention that bipolar disorder has a high suicide rate; more than 15 % in some studies. This is a real threat and must be taken very seriously. The caregiver will need to know the signs of suicidal thoughts and have a plan.

- **Suicide is not a right, but rather a complication of the disorder**

(Colom & Vieta, 2006:89). This is naturally the most dangerous part of BD. It is unnerving for a family member to observe suicidal behaviour, and it is very frightening when you hear your loved one say he or she wants to die. Suicidal ideation must be **treated aggressively with medications and help from a trained health care professional**. If you are afraid your loved one is going to try to commit suicide, you need to get him or her to appropriate help immediately, despite any protests. It is sometimes so difficult that you may feel you will not live through the event yourself, but you can. You need tools ready and in place for if and when suicidal threats do occur. You also need to be prepared to ask: “Are you suicidal?” as soon as you see **warning signs**, such as the person giving away possessions, crying all day, becoming aggressive and/or engaging in extremely risky behaviours. They might also say, “You would be better off without me.” It is also important to know that someone who is suicidal can appear calm and silent before actually attempting suicide.

Essential: Don’t wait until it’s too late to help your loved one (Fast & Preston, 2006:248).

Simple truth: **There are certain things relatives can and cannot control** – they can learn as much as possible about the illness, they can keep their own reactions from getting out of control, and they can communicate to the patient their desire to help and/or their frustration over his or her lack of acknowledgement of the disorder. However, relatives cannot single-handedly force the patient into the hospital, control his or her mood swings, or make him or her take medications. Relatives must determine **which actions on their part will help, and which will not**. Relatives must also take care of themselves during crises.

In conclusion, **any treatment strategy** should be based on the **needs** of the individual after **assessment** of the situation. The **prognosis** is always **better** if it is a **team effort**.

S2.4: SELF-MANAGEMENT OF BIPOLAR DISORDER TO REACH STABILITY

(For both the caregiver and patient to acknowledge – each will have a role to play). It needs to be said that there are some overlapping between warning signs of impending relapse, triggers and risk factors.

Role of caregiver: All athletes need trainers. You can play a significant role in helping your loved one find stability instead of simply watching them struggle (Fast & Preston, 2006:66). You can become the **coach**. Inevitably, you are walking the bipolar road with the patient, and being aware of some very important aspects will definitely make it easier for both of you.

It is important that the caregiver and the patient should realize that there are things they can do to not to become victims of BD. The following are possibilities to take note of.

S2.4.1. Warning signs of impending relapse (manic or depressive episode) that caregiver and patient must become aware of and steps that can be taken
S2.4.1.1 Specific mania guidelines
S2.4.1.2 Specific depression guidelines
S2.4.2 Identifying and managing triggers
S2.4.3 Know the risk factors and protective factors

S2.4.4	Healthy balanced lifestyle
S2.4.5	Stress management
S2.4.6	Clearing out chaos
S2.4.7	Learning to problem solve
S2.4.8	Support network available for patient and family
S2.4.9	Journal
S2.4.10	Set boundaries
S2.4.11	Create laughter and joy in your relationship
S2.4.12	Spirituality

S2.4.1. Warning signs of impending relapse (manic or depressive episode) that caregiver and patient must become aware of and steps that can be taken.

Alert: **Warning signs** are **changes** in the way the person behaves, thinks or feels that are much milder than the actual symptoms and indicate that they may be developing a bipolar episode. If the caregiver knows the person's warning signs, he/she may be able to help him/her to recognize when they occur and to take steps to prevent relapse (Berk et al., 2008:13, 27).

Detecting a **relapse** in good time is crucial for avoiding it. As soon as a patient detects the first sign of a relapse, it is probably less intense, less disruptive, and the amount of medication needed to treat it is less. Detecting relapse signals early is a process that requires both the persons suffering from bipolar disorder and the people around them to learn to recognize small changes in behaviour. These changes are often crucial in identifying a relapse and can initiate rapid, effective intervention (Colom & Vieta, 2006:166).

Simple truth: Some people with BD are very sensitive to stressful interactions (e.g. conflict or distressing criticism), and this can contribute to relapse (Berk et al., 2008:27).

The speed with which hypomania warning signs turn into a full-blown episode is far greater than in the case of depression. The caregiver can help the patient to identify a list of **valid personal (individual) warning (alarm) signs**:

- it must be regular for all episodes
- it must be easily identifiable (certain behaviour)
- it must not lead to arguments
- it should escalate to the symptom (warning signs that do not present until the episode is already advanced are not useful)

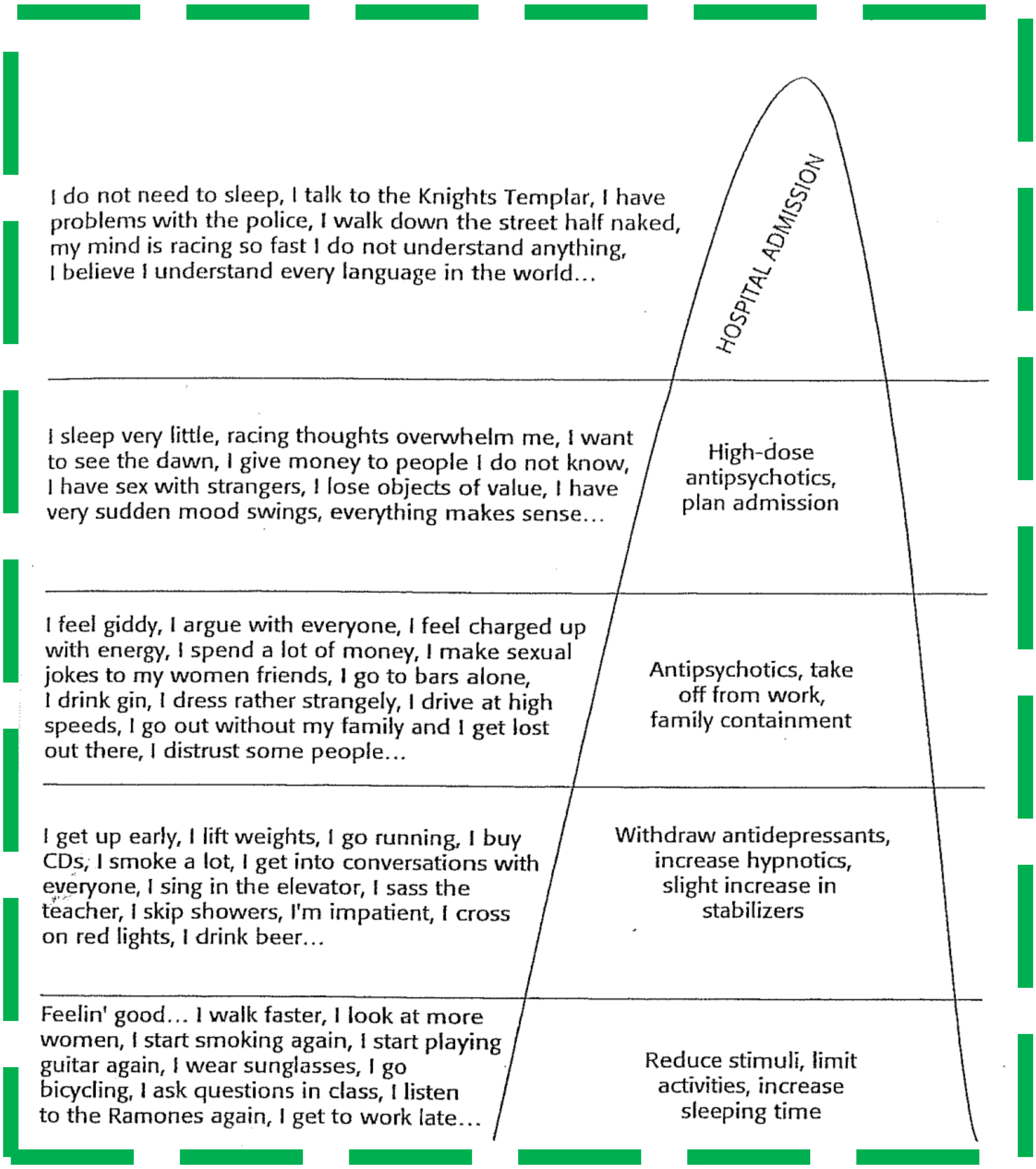
This list should be available for identification of future episodes. Remember that a **warning sign is not a symptom** (Colom & Vieta, 2006:156-159, 163, 164).

A person may have his/her own pattern of how warning signs and symptoms develop into a specific type of episode (mania, hypomania or depression). This is called a **'relapse signature'** (Berk et al., 2008:121). Looking for **personal early signs**, which are small changes that predate actual warning symptoms, can mean you have a greater chance of preventing an oncoming episode (Berk et al., 2008:121, 123).

Timing is important when you want to prevent an episode. As people become more hypomanic or manic, their insight into the fact that they are ill tends to diminish, so that they see less point in taking medications or using helpful strategies to control their symptoms (Berk et al., 2008:172).

Ways to assist the person with warning signs of **mania or hypomania** (Berk et al., 2008:28). Encourage the person to:

- contact their clinician
- reduce stimulation
- rest
- take medication that has been prescribed



I do not need to sleep, I talk to the Knights Templar, I have problems with the police, I walk down the street half naked, my mind is racing so fast I do not understand anything, I believe I understand every language in the world…

I sleep very little, racing thoughts overwhelm me, I want to see the dawn, I give money to people I do not know, I have sex with strangers, I lose objects of value, I have very sudden mood swings, everything makes sense…

High-dose antipsychotics, plan admission

I feel giddy, I argue with everyone, I feel charged up with energy, I spend a lot of money, I make sexual jokes to my women friends, I go to bars alone, I drink gin, I dress rather strangely, I drive at high speeds, I go out without my family and I get lost out there, I distrust some people…

Antipsychotics, take off from work, family containment

I get up early, I lift weights, I go running, I buy CDs, I smoke a lot, I get into conversations with everyone, I sing in the elevator, I sass the teacher, I skip showers, I'm impatient, I cross on red lights, I drink beer…

Withdraw antidepressants, increase hypnotics, slight increase in stabilizers

Feelin' good… I walk faster, I look at more women, I start smoking again, I start playing guitar again, I wear sunglasses, I go bicycling, I ask questions in class, I listen to the Ramones again, I get to work late…

Reduce stimuli, limit activities, increase sleeping time

Figure 7.7: **Example of a "mountain of symptoms"with corresponding therapeutic interventions (Colom & Vieta, 2006:165)**

Role of Caregiver: Assisting the patient in carrying out constructive strategies to stay well and prevent relapse and possible damaging consequences.

S2.4.1.1 SPECIFIC: mania guidelines

A relapse might be traced to a specific event or might appear without an obvious trigger. There are **things a person can do** to maintain an even pace of life, reduce stress, and reduce the chances of a relapse and hospitalization (Haycock, 2010:156).

S2.4.1.1.1 Be prepared to prevent relapse to reduce the potential damaging consequences of episodes (Haycock, 2010:156-160, Berk et al., 2008:120).

Recognizing specific triggering events or patterns of behaviour that is especially relevant to your particular illness can save you, and those around you, a lot of pain and inconvenience.

- **Stay out of the fast lane** - avoid highly stressful jobs; a job that gives you some freedom to pace yourself, provides flexibility, offers frequent short breaks, and is either staffed by understanding people or gives you a degree of autonomy might be better for you. Avoid highly stressful situations, ask for help when appropriate, pace yourself and avoid putting things off until the last minute.
- **Pay attention to the calendar** - be aware if your history of manic or depressive episodes tends to run in cycles; seasonal changes are sometimes associated with dramatic mood swings; the anniversary of a major life event can potentially trigger a manic episode; whether a forthcoming event is something stressful or something potentially positive; a major change can set in motion a manic episode.
- Studies have shown that when you have BD, disruption to regular activities, social stimulation and sleep patterns can upset your body clock or **circadian rhythms** and trigger hypomania or mania (Berk et al., 2008:173).
- Putting the **brakes** on by getting more sleep, reducing overstimulation, reducing caffeine, reducing causes of aggravation, choosing calming activities (do not try to exhaust yourself by doing much more exercise as this will just make you more stimulated), reducing number of activities, prioritising goals and tasks (Berk et al., 2008:176).
- **Challenge unhelpful thinking early**. In cognitive behavioural therapy people are taught to identify, challenge and replace their unhelpful thinking with more helpful thoughts and actions. Unrealistic thinking styles of a hypomanic person may include overconfident thinking, overvaluing one’s needs and goals, blaming and overestimating the goodness of the world (Berk et al., 2008:178-181).

S2.4.1.1.2 Monitor warning signals/clues

Become **familiar** with the warning signs that seem to apply especially to you. Important areas in which you can monitor yourself for marked changes indicating a potential manic episode include speech patterns (communicating nonstop); change in eating and/or sleeping patterns; busy without productivity; irritability; feeling threatened; living beyond your means; interfering – giving others advice whether they want it or not; overly generous with people you have not met; feeling a need to stand out from the crowd (Haycock, 2010:160-161).

Identifying a few symptoms you typically experience before or at the start of each of the types of episodes you have can help you to gain more control over the course of your illness. It can be useful to write down the prodromal symptoms separately for each type of episode and to keep the list on hand so that you can recognises and respond to them in future. You can develop your own **prodrome list** which can become part of your **action plan** to reduce relapse and should be considered a work in progress. Tips for identifying prodromes include learning from past experience and identifying noticeable changes from usual behaviours (Berk et al., 2008:127).

Role of caregiver: Be the extra pair of eyes to help identify the prodromes and to draw up the prodrome list. Be as specific as possible (Berk et al., 2008:125, 126).

S2.4.1.1.3 Protect your personal life

Prepare your loved ones (give them a list of warning signs and ask for their help to monitor your behaviour). After you have suffered a relapse, talk to everyone who might have been affected by it. You might have done something drastic like having an affair, selling the house or disowning a child and then you need to realize that those you hurt may not be able to let you back into their lives.

Alert: **Some ways to respond when a manic or hypomanic episode is coming on**: Contact your doctor; consciously strive to calm down; mentally, emotionally and physically. Take time off from work. Avoid stimulation and people who seek it. Retreat to a place free of distractions. Strive to replace negative thoughts with neutral or positive thoughts.

Some ways of responding to a developing manic mood that can make things worse: ignoring signs or omitting to contact the doctor, turning to alcohol, going shopping, and trying to distract yourself by doing something stimulating (Haycock, 2010:162-164).

The **South African Mental Health Care Act (17 of 2002)** mentions that the patient’s **reputation** must be protected.

- **Avoid risky sexual situations**: People tend to get themselves into risky sexual situations when their mood is escalating, often with disastrous results for themselves and their long-term relationships.
- **Avoid alcohol and drugs**: Alcohol and recreational drugs may aggravate the patient's escalating mood and inhibit self-control.
- Postpone major life decisions.
- Subject your ideas to the **CARE** test (consequences, asking others, being realistic and enough time) (Berk et al., 2008:186-186).

S2.4.1.1.4 Protect your assets

There are steps you can take to try to minimize damage to your finances, or other assets should you have a manic episode. You can for instance consult with an attorney about matters, such as requiring the **co-signature** of a spouse, or even a neutral third party - before you can spend, sell, trade or give away money or assets that exceed a predetermined amount. If you must have a credit card, make sure it has a low cash limit. Have precautionary measures in place to prevent overspending.

Self-employed individuals should live within a budget so they can have backup funds when work is slow (Haycock, 2010:164-168).

A patient may need to guard against spending sprees, gambling and wild investments. Beck et al (2008:185) gives the following **tips**:

- Temporarily give your credit cards to someone you can trust for safekeeping
- Stay away from the shops
- Don't surf the net if you are fond of online shopping
- Avoid investing in the stock market
- Put financial decisions on hold until you have fully recovered

S2.4.1.1.5 Protect your professional life

If you have a job, you do not want to jeopardize it or cause problems for your co-workers or clients if you have a manic or hypomanic episode. If you are sliding into a manic or hypomanic state; consider taking time off from work in the form of sick days or vacation until your mood can be stabilized (Haycock, 2010:167).

TIPS in case of a possible relapse into MANIC phase (for patient) (Colom & Vieta, 2006:177 and Du Toit, 2005:49):

- If your list of operational warnings tells you may be relapsing, contact your doctor so that he or she can evaluate the possible relapse. In addition, get into contact with other members of the mental health team.
- Increase the number of sleeping hours to a minimum of 10.
- Limit the number of your activities and eliminate all that are not absolutely essential.
- Spend a maximum of 6 hours being active.
- Never try to overcome your hyperactivity and increased energy by trying to exhaust yourself.
- Reduce stimuli: avoid exposure to highly stimulating environments.
- Avoid stimulating beverages, multivitamins, alcohol and other drugs.
- Limit spending.
- Never make important decisions if you suspect you are starting to suffer symptoms of hypomania.
- Never give yourself permission to “go up a little more”.
- Protect your money (limit on daily withdrawals).
- Stay home as much as possible.
- Eat regular, nourishing meals.
- Block telephone call service.
- Stay away from friends who tend to take advantage.

Table 7.7: Possible Scenario during manic phase (Miklowitz, 2010c:28, 29)

PATIENT		**CAREGIVER**	
EMOTIONS		**EMOTIONS**	
	Very happy		Anxious
	irritable		Worry
	helplessness		helplessness
	Rejection		
	Anger		Anger
	Losing control		Losing control
	loneliness		Feeling desperate
	Denial		Denial
	isolated		isolated
	Hostile		resentment

PATIENT		**CAREGIVER**	
	grief		
	High self esteem		
	Acceptance		Acceptance
BEHAVIOUR	Impulsive	**BEHAVIOUR**	Try to get help
	Hyperactive Spending money		Negotiate with patient
	Diminished sleep		
	Psychotic		
	Delusions		
	Hallucinations		
	Aggressive		
	Blames everybody		Blames patient and medical staff
	Refuse hospitalization		
	Reckless		
	Unrealistic plans		
ROLES	Sick role	**ROLES**	Supporter
	Role impairment: Fail to fulfil usual roles of spouse, parent, provider		Advocate Provider Protector

S2.4.1.2 SPECIFIC: depression guidelines

When dealing with bipolar disorder, we frequently encounter **depression without sadness** characterized mainly by fatigue, physical discomforts, increased hours of sleep, and inner void. Sometimes none of these symptoms makes the patient suspect he is depressed, but he thinks he has some type of non-psychiatric pathology (Colom & Vieta, 2006:171).

Ways to assist the person with warning signs of **depression** (Berk et al., 2008:28). Encourage the person to:

- restore or maintain a basic routine
- restore or maintain regular sleep patterns
- set small manageable goals
- acknowledge his/her small achievements
- recognize positive events
- discuss their warning signs with their clinician

- persist with whatever regular exercise he/she can manage

Role of caregiver: The caregiver has a very important **monitoring** role.

Antai-Otong (2003:217) mentions certain considerations for the **caregiver** of a patient experiencing **depression**:

- If a family member is depressed, encourage him/her to seek an accurate diagnosis and appropriate treatment.
- Learn as much as you can about depression and how it influences a person's thoughts, behaviour and mood.
- Learn how to communicate with the depressed person in a helpful way. Avoid comments like "Cheer up", "Oh, it is not so bad" and do not give advice such as, for instance, "Just try a little harder".
- Focus on being a good listener and convey empathy and understanding.
- Do not respond to his/her irritability with bad temper. Rather respond with brief withdrawal.
- Engage in neutral conversation as much as possible.
- Allow the depressed person to be alone if he wishes. Only if you believe him to be suicidal should you insist he not be alone.
- If you feel the person is suicidal, or he states he is, ask about it in detail. If you feel there is a risk, contact his health care provider and stay with him/her.
- Continue with your own life. You will be in much better shape to help if you stay physically and emotionally healthy. Make time to get away and do things you enjoy.
- Talk to others who can help you cope.

TIPS in case of a possible relapse into DEPRESSIVE phase (for patient) (Colom & Vieta, 2006:164 and Du Toit, 2005:50):

- Try to reach your psychiatrist by phone
- You should never self-medicate for your depressive symptoms
- Sleep 8 hours at most, as sleeping longer can worsen the depression
- Try to increase your activity level
- It is very important for you to do physical exercise and stay physically healthy
- Do not make important decisions
- Do not consume alcohol, marijuana, or cocaine to try to lift your mood

- Try to put notions of inferiority and pessimism in perspective
- Try to keep a regular schedule
- Move up your visit with the psychologist
- If you have suicidal ideas, always talk about them

Table 7.8: Possible scenario during depressive phase (Miklowitz, 2010c:25, 29, 34)

PATIENT		CAREGIVER	
EMOTIONS		**EMOTIONS**	
	Guilt feelings		Guilt feelings
	Anger		Sympathy
	Low self esteem		frustration
			Fear that patient will commit suicide
BEHAVIOUR	Looks lazy, but does not have any energy		
	Increased sleep		
	Eat less or more		
	Avoid social contact		
	Suicidal		
ROLES	Sick role	**ROLES**	Protector
	Role impairment: Fail to fulfil usual roles of spouse, parent, provider		Monitor
			Observer
			Container

S.2.4.2 Identifying and managing triggers

> I believe that only a part of managing my bipolar disorder is about putting out the fire and dealing with the symptoms. An important part is also managing those stressful things that trigger my symptoms, Sue (Beck et al., 2008:104).

When a person experiences stress – both good and bad stress – it activates a number of nervous system and hormonal responses. When the **normal brain** is faced with stress, the nervous and hormonal systems react as they should. The person feels stress and his or her brain, operating like an effective shock absorber, can respond and then quickly return to homeostasis. The result is some stress, but no major mood swings. When the **bipolar brain** is faced with stress on the other hand, it reacts abnormally. Stress symptoms arise, but the brain fails to regulate emotions and more severe mood symptoms can erupt. If the patient can learn to recognize and ultimately prevent his/her main bipolar disorder stressors (triggers) then he/she can bypass this incorrect response and create more stability. **Most people with bipolar disorder must carefully monitor their triggers in order to stay stable, even when they are taking medications** (Fast & Preston, 2006:112-113).

Simple truth: Symptoms are results; triggers are the cause (Fast & Preston, 2012:78). Symptoms are the **fruit**; triggers are the **seeds** (Fast & Preston, 2004:66).

Identifying and knowing stressful **triggers** and finding ways of responding to them to help prevent a relapse is a **strategy** used by many people with bipolar disorder. Knowing **what** may trigger your moods can help you to find responses that reduce the risk of relapse at these times. You can include your ideas for managing triggers in your plans to prevent relapse (Berk et al., 2008:119).

TIPS (for patient) in discovering triggers will include to:

- **Know yourself** (consider your personality) and to
- Track previous episodes

Role of caregiver to be a trigger detective: A key ingredient to successful management is to become a **trigger expert**. The importance of family members regarding trigger management cannot be stressed enough. Family members and friends are often much better trigger detectives than the person with the illness. Create your own list of the triggers you see and, if possible, compare lists with your loved one to create the most comprehensive trigger list possible (Fast & Preston, 2006:7, 112, 118). Outside of medication, knowing what triggers your partner's bipolar disorder is the most effective technique of your holistic treatment plan (Fast & Preston, 2004:67).

Common **bipolar triggers** (Fast & Preston, 2006:115-116, Fast & Preston, 2004:78, Berk et al., 2008:118, 119):

- Drug and alcohol use/abuse
- Sleep disruption/deprivation/erratic sleep patterns
- Disruption to routine
- Shift work
- Interpersonal conflict and stressful interactions with people
- Chasing goals
- Physical illness

- Relationship problems
- Travel
- Sensitivity to stimulation
- Work
- Chaotic lifestyle
- The seasons
- Poor diet with no exercise
- Caffeine
- Medications, including antidepressants, steroids, and stimulants
- Illness that is not treated or managed
- Stopping helpful medication
- CHANGE OF ANY KIND (**stability** is one of the most effective treatments for all bipolar disorder symptoms, especially mania)
- Move to new location
- ANYTHING NEW, new baby, work, relationship
- Obligations and deadlines
- Taking on too much
- Lack of set schedule
- Opiate drugs
- Over-the-counter products such as weight loss products
- Enjoyable social events
- Stressful negative or positive life events
- Activity disruption
- Too much stimulation from external sources (e.g. clutter, traffic, noise, crowds)
- Too much stimulation from within the person (e.g. lots of activity and excitement).

It is important that a patient must know his/her **personal** triggers. Once he/she has determined what triggers cause each of the bipolar disorder symptoms, the person can work on modifying and hopefully eliminating them.

Family and friends often trigger bipolar disorder symptoms in the person they love. Some of the trigger behaviours you can look out for in yourself include:

- Arguing
- Getting angry at the person for bipolar disorder behaviour
- Pressuring the person about money or work
- Considering a hospital visit a weakness

- Creating a noisy, stressful living environment
- Goading the person to go out, drink, or live as he/she did before he/she was diagnosed.
- Telling a person who has just been in hospital that he or she should "be better by now".
- Living a stressful life yourself that affects your loved one (Fast & Preston, 2006:126).

Simple truth for patient: Knowing **your personal triggers** is a strong tool to add to your treatment plan

For the patient

Once you determine which triggers cause each of your major bipolar disorder symptoms, you can work on modifying and hopefully, eliminating them. This is a very inexpensive way to prevent the mood swings. One result of managing triggers may be that with better control over these swings, at some point you may be able to have **lower doses** of medications, thereby reducing the side-effects of the medication. Trigger management can also result in improving **relationships**, and the ability to work and support yourself in the way you want to live. Discovering your personal triggers may take some time, but the results may be significant (Fast & Preston, 2006:116).

The **following exercise** will help you discover these triggers so that you can create a plan for modifying and preventing them in future. Trigger examples are listed under each symptom. You can then write your own ideas about what triggers your personal symptoms and think of ways to modify and eliminate these triggers. (It may be helpful to ask a family member or friend to help you with this list.) The section lists examples of the symptoms you may experience. You can follow the same process with any symptoms not covered in this section.

YOU'RE TRIGGERS (Fast & Preston, 2006:118-122)

Look over each symptom, read the examples, and add your own triggers.

Depression. Poor diet, lack of exercise, relationship issues, staying at home all day, lack of contact with people, medications that aren't helping, drinking at night, lack of purpose, feeling that there's nothing to get up for

---

Mania/hypomania. Staying out late, being around stressful people, taking a business trip, family problems, lack of day-to-day structure, arguing with your partner, trying a light box, exposure to upsetting or stimulating media, very stressful job, planning a wedding

---

Paranoia. Starting a new class with new people, depression, lack of medications for psychosis, doing too much, crowds

Anxiety. Caffeine, taking on too much, starting a new project at work, having no time to exercise, forgetting to breathe deeply

Irritation/anger/aggression. Depression, taking on too much, not getting enough sleep, an over-stimulating new antidepressant, poor relationships, trouble at work

Cognitive problems. Depression, medication side effects, taking on too many projects, trying to do too much, mania, overstimulation

Obsessions/compulsions. Depression, psychosis, staying up too late, caffeine, starting a new relationship, anxiety, new job

Feeling over-stimulated. Saying yes to everything, meeting new people, too many social events, going to the mall (or any other high-stimulus place)

WHAT YOU CAN DO

Look over each symptom, read the suggestions and then add your own ideas.

Depression. Change my diet, walk for twenty minutes each day even when I'm too tired, talk with my doctor about medications, do something I love every single day, ask for help, find something to look forward to

Mania/hypomania. Talk with my doctor and get medications that help, set a bedtime and stick to it, avoid caffeine, cancel some obligations, work on relationships, find some balance, turn off the television, recognize the desire to party or travel on a whim as a symptom that needs treatment,

Paranoia. Remind myself this is a normal bipolar symptom, try not to act on the thoughts, talk to my doctor about psychosis, limit stimulation in new situations

Anxiety. Take a few days off from obligations, do yoga, do breathing exercises, walk, avoid caffeine, meditate

Irritation/anger/aggression. Check my medications, stop caffeine, ask for help, treat the depression/mania first, and refuse to act on my thoughts

---

Cognitive problems. Learn about my medication's side effects and ask my doctor for help, take on less so that I can concentrate better, work on the depression, work on mania

---

Obsessions/compulsions. Do less until the obsessions stop, talk with my doctor about psychosis, work on anxiety, focus on treating the illness instead of focusing on a person, say no when my brain won't be quiet, set limits on computer and cell phone use

---

Feeling overstimulated. Stop everything extra for a week to calm down, say no even when it is difficult, and avoid crowds

---

BEING PREPARED FOR THE BIG TRIGGERS

Sometimes, no matter how hard you try to stay stable, the big triggers of life can make you ill. The end of a relationship, a legal battle, getting fired, the death or illness of a loved one, and world events that simply happen. Many people end up in the hospital after these triggers because they did not have a plan in place to treat bipolar disorder first, the minute the trigger happened. You know that your brain is different and that even with the right medications, it may respond to stressful triggers with a mood swing. If you are prepared for these triggers with a plan to notice the first signs that a mood swing is starting, you can immediately call your doctor, ask your friends and family for help, and watch yourself closely. This can save money, time and your relationships and prevent serious mood swings (Fast & Preston, 2006:123).

For Family and Friends

If you are going to participate in a **major event** with a loved one, such as a vacation or a family reunion, you have every right to make a list of your concerns and discuss them with your loved one. Here is an *example:* "I know that sleep problems cause bipolar disorder symptoms. Do you have a plan for the time change while we are on vacation? In the past, you've become very over-stimulated and angry at family events. What can we do together to make it different this time?" Though this may feel like babysitting, it's not. It prevents wrecked events and saves relationships (Fast & Preston, 2006:123-126).

It is terrifically frustrating and unfair that you have to watch your behaviour simply because someone in your life is sick, but unfortunately it is the reality of having someone with BD in your life. You must remind yourself that your loved one is seriously ill and that you play an **important role in helping maintain the stability** you both have worked so hard to establish.

Tools for SEE-SAW SURVIVING SUITCASE (S4): Life charting and using a mood chart to detect triggers

BD needs to be treated and monitored **daily** and not just when serious symptoms appear (Fast & Preston, 2006:xxi). The natural history of bipolar disorder is such that it is often useful to make a **graph** of a patient's disorder and to keep it up-to-date as treatment progresses (Kaplan & Sadock, 2003:558). Keeping a chart of daily mood symptoms, treatment, sleep patterns and life events (**life chart/mood chart**) can help the doctor track and treat the illness more effectively. If a person's symptoms change or if side effects become serious, the doctor may switch or add medication. The researcher have found that some experts indicate that these two tools are the same, but see the difference in that the **life chart** provides a long-term perspective, while the **mood chart** focuses on the day-to-day circumstances and has more detail. Both are useful when assessing the situation. I do think that it is important to keep the charts as simple as possible; otherwise the patient may not be motivated to fill it in – especially when depressed.

'Life charting' is a **tool** that involves reflecting on times of wellness and illness and working out whether particular **episodes** were sparked off by **particular triggers**. Episodes are recorded on a **timeline** that roughly indicates the date and duration of the episode as well as the type of relapse (Berk et al., 2008:118).

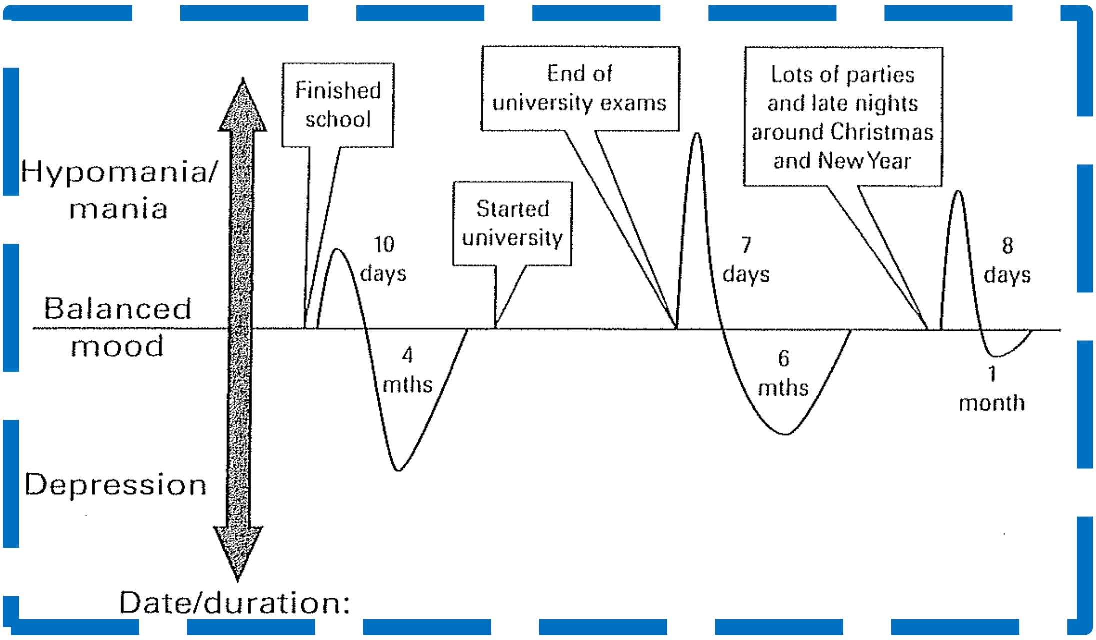


Chart 7.1: **Example of a life chart to indicate episodes of illness (Berk et al., 2008:117, 119)**

Essential: A **mood chart** is simply a **daily diary** of your mood states, with dates indicating when these moods start and stop. The chart can also incorporate information about your sleep, medications and life stressors. A mood chart helps to detect a **relapse** (warning signs), it can help to indicate if the medications are working and it can be used to identify environmental **triggers** of mood cycling, which can then lead to stress management strategies to lessen the impact of these triggers (Miklowitz, 2011:158). It helps patients to track the cycling of the disorder from **day to day** and to identify **triggers** (and often, protective factors) that influence cycling **patterns**. Recording your information on this chart on a daily basis will provide you and your doctor with an invaluable record of how things are going and assist you in making treatment decisions (Berk et al., 2008:198). Freeman (2011:7) also adds that a mood chart provides objective evidence and creates self-awareness.

Fact: One of the best things **a patient** can do to manage his/her disorder is simply to keep track of moods. This is one of the few concrete things a patient can do for him/herself other than just taking medication. It will give the patient and his/her doctor a more complete picture of what is affecting him/her and how (Miklowitz, 2010c:142).

Keeping a mood chart (Miklowitz, 2011: 60-167) (See **Appendix 7.2 for SEE-SAW Life Style chart and appendix 7.3 and appendix 7.4 for life charts)**

- **Rating your mood each day**

The mood can be elevated or depressed (mildly, moderately or severely). It can also be within normal limits (baseline).

- **Recording anxiety and irritability**

This can be on a 0-3 scale, where “1” would be feeling “snappish”, “2” would mean moderate irritability and “3” would mean severe irritability and anger (trouble functioning). Likewise a “1” anxiety would mean feeling mildly apprehensive, a “2” would mean moderate anxiety and a “3” would mean overt panic and severe, incapacitating anxiety.

- **Recording hours of sleep**

Make a daily rating of how many hours of sleep you had the previous night.

- **Take daily notes on life events and social stressors**

Record all events you feel may be important. The purpose is to observe the connection between specific events and specific mood changes. In addition, record in this section the use of any substances.

- **Recording treatments**

Record all medications and dosages, including medications that are not specifically for your bipolar disorder (for example, blood pressure pills).

- **Recording your weight and menses**

Record your weight at least once during the month. If you are a woman, circle the days on which you had your period. You and your doctor may wish to examine whether your mood cycles begin before, during, or after the onset of your menses.

- **Evaluating your mood chart**

Share your completed mood chart with your therapist or physician during each visit. You can evaluate the influence of certain stressors on your mood, the influence of sleep disturbances, and the effects of various medications. Take note of any patterns.

- **Problems with mood charting**

It can be challenging to do this every day. However, the more accurate the information is that you convey to your doctor, the better treatment decisions you and your doctor can make.

Role of caregiver: It is important that you as caregiver encourage the patient to fill in the life chart or mood chart. Help him/her to do the ratings and to take it with to the therapists at appointments.

S2.4.3. Know the risk factors and protective factors

While looking for differences in bipolar disorder rates in different countries, researchers found only one consistent **risk** factor: marital status; specifically, separation and divorce. The findings are not clear as to whether the stress of a broken marriage contributes to the development of the disorder or whether bipolar symptoms place unbearable stress on a marriage (Haycock, 2010:48).

Simple truth: Maintaining wellness means minimizing the risk factors and maximizing the protective factors (Miklowitz, 2011:156).

S2.4.3.1 RISK factors: Those things that increase the chances of becoming ill in someone who is already susceptible (e.g. abusing a substance, leading a chaotic life and not getting regular sleep).

Miklowitz (2010c:141, 155, 156) and Miklowitz (2011:157) mention the following risk factors:

- Alcohol/drug abuse
- Sleep deprivation
- Stressful life events
- Family conflict or distress: The post manic phase is an especially difficult time for everyone. The family tries to reorganize itself around the needs of a family member who is still quite ill (Miklowitz, 2010c:30)
- Provocative interpersonal situations
- Inconsistency with taking medications.

There is a risk of **self-medication** with antidepressants, since many bipolar patients misuse these drugs. This involves medical risks, the risks of shifts, rapid cycling, interaction and course worsening caused by this misuse (Colom & Vieta, 2006:123).

Bipolar patients need to have periodic tests in order to determine **serum levels**. Patients should understand that the value of establishing the lithium plasma concentration is that it serves to control the treatment and to make sure that the lithium does not reach toxic levels. The **risks of lithium poisoning** due to dehydration (when going to a sauna) must be acknowledged.

The patient must always consult her psychiatrist before deciding to become **pregnant**. The phase with the highest risk of relapse is not the pregnancy, but **postpartum**. Concretely, 50 % of untreated patients present with a manic or depressive episode after giving birth, caused by the sudden drop in estrogen. As to **breastfeeding**, it is preferable to bottle-feed the baby and give up breastfeeding, since certain medications (e.g. lithium) may pass from the blood to the mother's milk and constitute a risk of poisoning for the baby. Certain medications interact with oral contraceptives, for example carbamazepine, and their efficacy is reduced, so that the patients who take carbamazephine must utilise a different type of contraceptive measure (Colom & Vieta, 2006:126, 127, 130, 134).

Alert: **Risk of relapse**: Poor therapeutic adherence = relapses and possible hospitalization, suicidal ideation (the higher you go the harder you fall) (Colom & Vieta, 2006:144).

Risk of suicide

By some estimates, people with BD have a **15 times** higher risk of committing suicide than the general population (Miklowitz, 2011:241).

Add your own risk factors

____

Risk factors you can and can't control

Haycock (2010:23, 24) mentions that you cannot control genes, age and gender, but you may be able to influence stress and substance abuse.

S2.4.3.2 PROTECTIVE factors: Those things that keep you from falling ill when you are so predisposed (e.g. supportive relationships, keeping regular daily and nightly routines) (Miklowitz, 2010c:140).

- Observing and monitoring your own moods and fluctuating triggers. Keeping a regular mood chart is important.
- Maintaining regular daily and nightly routines

Simple fact: Actively maintaining daily and nightly routines is one of the most important behavioural changes you can undertake, aside from regularly taking your medication, to help keep you in the driver's seat in managing your disorder (Miklowitz, 2011:167). Colom and Vieta (2006:32) stress the importance of hours of **sleep** and **regularity of habits**. Many bipolar patients tend to organize their time rather erratically, although **regularity** would help them keep their disorder compensated. Regular schedules and better structuring of activities must thus be one of the key points in any individual intervention with a bipolar patient (Colom & Vieta, 2006:180).

Social rhythms: Those patterns of everyday activity, falling asleep, waking up, having meals and social interaction that structure daily life and set your body clock. Doing some things routinely may help regulate sleep/wake cycles. People with bipolar disorder are sensitive to changes in social rhythms, which can act as stressors to trigger symptoms (Berk et al., 2008:107).

The patient can obtain a degree of mood **stability** from having **predictable** “**social rhythms”** (social stimulation, e.g. when he or she eats, when he or she go to work, socializes, exercises). People also have daily sleep-wake cycles and patterns of neuroendocrine regulation, or biologically driven **“circadian rhythms”** (sleep-wake cycles). It is important that the patient learn to keep a regular schedule of sleeping and waking as a way of modulating his or her mood states. One of the best ways you can create stability is to institute regular meal and sleep times and stick to them. This scheduling helps to regulate the **body’s clock** and allows both of you (if a couple) to become used to having structure in your lives (Fast & Preston, 2004:84).

The patient can be encouraged to **track** his or her daily routines with a self-monitoring schedule, the Social Rhythm Metric (Miklowitz, 2010c:61, 99,155, 156).

Strategies to regulate daily routines (Miklowitz, 2011:171-173)

Maintaining a regular routine revolves around keeping a consistent sleep schedule: go to bed and get up at the same time every day as much as you possibly can. If you have been having trouble sleeping try to **avoid sleep bingeing**, in which you catch up from all the lost sleep during the week by sleeping more on weekends. Try to see if you can maintain the **same hours** each day at work, exercise at the same time.

Role of caregiver: Help patient to target times for various activities such as sleep and exercise and help him/her to stick to the programme.

For the patient: Draw up a weekly timetable to try to keep your social rhythms relatively stable so that they do not affect your mood (Berk et al., 2008:107).

- **Other protective factors include:**

- Using social/family/community supports
- Engaging in regular medical and psychosocial treatment
- Using communication or problem-solving skills
- Becoming educated about and cooperating with a recommended treatment regimen
- Avoiding provocative interpersonal situations (Miklowitz, 2010c:155, 156)
- Monitor stress levels
- Challenging negative thoughts

Add your own possible protective factors

Table 7.9: Risk and Protective Factors in Bipolar Disorder (Miklowitz, 2011:157)

Risk factors that increase chances of becoming ill

RISK FACTORS	EXAMPLES
Stressful life changes	Loss of job, gaining or losing a new relationship, birth of a child
Alcohol and drug abuse	Drinking binges; experimenting with cocaine, LSD, or Ecstasy; excessive marijuana use
Sleep deprivation	Changing time zones, cramming for exams, sudden changes in sleep-wake habits
Inconsistency in taking medications	Suddenly stopping mood stabilizers, regularly missing one or more dosages
Family distress or other interpersonal conflicts	High levels of criticism from a parent, spouse, or partner; provocative or hostile interchanges with family members or co-workers

Protective factors that help keep you from becoming ill

PROTECTIVE FACTORS	EXAMPLES
Observing and monitoring your own moods and fluctuation triggers	Keeping a daily mood chart or social rhythm chart
Maintaining regular daily and nightly routines	Going to bed and waking up at the same time; having a predictable social schedule
Relying on social and family supports	Clear communication with relatives; asking your significant others for help in emergencies
Engaging in regular medical and psychosocial treatment	Staying on a consistent medication regimen, obtaining psychotherapy, attending support groups

S2.4.4 Healthy balanced lifestyle

This is an important factor for both the caregiver and the patient.

Scientific research has unambiguously demonstrated that consistent sleep patterns, diet change, exercise, and appropriate bright light exposure at constant levels year-round can make a significant difference in maintaining stability, and are critically important for helping people achieve the best outcome in treatment for bipolar disorder (Fast & Preston, 2006:85).

BD brains do not readily adapt to changes in certain physical experiences or stressors even when a person is on medications. In addition, it makes sense that if a person is healthier physically, he/she will be healthier mentally. If a patient has the goal of a stable and happy life, free from the symptoms of BD, he/she **will have to work every day towards staying well** (Fast & Preston, 2006:65, 66).

Last (2009:ix) writes about a husband who shares that he found the best coping strategy for him was not to talk to other people. It was to devote time to his hobbies and interests, which allowed him to take a mental break. He mentions that everyone has to find a way to let off steam and refuel in the face of a challenge like bipolar disorder. For him, the secret was to **maintain a balanced life style** (relax, have hobbies, exercise). It is therefore also very important that caregivers should also have a look at their life style.

Sleep, Stimulation and Activity Levels

As was already mentioned one of the best ways to maintain stability is to keep to a regular sleep schedule (Fast & Preston, 2006:67-69).

WARNING: Alcohol, tranquillizers, marijuana, and caffeine are not treatments for sleep problems (Fast & Preston, 2006:71).

Helpful tips for avoiding sleep problems:

- Avoid working odd hours, especially shift work
- Limit travel in different time zones
- Set a go-to-sleep time and wake-up time, and stay in bed the entire time, whether you are asleep or not
- Create a sleep ritual that helps you get to sleep normally
- Learn about natural sleep aids
- Know what triggers your sleep problems
- Call your doctor at the first signs of mania.
- Go to bed only to sleep (or for sex)
- Keep the room well ventilated during the day

- Be sure not to eat heavy meals
- Avoid chocolate and coffee (caffeine) for at least eight hours before bedtime
- Your last cigarette should be smoked, at the latest, half an hour before bedtime
- During the last half hour before bedtime, it is not advisable to have the computer of TV on, as the light from the screen is a stimulant
- If working late, spend an hour unwinding with a relaxing activity such as listening to music before going to bed
- Do not use an illuminated clock because you tend to watch the time passing (Colom & Vieta, 2006:186).

Berk et al. (2008:109) advise that you keep your bedroom clear of stimulation such as noise or lights; drinking alcohol within six hours before bedtime can also reduce the quality of your sleep, daytime naps can make it harder to fall asleep at night, and can decrease the quality of your sleep; exercise just before sleep can make sleeping more difficult; going to bed very hungry can disturb sleep – a light snack (such as a glass of warm milk at bedtime) can be helpful.

Keep a **sleep diary** to become aware of any sleep problems. Regular sleep is probably one of the foundations of mood stability, because sleep has a **twin function** for a bipolar patient:

- Observing how a patient sleeps can give the patient information on the status of his/her bipolar disorder: if a patient sleeps only a little he/she is probably verging on hypomania, while oversleeping he/she is probably verging on depression.
- A patient can use this information to help him/herself. If he/she starts to feel depressed, it may be useful to reduce the number of sleep hours to improve mood. A good way to head off a hypomanic decompensation is to make sure a patient is sleeping a good number of hours for a few days.

An adult should sleep between 7 and 9 hours a day to repair physical and mental wear. These hours should be sequential and at night (Colom & Vieta, 2006:184, 185).

Worry may intrude on getting sleep. It can help to write a ‘worry list’ of these to deal with the next day. If you cannot sleep, you can do some relaxing activity; do not engage in any stimulating activity (Berk et al., 2008:111).
People with BD can be sensitive to even minor changes in stimulation, especially when they are a bit symptomatic. For example, a cluttered house, noise, traffic, lots of

activity going on around you, time pressures or extra social stimulation may increase symptoms of hypomania, mania or even depression. **Depression** may also be linked to under-stimulation, such as having little social contact, lack of light over the winter months, lack of structure and doing nothing. Sometimes chasing your goals can lead to overstimulation. Many people with BD find that keeping well requires them to adjust their goals and the way they pursue them (Berk et al., 2008:108).

Diet

Sweet, sugary and starchy foods may temporarily fulfil a craving brought on by sudden tiredness and irritability, but they can also cause **blood sugar levels**, and with them, energy and mood, to see-saw. Maintaining even blood sugar levels is therefore one of the most crucial factors in improving moods. What a person eat and drink affects your brain. BD is affected by what you put in your body. Research strongly suggests that omega-3 supplementation along with medications can help stabilize mood in BD (Fast & Preston, 2006:72, 73, 74).

Bipolar Friendly Foods

- Whole grains for fibre, such as heavy, whole wheat bread
- Fruit for fibre and vitamins
- Dark green vegetables for vitamins and energy
- Meat and eggs in the morning for protein

Weight gain is one of the many reasons people stop taking their medications. Fast & Preston (2006:75, 76) mention a **few steps that may be followed**:

- Ask for help from a health care professional (e.g. nutritionist)
- Talk to your doctor about the newer drugs that have fewer weight gain side effects
- Increase your exercise
- Reduce portions
- Reduce the amount of fat, white sugar, and white flour in your diet
- Recognize that the hunger is drug-induced and learn to live with it.

It is advisable for a bipolar patient never to go on a very strict diet, which involves going hungry, and in any case it is advisable for the diet to be monitored by a dietician and psychologist. Patients who are on lithium should not suddenly start a low-salt or salt-free diet. Some bipolar patients often act out by "binging". If a patient notice binging behaviour, he/she should tell the psychiatrist about it (Colom & Vieta, 2006:184, 187).

Caffeine

This does provide energy when a person is tired, but it is drug-induced energy. A person needs to keep ingesting the caffeine in order to feel energized. It then builds up in your system and can destabilize your mood by affecting your sleep patterns. Try to limit caffeine consumption to 250 mg or less per day, and only have it in the morning (Fast & Preston, 2006:77, 79).

Exercise

Exercise and physical movement, especially repetitive movement, have been associated with the stimulation of the production and release of the neurotransmitter serotonin. Elevations in serotonin have been found to have beneficial effects for some people experiencing clinical depression. Regular exercise has also been demonstrated to be very effective in improving the quality of sleep. **Walking** is the best overall exercise when a person is unmotivated and lethargic. Even a ten-minute brisk walk can result in more energy and often a noticeable shift in mood (Fast & Preston, 2006:80, 81).

We usually talk about physical exercise as a natural antidepressant; it is highly indicated in euthymic periods and depression, but is completely inadvisable for mixed and (hypo) mania. **Physical exercise is a stimulant, and any stimulant is ill advised if a mixed relapse or (hypo) mania is suspected**. Physical exercise during hypomania only makes the situation worse, due to overstimulation (Colom & Vieta, 2006:174, 185).

Simple truth: While medication makes recovery possible, a healthy diet and exercise increase the patient’s ability to cope with stress and decrease the chances of developing health problems that can complicate recovery (Haycock, 2010:94).

Light

Bright light exposure has an impact on regulating certain neurochemicals that affect mood. The critical factor is the daily exposure to very bright light entering the eye and striking the retina. This activates a nerve pathway, the retinal-hypothalamic nerve, which goes to the hypothalamus, a brain structure that significantly influences mood states, sleep cycles, appetite and sex drive. Because of this, natural bright light exposure is a critical factor in BD mood swings. However, for many people with BD, too much light exposure can provoke mania and too little can lead to depression (Fast & Preston, 2006:81).

In South Africa we are privileged in that we have a long sunny summer and relatively short winter.

S2.4.5 Stress management

Stress clearly plays an important role in triggering BD episodes, especially the early episodes, but seems to gradually lose its power with subsequent relapses. There is a possibility that an apparently positive stress can trigger a depressive phase while, conversely, a clearly negative stressor can trigger a (hypo) manic episode (Colom & Vieta, 2006:189).

Engaging in relaxing activities, prioritising tasks, challenging negative thinking, good communication skills and keeping expectations realistic may help to combat stress. Adequate support is also very important.

Question: What is stress?

Stress is a **broad concept** and refers to positive or negative overstimulation by the environment. In health science, stress is define as the sum of non-specific changes in the body with respect to a stimulus. Stress is an automatic response of the body to any change in the outer or inner environment, a response that prepares the body to deal with the possible demands generated by the new situation. This implies a significant increase in the level of physiological, motor, and cognitive activation. Hence, stress depends both on the **stimulus** and on its **perception** by the individual and their **resources** for dealing with it. Chronic, sustained over-activation can result in physical and mental problems. A sustained stress situation has extremely damaging consequences for everyone, but especially someone suffering from bipolar disorder. It is advisable to try to stop or relieve stress before it causes a relapse. Circumstances should be put in perspective and the person should learn relaxation techniques (Colom & Vieta, 2006:189-191).

Breathing exercise for relaxation

S2.4.6 Clearing out chaos

Order is obviously a better choice for someone with bipolar disorder than chaos or disorganization, which can promote stress and make it hard to relax (Haycock, 2010:140).

Role of caregiver: Help patient to organize his/her life. Often when a patient is very manic or even depressed, he/she might lose valuables (even the ID or other documents). If a patient is helped in this regard, he/she may start to feel more in control of his/her life.

S2.4.7 Learning to problem solve

The patient might find it useful to approach problems logically, and with a certain amount of detachment. It is important to break down the problem, to produce more than one solution and to remember the big picture. Losing a sense of perspective can inspire dramatic shifts of mood for people with bipolar disorder (Haycock, 2010:153-155).

S2.4.8 Support network available for patient and family

Fast & Preston (2006:xxii) point out that serving as a support system for someone with BD can cause severe stress. It is therefore important that the caregiver should also be supported.

Formal (professionals) and **informal** (support and self-help groups, church, friends, selective work colleagues) are very important. **Drug rehabilitation programmes** (where applicable) should also be utilized. The patient's GP is another important support system for the patient and the caregiver.

S2.4.9 Journal

A technique to use is to have a **journal** and then write your (patient or caregiver) ideas; for example, on what you can do to prevent the bipolar disorder symptoms that cause you to feel upset. The act of writing can distract you somewhat from your depression, and the insights you discover may give you a sense of satisfaction (Haycock, 2010:177). Feelings may also be expressed through music or art.

S2.4.10 Maintaining boundaries and setting limits

A caregiver must separate herself/himself in some way for some time from her responsibilities (Haycock, 2010:232). Friends and family are often expected to be the support system for the person with bipolar disorder, and it's up to you to set **boundaries if you need them**. You will have to do this in a loving way; people with BD are usually oversensitive when they are sick (Fast & Preston, 2006:xxiv).

There are things you can do to help someone with this disorder, but there are also a number of things **you cannot** do. It is important to remember these boundaries:

- You cannot make the disorder go away

- You cannot fully predict if or when an episode will start or end
- You cannot make someone having a full-blown manic episode calm down
- You cannot make someone having a major depressive episode become cheerful
- You cannot control whether or not someone decides to go off medication.
- You are ultimately not responsible for an adult with BD, even if you are the parent (Haycock, 2010: 234-235).

S2.4.11 Create laughter and joy in your relationship

Simple truth: It is okay for you to have fun when your partner (the patient) is ill. This will help you have fun in the future (Fast & Preston, 2012:210).

Many relationships where one partner has unmanaged bipolar disorder are often completely under the control of bipolar disorder and its symptoms. The good news is that it is never too late to change. Fun can be created. Laughter does provide relief from pain. Even if this relief lasts just for a moment, it starts the healing process and helps you find yourself again, despite the stress and grief in your relationship caused by your partner's (patient's) bipolar disorder (Fast & Preston, 2012:210-216).

- **The Bipolar – Free Zone**: Create a time when you and the patient can be together without talking, thinking, or worrying about bipolar disorder. This is called the bipolar-free zone.
- **Laugh about the serious things**: It is okay for you to laugh and feel joy even while someone you love is very ill. Do not be ashamed and embarrassed to see your friends or to have a moment when you are not thinking of the patient.
- **Acting as if**: This is a powerful tool you can teach the patient. Just as a negative thought, whether true or not, affects how you feel about yourself and the world, a happy thought, whether true or not, can trick your brain into thinking that things are better than they are. And the miracle is that, when you act as if, something happens and things suddenly *do* feel better than they had been feeling. This is not about being unrealistic about your life. It is about accepting your present situation and deciding you are going to act as if "things are okay anyway".

S2.4.12 Spirituality

If spirituality is important to the caregiver (and the patient), it is essential to integrate it into the treatment plan along with medications and therapy. It can be a source of great strength and reassurance. Many organized religions or informal spiritual practices are accommodating to the realities of mental disorders; however, some are not (Haycock, 2010:98).

S2.4.13 Self-education

It is important that the patient and the caregiver should go out of their way to learn as much as they can about the illness and ways to manage it. If this is done, it will be very **empowering** for the specific individuals.

S2.5 STUMBLING BLOCKS

It is very important that the caregiver and the patient should be aware of stumbling blocks on the road to better health.

- **Lack of insight (patient or caregiver)**: If the patient or caregiver does not admit that the patient has a serious mental illness, management becomes a big challenge.
- **Interpersonal conflict**: When the patient has been manic, the **conflicts** tend to centre on his or her residual hostility, grandiosity and denial of the disorder, as well as his or her need to re-establish independence and the often-associated rejection of a medication regimen. Family members in turn may react with **criticism** or **over protectiveness** (Miklowitz, 2010c:11). They may also be judgemental.
- **Anger and irritability**: Irritability or anger can be a sign that the patient is feeling frustrated. Anger is often linked to mania as when people are manic, they develop a grandiose opinion of themselves and can be very sensitive to anything they perceive as challenging their point of view or testing their patience (Berk et al., 2008:188).

Whether caused by depression or mania, irritation, anger, and aggression can create serious difficulties in a patient’s life. A caregiver might sometimes experience being abused by the patient (physically or emotionally) and it would then be important to ask for help, from the police, a counsellor or a health facility.

Alert: **Family members** are often on the receiving end of irritation and anger mood swings. Sometimes they may be assaulted. This is where bipolar disorder behaviour in your loved one can actually **endanger your life**. The milder version of the anger may be successfully treated, but the rage and violence that sometimes come with a mood swing, particularly if drugs or alcohol are involved, may be too demanding for you to address without outside help (Fast & Preston, 2006:239).

Recommendation: It is **recommended** that the family do **lay a charge** when the patient reverts to any aggressive behaviour damaging property or injuring somebody else. Such a transgression can then be recorded, because it can happen that a person could do something wrong, knowing very well what he/she is doing, but then hide behind the mental illness. If the patient was mentally ill during the incident, he/she can be send to a designated psychiatric hospital according to the Criminal Procedure Act (article 77, 78 and 79) for 30 days observation and it can be decided if the patient can stand trail and/or can be held accountable. If treatment is needed, it can be recommended.

Alert: Ways to protect yourself from physical aggression include to learn to recognize warning signs of impending aggression, to take casual threats of violence seriously, to work out in advance how to ensure your safety and that of others, to remove objects that could be used as weapons, to use services available to assist you to put safeguards in place to prevent this abuse, to consider professional counselling (Berk et al., 2008:5).

- **Risky behaviour (e.g. spending sprees, sexual indiscretions, reckless driving)**: Discuss with the person, when he/she is relatively well, *precautions* they can take to prevent risky activity and negative consequences.
- **Rejection of help**: It might be that the patient does not want any help and will thus become more ill before steps can be taken to stabilize him/her.
- **Relationship issues**: When the person is ill, try to separate the BD talk and behaviour from the person. Try to detach from the situation. Do not take the sometimes hurtful things the person says when they are ill, personally. However, set limits regarding verbal abuse. Bipolar disorder can challenge relationships and sometimes it takes time, patience and effort to maintain or rebuild those. Using **good communication skills**, such as active listening, making a positive request for change, calmly expressing your feelings about the person's behaviour, problem solving together, reaching a compromise together and communicating about positive things, to help sort out difficulties are important. Caregivers sometimes report that they have learnt to be more tolerant and empathetic and gained confidence in their ability to cope from care giving (Berk et al., 2008:5, 36).

It can be very hard to maintain perspective if the person who is ill is also very irritable and **criticizes you a lot**. **Some ideas**: detach from the situation by reminding yourself that the person is ill; not to try defending yourself by arguing logically with the person if he/she has become so ill that he/she is not thinking rationally; to address the specific comments or behaviour that are unacceptable; to set limits to the person's verbal abuse and to take some time out or talk things through with someone you trust, to help maintain your perspective (Berk et al., 2008:5, 40).

For the caregiver: Be careful that you do not simply accept verbal, emotional, physical or financial abuse because the person is ill.

S2.6: SUPPORTING THE PERSON WHEN HE/SHE IS ILL

Caregivers differ in how much and what type of support they provide (e.g. some help only when there is an emergency, while others also assist the person to try to prevent relapse). The phase and severity of the illness influences the support the person needs.

Simple truth: Different kinds of support can include practical help, information or suggestions, companionship, emotional support and non-verbal support e.g. being available and monitoring symptoms (Berk et al., 2008:15).

TIPS for supporting a person with depression (in addition to helping them to access medical treatment)

- letting her/him know you care
- do not force the person to talk or 'snap out of it'
- consider suicide risk
- encourage small activity goals
- try not to take over
- encourage as much lifestyle routine as possible
- provide a bit of perspective (acknowledge their achievements)
- offer kindness, patience and attention
- it is vital to take care of yourself when the person you care for is depressed as caregivers can become exhausted and depressed too (Berk et al., 2008:17).

TIPS for supporting a person who is manic or hypo-manic (in addition to helping them to access medical treatment)

- help create a calm environment
- don't believe that you have to participate in the person's numerous projects and goals
- set limits on certain behaviour

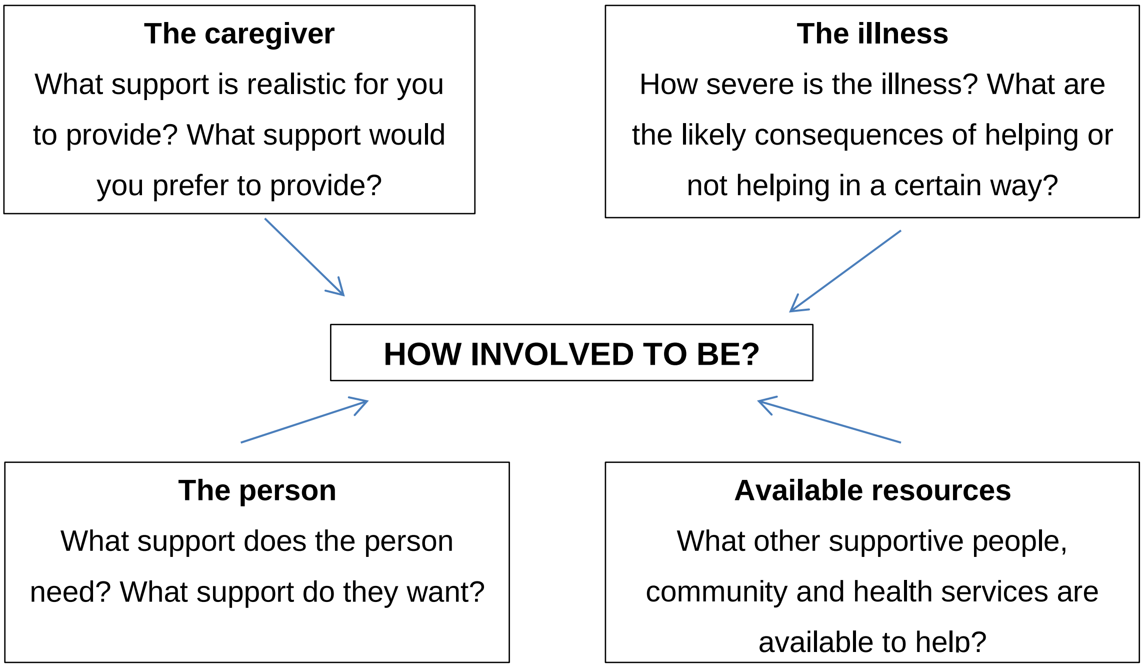
- better ways of communication include briefly and honestly answering questions and avoid being drawn into long conversations or arguments. If the person starts to argue, try to remain detached (Berk et al., 2008:17).

TIPS for supporting a person after a bipolar episode

- some of the things a person might need when trying to get well are: rest, routine, something to do, something to look forward to, love and friendship
- ask how you can help and listen if the person needs to talk
- try to be available
- when possible, focus on wellness and positive behaviour, rather than illness and problem behaviour
- do things **with** the person rather than **for** him/her (taking over may undermine self-confidence)
- offer to discuss solutions to problems, without solving it for him/her
- help the person to prioritize essential tasks
- let the person recover at his/her own pace
- encourage him/her to set a small manageable goal
- offer assistance if the person has difficulties with remembering things or concentrating
- when appropriate, mention things you appreciate about them
- when appropriate, do things together that have nothing to do with the illness and let the person know that they are important to you
- discuss ways to prevent future relapse (Berk et al., 2008:23, 29).

Simple truth: Adjusting to the illness may be easier for the person if they set **manageable goals** that involve their interest, talents, skills or values. If the person needs to make changes to their jobs or study plans in order to keep well, take time to listen and discuss alternatives, as this can be a challenging time for the person (Berk et al., 2008:29).

Another important aspect is considering **how involved to be** in helping the person with their illness (see **Figure 7.8**).



The caregiver
What support is realistic for you to provide? What support would you prefer to provide?

The illness
How severe is the illness? What are the likely consequences of helping or not helping in a certain way?

HOW INVOLVED TO BE?

The person
What support does the person need? What support do they want?

Available resources
What other supportive people, community and health services are available to help?

Figure 7.8: How involved to be in helping the person with their illness (Berk et al, 2008:42)

S2.7 SURVIVAL PLANS (for S4)

- Psychiatric emergency (Appendix 7.5 for Crisis Plan)
- Relapse prevention (minimising relapse) (Appendix 7.6 for Relapse prevention plan)
- Suicide risk personal prevention plan (Appendix 7.7 for Suicide risk prevention plan for the patient, appendix 7.8 for Sample Contract for Suicide Prevention and appendix 7.9 for Support and activity strategies when becoming depressed).
- Well-being or wellness plans (Table 7.10)
- Treatment contract
- Social Rhythm Metric (SRM)

It is important to establish **helping plans** when the patient is well. Remember that a comprehensive plan does not leave anyone out. **Always be prepared for warning signs**; in that way **damaging consequences** can be minimised. Plans should be simple and easy to follow; consider writing them down and keeping them in an easily accessible place. Consider whether you can be reasonably consistent in providing the special help you offer and review your plans as circumstances change or you acquire new information (Berk et al., 2008:43).

S2.7.1 Psychiatric emergency

In the event of an emergency, the **caregiver's** main responsibilities will be to prevent anyone involved being harmed and to obtain medical help for the sufferer. First, determine if anyone: patient, relative, or bystander, is in **danger**. If you feel threatened, get away and call for help. While waiting for help to arrive, try to **reassure** and **calm** the patient in a low key manner; if possible, away from others. If it is safe for you to make a private call, describe his/her history and symptoms completely to the mental health professional you contact. Call the **police** if necessary – however, they need to know they are dealing with a mentally ill individual and not a criminal (Haycock, 2010:224).

In the event of a serious mood episode:

- Always have an escape route clear in your mind.
- Do not stop trying to get help if someone refuses to respond.
- Keep emergency phone numbers ready.
- Do not confront or argue with the patient. Instead, be a reassuring, calming presence.
- Tell the patient who the responders are, they are there to help, what they will do, and that you will stay with him/her.
- Arrange hospitalization or emergency outpatient evaluation (Miklowitz, 2010c:289).
- **There are certain things relatives can and cannot control** – they can learn as much as possible about the illness, they can keep their own reactions from getting out of control, and they can communicate to the patient their desire to help and/or their frustration over his or her lack of acknowledgement of the disorder. However, relatives cannot single-handedly force the patient into the hospital, control his or her mood swings, or make him or her take medications.
- Relatives must determine which actions on their part will help during a manic relapse, and which will not.

Alert: Relatives must take care of themselves during crises. If you live with someone whose treatment is ineffective – especially one who has a history of violent behaviour – you should safeguard your environment. It is important to keep drugs and alcohol out of reach, keep weapons locked up, have a safe space and if a loved one assaults you, do not live under the same roof (Haycock, 2010:233).

S2.7.2 Relapse prevention (minimising relapse)

Knowing **what** may trigger your (patient's) moods can help you to find responses that reduce the risk of relapse at these times. You can include your ideas for **managing triggers** and detecting episodes in your plans to prevent relapse. Fortunately, there *are* effective treatments and personal strategies for managing episodes and preventing relapse. It is very important to be informed about the disorder and to comply with treatment (Berk et al., 2008:xii, 119).

Development of an advance directive/**relapse prevention plan** or an emergency contingency plan in the event a mood becomes out of control is necessary. Such **written** guidelines will provide clear steps to take in the event of an emergency, including who and how to contact for help (Haycock, 2010:207). Colom and Vieta (2006:101) also refer to the importance of a relapse prevention plan.

Miklowitz (2010c:157, 158) explains that **a RELAPSE DRILL** is like a fire drill.

In **this drill**, the patient and his or her family members do a "dress rehearsal" for the actions they will perform when the patient shows the incipient signs of a manic or depressive recurrence. The drill drives home the point that the patient is vulnerable to subsequent episodes of mood disorder. There are several steps to the drill:

- Review the patient's prodromal signs (e.g. when becoming manic or depressed)
- Review what the family might do if these signs became evident
- Review and explore which of these alternatives would be most helpful
- Encourage the patient and family members to choose one or a combination of these alternatives for future implementation.

Discuss the **practicalities** of implementing these solutions – who will do what? If possible, **contract** with the patient, agreeing who will take control of the situation. It is important to know what **resources** are available.

S2.7.3 Suicide risk personal prevention plan

> While you are waiting for the crisis to subside, be patient.
> This will pass, but only if you stay alive *(Berk et al., 2008:158).*

Certain **risk factors** can alert you to be extra vigilant in dealing with suicide risk. According to Berk et al (2008:159 – 160) and Miklowitz (2011: 242) these include:

- A pervious suicide attempt
- Being isolated from others
- Having recently experienced a major stressful event
- Feeling hopeless or already having a specific plan to commit suicide
- Abusing drugs or alcohol
- Anxiety disorder
- Being male
- Being prone to impulsive acts
- Having recently been hospitalized
- Family history of suicide
- Do not have ready access to a psychiatrist or other mental health care helper
- Do not have a strong reason to keep living.

Be aware of the following **danger signs**:

- Giving things away
- Thinking about suicide
- Resigning from commitments
- Writing letters to deal with unfinished business
- Finalising a will
- Having a plan to commit suicide.

Alert: More than 45 percent of people with BD attempt suicide (Haycock, 2010:103).

Manage strategies when the patient is well. Suicide prevention involves **decreasing** a patient's access to the means to commit suicide and **increasing** his/her access to support systems (doctors, therapists, family members and friends) (Miklowitz, 2011:243).

S2.7.3.1 What can the patient do? (Berk et al., 2008:162-170 and Miklowitz, 2011:242-252).

Although suicidality is a dangerous symptom of illness, it is unfortunately often a taboo topic. Suicidal impulses can be managed and controlled and it is important not to feel alone with or to be ashamed of this common symptom of bipolar disorder.

S2.7.3.1.1 Safety first

- Make contact with the therapist and inform him/her about the suicidal thoughts or plans, and book an emergency appointment. Contact the local hospital emergency department if the therapist is not available.
- Get rid of the means to hurt yourself.
- Inform family and friends that you are feeling suicidal.
- Stay with someone so that you are not alone.
- Abstain from substances if you are feeling suicidal.

S2.7.3.1.2 Getting through this time

- Talk with a trusted person or call a suicide hotline.
- Get some distance from your suicidal thoughts by recognising that they are only temporary symptoms and that you do not have to agree with them or act on them.
- Focus on getting through the next hour of the day.
- Do things that make your distress easier to tolerate and that can lift your mood, like spending time with a loved one, listening to music, expressing your feelings through art, writing or playing a musical instrument, playing with a pet and doing relaxation exercises.
- If religion or spirituality is meaningful to you, you could consider seeking support from religious or spiritual leaders.

S2.7.3.1.3 Reducing symptoms

- Put your strategies for reducing relapse into practice.
- Identify your negative thinking and find more helpful perspectives.
- Often suicide is not about wanting to die but about wanting to escape situations or problems in which you feel hopeless and stuck. Finding new ways of responding to old problems can make you feel very differently about the future and reduce your hopelessness.
- Prioritise and delegate stressful demands that make you feel overwhelmed.

S2.7.3.1.4 Compile a "Reason to Live" list

People are protected from suicide when they can access good reasons to live.

You could develop a **Reason to Live list** when you are well and keep it in easy reach for times when you feel suicidal. **Examples include**: You don't want to devastate your children, family or friends; you want to watch your children grow up; things might be different in the future; there are still things you want to do, when you are well; there are things that mean a lot to you; you are scared that your suicide attempt will fail and you will be left damaged in some way; you have a mission in life and there is hope that things will improve.

Develop your personal Suicide Risk Prevention Plan: The idea of a Suicide Risk Prevention Plan is to compile contact numbers of people who have agreed to help if you become suicidal and a list of very specific things that you and others have agreed to do to prevent suicide and help you through this time. Keep instructions simple and brief so that the plan is easy to use when you are ill. Give everyone a copy of your plan so that they have it at hand if the need arises – they may even sign it. Remember to update your plan as circumstances change.

What can family and friends do?

When a patient becomes suicidal, contact and support from others is absolutely critical to keep you as the caregiver from sinking further. You may feel helpless, being unsure of what to do when the patient is suicidal. Ways in which you might boost the patient's constructive coping skills include: taking away anything that may be potentially lethal; spending time with the patient; listening to the patient, without being critical; brainstorm with the patient to find alternative solutions to difficulties that seem overwhelming and to create new, achievable goals; helping with burdensome demands, such as childcare; distracting the patient's thoughts; doing pleasant things together; calling the doctor on the patient's behalf and if necessary driving him/her to the hospital. According to Miklowitz (2011:248) it does also help to use distraction – increase the amount of low-stress, low-demand social time you spend with the patient, like see a movie with the patient, go for a walk, take a drive or read together.

Question: Can anyone share a personal experience?

S2.7.4 Well-being or wellness plans

There is no uniform format for a well-being plan – it may range from a private decision by an individual to adopt a certain strategy, through to a formal document drawn up by an individual to consult family, friends and health professionals. A primary consideration is **‘what will work best for the individual involved?**’ The individual needs to feel confident that the plan will serve their particular interest and circumstances, both in the short and the long term. Well-being plans should incorporate experiences from the past, identify early **warning-signs** and **triggers**, set out action plans for minimizing or preventing future episodes, and include quality of life commitments to advance the individual beyond merely ‘managing’ episodes. Such a plan is a living document, a guide and often developed with others (Parker & Ketter, 2010:350).

Table 7.10: Example of wellness plan (for S4) (Freeman, 2011:16)

Trigger	**Early Warning Sign**	**Stay Well Strategy**
Jet lag	N/A	Travel with extra mood stabilizers. Schedule down time for immediately after travel.
Disrupted sleep	Difficulty getting to sleep or staying asleep	Use sleep aid medication short term until stable again. Increase exercise.
Stress from family issues	Irritable, paranoid, argumentative.	Increase exercise. Get “thought checks” and “reality checks” from caregiver.
Stress about work or money	Impulsive spending and financial extravagance.	Share with spouse. Avoid internet banking. Stop carrying credit cards and avoid stores. The patient might have to confide in his/her investment broker that he/she will notify the caregiver if any unusual transactions are requested.

S2.7.5 Treatment contracts (the patient’s plan made ahead of time to ensure prompt treatment based on his/her own choices and instructions if he/she becomes unwell).

The Massachusetts General Hospital Bipolar Clinic & Research Programme defines a treatment contract as a document that the patient writes while feeling well to plan for the times when he/she does not feel so well. It is written so that the patient, family, friends, and doctors can recognize symptoms of illness and can comply with the patient’s wishes for treatment. Suggested contents of the contract may include **purpose, who** should be involved in the care, **baseline** of wellness (mood), **signs** of depression and **agreed intervention** for depression, **signs** of mania and **agreed intervention** for mania and steps to be taken in an **emergency**. This might include permission for the caregiver to communicate directly to the MDT or it might include a power of attorney (Freeman, 2011:19-

21). This contract is a tool, but it should be applied recognizing the individuality of each patient.

S2.7.6 Social rhythm metric (SRM)

The **patient** can be encouraged to **track** his or her daily routines with a self-monitoring schedule, the SRM. In this chart he/she keeps track of when he/she eats, sleeps, exercises, and socializes, and makes ratings of his/her daily mood. Over time, the patient can work on stabilizing his/her daily routines as a means of stabilizing his/her mood. This involves planning regular activities for predictable times of the day or night. The purpose of social rhythm tracking is to allow the patient to discover the relationship between changes in his/her daily routines, levels of interpersonal stimulation, sleep-wake cycles, and mood. Certain **patterns** will emerge. Sleep and activity patterns can be a sign of whether mood problems are getting better or worse (Miklowitz, 2010c:61, 99,155, 156).

A

A1 Aid

TIP Compile a filing system: Kowatch, Fristad, Birmaher, Wahner, Findling, Hellander and the Child Psychiatric Workgroup (2005) writing on bipolar disorders recommend that **family** should be instructed to keep **daily logs** for at least a two week period before their visit. A **timeline** should also be developed with the primary informant to establish onset, offset and duration of symptoms to understand the unfolding of the bipolar phenomena.

Zetin, Hoepner and Kurth (2010:115, 116) mention that it is a good idea for the patient to put together a **file** of past medical, psychiatric, psychological, hospital and pharmacy records for the first visit – list major and minor symptoms, document prior similar episodes and treatment responses. Past records (e.g. scans, results of tests conducted, psychologist’s reports, laboratory data, records about any medical illnesses), a medication list, a life chart, a family history, and a list of symptoms are several of the items that can be very helpful to your clinician on your first visit. If there has ever been a psychiatric hospitalization, the admission and discharge summaries can be very informative. The family might have to help with this – **keep all reports**.

Family and friends: When your loved one comes out of hospital or has just been diagnosed, he or she will need help keeping all of the paperwork in one place. You can set up the filing system and have it clearly labelled and ready for when he or she is more able to take care of it personally (Fast & Preston, 2006:204).

Table 7.11: **Guideline of areas of patient's history on which caregiver can report in order to assist the therapist to complete the diagnostic assessment (researcher)**

Guideline

Current reason for admission

Genogram of family of origin

- Psychiatric illness in family (diagnosed, treatment, suicide, substance abuse)
- Interpersonal relationships

Personal history

- Birth (normal or problematic)
- Developmental milestones
- Childhood (report any problems)
- Adolescence (report any problems)
- Educational history
- Work history
- Relationships (single, married, children other family)
- Sexual aspects (asexual or hypersexual)
- Hobbies
- Socio economic aspects (past and current)
- Cultural and religious aspects
- Criminal history
- Strengths
- Personality

Medical history

- Operations
- Head injuries (ever unconscious?)
- Epilepsy
- Other illnesses like diabetes, HIV

Psychiatric history

First symptoms	Date	Mania /hypomanic	Depression	Psychosis	Substances Type, duration and amount

First official diagnosis	Date	Doctor Name Telephone	Hospitalized Yes, No	Name of Hospital Duration	Adherence to treatment
Second official diagnosis					

Medications prescribed previously or currently

Support system for patient

Areas of concern for the caregiver (aggressive, non-compliant/risk factors)

Future plans after discharge from hospital

Date

Name and capacity of Caregiver

It might happen that the caregiver wants to convey information to the doctor, but the patient will not allow the caregiver to visit the doctor with him. The caregiver can then possibly write a **letter** to the doctor for him/her to take cognisance of the situation.

An example of letter to the doctor/team

Address
Date

Dear Doctor
Re: Name of patient/File number

The purpose of this letter is to give you feedback/information about what the situation at home is. I know that for confidential reasons and because of your ethical responsibilities it might be difficult for you to see me in person, but I still feel that there are important things I would like you to be aware of. My husband/wife/parent/child can be very convincing/manipulative and he/she does not always reveal the truth.

I am very concerned that he/she has not been taking his/her medication for the last month, because he/she denies that he/she has any illness. He/she has been consuming alcohol every night for the last three weeks and I do suspect other substances as well. He/she is also taking sleeping tablets every night that he/she obtains from our GP. He/she is currently very irritable and there have been occasions when he/she became verbally and even physically abusive towards me and the children. He/she has not been sleeping well for the last week and did not come home for a few nights. My guess is that he/she went gambling, because some R6 000 has been withdrawn two days ago from our joint savings account and he/she cannot account for the money. At the moment he/she is thinking that he has got millions in the bank, where the reality is that I am afraid that we may lose our home. He was also involved in an accident in our only car.

This letter is not to put him/her in a negative light, but I feel afraid that this current behaviour may lead to a relapse and again to hospitalization.

I do trust that you will handle this information with the necessary discretion, because my relationship with him/her has already deteriorated. If however you want to call me in or talk to me on the telephone, I shall be more than willing. My telephone number is:

Yours sincerely

------------------------- (primary caregiver)

Letter 7.1: An example of a letter to the doctor/team (researcher)

A2 ANIMAL - Ostrich

An ostrich like to puts his head in the sand. If the caregiver does that it might mean denying the illness. The ostrich is on the other hand an animal that eats anything and that has very strong eggs – there is inner strength and a thick skin. These are aspects that are very important for the caregiver to be able to persevere.

A3 ASK for help and information – it is **AVAILABLE**

A4 ASSESSMENT will always be an on-going process and the patient and caregivers will constantly be **AWARE** of the disorder.

A5 AWARENESS of personality

The family may begin to see everything the patient feels or does as a sign of his or her disorder. These perhaps over-generalized attributions cause great resentment in the patient, who may begin to lose the ability to distinguish his or her normal emotions or desires from pathological ones. Like the proverbial centipede that, when asked how he moved all 100 legs in such beautiful coordination, could not do it any more once he thought about it, the person with bipolar disorder can be similarly paralyzed by an excessive vigilance for signs of his or her disorder (Miklowitz, 2010c:9).

A6 ADMISSION to hospital (Mental Health Care ACT 17 of 2002)

When someone refuses to acknowledge that they are sick or refuses to take medication, it is important to consult with a health care professional and to explore your legal rights in terms of helping your loved one. It might also be that the person has symptoms that exert a disruptive effect on their life, and they need timeout to focus on getting well (Berk et al., 2008:16).

According to Baumann (2007d:795) **admission to a psychiatric hospital** is strictly defined in terms of the **Mental Health Care Act 17 of 2002** (South Africa) with regard to the patient's consent to admission, capacity to give consent, and the nature of the illness, which should be psychiatric in nature and not primarily due to a general condition. It might also be that the patient has been abusing substances. Patients should be referred to psychiatric hospitals only once general medical conditions have been excluded.

- **Voluntary**: **(article 25)** capacity for informed consent to care, treatment and rehabilitation.
- **Assisted**: **(article 27)** care to those incapable of making informed decisions due to mental illness and who do not refuse treatment (form 04). Likelihood of harm to self or others due to mental illness and to protect financial interest or reputation.
- **Involuntary**: **(article 34)** care to those incapable of making informed decisions due to mental illness and who refuse treatment (form 04). Likelihood of harm to self or others due to mental illness and to protect financial interest or reputation.

Simple truth: Most people agree that mental disorders frequently render patients incapable of understanding their need for help and that their behaviour may necessitate intervention for their own good and for the good of others (Haycock, 2010:247).

Zabow (2007:581) states that if a member of the **SAPS** has reason to believe that a person, owing to his/her mental illness or severe or profound intellectual disability, is likely to inflict serious harm on him/herself or on others, the member must apprehend the person and cause that person to be taken to an appropriate health establishment administered under the auspices of the state for assessment **(Art. 40 of Mental Health Care Act)**.

In case of absconding; the SAPS must assist to return the user to the health establishment. In practice it is still unfortunately a serious problem to obtain cooperation from SAPS. It does seem that training is needed to empower them. It is recommended that caregivers go personally to their local station commander to negotiate help. Another resource from which you may ask for help is the staff at the local clinic or the GP/private psychiatrist. If they are a known psychiatric patient it is important to find out if such a patient is an involuntary outpatient or if he/she has been discharged totally. In the last instance, a **72 hour assessment**, at another referring hospital, must first be done.

Location of treatment

- Vieta (2009:52) mention that patients should be treated at the most appropriate level of care, depending on their severity and treatment considerations.
- Sadock and Sadock (2003:560) state it must be decided if a patient must be **hospitalized** or treated as an **outpatient**. Clear indications for hospitalization are the need for diagnostic procedures, the risk of suicide or homicide, and a patient's grossly reduced ability to get food and shelter. A history of rapidly progressing symptoms and the rupture of a patient's usual support systems are also indications for hospitalization. Patients with mood disorders are often unwilling to enter a hospital **voluntarily**, and may have to be **involuntarily** committed.
- Manic patients often have such a complete lack of insight into their disorder that hospitalization seems absurd to them. Haycock (2010:5) mentions that manic episodes can require hospitalization, for the safety of both the patient and those around him/her. Untreated, these can have tragic consequences. Miklowitz (2011:5) comments that patients can find the hospital experience confusing and frustrating.

The researcher's experience is that even once a patient is admitted to a hospital, teams are under considerable pressure to discharge people from the hospital quickly; as a result, proper psycho-education and discharge planning is not done. Important aspects that often go unanswered because mental health providers simply do not have time, include the symptoms and the factors that cause the cycling of bipolar disorder as well as what a patient can **expect** from his/her future. This can lead to a patient discontinuing his/her medication, **relapsing** and being **readmitted (revolving door)**. The patient may have been admitted to a hospital and discharged in less than a week, which is not nearly long enough for the episode to remit (Miklowitz, 2010c:29).

Simple truth: For virtually every patient and family member the process of hospitalization and the hospitalization itself are **quite traumatic experiences**. Many relatives have been deeply humiliated by the hospitalization experience, particularly if the police were involved or if they were embarrassed in front of neighbours (Miklowitz, 2010c:123).

Fact: For many family members, a trip to the hospital with a loved one is one of the most traumatic experiences they will ever know. The more you are able to take care of yourself in this situation and keep on with your life, the more help you can be when your loved one comes home (Fast & Preston, 2006:185).

Simple truth: Hospital visits work for a reason. They offer a low-stimulation environment where a person can focus on healing without having to deal with the outside world (Fast & Preston, 2006:186).

For the caregiver: Take time to rest while the person is in hospital.

Try to take measures to re-create the hospital environment at home – that can make a difference in acclimating back to the person's regular life (Fast & Preston, 2006:186). Hospital visits often seem to come out of the blue, but this is not actually a realistic picture of what leads up to a hospital visit. Hospital visits **never** emerge from a void. One of the biggest mistakes that family members make is to think that recovery from a hospital stay should be quick. It can take people a year or more to recover from a serious hospital stay (Fast & Preston, 2006:191, 194).

TIPS to **prevent** another trip to the hospital (Fast & Preston, 2006:197):

- Know the first symptoms of a mood swing
- Chart mood swings daily
- Contact with the health care professionals
- Regular medication use
- Beware of substance use

SIGNS that the patient needs **immediate** help (Fast & Preston, 2006:199):

- Active suicide thoughts
- Mania or depression that can no longer be treated at home
- Dangerous behaviour
- An inability to doing anything, including getting out of bed, eating, working, or having a normal conversation
- Cancelling doctor's appointments
- Stopping all medications and saying that he/she is cured when it is obvious to others that the person is still sick.

Simple truth: Bipolar disorder **AFFECTS** the patient as well as those **AROUND** him/her.

A7 Team APPROACH

Last (2009:127) **defines** the "treatment team" as a group of individuals who share the common goal of promoting the patient's mental health. In any "team", each individual has a distinct role to play.

Role of caregiver: The team also includes the caregiver whose roles might include learning about bipolar disorder, to stay in contact with the patient's doctors and to know about early warning signs of mania and depression. The caregiver may also have an advocacy role to act in the best interest of the patient.

Patients require a long-term, multidisciplinary management plan. A multidisciplinary approach may also enhance long-term patient outcomes such as mood stability, occupational and social functioning, and overall quality of life (Vieta, 2009:50, 64). Taylor (2006:15) reminds us that bipolar illness is a complicated disease that cannot be cured. As in diabetes, for example, the symptoms must be managed, and are often controlled to the point that people live full and meaningful lives. However, because bipolar illness is **lifelong**, it occurs in episodes, requires multiple forms of intervention, can quickly change and is best treated by a **mental health team**.

Role of treating team: ASSIST the patient and family to **ADAPT** to and **ACCEPT** the changes the illness brings to their lives. See the team as **ALLIES** in your battle to manage the illness.

A8 ACCEPTANCE (hard work for both the patient and the caregiver)

We frequently find in the patient's relatives a struggle to **accept** the existence of a major psychiatric disorder in a loved one. It can be a slow, painful process (Miklowitz, 2010c:7, 167).

You had dreams yourself which now might have to change significantly. And yet, as with many big changes, people **acclimate**. Lives may have to change, but they often change for the better. Communication can become more effective, families can become closer (Fast & Preston, 2006:255).

Question: Can you give any reasons why patients **ABANDON** their treatment?

Possible reasons: (Colom & Vieta, 2006:145)

- Missing hypomania
- Denying the disorder

- Believing one is capable of controlling the bipolar disorder without need to take any drug
- Feeling bad because it is the medication and not the person controlling the mood.

A9 ADHERENCE to treatment

Miklowitz (2011:60) refers to the challenge that inconsistency in taking medication is a major problem among people with bipolar disorder, with more than 50 % discontinuing their drug regimen at some time in their lives. Miklowitz (2011:132) concludes saying: **"Committing to a long-term programme of medications is an important personal decision"**.

According to Fast & Preston (2006:xii) it is normal for a patient to have a **love-hate** relationship with their medication. Extensive research does however show that medications are the first line of defence against bipolar disorder mood swings. Finding the right medications can be very difficult. It can take a long time and the **side effects** can range from mild to very severe.

Caregivers should take note of the following possible reasons for non-adherence (Miklowitz, 2010c: 191):

- Lack of understanding about the purposes of medication
- Complexity of the regimen
- All medications have side effects, and, unfortunately, the drugs used to treat BD are known to produce side effects for the majority of people taking them (Fast & Preston, 2006:51, 60). Once a patient can accept that he/she have an illness that needs medical treatment, accepting medications can become easier.
- Discomfort with blood tests
- Missing high periods
- Loss of creativity
- Disbelief in the diagnosis
- Desire to rebel against spouse or parents
- Co-morbid personality disorders
- Simple forgetting

Simple truth: The safe and successful delivery of efficacious treatments for bipolar disorders relies upon the patient's (and often their caregiver's) ability and willingness to accept and engage with the services provided, and to adhere with an agreed regime of medication and/or other interventions that make up the individual's treatment plan (Scott & Tacchi, 2010:275).

It is the researcher's firm belief and experience that treatment will be of no avail if the patient does not cooperate. A person can initially be treated against his/her will, but if this person does not believe that he/she has an illness, he/she will abort the treatment and relapse after a while. I therefore view treatment **adherence and the therapeutic relationship** as the cornerstone of any treatment for the bipolar patient.

Fortunately, today we have very effective treatments to keep BD in check. Improvement of treatment **adherence** must be one of the main objectives of any psychological intervention in bipolar disorders, since the problem of poor adherence is certainly the cornerstone of the poor progress in many of our patients. The problem is severe if we consider that practically all bipolar patients seriously think **at least once** in their life of abandoning treatment, and it is not risky to affirm that more than half of the patients stop taking the prescribed treatment without indication from their psychiatrists, even including during periods of euthymia (stable mood). Treatment withdrawal is the most common cause of relapse among bipolar patients and in fact, the risk of hospitalization is four times higher among the patients who do not comply with their treatment. Mortality, especially by suicide, is also higher in untreated patients (Colom & Vieta, 2006:104).

ROLE of caregiver: It may be up to you to help a loved one manage medication, especially if he or she was just diagnosed or is recently out of hospital**.**

Fast & Preston (2006:35) state that not only do many of the medications used to treat BD reduce symptoms and help people maintain emotional stability, but some have neuro-protective properties: they are able to protect the brain from being damaged by the illness, and may actually activate natural mechanisms for the growth of new nerve cells.

When new medication is being introduced, it is imperative to keep a record of what is taken (dosage and time taken). The pathway to recovery more often than not is complicated. The rule is trying several medications in the search for the right combination. It is a time-consuming process (Fast & Preston, 2006:47).

Types of poor ADHERENCE to treatment (Colom & Vieta, 2006:105-107)

- **Absolute poor adherence**: Complete negligence of the patient in following the indications of the responsible therapist, or refusal to visit the therapist.
- **Selective partial adherence**: This is the case of the patient who does not really believe in the chronic and the recurrent nature of their bipolar disorder. Patients may accept treatment for the acute phase, but reject prophylactic treatment.

- **Intermittent adherence**: These patients allow themselves periods of "vacations" from treatment.
- **Late adherence**: Some patients show initial resistance to admitting the need to receive treatment and only decide to start taking the medication prescribed after a few relapses.
- **Late poor adherence**: After 2 or 3 years of good adherence, some patients start abandoning their mood stabilizers without apparent reason.
- **Abuse**: Taking more medication is also a rather common form of poor adherence among bipolar patients. The abuse of benzodiazepine is, obviously, very common, but there are also cases of abuse of antidepressants, neuroleptics and even atypical antipsychotics.
- **Behavioural poor adherence**: Certain patients correctly take the medications prescribed but fail to comply with behavioural indications.

The outlook for this disorder worsens significantly when patients suddenly stop their medication. Relapses come sooner and are more severe, while suicide is more likely. The long-term implications for "**start-stop**" medication taking on adults certainly do not bode well (Miklowitz, 2010c:46).

Family and interpersonal problems may constitute a path to poor adherence. Some family members will tell the patient that he will "become stupid" from so much medication or that he "looks like a zombie" (Colom & Vieta, 2006:108, 144). When, despite clinical improvement following the most recent episode, the patient and close relatives can accept, that there is an underlying **vulnerability** to future episodes, acceptance of the need for a prophylactic medication regimen is more readily achieved (Miklowitz, 2010c: 9).

TIPS on how to improve adherence (Miklowitz, 2010c:193-199)

- Some patients benefit simply by knowing the risks they face by not taking medications; one's chances of having a recurrence in a 1 year period are halved by taking medications.
- Encourage the patient to discuss the side effects of medication and the necessity of blood tests with his/her doctor. Blood tests verify therapeutic dosages and help minimize the likelihood of toxic reactions of certain medications, such as lithium.
- Remember that taking medication is often interpreted by bipolar patients as giving up of independence or control. The patient should be encouraged to view medication as a way to gain, rather than give up, independence and control.
- Be aware that a patient's non-adherence may be a way of **rebelling against the family**.

- Compare psychiatric medication to medications used in the treatment of chronic medical disorders, such as diabetes and high blood pressure. These illnesses require long- term medication to correct chemical imbalances, as does bipolar disorder.
- Do not over-monitor; reach an agreement that strikes a compromise between the relatives' need for reassurance and the patient's need for autonomy (Miklowitz, 2010c:274).

A10 ALTERNATIVE treatment

Zetin et al. *(*2010:15) state that complementary and alternative medicine (CAM), as defined by the National Centre for Complementary and Alternative Medicine, is a group of diverse medical and health care systems, practices, and products that are not currently considered to be part of conventional medical practice. *Alternative medicine* refers to unconventional treatments as an alternative to allopathic treatments (conventional medical modalities); *complementary medicine* refers to unconventional treatments as adjuncts or cotherapy to usual medical care.

NIMH (2010:8) reports that in general, there is not much research about **herbal** or **natural supplements**. Little is known about their effects on BD. An herb called St John's Wort (Hypericum perforatum), often marketed as a natural antidepressant, may cause a **switch** to mania in some people with BD. It can also make other medications less effective, including some antidepressant and anticonvulsant medications. There is no evidence that any natural substance is both free of side effects and effective as a mood stabilizer or antidepressant. Hypericum (St. John's Wort) can cause high blood pressure and headaches (Miklowitz, 2011:107). Haycock (2010:99) furthermore states that it can potentially **trigger** manic episodes in select individuals.

Scientists are researching **omega-3 acids** (most commonly found in fish oil) to measure their usefulness for long-term treatment of BD. Miklowitz (2011:122) also refers to this popular alternative, the **omega-3 fatty acid plan**. In an early, randomized trial, fish oil did better than placebo tablets in prolonging periods of wellness among people with Bipolar disorder who were also getting mood stabilizers. Subsequent studies of omega-3 have not really proved its efficacy, although it may have some weak effects on depression.

Alert: The **mystical-religious-spiritual-esoteric-orientalist type therapies** are of greater concern, however. Without doubt, a bipolar patient treated only with homeopathy will suffer constant relapses and in addition, will experience an aggravation of the evolution of the disorder (Colom & Vieta, 2006:138, 139).

Question: What do you think may be the role of spiritual cure, astrology, yoga, meditation and other alternative therapies in the treatment of a bipolar patient?

A11 ADMINISTRATION of property

Zabow (2007:581) mentions that Chapter V111 of the Mental Health Care Act provides for the care and administration of the property of the patient. Provision is made for an **administrator** to be appointed to administer and manage the property of a mentally ill person when the need for this arises. Any person over the age of 18 years may apply to a Master of a High Court for the appointment of an administrator for a mentally ill person or a person with severe or profound intellectual disability. The Master must, after considering the application, either appoint an administrator or decline to do so. The procedures to appeal the decision as well as the powers and functions of the administrator are set out in the Act.

W

W1 WELLBEING OF THE CAREGIVER

Caregiver stress appears to increase with the severity of the illness. Watch for indications of depression, irritability, anxiety, frustrations, anger, fatigue, insomnia and difficulty in concentrating. Another sign the caregiver has taken on too much is poor physical health due to a weakened immune system and exhaustion. The caregiver living with a person who has a major mood disorder, deserves a chance to grow and set personal goals as much as anyone. Depending on the person's degree of illness, the caregiver may however, find this more challenging than others can imagine (Haycock, 2010:192).

Identifying caregiver's needs (Last, 2009:270-271)

Alert: Neglecting your own needs while caring for a loved one is perhaps the most serious potential problem you face. The stress you can experience as a caregiver can seriously affect your health particularly if you feel trapped (Haycock, 2010:192, 204).

Exercise: Look at the list below. After reviewing it, fill in any other needs that are important to you. Then prioritise the list by assigning a numerical score to each item, using a "1" to indicate your most important need, a "2" designating your second most important one, and so on, until you have rated each of them.

- To be physically fit
- To feel connected to and supported by other people

- To have a spiritual connection
- To pursue my interest and hobbies
- To give of myself to others
- To be productive at home, school or work
- To be intellectually stimulated
- Other important needs and how am I currently meeting these needs? ____

Discuss in group

The caregiver should take care of him/herself. Berk et al. (2008:2, 3, 34) give the following suggestions:

- Become informed
- Give yourself time to adjust to the illness
- Use helpful resources
- Make advance plans to deal with the bipolar disorder
- Use problem solving plans to sort out difficulties
- Use stress reduction strategies when the person is ill
- Maintain contact with friends and family
- Maintain healthy boundaries with the person and their illness
- Develop healthy habits e.g. exercise and diet
- Try not to abuse any substance, to neglect your own health or to isolate yourself
- Develop realistic expectations
- Acknowledge your natural reactions
- Maintain or rebuild your relationships with the person
- Recognize the positive
- Acknowledge the support you provide
- Be alert to signs that you may be stressed or depressed

General TIPS for caregivers

- Get enough sleep
- Go with the patient to the doctor and ask questions about things that you are worried about
- Set small goals
- Take time for yourself, relax and have a balanced diet
- Identify a confidant with whom you can share your feelings

- Try to still do things that you enjoy (with or without the family)
- Join a support group
- Allow yourself to express your feelings
- Keep a diary
- Become involved with something creative

The rights of caregivers of people with the diagnosis of BD

Caregivers have rights. Some that can be mentioned include:

- The right to be treated with respect by the patient, MDT and the community
- The right to information about the illness and skills how to approach it
- The right to feel safe and not tolerate any threats from the patient
- The right to ask for help
- The right to be recognized and acknowledged
- The right to be listened to
- The right to have needs and dreams
- The right to become tired, frustrated and even angry
- The right to have emotions
- The right to a break
- The right to have choices
- The right to support
- The right to also have an opinion regarding the patient's symptoms and treatment
- The right to be honest about your feelings
- The right to decline or limit contact with someone who makes your life unbearably difficult.

Question: which rights do you consider as the most important? Can you add more?

W2 WORK and finance

W2.1 Work

BD is notorious for **causing work and financial problems**. From depression to mania and everything in between, the illness can seriously impair the ability to work effectively and the management of money. Many people with BD simply cannot handle the stresses of everyday work. BD is an illness frequently triggered by outside events and for many people work is one of the biggest triggers (Fast & Preston, 2006:89).

Family and friends: There is a good chance your loved one has caused some family financial problems. Sometimes you just have to accept the consequences of this illness and then do everything possible to ensure the larger problems are prevented in the future (Fast & Preston, 2006:90).

Many BD patients lead entirely well-adjusted social and family lives and hold down jobs as well as anyone does who is not bipolar (Colom & Vieta, 2006:72).

Bipolar disorder may, HOWEVER, prevent a person from working for shorter or longer periods of time. The Job Accommodation Network provides recommendations for accommodating workers with bipolar disorder. To learn more go to http://www.jan.wvu.edu/media/Bipolar.html (Haycock, 2010:134).

It is often the family members who feel the burden of a relative who can't work or make much money (Fast & Preston, 2006:89). Remember not to pressurize the patient to have to be a high-powered professional or the best in her/his field. Many people have found happiness giving up prestigious, high-paid jobs to do something they love for much less money, prestige, social status, and personal recognition (Haycock, 2010:132).

Essential: It is desirable for people suffering bipolar disorders to have a job with a **strict habit** schedule; hence jobs with constant shift changes, or no schedule, are not advisable. If a bipolar patient holds a job requiring a lot of night work, such as a nurse or a waiter, he/she should try to stay off the night shift (Colom & Vieta, 2006:187). High-powered jobs with many obligations or deadlines may be a **trigger** for bipolar symptoms, as can working with stressful people. A job that enables the patient to work in a non-stressful environment may be the best way to maintain stability (Fast & Preston, 2006:105).

The caregiver can help your loved one by creating a **work history chart** in order to create a realistic picture of future work prospects. According to Fast & Preston (2006:95-97), important aspects that should be documented include:

- Chronological work history (duration and reason for terminating)
- Patterns observed when looking at the work history
- Income
- Current work situation
- Future prospects

Patients can apply for a disability grant, given an evaluation by the psychiatrist and/or the occupational therapist. Speak to the social worker. They are not permitted to apply if they are abusing substances.

Role of caregiver: You might have to **advocate** for your loved one at his/her workplace, because it is a given that many employers are not well informed about bipolar disorder.

Finding stability around work and money (Fast & Preston, 2012:168-171).

- **Forget the guilt trips** – It won't work if you try to **force** the patient to find employment and make money.
- **Face the truth** – it is a reality that the normal, fast-paced work environment may never work for the patient.
- **Redefine success** – success may be measured in many other ways than financial rewards and accomplishments.
- **Foster self-esteem outside of work** – focus on what the patient does well and let him/her know you appreciate it.
- Is work worth getting sick for?
- Look for work alternatives
- **Talk honestly** – do you feel the patient does what he/she can do to stay well, or do you feel as if you are being used to support someone who does not want to work?
- **Change priorities** – can you and the patient accept the idea that work may not come first for some people with bipolar disorder and that this may be a gift instead of a curse?
- **Understand the role of pressure** – a job with little or no pressure may be better for the patient than a creative job filled with deadlines and obligations.
- **Make lemonade**: if the patient has serious work and financial limitations, help him/her turn the limitations into opportunities.

Simple truth: A positive work situation makes an enormous difference in anyone's life.

W2.2 Finance: There is a good chance that your loved one has caused some family financial problems (Fast & Preston, 2006:89, 99). Set up checks and balances to prevent a financial disaster because of bipolar disorder.

TIPS

- The patient must take his/her medication.
- The patient should write down everything they spend.
- If credit cards are a problem, the patient should not have them.
- Create a **financial history chart** (debts and assets).
- The patient should rather have his/her financial accounts in his/her partner's name.

- Consider applying for an administrator to be appointed by court.

Dealing with a **financial crisis** (Fast & Preston, 2006:106)

- Ask for a letter from the patient's doctor.
- Let the patient call and consolidate his/her debt.
- Let the patient go to consumer credit counselling.
- If necessary, let the patient explain the situation honestly at his/her workplace.

For friends and family: Disability is not a failure. If your loved one had cancer and could not work, you would not consider it a failure. Bipolar disorder, too, is a serious illness, and needing time off from work to get better is normal. This is especially true after a hospital stay.

W3 WELL KNOWN people: The list of people affected by BD who now hold prominent places in history is extensive: political leaders such as Churchill, painters such as Van Gogh and brilliant composers such as Schumann and Tchaikovsky (Colom & Vieta, 2006:72).

W4 WHAT WORKS?

It is often difficult to know how to help your partner (the patient) when they are ill. The solution is to **write down what works** and what does not, so that you can read the list as soon as you see the first signs of bipolar disorder (Fast & Preston, 2004:51).

What works list for depression? (S4) (Fast & Preston, 2004:61-63, 64). Although the list focuses on what the caregiver can do to help, eventually the patient should add his/her own ideas on what he/she can do to help themselves when he/she is depressed.

- Exercise with the patient.
- Help the patient to set small goals.
- Encourage regular bedtimes.
- Create a less chaotic environment.

The list should also include a section on medication, doctors and hospitalization.

What does not work for depression?

- Thinking that the patient's behaviour is deliberate.
- Becoming frustrated when the patient lies around all day.
- Using alcohol or drugs.

The **What Works list** can free you from the constant worry of what to do and what not to do when you see the signs that the patient is becoming sick. You can take out the list and read what has worked in the past. This will help you think clearly and to take action during a crisis (Fast & Preston, 2004:64).

Please **refrain** from asking judgemental type questions that imply disapproval, such as:

- You had sex with a stranger?
- Are you out of your mind?
- Don't you have any respect for yourself? (Fast & Preston, 2006:8).

The caregiver might encourage the patient to write a letter if they find it difficult to talk. The caregiver must try to see the situation from the patient's point of view.

Letter to the caregiver from the patient

Address
Date

Dear

Re: My bipolar illness

I am writing this letter today to tell you that I am sorry for the times I hurt you when I was very ill and not myself. I know that it is sometimes very hard for you to know how to handle me. Can I give you a few ideas?

- Try not to regard the illness as a family disgrace
- Please do not ignore me
- Do not nag, preach or lecture me
- Please offer love, support and understanding
- Please talk to professionals and read about the illness

I do trust that you will not reject me, because I really do need your unconditional love and acceptance.

Letter 7.2: An example of letter to the caregiver (researcher)

W5 WAYS of keeping WELL

You and the patient might sometimes feel like you have been in a **WASHING MACHINE, worn out and left out to dry**, but there are **ways of keeping well (a prevention, not crisis-control mode)** and you should know that **you have choices**.

A patient can create a **bipolar disorder check-in list (S4)** and this can become a lifesaver. It's a simple process that can help the patient to manage the illness successfully so that an episode doesn't sneak up and ruin the person's life once again. On a regular basis, the patient should be encouraged **to stop** what he or she is doing and to ask him or herself how he/she is on a scale of 1 to 10 in terms of mood swings (1 means that the person is stable, while 10 means that he/she really needs some help). The person can ask these **questions** during the check-in:

- How is my sleep; am I irritated, manic or depressed; how is my spending; am I having hallucinations; are people acting concerned about me and how are my relationships?

You can also create **your own check-in list**. How are you feeling about bipolar disorder; are you doing too much caretaking; are you frustrated with how slowly things are changing; do you see signs that your loved one is getting sick? (Fast & Preston, 2006:258-259).

People go through a natural **grieving process** when coming to terms with their bipolar disorder. It can take time to adjust to the illness. **Recovery** is a term used to describe a way of living a satisfying, hopeful and contributory life, even with limitations caused by the illness. Rather than being an end point that the person achieves, recovery may be a chronic and very personal process of finding ways to manage the illness and live well (Berk et al., 2008:29).

Being well can free a person to enjoy life; however, some people find it hard to adjust to wellness. They may struggle to take on new opportunities that become available when they are well, or be reluctant to engage in social activities. They might find it hard to step out of the **“sick role**” (Berk et al., 2008:30).

Caregiver to take note: Caregivers become used to caregiving relationships. Some caregivers find it hard to step back and adjust to the person’s independence, even though they are happy that the person is well. Look at the benefits of being less involved in caregiving, take time to relax and find ways to relate to the person that do not involve the person’s bipolar disorder (Berk et al., 2008:30).

W6 WAY forward (post episode period)

- Resumption of prior **work and social roles**. The financial realities for patients who have had an episode of bipolar disorder usually require that the patient return to work or school as soon as possible. The patient and family should be helped to set realistic goals for functioning during the stabilization and maintenance periods to establish a functional recovery.
- **Life trashing**. Patients may “trash” much of their lives and accomplishments during manic or depressive episodes. The question may be “How do I get my life back?” It is

good to develop preventative plans so that the next episode is not accompanied by the same level of destructiveness. Apply problem-solving interventions.

- **Relationships and living situation problems**. Relationships may go awry during the post episode period. Family members become too enmeshed or too distant; the recovery patient is viewed by others as over intrusive or, in contrast, too avoidant (Miklowitz, 2010c:275-278).

If BD has created chaos in your past, you may welcome the thought that **your future** can be more stable. You can make choices now that ensure a future you‘ll look forward to. The more **prevention** you can carry out during the patient’s stable times, the more able you will be to recognize, treat, and end the mood swings before they go too far.

A BD diagnosis may feel like a death sentence to your hopes and dreams (and that of the patient), but it does not have to be like that. There is no question that many of your dreams and goals will have to be modified, and some of them will have to be let go of completely, but once you use a comprehensive treatment plan that helps you manage the illness successfully, you can reclaim your dreams and goals (Fast & Preston, 2006:256).

Letting go of the past

Examine what you have lost in the past due to this illness, grieve for it, and then say you’re ready and willing to manage the illness in the present, so that the grief of the past can be healed (Fast & Preston, 2006:259).

Exercise: Please write on a paper a few things that the illness of your relative made you to lose. Think about this loss for a few moments and now tear up the paper.

W7 Make the mental health system WORK for you

It is important to equip yourself with knowledge, to be assertive and to complain when there is discrimination.

For family and friends: Depending on how ill a person is, family members are often the only people to advocate for appropriate health care (Fast & Preston, 2006:147).

The future can be and often is more positive than you can even imagine. Never give up. Bipolar disorder is an illness that may be very effectively treated. There is hope, and things can get better. With time and commitment, you can have a normal relationship with your loved one.

THE COMPLETE SEE SAW SURVIVAL SUITCASE for caregiver's and patient's wellbeing

Bipolar disorder is like a **journey**. It is therefore important to be prepared and to put certain items in your suitcase to have with you if anything happens to challenge stability.

It will be important that it should be kept clean and uncluttered, with enough space. **There will be big items and small items to use as the need arises**. Some items will be more applicable for the caregiver, others for the patient and others for both.

Table 7.12: SEE SAW Survival Suitcase (S4)

A correct **DIAGNOSIS (second opinion)**	**KNOWLEDGEABLE** about: **Bipolar disorder** and **co morbid** conditions, **treatment** modalities, the patient's episode **patterning**, **medication** and its side effects, **Mental Health Care Act** and admission procedures.	**DAILY MONITORING** of BD and not just when serious symptoms happen to show up. **Mood chart** **Life chart** **Social Rhythm Metric**
RESOURCES (names and telephone numbers) Websites and books.	**BALANCED life style** Remember to **RELAX**	**TIPS** to modify and stop the triggers.
Prepare and update a **FILE** to keep record of the **patient's personal history**, medical and psychiatric aspects including admissions and treatment. Keep record of any tests that were done (CT scans, doctors' reports). **Basic information includes** patient **ID,** address, names, telephone numbers of relatives, hospital card.	**PLANS: Specific plans** for problems caused by BD – emergency plan, personal prevention plan to prevent/minimise relapse and prevent readmission, well-being plans, plan to prevent suicide. Remember a comprehensive plan doesn't leave anyone out.	**LISTS: Specific signs of relapse** A list of patient's BD personal **triggers** A list of patient's **major symptoms** Developing a **prodromal list** (typical **warning** or early symptoms for each type of episode) Personal list of **what works** to prevent depression and mania.
ATTITUDE: Patience, hope, perseverance, acceptance, **resilience**, ability to adapt to change, sense of humour,	**DO NOT** take anything your ill relative says personally and be able to carry on in spite of it. The patient and caregiver must try to	**RIGHTS** of caregivers and patients.

assertiveness, non-judgemental, forgiveness and assertiveness. The patient should try to appreciate what the caregiver does.	live with the stigma of mental illness.	
SELF HELP is relevant for the patient and caregiver. **For the patient** a bipolar-friendly **diet**, a daily **walk**, regular and appropriate **bright light** exposure are important while **for the caregiver** it becomes important to manage stress, manage conflict and be able to problem solve. Caregiver should give him/herself treats on a regular basis.	Set realistic **EXPECTATIONS** of self (caregiver) and the patient. **GOALS** set for the patient should also be realistic because unrealistic expectations and goals to the patient can cause a relapse.	**REGULAR HABITS/ROUTINE** for the patient (a regular sleep schedule, work with regular hours). Order and structure. Routine.
Appropriate **WORK** for the patient Night work (shifts) is usually not a good idea.	**SUPPORTIVE** family and friends, community and **ACCESS** to the treating team who should also be supportive**.**	Well-planned prepared **APPOINTMENTS** with the team. **SUPPORT** when patient sees the doctor.
SUBSTANCE USE/ ABUSE should be avoided at all costs by the patient. This includes over-the-counter medications.	Wear a **MEDIC ALERT DISC**, indicating diagnosis and medical emergency information.	**COMPLIANCE** with treatment**, INSIGHT** regarding diagnosis and treatment is important for both the patient and caregiver.
DEVELOP A CHECKLIST Eating/sleeping regularly, finishing one task before starting another one, seeking help when starting to feel stressed, getting help when wanting to abuse substance, talking to MDT before stopping medication.	**OPEN COMMUNICATION** between the patient and caregiver, the patient and the team and the caregiver and the team.	**WORK HISTORY CHART** Keep record of patient's jobs and patterns that repeat at different places of employment.
Attend **SUPPORT GROUP** meetings in your area.	**PRACTICAL approach to** deal with side effects of the medication	**MEDICAL AID** information
Caregiver must look after him/herself and own **NEEDS**	**FREQUENT CONTACT** with your mental health care team.	**DECIDE before the time** whom you are going to tell about the illness.

FINANCIAL PLANNING is very important. Apply for an administrator if necessary. If needs be, the patient should not have access to his bankcards while he is manic.	Give each other **SPACE/ TIME OUT**	**DO NOT OVERSTIMULATE** when manic. Always try to create a **calm** environment. Do not argue.
Caregiver must **KNOW him/herself well**	**POSITIVE** self-talk. Avoid negative input.	Patient must be encouraged to develop his **OWN INTEREST**
COUNSELLING/family **therapy**	Consider **ALTERNATIVE** placement options or rehabilitation where necessary	**FOCUS** on important aspects
Caregiver must look after her/his own **health**		Patient and caregiver could keep a **DIARY**

To acquire knowledge, one must study; but to acquire **wisdom,** one must observe (Berk et al, 2008: 196):

> Well, even in that deep misery I felt my energy revive, and I said to myself: In spite of everything I shall rise again, I will take up my pencil, which I have forsaken in great discouragement, and I will go on with my drawing, and from that moment everything has seemed transformed in me Vincent van Gogh (Fast & Preston, 2006: 28).

My message to you today is to **NEVER GIVE UP!** Bipolar disorder is, in spite of everything, an illness that can be very effectively treated. There is hope, and things can get better. With time and commitment, you can have a normal relationship with your loved one. You will realize that there are things that you **have to see** (present), **have seen** already (past) and **will still see** (future). It is important to **learn** from past experience to progress in future. I hope that today's programme will give you **WINGS** to be able to face challenges in future.

There is an African proverb which you should always remember:

> However long the night, the dawn will break (Haycock, 2010:i).

All the respondents received a certificate (**Appendix 7.10**) and a small see-saw.

See **Appendices 7.1-7.11** as utilized during programme presentation.

7.6 SUMMARY

This chapter started with a literature overview of available international psychoeducational programmes. The researcher is not aware of specific original South African psychoeducational programmes that are available, although an organization like SADAG does provide valuable information to the public. The main focus however of this chapter was a detailed presentation of the SEE-SAW programme that the researcher developed. Different members of the MDT will be able to use this programme or parts thereof in future to psychoeducate caregivers and also patients.

It is the researcher's opinion that psychoeducational programmes should follow a biopsychosocial approach, because with such an approach the focus is on prevention and rehabilitation - a very important aspect with an illness like BD which is recurrent. If the caregiver of the BD patient is empowered with knowledge he or she can help to prevent a relapse.

The next step in the research process was to present the intervention that was designed and also to gather quantitative as well as qualitative data by means of a pre-test and a post-test. The procedures followed during data gathering as well as empirical findings will be discussed in the following chapter.

8. CHAPTER 8: EMPIRICAL RESEARCH FINDINGS OF THE QUANTITATIVE PHASE OF THE STUDY

8.1 INTRODUCTION

It may be argued that the **mental health** of the individual is interdependent with the ecological health of the larger nationwide system (Smith, 2007:654). In this research, the impact of patients' BD on their caregivers was explored within an ecological systems perspective. A system is defined as a set of objectives together with relationships between the objects and between their attributes. The individuals with which one deals in social work are best represented as complex **adaptive systems**. They are also living systems (Hearn, 1979:335). As Hearn (1979:336) states, systems exchange energy and information with their environment, they have important inputs and outputs and tend to maintain themselves in a steady state. After any disturbance, a system tends to re-establish a stable state. It is especially the concept of such a state or homeostasis that the researcher tried to accomplish through her intervention (SEE-SAW programme), because the introduction of a mentally ill person to a system may destabilise the said system.

As was mentioned in Chapter 1, family members of such patients must contend with multiple and qualitatively different sources of stress, including stress relating to their relative's illness, symptoms and problem behaviours, as well as stress relating to societal stigmatisation of people with mental illnesses and their families (Perlick et al., 2008:484-485). Consequently, the focuses of the first three literature review chapters (Chapters 2, 3 and 4) were placed respectively on bipolar disorder, the treatment thereof and the needs and psychosocial challenges for caregivers. In Chapter 7, the researcher presented literature on psychoeducation programmes.

The goal and objectives of the research were developed from the rationale and problem formulation, furnished in Chapter 1. The research methodology which guided the research process was described in Chapter 5. An exploratory, mixed methods research was motivated and discussed in this chapter. The research process was guided by the Design and Development model of Rothman and Thomas (1994), on intervention research. Categories, themes and sub-themes identified while exploring and analysing the research topic qualitatively were considered in Chapter 6 (**phase one** of the research). This was a prerequisite for the development of the intervention (**phase two** of the research) (the SEE-SAW programme in Chapter 7). A quantitative data gathering instrument (questionnaire) was also devised and implemented by administering a pre-test prior to the SEE-SAW programme and a post-test after the presentation of the SEE-SAW programme. This combination of the research methods was complementary and allowed for a more complete analysis.

The **hypothesis** for **phase two** of this study was as follows: If caregivers of people diagnosed with BD participate in an unique psychosocial educational programme that has been specifically developed based on their unique needs, then their level of knowledge about the illness and skills to approach it, will improve. The qualitative data, literature study, discussions with experts, as well as the researcher's experience of this particular field provided the context and background for the design of a questionnaire on the research topic. This chapter thus provides and discusses the results of the **quantitative** phase of the study. It needs to be pointed out that the questionnaires also contained open-ended questions which provided **qualitative** data that is reflected in this chapter.

8.2 QUANTITATIVE RESEARCH METHODOLOGY

8.2.1 Research design

It was indicated in Chapter 1 and Chapter 5 that the researcher used the **exploratory mixed method design**. This design is employed when a researcher first needs to explore a phenomenon using qualitative data before attempting to measure or test it quantitatively. As a two-phase design, the results of the first phase (**qualitative data**) are able to help develop or inform the second phase (**quantitative data**) (Delport & Fouché, 2011:441). In phase one a **collective case study** design was used which, according to Fouché (2005:272), is a qualitative design that furthers the understanding of the researcher about a social issue or population being studied. In phase two the specific experimental design that was chosen as being the most appropriate for the study was a pre-experimental design, the **one group pre-test - post-test** design. This is a useful design, and certainly one that is often used in programme evaluations. It is also a useful design to use when no comparison group is feasible (Marlow, 2011:96).

8.2.2 Quantitative data collection

A questionnaire was developed to evaluate the impact of the SEE-SAW programme, which the researcher presented during a one day workshop.

The sampling method was discussed in Chapter 1 and also in Chapter 5. Non-probability purposive sampling was used to select caregivers of people with the diagnosis of BD who met certain selection criteria. Twenty seven respondents were included in phase two. Five respondents took part in both phase one and phase two. It needs to be mentioned that the respondents stepped forward voluntarily to partake in the study after the researcher marketed it at a bipolar support group and that the contact details of caregivers of patients, who were interested in participating, were obtained from other colleagues of the MDT and a private psychiatrist.

8.2.2.1 Data collection methods utilised

The following was carried out **before** the process of quantitative data gathering:

- The questionnaire was developed and then discussed on a few occasions with the assigned statistical consultants and the research supervisor.
- During the researcher's first contact with the respondents, face-to-face, via email or telephone, the research procedure was explained to them. Everyone was informed that a questionnaire would be filled in before and after the presentation of the SEE-SAW Psychoeducational Programme.

The following was done **during** the process of quantitative data gathering:

- Every respondent was provided with an information leaflet, explaining the research, as well as the letter of informed consent, which they went through and then signed (prior to this, they had verbally consented). The researcher was available for any questions.
- Each respondent received a number as a pseudonym that they were required to indicate on their questionnaire. It was also very important that they indicated if this was the first time they were filling in the questionnaire (pre-test) or the second (post-test).
- The ethical considerations, discussed in Chapter 5, were addressed before respondents started to complete the questionnaires. Permission and ethical clearance to undertake the research, previously granted by the relevant authority figures at the tertiary institution, were conveyed to respondents.
- The format of the questionnaire, which required respondents to write the answer in the shaded space provided or to circle the appropriate number in a shaded box, was explained.
- Respondents were informed that the pre-test that had to be filled in consisted of sections 1-14 and the post-test, sections 2-15. Section 1 contained the biographical (demographic) information and section 15 the evaluation of the programme.

During the presentation of the programme no data was gathered.

8.2.3 Quantitative data analysis

The following procedure was utilised **after** the process of data gathering was completed:

- Questionnaires were coded and submitted to the Department of Statistics of the relevant tertiary institution who provided support in analysing the quantitative data. Questionnaire responses were captured electronically in Microsoft Excel by a trained data capturer.
- The researcher then checked captured data for accuracy against questionnaire responses. Minor inaccuracies were subsequently indicated and corrected by the research consultant.
- The persons involved in the study, namely the statistician and research consultant, the research supervisor and researcher, met on several occasions to discuss the data analysis and the statistical procedure. It became evident that some of the questions would be better accounted for by providing a qualitative description. The mixed method research design did leave room for this.
- A descriptive univariate analysis was mainly done throughout this chapter using frequencies and percentages. Univariate analysis involves describing a case in terms of a single variable (Babbie, 2007:409).
- In contrast to univariate analysis, subgroup comparisons involve two variables. In this respect subgroup comparisons constitute a kind of **bivariate analysis** - that is, the analysis of two variables simultaneously (Babbie, 2007:419). The statistician and research consultant appointed for this study by the Department of Statistics, UP assisted in doing some bivariate analyses.
- Various appropriate statistical tests to determine the significance of the finding were done, namely the Chi-square Test, the Fisher's Test and McNemar's Test.
- The research data will be presented in terms of (a) a demographic profile of the respondents and (b) a detailed analysis of the quantitative research findings. In order to provide a comprehensive profile of the sample, the researcher will thus commence with presentation and discussion of the demographic profile of the respondents.

8.3 RESEARCH FINDINGS

8.3.1 Demographic profile of respondents

The 27 respondents were sourced from the following:

Seventeen respondents were from a bipolar support group, two from the private psychiatrist and eight from the hospital where the researcher works; however they were sourced from another MDT. The researcher observed that some respondents came in "pairs" - either as husband and wife, parent and child or as two siblings.

Questionnaires were completed by a total number of 27 respondents. All of these respondents were asked to fill in the pre-test prior to commencing the programme, and also the post-test after completing the programme. The programme was presented as part of the **early development and pilot testing phase** (refer to 5.5.2.4 in chapter 5) of the Rothman and Thomas model (1994:9-12). It was then improved according to evaluation and presented again as a second pilot.

Demographic variables will be graphically presented in the form of figures and tables where applicable. The following were relevant in the context of this study: gender, age, marital status, race, highest level of education, relationship to the patient, the year the patient was first diagnosed with a mental disorder and the year the patient was diagnosed with BD. The researcher will present the demographics, but also make some evaluative comments regarding the demographics and other aspects that she observed. It was mentioned previously that the presentations of the programme must be regarded as a pilot project and that the programme will still evolve since it will be presented more frequently in the future after completion of this study.

Fifteen respondents attended the first day's SEE-SAW programme and **twelve** the consecutive presentation of the programme. Some respondents came from other cities and another province. The researcher was satisfied with the number of people that attended. It would have been difficult to give attention to everybody if the groups had been bigger. Only two people who committed themselves to attend the second session did not come: one of them had been admitted to hospital. Attendance was voluntary and the researcher could therefore not blame the other person for not attending. The response rate was thus 93 %.

The researcher will present the demographics of the two groups that attended the SEE-SAW programme (**Table 8.1** and **Table 8.2**) and then discuss them briefly.

Table 8.1: Demographics of respondents attending the first SEE-SAW programme implementation

Name	Gender Age Relationship to patient	Marital status	Race	Qualifications
Respondent 1	Female 58 years Wife	Married	White	Degree
Respondent 2	Male	Married	White	Degree

Name	**Gender** **Age** **Relationship to patient**	**Marital status**	**Race**	**Qualifications**
	68 years Stepfather			
Respondent 3	Female 57 years Mother	Married	White	Diploma
Respondent 4	Female 37 years Wife	Married	White	Diploma
Respondent 5	Male 70 years Father	Married	White	Diploma
Respondent 6	Female 64 years Mother	Married	White	Grade 12
Respondent 7	Male 79 years Father	Married	White	Degree
Respondent 8	Female 77 years Mother	Married	White	Diploma
Respondent 9	Female 55 years Mother	Widowed	White	Post graduate degree
Respondent 10	Female 45 years Wife	Married	White	Grade 12
Respondent 11	Female 19 years Child	Single	White	University student
Respondent 12	Female 56 years Sibling	Married	White	Post graduate degree
Respondent 13	Female 53 years Sibling	Married	White	Grade 12
Respondent 14	Male 42 years Sibling	Married	White	Diploma
Respondent 15	Female 84 years Mother	Divorced	White	Post graduate degree

Table 8.2: Demographics of respondents attending the second SEE-SAW programme implementation

Name	Gender Age Relationship to patient	Marital status	Race	Qualifications
Respondent 16	Female 63 years Mother	Married	White	Post graduate degree
Respondent 17	Male 58 years Father	Married	White	Post graduate degree
Respondent 18	Female 65 years Mother	Widowed	White	Diploma
Respondent 19	Female 54 years Wife	Married	White	Grade 12
Respondent 20	Female 47 years Mother	Married	Indian	Grade 12
Respondent 21	Female 55 years Wife	Married	White	Grade 12
Respondent 22	Male 64 years Father	Married	White	Degree
Respondent 23	Female 55 years Mother	Married	White	Degree
Respondent 24	Female 53 years Mother	Married	White	Diploma
Respondent 25	Female 59 years Wife	Married	White	Grade 12
Respondent 26	Female 30 years Child	Married	White	Post graduate degree
Respondent 27	Female 45 years Mother	Married	Black	Diploma

8.3.1.1 Gender of respondents

In the first session four of the fifteen respondents were **male** - three came with their wives and one with his mother. The second session was attended by two males who also arrived with their wives. All the men, except one, were fathers of the patients; the remaining one was a brother of the patient. It was interesting that more **females** came forward to attend the programme, which could be attributed to women traditionally being more in the caregiver role. The researcher observed that no husbands volunteered to participate in the research. **Men** whose wives have BD might need to make more of an effort to develop a support system. In general, as noted, women are more likely than men to have a support system outside the nuclear family unit (Haycock, 2010:209).

8.3.1.2 Age of respondents

At the first programme presentation, the ages of the respondents varied from 19 years to 84 years and at the second session from 30 years to 65 years. Although the criteria for selection of respondents did not stipulate age, the researcher realised that it is better to have a more **homogenous** group during a particular presentation. During the first implementation some of the respondents were slower than the rest and struggled to see and hear. A DVD was shown during the programme; the elderly respondent with the eye problem could not follow the DVD. The fact that some of the respondents were older also contributed to the facts that they struggled to complete the questionnaire and took much longer than the rest of the group to complete it. The group was therefore obliged to wait for them, which wasted time. The age variation was not so wide during the second implementation, so that all the respondents could move at the same pace.

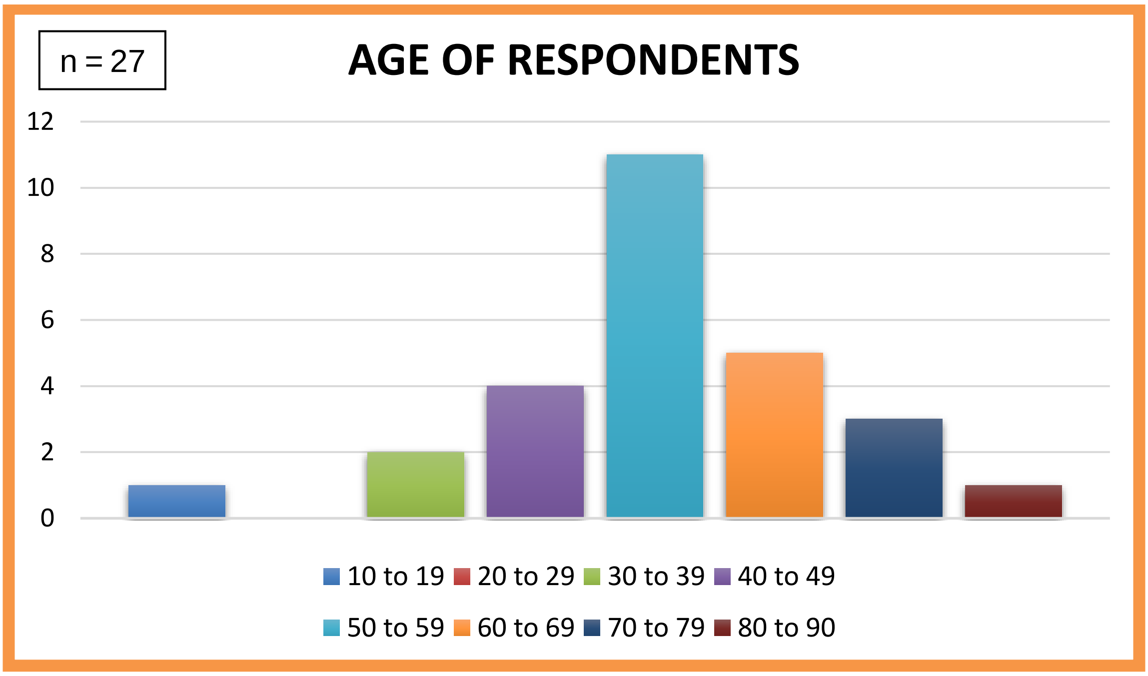


Figure 8.1: **Age of respondents**

Altogether, the highest percentage (11.11 % = 3) of respondents were 55 years of age, followed by 7.41 % (2) for ages 45 years, 53 years, 58 years and 64 years. Nine respondents were above the age of 60 years. Only three respondents were younger than 40 years (refer to **Figure 8.1**). Thus it can be concluded that the majority of respondents were all of a mature age, in late adulthood or adulthood.

The researcher observed that the 19 year old was very interested – she was the only one that indicated that the programme was too long. She did also mention that the part of the DVD discussing suicide was slightly “upsetting”. The researcher attributed this to her youthfulness and also to the fact that this respondent, who was the child of a patient, had made a suicide attempt herself in the past. This could be indicative of BD traits in a family (the genetic component).

8.3.1.3 Relationship to patient

The emotions, needs and challenges differed, depending on the **role** of the specific caregiver in the system. Overall, 17 of the respondents were in the role of a parent of the patient, 5 were spouses, 3 were siblings and 2 were children (refer to **Figure 8.2**).

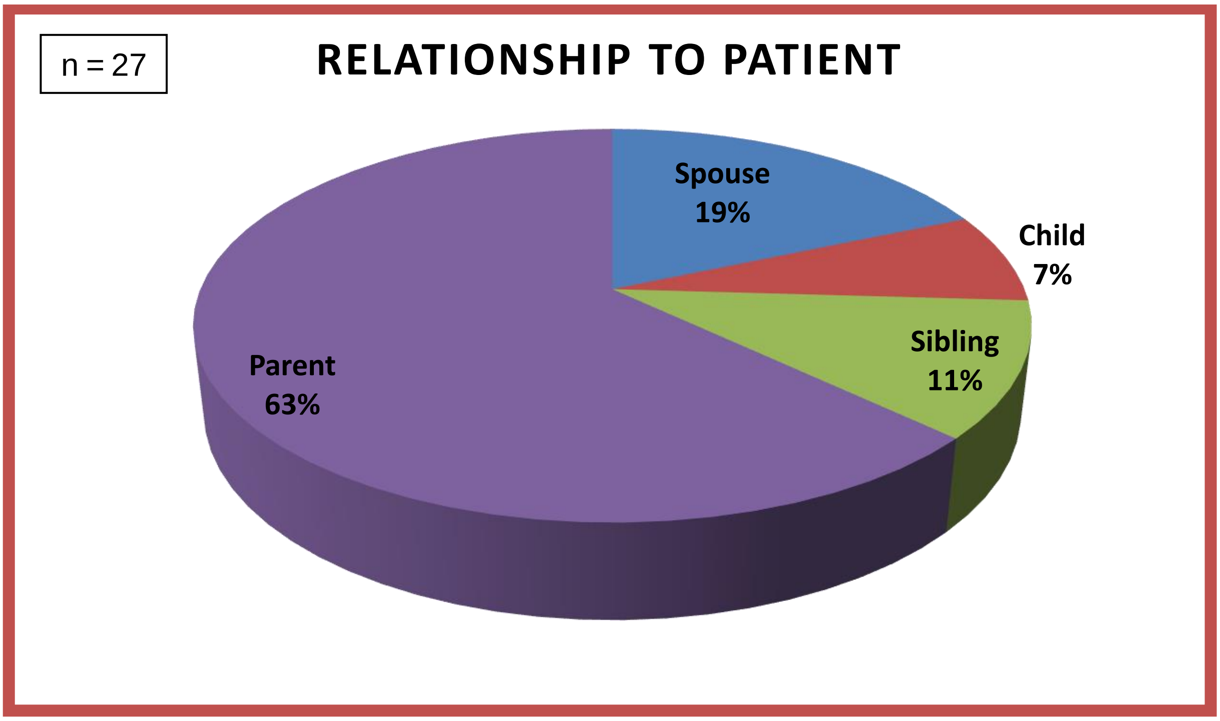


Figure 8.2: **Relationship to patient**

The researcher was aware of the stress that is often present in relationships with a BD patient. It is difficult to conduct a loving and intimate relationship when one **partner** is a caretaker and the other is a patient. It is important that they should talk about what both **want** and **need** from the relationship (Fast & Preston, 2004:175, 12). Tranvag and Kristoffersen (2008:6, 9, 10) indicate that, due to lack of security, the spouses are in a constant state of alertness to enable them to identify stress factors in their surroundings and changes in their partner's mental health.

Parents may provide decades of extended caregiving for their adult son or daughter with BD during times when debilitating symptoms produce obstacles to social and occupational functioning and independent living. Parents of adults with serious mental illness are at an increased **risk** for poorer physical health, mental health and marital disruption (Aschbrenner et al., 2009:298, 303).

Children may feel an overwhelming sense of responsibility, even blaming themselves for the parent's disorder. Sometimes the child might experience feelings of anger, sadness, fear, insecurity, worry, confusion, loneliness, pain, stress, helplessness and frustration (Aiken, 2010:83, 88, 90). A child of someone with BD might experience a **role reversal** that leaves him or her feeling more like a parent than a child. Children may feel responsible for events involving family life such as marital strife, divorce, illness, and tragedy that are, in fact, outside of their control (Haycock, 2010:209, 210).

Siblings might think it is not their problem or responsibility to deal with the sick sister/brother. This attitude becomes a particular problem when the parents are deceased or too old or ill to continue taking care of the patient (Haycock, 2010:212, 213).

8.3.1.4 Marital status

Twenty three (85 %) of the respondents were married, while one was single, one was divorced and two were widowed. There were five couples (being parents of a child diagnosed with BD) and it is the researcher's opinion that it might be easier for a parent with a BD child if at least there is a spouse for support. The fact that they accompanied each other to attend the SEE-SAW programme can also be regarded as a positive sign.

8.3.1.5 Race

Ninety two percent (25) of the respondents were white. The researcher attributes this to the fact that the bipolar support group from which respondents were sourced is mainly being attended by white people, although the one respondent who did not attend was a black lady from the support group.

The SEE-SAW programme could in future be presented to any cultural group, because it is flexible and will always be presented to fit the needs of the specific target group.

8.3.1.6 Education

Seventy percent (19) of the respondents had attained a diploma, degree or postgraduate **qualification** (refer to **Figure 8.3**). Possibly a higher education assists caregivers in being more resilient towards the stress that a mentally ill relative involves and possibly such caregivers have a greater capacity to absorb information. Usually a better education also gives an individual easier access to better employment and therefore to more resources.

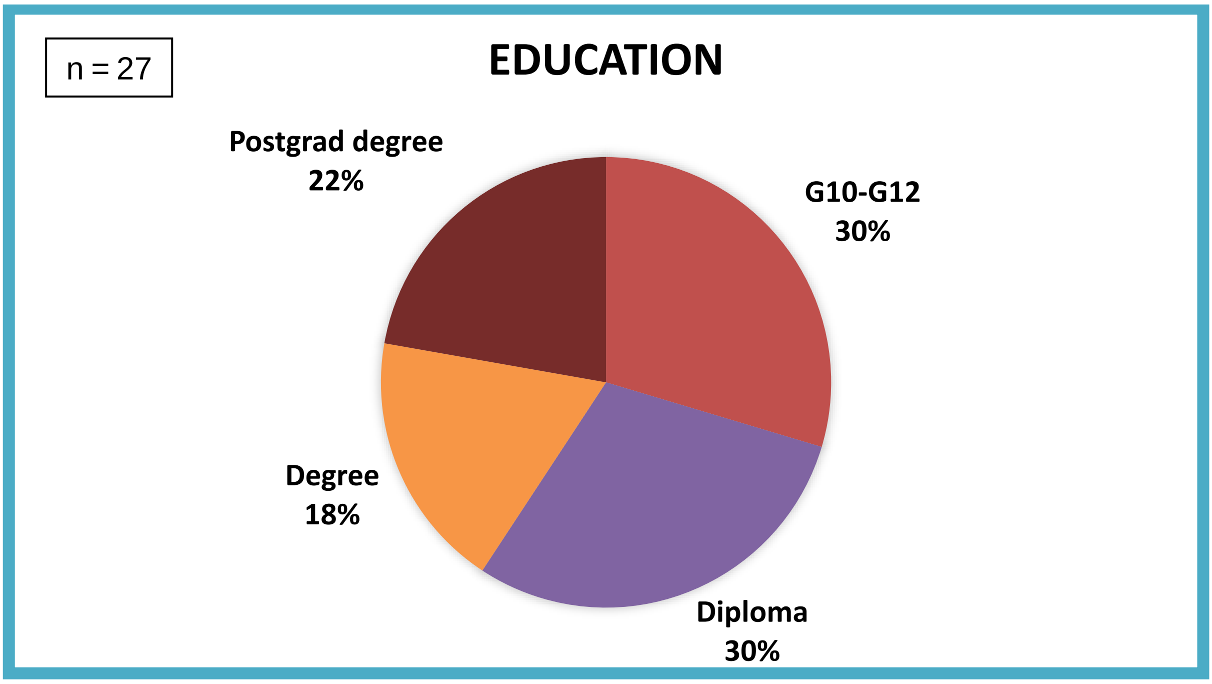


Figure 8.3: **Level of Education**

8.3.1.7 Diagnosis

Fourteen of the respondents indicated that their family member had already been **mentally ill** in the period from 1982 to 2006 (therefore in some cases for 32 years at the time the research was conducted). It can therefore be said that most of the caregivers were quite "experienced" as caregivers and as regards the mental health field. The question in the questionnaire, regarding the year the patient was first diagnosed with a mental illness and the year he/she was diagnosed with BD, was included to determine whether there was a period of **uncertainty** before the correct diagnosis was made. Not all of the respondents could remember dates or simply did not know the answer. There was also a case where the parents differed in their answer relating their daughter's illness. In most of the cases, however, it took some years before the correct **diagnosis** was made (for one patient 18 years, one patient 9 years, one patient 8 years and another one 7 years). One of the respondents had a mentally ill husband as well as a mentally ill daughter. This respondent was also receiving treatment for depression, again possibly indicative of family genetics or the impact of caregiving.

The **differential diagnosis** of BD is very difficult to make. The boundaries between bipolar and other disorders have been debated for years; it is still unclear where the disorder ends and other disorders begin. The diagnosis is often of great concern to patients and family members (Miklowitz, 2010c:31). “Bipolar” can be a very frightening word, especially when it is used to describe someone one loves (Last, 2009:7). Some deny the reality of the disorder, some overcommit themselves to the diagnosis while others reluctantly agree to it, but continue living their lives as if they were illness free (Miklowitz, 2010c:51).

Co-occurrence of two or more psychiatric disorders in the same person is possible; this was discussed in Chapter 2. When a patient has comorbid conditions, these will place additional stress on the caregiver. The researcher focused on the BD diagnosis and did not establish whether some of the patients also had a substance, or personality, problem. It often happens that caregivers are not aware of a patient’s personality disorder, and then attribute all the patient’s behaviour (even being anti-social) to the BD diagnosis.

8.3.2 Analysis of the quantitative research findings (questionnaires)

Quantitative analysis may be defined as the numerical representation and manipulation of observations for the purpose of describing and explaining the phenomena that those observations reflect; in other words, the techniques by which researchers convert data into a numerical form and subject it to statistical analyses (Babbie, 2007:405).

The results from the **questionnaires** are discussed in the following section. It should be noted that the results of the two groups (attended on different days) have been combined. It was important to highlight the differences in pre-test and post-test data collection. The researcher followed the same layout as in the questionnaire. When the researcher refers to “the programme” she means the SEE-SAW programme; when she refers to **pre** it was to indicate the pre-test while **post** indicated the post-test. **Percentages** are of the total of 27 respondents who attended the two days. The frequencies will be put in brackets where the percentages are indicated.

8.3.2.1 Bipolar disorder (Questions 2.1-2.7)

The researcher found that there were questions where the answers, pre and post programme, did not reveal significant differences. Therefore the focus will be on those questions where there were a substantial difference. It should also be noted that respondents did not always answer all the questions or that they chose more than one answer although it was stated that only one should be chosen.

It was mentioned in Chapter 4 that families need to **know** about the illness of their relative if they are to be informed consumers and are expected to help the recovering individual (McElroy, 1987:227). Family members of people with BD are usually hungry for **information** about the disorder, particularly during or after a manic or depressive episode, whether or not the episode involves hospitalisation. Relatives may harbour many **misconceptions** about the illness. Well-meaning relatives who do not understand the disorder may view drug treatment or psychotherapy as crutches. They should understand that the patient’s behaviour is, at least partially, biologically and chemically determined (Miklowitz, 2011:5, 283, 284, 286). It is important that everyone in the family learns as much about the illness as possible in order to know what they are dealing with (Aiken, 2010:121). People close to the patient can supply important information and can help keep the patient involved in treatment rather than taking the next plane to anywhere (Frances, 2013:52).

- **Knowledge of BD**

Table 8.3: Knowledge of BD

	Pre-test		**Post-test**	
	Frequency (ƒ)	**Percentage (%)**	**Frequency (ƒ)**	**Percentage (%)**
Did not fill in			1	3.7
Excellent	2	7.41	4	14.81
Good	11	40.74	12	44.44
Average	11	40.74	10	37.04
Poor	3	11.11	0	0
Total	27		27	

Prior to attending the programme, 7.41 % (2) of respondents rated their **knowledge** of BD as excellent while afterwards 14.81 % (4) of respondents rated it as excellent (refer to **Table 8.3**). While there were 11.11 % (3) of respondents who thought their knowledge of BD was poor before the programme, nobody thought their knowledge was poor after attending the programme.

It is clear that the majority of respondents evaluated their knowledge in the good/average bracket in the pre- as well as the post-test.

- **Diagnosis (BD I and BD II)**

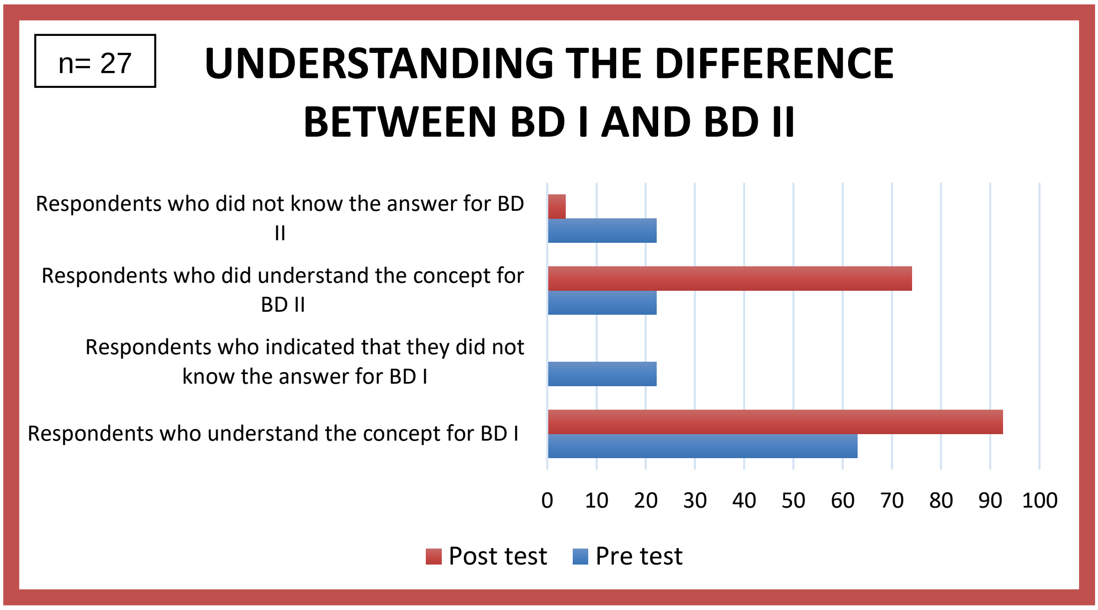


Figure 8.4: **Understanding the difference between BDI and BDII**

The respondents who did understand the concept of **BD I** increased from 62.96 % (17) to 92.59 % (25). Those who indicated that they did not know the answer decreased from 22.22 % (6) to 0 afterwards. In the case of **BD II** there was an increase from 22.22 % (6) to 74.07 % (20) who provided the correct answer in the post-test. There were only 3.7 % (1) who indicated afterwards that they did not know the answer, versus 22.22 % (6) in the pre-test (refer to **Figure 8.4**).

- **General statements about BD**

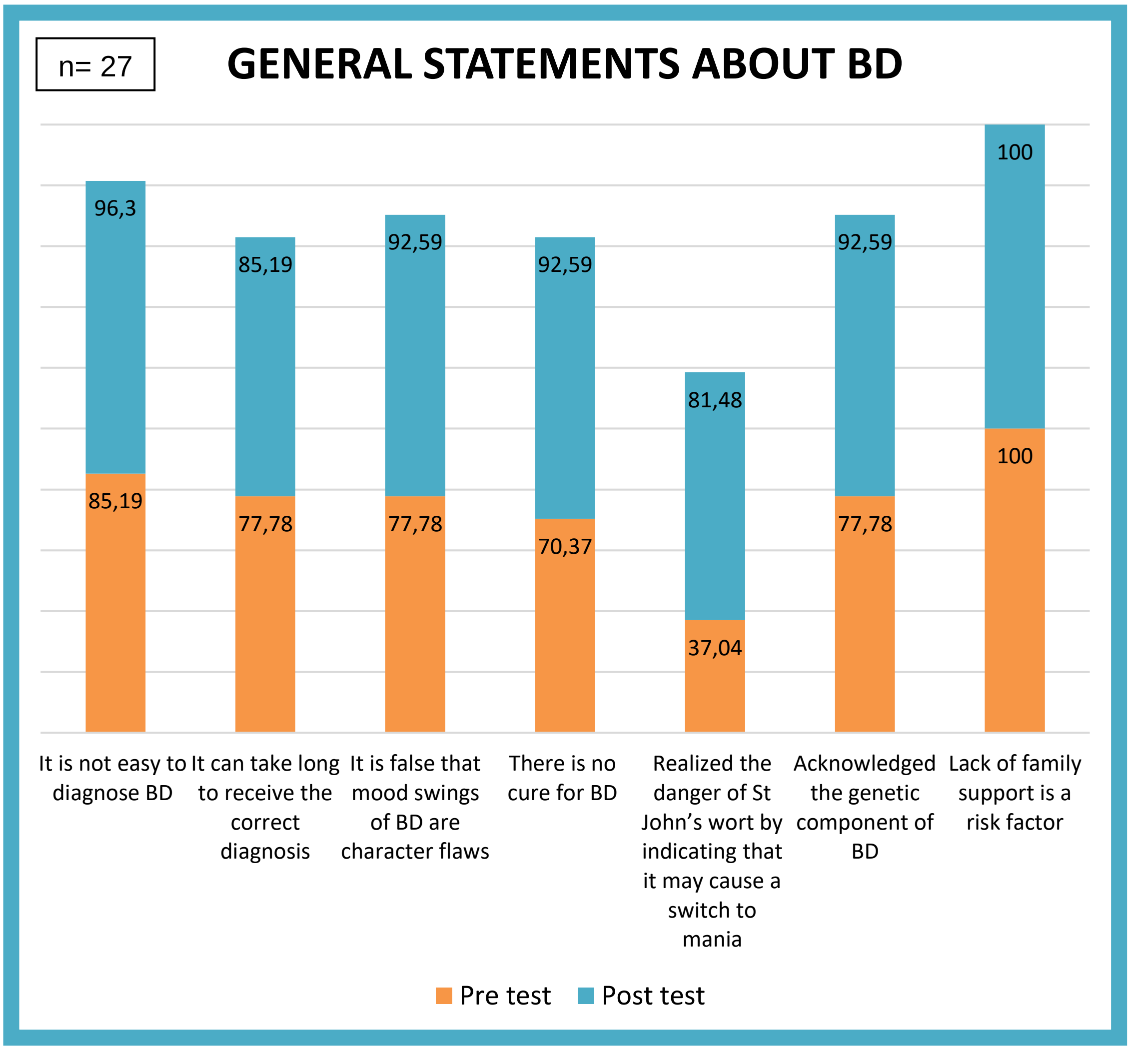


Figure 8.5: **General statements about BD**

In the questionnaire there were some **general statements about BD** where respondents were required to indicate a true or false answer (refer to **Figure 8.5**). In the pre-test 85.19 % (23) respondents said that it is not easy to diagnose BD compared to 96.3 % (26) afterwards. Most of the respondents (77.78 %) (21) knew before the programme that it could take a long time to receive the correct diagnosis. In the post-test 92.59 % (25), versus 77.78 % (21) in the pre-test, believed that it is false that mood swings of BD are character flaws. Pre-test 70.37 % (19) believed that there is no cure for BD while 92.59 % (25) acknowledged it afterwards. Respondents (81.48 % = 22) realised the danger of St John's Wort by indicating that it may cause a switch to mania versus the 37.04 % (10) who indicated it in the pre-test. Most of the respondents acknowledged the genetic component of BD, although the 77.78 % (21) in the pre-test became 92.59 % (25) in the post-test. In the pre and post-test 100 % (27) of the respondents indicated that lack of family support is a risk factor, showing that the respondents who attended the programme were sensitive towards their role in the lives of the patients.

- **Recurrence of BD**

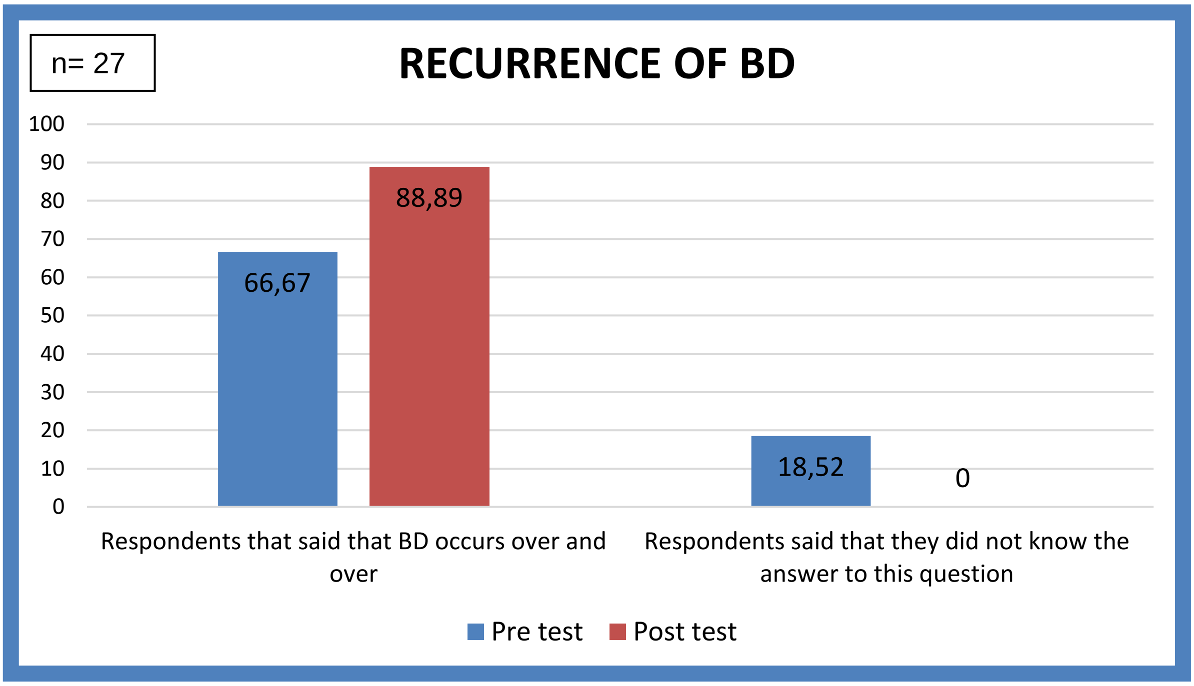


Figure 8.6: **Recurrence of BD**

In the pre-test 66.67 % (18) respondents said that BD **occurs over and over** again versus 88.89 % (24) afterwards. Before the time 18.52 % (5) said they did not know the answer to this question, while nobody claimed that they did not know afterwards (refer to **Figure 8.6**).

- **Insight, beliefs and opinion**

The question that tested the respondents' **insight, beliefs and opinion** regarding people being diagnosed with BD revealed the following (refer to **Table 8.4**).

Table 8.4: **Description of people with BD**

	Pre-test		**Post-test**	
	Frequency (*f*)	**Percentage (%)**	**Frequency (*f*)**	**Percentage (%)**
Are not just lazy	20	74.07	25	92.59
No, cannot pull themselves together	17	62.96	22	81.48

	Pre-test		**Post-test**	
	Frequency (ƒ)	**Percentage (%)**	**Frequency (ƒ)**	**Percentage (%)**
No, did not bring this illness upon themselves	19	70.37	23	85.19
No, not looking for sympathy	20	74.07	25	92.59
Yes, misdiagnoses happen	24	88.89	26	96.3
Are really ill	19	70.37	24	88.89
No, are not always violent	22	81.48	25	92.59

In the pre-test 74.07 % (20) believed that the latter are **not just lazy** versus 92.59 % (25) in the post-test while 81.48 % (22) versus 62.96 % (17) in the pre-test believed that the patients cannot "**pull themselves together**". In the pre- and post-test there were 7.41 % (2) of respondents who believed that the patients brought this illness **upon themselves**, but after the programme 85.19 % (23) respondents believed they did not. The post-test indicated 92.59 % (25) versus 74.07 % (20) in the pre-test who believed that patients are **looking for sympathy** and attention. This might have been because the researcher emphasised to the caregivers that they also have rights and the concept of their burden was also discussed. Respondents were aware of **misdiagnoses** that often occur – 88.89 % (24) indicated this in the pre-test and 96.3 % (26) afterwards. There were 88.89 % (24) of respondents afterwards in comparison to 70.37 % (19) in the pre-test who answered "no" to the question whether people with BD are not **really ill**. Concerning **aggression** 81.48 % (22) of respondents in the pre-test and 92.59 % (25) in the post-test felt that people with BD are not always violent.

It became clear that some of the results did not differ very much between the pre-and post-test. In most of the questions there were a few respondents who did not answer.

The simplest form of quantitative analysis, **univariate analysis**, involves describing a case in terms of a single variable (Babbie, 2007:409). In contrast to univariate analysis, subgroup comparisons involve two variables. In this respect subgroup comparisons constitute a kind of **bivariate analysis** - that is, the analysis of two variables simultaneously (Babbie, 2007:419). Whenever we classify subjects in relation to two separate variables simultaneously for the purposes of determining their degree of association, we create what is known as a cross-tabulation. This is a test to determine whether two independent variables are associated (Fouché & Bartley, 2011:266).

The researcher was faced with the question, whether the **level of acquired knowledge** (reflected in question 2.4 and question 2.6) is dependent on the **academic qualifications** of the respondents (reflected in question 1.5). The tables (**Table 8.5** and **Table 8.6**) below provides an indication of the statistical analysis that was done.

Table 8.5: **Relationship between level of academic qualification (question 1.5) and increase of knowledge (question 2.4)**

Frequency
Row Pct
Col Pct

Table of vv1_5 by Q2_4ChangeCat

vv1_5	**Q2_4ChangeCat** **Increase**	 **No increase**	 **Total**
School	6 *75* *30*	2 *25* *28.57*	8
Tertiary	14 *73.68* *70*	5 *26.32* *71.43*	19
Total	20	7	27

Statistics for Table of vv1_5 by Q2_4ChangeCat

Statistic	**DF**	**Value**	**Prob**
Chi-Square	1	0.0051	0.9432
Likelihood Ratio Chi-Square	1	0.0051	0.9431
Continuity Adj. Chi-Square	1	0	1
Mantel-Haenszel Chi-Square	1	0.0049	0.9443
Phi Coefficient		0.0137	
Contingency Coefficient		0.0137	
Cramer's V		0.0137	

WARNING: 50 % of the cells have expected counts less than 5. Chi-Square may not be a valid test.

Fisher's Exact Test	
Cell (1,1) Frequency (F)	6
Left-sided Pr <= F	0.6988
Right-sided Pr >= F	0.6678
Table Probability (P)	0.3666
Two-sided Pr <= P	1

Sample Size = 27

Table 8.5 shows 75 % (6) of the respondents with school qualifications only had an increase in knowledge and 73.68 % (14) of the respondents with tertiary qualifications had an increase in knowledge. Thus it seems regardless of their qualifications, they all showed an increase in knowledge in the post-test.

The **Chi-square Test** for independence was initially used in order to test whether the increase in knowledge of BD is dependent on the level of the respondent's qualification. Chi-square, also known Pearson's chi-square, is a common statistical test for bivariate analysis. It is used when both variables are nominal-level variables. Chi-square is a statistical measure of the difference between expected and observed frequencies (Marlow, 2011:270).

The two hypotheses were: Ho (Null hypothesis) - the increase in knowledge of BD is independent of qualifications or Ha (Alternative hypothesis) - the increase in knowledge of BD is dependent upon qualifications.

The p-value of the test was 0.9432. Therefore the null hypothesis was not rejected at a 5 % level of significance and it can be concluded that there is not enough statistical evidence to suggest that an increase in knowledge is dependent of qualifications. However, there was insufficient information in some of the cells in the contingency table and therefore the **Fisher's Exact Test** was used to test the same hypothesis as above - a test which is formulated for situations in which there is sparse data. The p-value for this test was equal to 1. The null hypothesis is not rejected at a 5 % level of significance and it can be concluded that there is not enough statistical evidence to suggest that an increase in knowledge is dependent on the level of education of the respondent. It can therefore be stated that the respondents benefitted by attending the SEE-SAW programme regardless of their academic qualifications. It was the researcher's intention to make this programme accessible to all caregivers – irrespective of their level of education – thus this goal was reached.

Table 8.6: Relationship between level of academic qualification (question 1.5) and increase of knowledge (question 2.6)

Frequency ***Row Pct*** ***Col Pct***	**Table of vv1_5 by Q2_6ChangeCat**			
	vv1_5	**Q2_6ChangeCat**		
		Increase	**No increase**	**Total**
	School	3 *37.5* *30*	5 *62.5* *29.41*	8

Tertiary	7 *36.84* *70*	12 *63.16* *70.59*	19
Total	10	17	27

Statistics for Table of vv1_5 by Q2_6ChangeCat

Statistic	**DF**	**Value**	**Prob**
Chi-Square	1	0.001	0.9742
Likelihood Ratio Chi-Square	1	0.001	0.9742
Continuity Adj. Chi-Square	1	0	1
Mantel-Haenszel Chi-Square	1	0.001	0.9747
Phi Coefficient		0.0062	
Contingency Coefficient		0.0062	
Cramer's V		0.0062	
WARNING: 25 % of the cells have expected counts less than 5. Chi-Square may not be a valid test.			

Fisher's Exact Test	
Cell (1,1) Frequency (F)	3
Left-sided Pr <= F	0.6839
Right-sided Pr >= F	0.6506
Table Probability (P)	0.3345
Two-sided Pr <= P	1

Sample Size = 27

Table 8.6 shows 37.5 % (3) of the respondents with school qualifications only had an increase in knowledge and 36.84 % (7) of the respondents with tertiary qualifications had an increase in knowledge. Thus it seems regardless of their qualifications, they all showed some increase in knowledge in the post-test.

The two hypotheses were: Ho (Null hypothesis) - the increase in knowledge of BD is independent of qualifications or Ha (Alternative hypothesis) - the increase in knowledge of BD is dependent upon qualifications.

Due to the fact of insufficient data in some of the cells in the contingency table the **Fisher's Exact Test** was used. The p-value for this test was equal to 1. The Null hypothesis is not rejected at a 5 % level of significance and it can be concluded that there is not enough statistical evidence to suggest that an increase in knowledge is dependent on the level of education of the respondents. It can therefore be stated that the respondents benefitted by attending the SEE-SAW programme regardless of their academic qualifications.

The researcher was interested in investigating the possible relationship between the **level of acquired knowledge** (reflected in question 2.4 and question 2.6) and the **relationship that the respondents had with the patients** (question 1.6), refer to **Table 8.7** and **Table 8.8**).

Table 8.7: **Relationship between level of acquired knowledge (question 1.6) and relationship that the respondents had with the patients (question 2.4)**

Frequency
Row Pct
Col Pct

Table of vv1_6 by Q2_4ChangeCat

vv1_6	**Q2_4ChangeCat** Increase	No increase	**Total**
Other	8 *80* *40*	2 *20* *28.57*	10
Parent	12 *70.59* *60*	5 *29.41* *71.43*	17
Total	20	7	27

Statistics for Table of vv1_6 by Q2_4ChangeCat

Statistic	**DF**	**Value**	**Prob**
Chi-Square	1	0.2904	0.59
Likelihood Ratio Chi-Square	1	0.298	0.5851
Continuity Adj. Chi-Square	1	0.0071	0.9329
Mantel-Haenszel Chi-Square	1	0.2797	0.5969
Phi Coefficient		0.1037	
Contingency Coefficient		0.1032	
Cramer's V		0.1037	

WARNING: 50 % of the cells have expected counts less than 5. Chi-Square may not be a valid test.

Fisher's Exact Test	
Cell (1,1) Frequency (F)	8
Left-sided Pr <= F	0.8387
Right-sided Pr >= F	0.4748
Table Probability (P)	0.3136
Two-sided Pr <= P	0.6784

Sample Size = 27

Table 8.7 shows 80 % (8) of the respondents were either the spouse, child or sibling of the patient and had an increase in knowledge and 70.59 % (12) of the respondents were parents and had an increase in knowledge. Thus it seems regardless of their relationship with the patient, they all showed an increase in knowledge in the post-test.

The **Chi-square Test** for independence was initially used in order to test whether the increase in knowledge of BD is dependent on the level of the respondent's relationship with the patient. The two hypotheses were: Ho (Null hypothesis) - the increase in knowledge of BD is independent of the relationship with the patient or Ha (Alternative hypothesis) the increase in knowledge of BD is dependent of the relationship with the patient. This test indicated that the level of education and relationship with the patient were **independent** of each other. But due to insufficient data it was invalid. The **Fisher's Exact Test** was used to test the same hypothesis as above. The p-value for this test was equal to 0.6784. The null hypothesis is not rejected at a 5 % level of significance and it can be concluded that there is not enough statistical evidence to suggest that an increase in knowledge is dependent on the specific relationship between the caregiver and the patient.

Table 8.8: Relationship between level of acquired knowledge (question 1.6) and relationship that the respondents had with the patients (question 2.6)

Table of vv1_6 by Q2_6ChangeCat

Frequency ***Row Pct*** ***Col Pct***	**vv1_6**	**Q2_6ChangeCat**		
		Increase	**No increase**	**Total**
	Other	4 *40* *40*	6 *60* *35.29*	10
	Parent	6 *35.29* *60*	11 *64.71* *64.71*	17
	Total	10	17	27

Statistics for Table of vv1_6 by Q2_6ChangeCat

Statistic	**DF**	**Value**	**Prob**
Chi-Square	1	0.0598	0.8068
Likelihood Ratio Chi-Square	1	0.0596	0.8072
Continuity Adj. Chi-Square	1	0	1
Mantel-Haenszel Chi-Square	1	0.0576	0.8104
Phi Coefficient		0.0471	
Contingency Coefficient		0.047	
Cramer's V		0.0471	

WARNING: 25 % of the cells have expected counts less than 5. Chi-Square may not be a valid test.

Fisher's Exact Test	
Cell (1,1) Frequency (F)	4
Left-sided Pr <= F	0.7455
Right-sided Pr >= F	0.5626
Table Probability (P)	0.3081
Two-sided Pr <= P	1

Sample Size = 27

Tabel 8.8 shows 40 % (4) of the respondents which were the spouse, child or sibling of the patient did show an increase in knowledge and 35.29 % (6) of the respondents which were parents did show an increase in knowledge. Thus it seems regardless of their relationship with the patient, they all showed some increase in knowledge in the post-test.

The **Fisher's Exact Test** was used to test the Ho (Null hypothesis) - the increase in knowledge of BD is independent of the relationship with the patient. The p-value of the test was equal to 1. The null hypothesis is not rejected at a 5 % level of significance and it can be concluded that there is not enough statistical evidence to suggest that an increase in knowledge is dependent on the specific relationship between the caregiver and the patient. It was thus indicated that the level of knowledge is not dependent on the specific relationship between the patient and the caregiver.

It was mentioned in chapter 4 that the most important point to remember is that **anxiety** or discomfort about being close is a natural part of coping with BD as a couple, particularly during the recovery period (Miklowitz, 2011:299). The anxiety to be in any relationship with a BD patient might make it difficult to integrate new information. **Children** can feel an overwhelming sense of responsibility, even blaming themselves for the parent's disorder. Sometimes the child might experience feelings of anger, sadness, fear, insecurity, worry, confusion, loneliness, pain, stress, helplessness and frustration (Aiken, 2010:83, 88, 90).

- **Document for diagnosis**

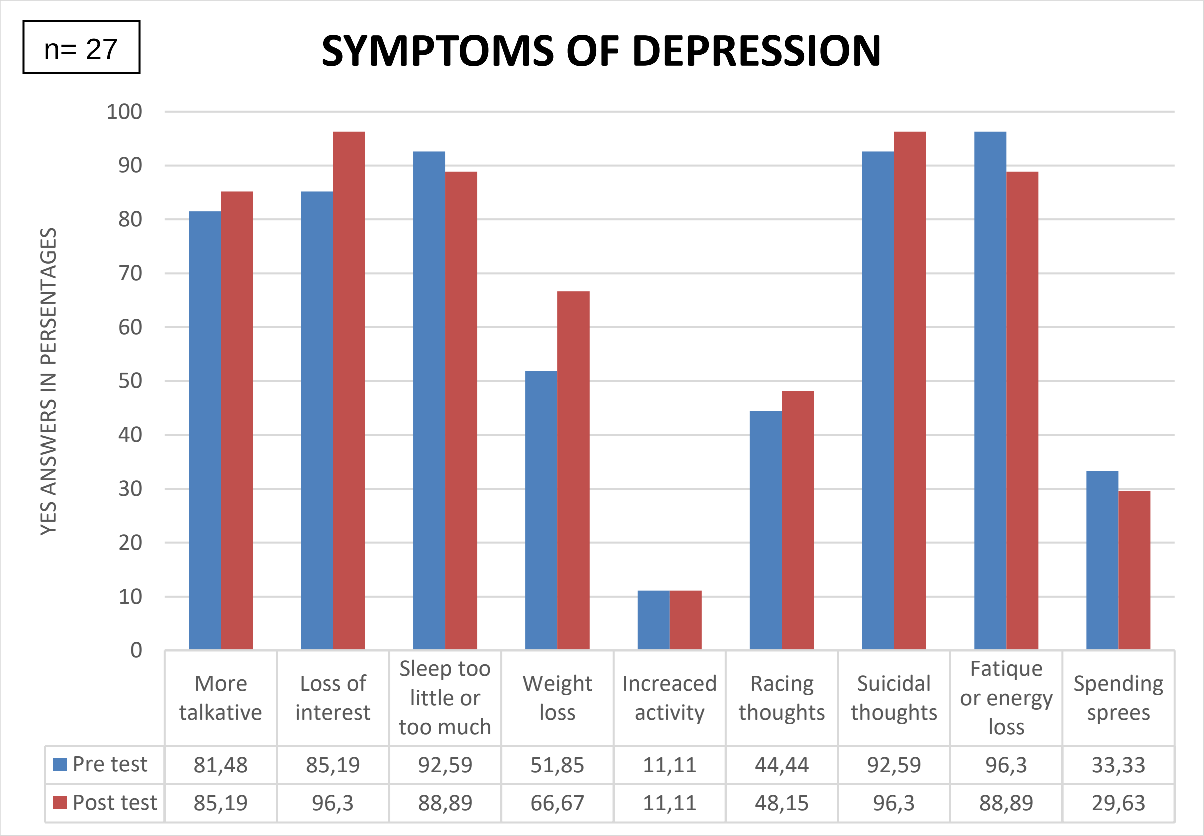
Concerning the document that psychiatrists use to make diagnoses, the results were as follows: in the pre-test 7.41 % (2) did not answer, whereas 7.41 % (2) said it was the bipolar survival guide and 7.41 % (2) indicated that it comprised mental health policy documents. All the respondents answered in the post-test that the **DSM** is the document that is used to make the diagnosis.

The researcher referred in the SEE-SAW programme to the DSM, from which it was clear that respondents did realise the importance of this document for diagnosis by the MDT.

8.3.2.2 Depression (Question 3)

It was stated in Chapter 2 that major depressive episodes range from **mild to severe**, depending on how intense symptoms are and how much they interfere with one's daily life, relationships and safety. It is important to note that the symptoms of depression are not always static throughout an episode (Berk et al., 2008:24). Patients with BD I are likely to experience depressive symptoms approximately three times more frequently than symptoms of mania (The International Consensus Group on the Evidence-Based Pharmacologic Treatment of Bipolar I and II Depression, 2008:1632). Ghaemi, Saggese and Goodwin (2006:11) contend that it is important to realise that the most common first mood episode in BD appears to be a major depressive episode, rather than a manic episode. About 90 % of people with BD experience depression at some time (Berk et al., 2008:17).

It does seem that respondents had quite a good idea of the concept of depression even **prior to** the programme. The researcher suggests this is because most people understand what depression is and even BD patients are more often depressed than manic. An aspect during the depressive episodes is the fact that many patients experience a cripplingly low self-esteem, feel suicidal or make a suicide attempt (Aiken, 2010:56).



	More talkative	Loss of interest	Sleep too little or too much	Weight loss	Increaced activity	Racing thoughts	Suicidal thoughts	Fatique or energy loss	Spending sprees
🟦 Pre test	81,48	85,19	92,59	51,85	11,11	44,44	92,59	96,3	33,33
🟥 Post test	85,19	96,3	88,89	66,67	11,11	48,15	96,3	88,89	29,63

Figure 8.7: Symptoms of depression

When respondents were required to identify the **symptoms** of depression in the **pre-test**, 81.48 % (22) said such a person would not be more talkative versus 85.19 %(23) in the post-test, 85.19 % (23) answered a person would lose interest in almost all activities, while 92.59 % (25) said a person would sleep too little or too much and 92.59 % (25) responded that a person would have suicidal thoughts. Other results of the symptoms of depression that were reported pre and post-test are illustrated in **Figure 8.7**.

Respondents were given the option also to name **other symptoms** of depression, which included the following: loss of sexual drive, crying non-stop, lack of drive, pessimistic about life, hopelessness and withdrawal from everything and everybody.

8.3.2.3 Mania (Question 4)

Miklowitz (2011:187) reports that a manic episode can wreak havoc with a person's life. It might drain finances, ruin marriages and long-term relationships, destroy a person's physical health, produce legal problems, and lead to loss of employment. It may even lead to loss of life.

Respondents were required to identify a word that they had learnt in the SEE-SAW programme to help them to remember the symptoms of **mania**. In the pre-test 18.52 % (5) indicated that they did not know the word; some however had their own ideas regarding mania and wrote: "out of the box", "Jack Russell", "energy burst", "master of all", "high on life", "overactive" and "racing". After the programme 66.67 % (18) could identify the word as being "DIGFAST" (refer to chapter 2 and chapter 7 where it was discussed). Ghaemi, Saggese and Goodwin (2006:6) suggest this useful acronym.

Distractibility:	An inability to maintain one's concentration.
Insomnia:	A decreased need for sleep.
Grandiosity:	Inflated self-esteem.
Flight of ideas:	A subjective experience of racing thoughts.
Activities:	An increase in **goal-directed** activities (social, sexual, work, home).
Speech:	Pressured or increased talkativeness.
Thoughtlessness:	Commonly called *risk-taking behaviour*, for example sexual indiscretions, spending sprees, impulsive travelling and reckless driving. Ghaemi, Saggese and Goodwin (2006:7) conclude that mania is diagnosed when **euphoric mood** is present for **one week** with three of the DIGFAST symptoms, or **irritable mood** with four symptoms, and there is significant social or occupational dysfunction.

Further statistical investigation showed that in the pre-test 27 respondents gave other words than DIGFAST in their answers, but as stated above, in the post-test 66.67 % (18)

respondents could identify the word as being DIGFAST. There were 33.33 % (9) respondents that still chose other categories when faced with this question.

8.3.2.4 Psychosis (Question 5)

Severe episodes of mania or depression may include **psychotic symptoms**, such as delusions and/or hallucinations.

Table 8.9: Signs of psychosis

	Pre-test		**Post-test**	
	Frequency (ƒ)	**Percentage (%)**	**Frequency (ƒ)**	**Percentage (%)**
Yes, a psychotic person may have delusions	24 (2 did not answer)	88.89	25 (1 did not answer)	92.59
No, sleeping too much is not a sign of psychosis	12 (6 did not answer)	44.44	17 (1 did not answer)	62.96
Yes, substance abuse is a sign of psychosis	17 (4 did not answer)	62.96	18 (1 did not answer)	66.67
Yes, anxiety is a sign of psychosis	21 (5 did not answer)	77.78	25 (everybody answered)	92.59
Yes, hallucinations are a sign of psychosis	21 (5 did not answer)	77.78	24 (2 did not answer)	88.89

In this question signs of psychosis had to be identified and respondents were asked to answer all questions with a “yes” or a “no”. Some, however, left questions open, which indicated to the researcher that respondents did not understand this concept very well, e.g. the percentage of 66.67 (18) who said in the post-test that substance abuse is a sign of psychosis. Also in the post-test, a percentage of 92.59 (25) of respondents indicated that anxiety is a sign of psychosis. In practice it is found that psychotic patients might be anxious, but it is not a prerequisite for the definition of psychosis.

In the pre-test most respondents did identify that **delusions** and **hallucinations** are indicative of a psychosis. There were 88.89 % (24) who indicated the presence of delusions and 77.78 % (21) the presence of hallucinations. These symptoms were also indicated in the post-test, respectively at 92.59 % (25) and 88.89 % (24). In **Table 8.9**, tendencies indicated in this question are highlighted.

Prior to the programme respondents wrote under **other signs of psychosis**: **"**aggressiveness", "different identities and personalities", "lost myself", "don't know who I am", "sleep too little", "don't know", "hearing voices or seeing imaginary people", "illusions of grandeur" and "tell lies".

8.3.2.5 Relapse in BD (Questions 6.1-6.3)

- **Evaluation of triggers of a relapse of BD**

In CAMH's information guide (2000:11) it is stated that too much stress or difficult family relationships **do not cause** BD. However, these factors may "trigger" an episode in someone who already has the illness. The patient and family must be assisted in recognising and learning to cope with stressful life events that trigger recurrences of BD (Miklowitz, 2010c:10).

The concept of relapse and the prevention thereof is very important in BD, because if symptoms of relapse can be identified this could lead to immediate remedial action. Respondents were asked to evaluate some factors in terms of their contribution towards triggering a relapse in BD, whether **weak**, **moderate** or **strong**. It is the researcher's opinion that there were no right or wrong answers – these depended on individual perceptions. The researcher will indicate which responses were chosen by **the most respondents** in the pre and post-test (refer to **Table 8.10**).

Table 8.10: **Evaluation of triggers of a relapse of BD**

	Pre-test		**Post-test**	
Factors leading to a relapse	**Frequency (*f*)**	**Percentage (%)**	**Frequency (*f*)**	**Percentage (%)**
Stressors can **strongly** contribute towards relapse	21	77.78	25	92.59
The use of a **substance** can **strongly** lead to a relapse	18	66.67	22	81.48

An **overinvolved family** have a **moderate** role in relapse	12	44.44	14	51.85
Lack of supportive MDT has a **strong** effect on relapse	14	51.85	20	74.07
Poor compliance with treatment has a **strong** effect on relapse	23	85.19	23	85.19
Lack of family support has a **strong** effect on relapse	13	48.15	15	55.56
Patient does not take responsibility has a **strong** effect on relapse	18	66.67	22	81.48

The researcher did emphasise the role of the MDT during the programme but it can be said that patients and caregivers in the private sector mostly do not have the benefit of a supportive MDT, as compared to the public sector/ academic hospital. Respondents felt very strongly about **poor compliance** being a reason for relapse - again pointing to the caregivers' insight even before the SEE-SAW programme. The results of this question showed that the respondents had sound insight regarding reasons for relapse.

- **Major role player to prevent a relapse of BD**

Respondents indicated that it is mainly the **patient's** responsibility to prevent a relapse – this was the opinion of 55.56 % (15) in the pre-test and 77.78 % (21) in the post-test. In the pre-test 33.33 % (9) said it is the **caregiver's** responsibility, but in the post-test only 14.81 % (4) held this opinion. During the programme the researcher reiterated that it is very important that patients should take responsibility for their own lives.

- **Rationale to use alcohol, dagga or other drugs**

It was mentioned in Chapter 2 that about 60 % of people with BD have had an alcohol or substance use disorder at some point in life: a rate that is much higher than the rate of the general population, at 10-20 % (Miklowitz, 2011:44, 52; Mondimore, 2006:177). Many people turn to alcohol or drugs during manic episodes. Substance use problems and addictive behaviours are not essential symptoms of BD, but they can become intertwined with mood disorder symptoms in such a way that each worsens the other (Miklowitz, 2011:27).

Many people with BD **self-medicate** with street drugs and/or alcohol. This may make the symptoms worse over the long term (Haycock, 2010:25). Sadock and Sadock (2003:553) consider that the abuse of substances may be involved in precipitating an episode of illness or, conversely, may represent patients' attempts to treat their own illnesses.

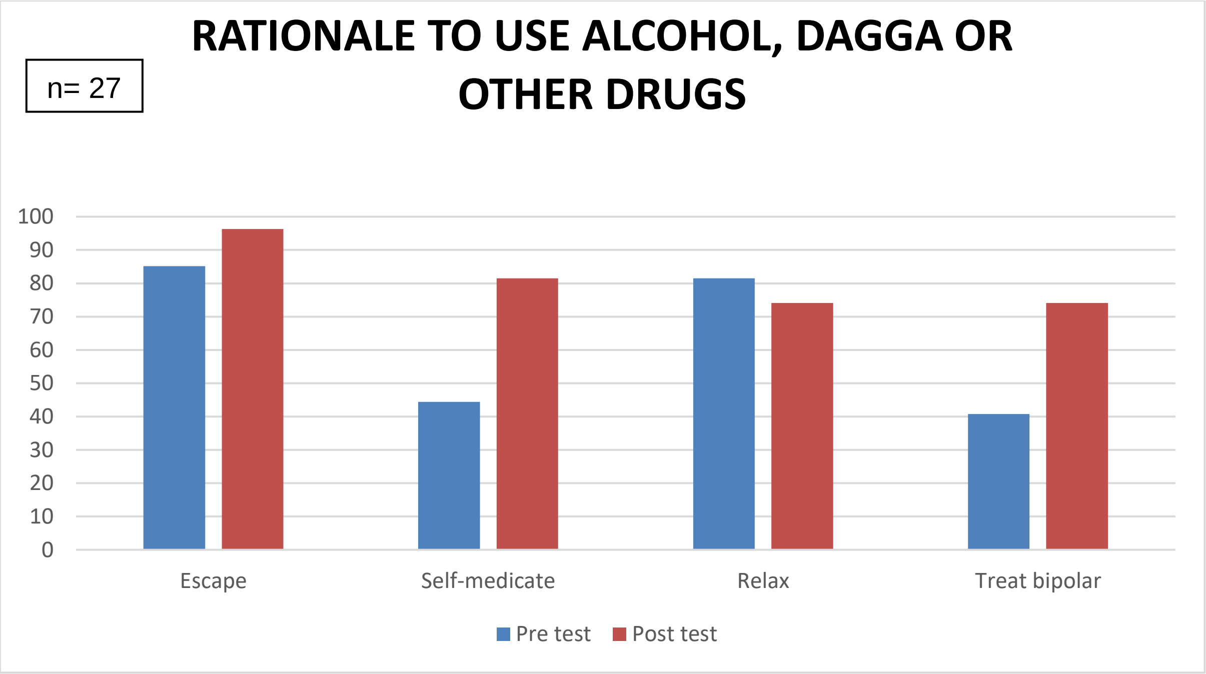


Figure 8.8: **Rationale to use alcohol, dagga or other drugs**

Respondents' views regarding the reasons for the use of **substances** by BD patients were solicited and in pre- as well as post-tests 85.19 % (23) and 96.3 % (26) respectively, they indicated that patients use these to **escape**. In the pre-test 44.44 % (12) said they use substances to **self-medicate**, but in the post-test 81.48 % (22) said this might be for self-medication. This was an aspect that was discussed in the programme. Pre and post the programme, respondents said substances are used by patients to **relax** (81.48 % before the time and 74.07 % after the time) (refer to **Figure 8.8**). One of the respondents referred to the use of coffee (**caffeine**) by her husband, while **smoking** was also mentioned. It is the researcher's experience that most psychiatric patients smoke and that it is very difficult for them to stop. It was also mentioned that patients use substances to feel better.

8.3.2.6 Suicide (Questions 7.1-7.4)

Bipolar depression is a major cause of suicide, so much so that the lifetime prevalence of a suicide attempt is approximately 29 % in these patients (International Consensus Group on the Evidence-Based Pharmacologic Treatment of Bipolar I and II Depression, 2008:1632).

It was mentioned in Chapter 4 that suicide may be accomplished in a sudden impulsive act or a carefully planned event. It usually occurs during a depressive or a mixed episode, but some people with BD kill themselves accidentally or on impulse when they are psychotic and in the manic phase. By some estimates, people with BD are at **15 % times** the risk of committing suicide as are people in the general population. Of the BD population, up to 15 % die by suicide, and as many as **one in three** attempt suicide at least once in their lives. One of the risk factors for committing suicide exists if a person is **isolated** from friends and family members (Miklowitz, 2011:241, 242).

Chessick et al*.* (2007:482) furthermore report that the suicide attempt of a spouse or family member is an experience that has enduring effects on the caregiver, even years after the event. Their study also found that **caregivers** of those with BD who are experiencing current suicidal ideation or who have made a suicide attempt report significant health difficulties. Suicide is therefore a very real fact in the lives of those who are confronted with BD and it was important to include this aspect in the programme.

In the SEE-SAW programme (Chapter 7) **risk factors** when dealing with suicide were discussed. According to Berk et al (2008:159-160) and Miklowitz (2011:242) these include:

A previous suicide attempt; being isolated from others; having recently experienced a major stressful event; feeling hopeless or already having a specific plan to commit suicide; abusing drugs or alcohol; anxiety disorder; being male; being prone to impulsive acts; having recently been hospitalised; family history of suicide; do not have ready access to a psychiatrist or other mental health care helper and do not have a strong reason to keep living.

- **Risk factors for suicide**

Table 8.11: Prioritised listing of the STRONG CATEGORY of risk factors for suicide

Pre-test			**Post-test**		
Factor	**Frequency (*ƒ*)**	**Percentage (%)**	**Factor**	**Frequency (*ƒ*)**	**Percentage (%)**
Being isolated	20	74.07	**Previous attempts**	22	81.48
Previous attempts	16	59.26	**Being isolated**	21	77.78
Suicide plan	13	48.15	**Suicide plan**	21	77.78
Prone to Impulsivity	11	40.74	**Prone to Impulsivity**	19	70.37
Family history	6	22.22	**Family history**	18	66.67
Male	1	3.7	**Male**	8	29.63

In this question respondents were required to choose **weak, moderate** or **strong** in relation to risk for suicide. Respondents seemed surprised that being a **male** can be a risk factor: in the pre-test only 3.7 % (1) indicated it as a strong factor, but in the post-test 29.63 % (8) said it is a strong risk factor (refer to **Table 8.11**). About four times more males than females die of suicide, though females are more likely to attempt it (Haycock, 2010:104).

After attending the SEE-SAW programme the respondents realised that a **family history** of suicide attempts is a strong risk factor as it was indicated that only 22.22 % (6) chose it before the programme but 66.67 % (18) did so afterwards. It is clear to the researcher that respondents did become aware of the importance of the factors that can contribute to suicide risk.

At question 7.1 the **McNemar's Test** was administered to establish if there was a significant difference in the number of respondents that chose the strong category in the pre- and post-tests.

McNemar's test measures the significance of the differences between two proportions, based on the same sample of subjects. In this case an individual was asked to answer a set of questions in a pre-test and the proportion of individuals who gave the correct answer to each question was calculated. The individuals then attended a programme to explain the concepts and after the programme (post-test) the individuals were asked to answer the same set of questions again. The proportion of individuals who gave the correct answer after the test was also calculated. The McNemar test was used to determine whether there were signigicant differences between an individual's answer in the pre- and post-test (information obtained after consultation with UP statistician, dr J. Kleyn).

The two hypotheses were: Ho (Null hypothesis) - there is not a significant difference between the pre- and post-tests and Ha (Alternative hypothesis) - there is a significant difference between the pre- and post-test results. In question 7.1 (a) it can be seen that of the 23 respondents who did not choose the strong category in the pre-test, 7 respondents chose it as a strong category in the post-test. The p-value of the test was 0.0082. Therefore the null hypothesis was rejected at a 5 % level of significance. There is enough statistical evidence to suggest that there are significant differences between how respondents rated "being a male" as a risk factor, in the pre- and post-test. From the table (**Table 8.12**) below it can be seen that there was a significant improvement in their knowledge regarding this risk factor.

Table 8.12: Suicide risk factor – being male (question 7.1a)

Frequency *Row Pct* *Col Pct*	**Table of vv7_1a by post7_1a** **vv7_1a(Male)**	**post7_1a**		
		Post Not	**Post Strong**	**Total**
	Pre Not	16 *69.57* *100*	7 *30.43* *87.5*	23
	Pre Strong	0 *0* *0*	1 *100* *12.5*	1
	Total	16	8	24
	Frequency Missing = 3			

Similar tests were conducted for the following risk factors and the p-value for each test is given in the table (**Table 8.13**) below.

Table 8.13: P-value for McNemar's test conducted at question 7.1

Question	Risk factor	p-value
7.1 (b)	Specific suicide plan	0.0047*
7.1 (c)	Being isolated from friends and family members	0.7055

Question	Risk factor	p-value
7.1 (d)	Being prone to impulsive acts such as driving recklessly	0.0196*
7.1 (e)	Having a family history of suicide attempts	0.0005*
7.1 (f)	Having previous suicide attempts	0.0339*

*p<0.05

Table 8.14: **Suicide risk factor – specific suicide plan (question 7.1b)**

Frequency
Row Pct
Col Pct

Table of vv7_1b by post7_1b

vv7_1b(Suicide plan)	**post7_1b**		
	Post Not	**Post Strong**	**Total**
Pre Not	4 *33.33* *100*	8 *66.67* *38.1*	12
Pre Strong	0 *0* *0*	13 *100* *61.9*	13
Total	4	21	25

Frequency Missing = 2

In question 7.1 (b) it can be seen (refer to **Table 8.14**) that of the 12 respondents who did not chose the strong category in the pre-test, 8 respondents chose it as a strong category in the post-test.

Table 8.15: **Suicide risk factor – being insolated from friends and family members (question 7.1c)**

Frequency
Row Pct
Col Pct

Table of vv7_1c by post7_1c

vv7_1c(Isolated)	**post7_1c**		
	Post Not	**Post Strong**	**Total**
Pre Not	2 *33.33* *40*	4 *66.67* *19.05*	6
Pre Strong	3 *15* *60*	17 *85* *80.95*	20
Total	5	21	26

Frequency Missing = 1

In question 7.1 (c) it can be seen (refer to **Table 8.15**) that of the 6 respondents who did not chose the strong category in the pre-test, 4 respondents chose it as a strong category in the post-test. The p-value of the test was 0.7055. Therefore the null hypothesis was not rejected at a 5 % level of significance. There is not enough statistical evidence to suggest that there are significant differences between how respondents rated "**being isolated from friends and family members**" as a risk factor, in the pre and post-test. There was also a slight negative shift, since 20 respondents chose the strong category in the pre-test but in the post-test 3 of these respondents, did not chose the strong category. Even though this was observed, there was not a significant difference between the pre and the post- test answers for this question.

Table 8.16: Suicide risk factor – being prone to impulsive acts such as driving recklessly (question 7.1d)

Frequency *Row Pct* *Col Pct*	Table of vv7_1d by post7_1d			
	vv7_1d(Impulsive acts)	**post7_1d**		
		Post Not	**Post Strong**	**Total**
	Pre Not	6 *42.86* *85.71*	8 *57.14* *44.44*	14
	Pre Strong	1 *9.09* *14.29*	10 *90.91* *55.56*	11
	Total	7	18	25
	Frequency Missing = 2			

In question 7.1 (d) it can be seen (refer to **Table 8.16**) that of the 14 respondents who did not chose the strong category in the pre-test, 8 respondents chose it as a strong category in the post-test. The p-value of the test was 0.0196. It can also be stated that in the pre-test 11 respondents (40.74 %) indicated that if a patient is prone to impulsive acts such as driving recklessly it is a risk factor versus 19 (70.37 %) in the post-test (refer to **Table 8.11**).

Table 8.17: Suicide risk factor – having a family history of suicide attempts (question 7.1e)

Frequency *Row Pct* *Col Pct*	Table of vv7_1e by post7_1e			
	vv7_1e(Family history)	**post7_1e**		
		Post Not	**Post Strong**	**Total**
	Pre Not	7 *36.84* *100*	12 *63.16* *66.67*	19
	Pre Strong	0 *0* *0*	6 *100* *33.33*	6
	Total	7	18	25
	Frequency Missing = 2			

In question 7.1 (e) it can be seen (refer to **Table 8.17**) that of the 19 respondents who did not chose the strong category in the pre-test, 12 respondents chose it as a strong category in the post-test. In the pre-test 11 respondents (40.74 %) indicated that if a patient is prone to impulsive acts such as driving recklessly it is a risk factor versus 19 (70.37 %) in the post-test (refer to **Table 8.11**).

Table 8.18: Suicide risk factor – having previous suicide attempts (question 7.1f)

Frequency *Row Pct* *Col Pct*	**Table of vv7_1f by post7_1f**			
	vv7_1f(Previous attempts)	**post7_1f**		
		Post Not	**Post Strong**	**Total**
	Pre Not	2 *22.22* *66.67*	7 *77.78* *31.82*	9
	Pre Strong	1 *6.25* *33.33*	15 *93.75* *68.18*	16
	Total	3	22	25
	Frequency Missing = 2			

In question 7.1 (f) it can be seen (refer to **Table 8.18**) that 9 respondents did not chose the strong category in the pre-test, 7 respondents chose it as a strong category in the post-test. In the pre-test 16 respondents (59.26 %) indicated that if a patient had previous suicide attempts it is a risk factor versus 22 (81.48 %) in the post-test (refer to **Table 8.11**).

- **Prevention of suicide**

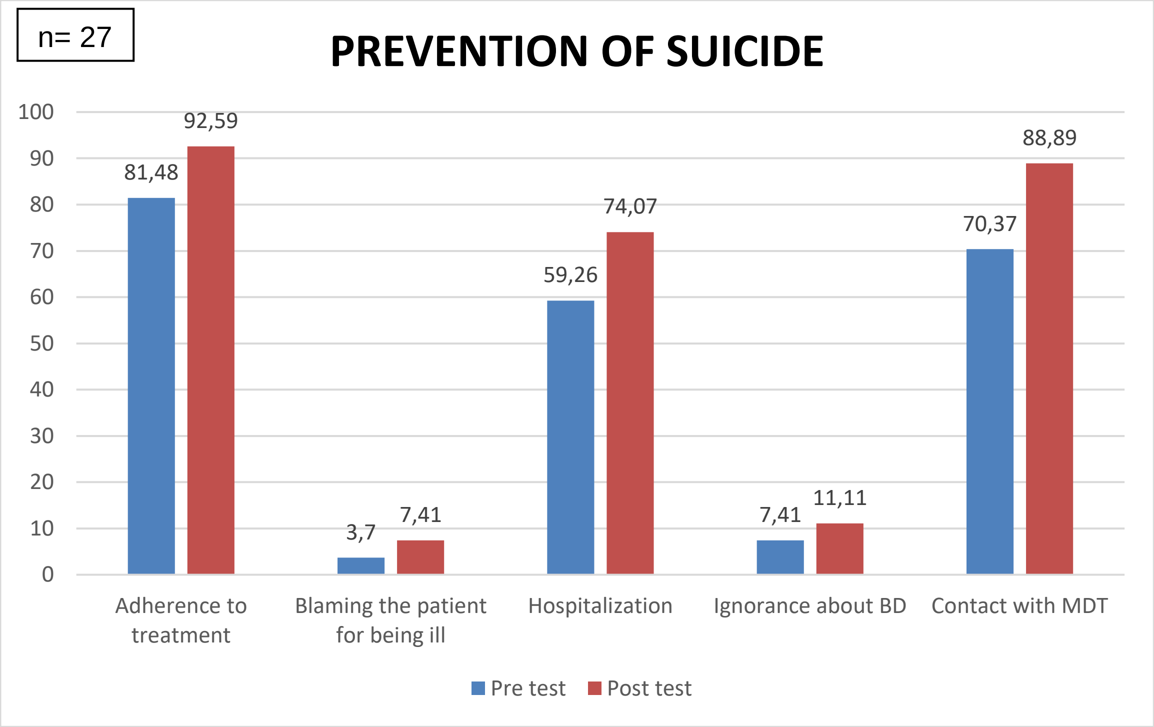


Figure 8.9: Preventin of suicide

In terms of the **prevention** of suicide respondents indicated that adherence to treatment, frequent contact with the MDT and hospitalisation can most likely prevent suicide. It was clear that already in the pre-test 81.48 % (22) of respondents had realised the importance of **adherence** to prescribed treatment, but this percentage did increase to 92.59 % (25) afterwards. Pre and post-tests showed that most respondents were of the opinion that it would not help to **blame** the patient, respectively 3.7 % (1) and 7.41 % (2). The pre- and post-tests indicated that only 7.41 % (2) of respondents initially and thereafter 11.11 % (3) thought that being ignorant about BD would prevent suicide.

- **Alert for warning signs**

Seriously depressed people can seem strangely energised before taking their own lives (Haycock, 2010:6). Family or friends might even think that the person is "getting better" (Vieta, 2009:45). The risk of suicide may be greater in bipolar II than bipolar I disorder, in the light of the greater preponderance of recurrent severe depression.

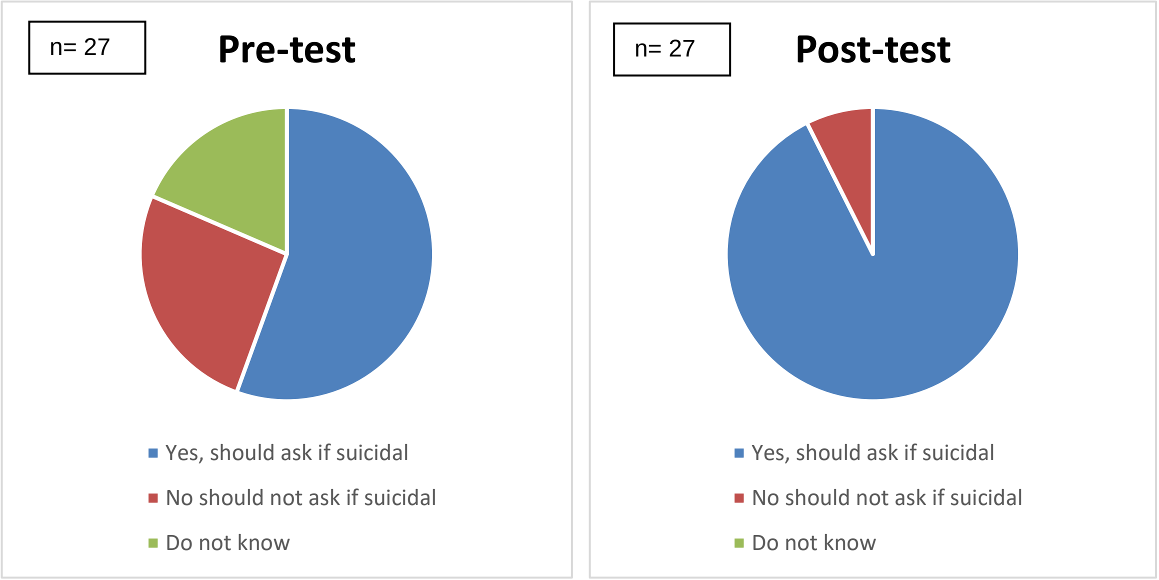


Figure 8.10: **Alert for warning signs**

During the programme the researcher emphasised that it is important to communicate with the patient about possible suicide intentions; whereas 55.56 % (15) of respondents agreed with this before the programme, 92.59 % (25) agreed after it (refer to **Figure 8.10**).

Table 8.19: **Warning signs for suicide ideation (question 7.3)**

Frequency	**Table of vv7_3 by post7_3**	
Row Pct	**vv7_3(Should you ask if**	**post7_3**
Col Pct		

Frequency	**Table of vv7_3 by post7_3**			
	suicidal)	**Post Not**	**Post Yes**	**Total**
	Pre Not	2 *16.67* *100*	10 *83.33* *40*	12
	Pre Yes	0 *0* *0*	15 *100* *60*	15
	Total	2	25	27

It was important for the researcher to test if specific respondents did learn from the programme and that they should realized that any suicide ideation should not be ignored by the caregiver. The **McNemar's Test** was done and it can be seen that of the 12 respondents who did not chose the yes option in the pre-test, 10 chose it in the post-test (refer to **Table 8.19**). The p-value of the test was 0.0016. Therefore the null hypothesis was rejected at a 5 % level of significance. There is enough statistical evidence to suggest that there is significant difference on how respondents viewed the question in the pre and post-test.

- **Action to take when patient is suicidal**

Respondents were given the chance to write what they **should do** when a family member is suicidal. This question showed the researcher that the caregivers had sound insight and judgement even **prior** to the programme because 92 % (25) said they would seek immediate **professional help** from the psychiatrist or other member of the MDT, call the hospital or suggest admission to a hospital. They also indicated that communication with and support to the patient would be important. **Other ideas** that were mentioned included: to monitor the patient closely, to give attention to the patient's problems and help him/her to put his/her thoughts in perspective, to convince the patient of his/her self-worth, to include other family members and to make sure that the patient takes his/her medication.

After the programme (post-test) caregivers still indicated the same chain of action that they would follow, but some added that it is important to give the patient a reason not to commit suicide, not to ignore or isolate the patient, to confront the issues and to seek the help of the police.

It should be noted that the researcher discussed measures such as a suicide risk prevention plan for the patient and a contract for suicide prevention during the SEE-SAW programme.

8.3.2.7 Treatment (Questions 8.1-8.7)

- **Oldest treatment for BD**

Respondents were well aware that **lithium** is the oldest medication that is still used for BD – 88.89 % (24) indicated this in the pre-test while 96.3 % (26) indicated it in the post-test.

- **Safety of anti-depressants**

One of the most serious concerns about anti-depressants, alluded to earlier in Chapter 3, is that they can cause people to become **suicidal** (their lethality when taken in **overdose**) while another is that they can bring on **hypomanic**, **manic**, or **mixed** states and cause rapid cycling. Sadock and Sadock (2003:566) are of the opinion that adequate patient education about the use of **antidepressants** is as critical to treatment success as is choosing the most appropriate drug and dosage.

In the pre-test 81.48 % of respondents (22) said that **anti-depressants** are not always safe for BD patients whereas this was the opinion of 92.59 % (25) in the post-test.

- **Viewpoint about ECT**

As was mentioned in earlier chapters, Keck, McElroy and Hawkins (2010:289) argue that **ECT** remains an important non-pharmacological treatment option for patients who do not respond well to or tolerate pharmacotherapy, or those who display severe, psychotic or catatonic symptoms. Miklowitz (2011:123) states that ECT is one of the more powerful treatment options available for people with BD and other severe forms of depression. ECT works quickly and efficiently. It is mainly an acute treatment. The researcher asked for the respondents' feelings regarding ECT (refer to **Table 8.20**). The advantages of ECT were indicated during the programme, but individuals' opinions were still respected, because it can be a **controversial** treatment.

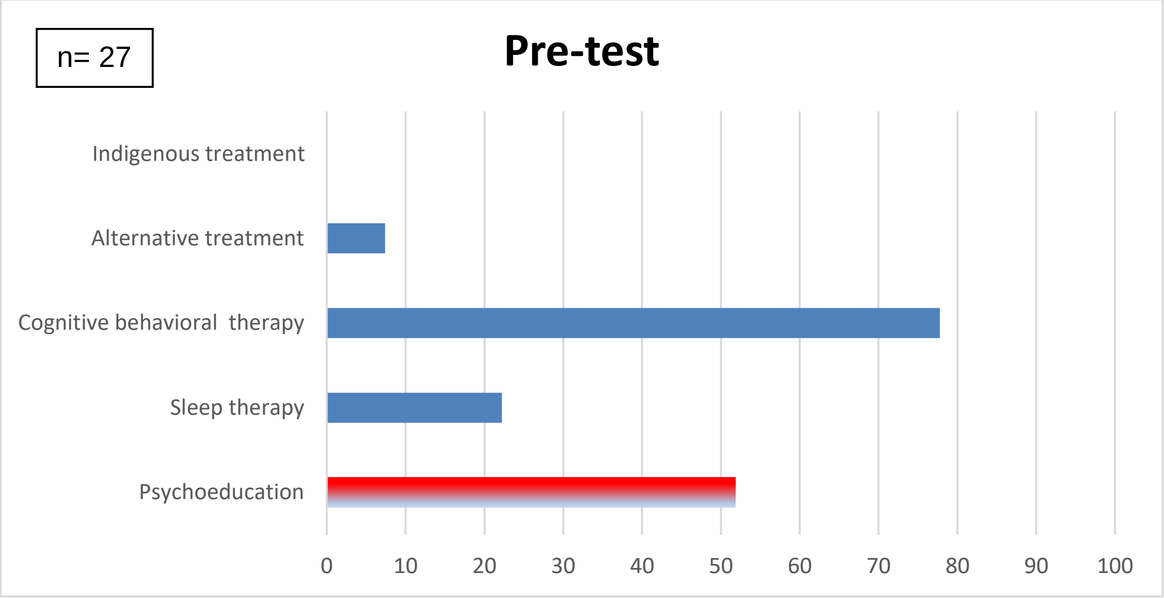
Table 8.20: Viewpoint about ECT

	Pre-test		**Post-test**	
	Frequency (ƒ)	**Percentage (%)**	**Frequency (ƒ)**	**Percentage (%)**
Positive	7	25.93	9	33.33
Neutral	8	29.63	15	55.56
Negative	7	25.93	2	7.41
Don't know	5	18.52	1	3.7
Total	**27**		**27**	

These results indicated to the researcher that in the post-test the majority of respondents had a neutral feeling about ECT.

- **Other relevant treatment apart from medication and ECT**

The results of this question are illustrated in **Figure 8.11**.



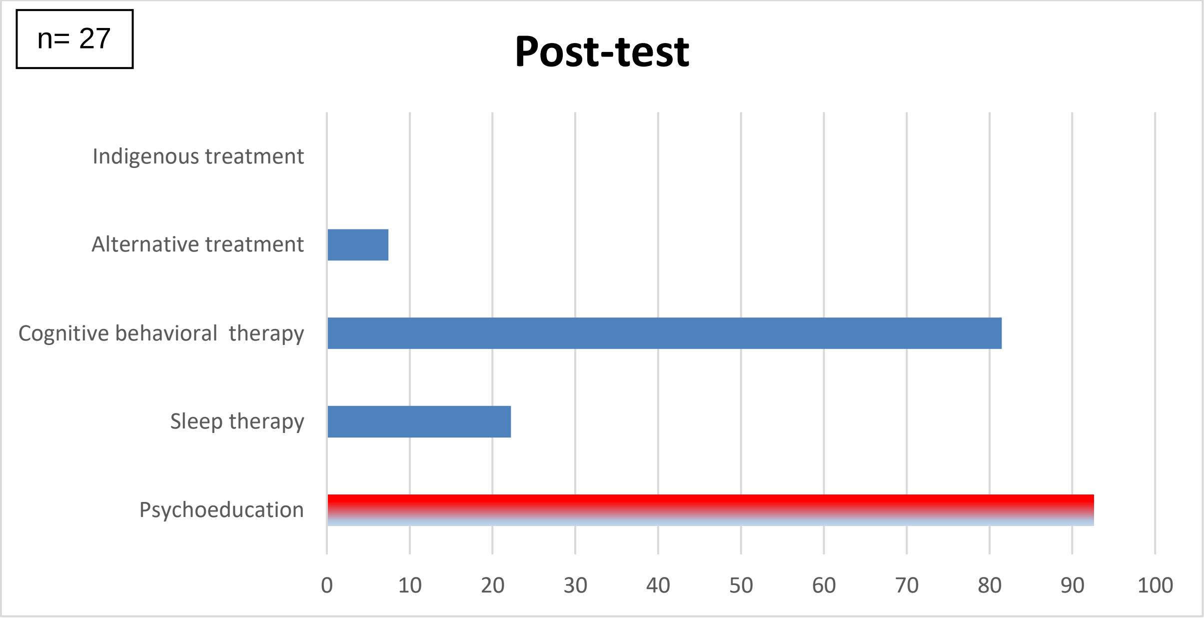


Figure 8.11: **Other relevant treatment apart from medication and ECT (pre- and post-test)**

It is clear that most respondents chose **psychoeducation** as a relevant **other treatment**. It was interesting that although the researcher said that **sleep therapy** is no longer considered a reliable treatment option, 22.22 % (6) chose that option (the same as in the pre-test). This might be because the respondents think sleep is a good option for a manic person as well as owing to the fact that it was used for a long time in the private sector. **Cognitive behavioural therapy** was indicated pre and post programme as a good adjunctive option (77.78 %, (21) of respondents, pre-test and 81.48 %, 22 respondents, post-test). **Alternative** treatment was chosen by 7.41 % (2) of respondents both pre- and post-test, while **indigenous** treatment was not chosen by anybody. **Other options** that were mentioned by respondents included the attendance of support groups, occupational therapy, psychotherapy and support to families. It was mentioned that each case should be treated as unique.

Table 8.21: Psychoeducation as other relevant treatment

Frequency *Row Pct* *Col Pct*	**Table of V8_4A by post8_4a**			
	V8_4A(Psychoeducation)	**post8_4a(V8_4A)**		
		Post No	**Post Yes**	**Total**
	Pre No	2 *15.38* *100*	11 *84.62* *44*	13
	Pre Yes	0 *0* *0*	14 *100* *56*	14
	Total	2	25	27

The **McNemar's Test** was done and it is clear that of the 13 respondents who did not chose psychoeducation in the pre-test, 11 chose it in the post-test (refer to **Table 8.21**). The p-value of the test was 0.0009. Therefore the null hypothesis was rejected at a 5 % level of significance. There is enough statistical evidence to suggest that there is a difference on how respondents viewed the value of psychoeducation in the pre and post-test. This was a very positive finding for the researcher, because she emphasized throughout the presentation of the SEE-SAW programme that psychoeducation can empower caregivers.

- **Factors contributing to discontinuation of medication**

Chapter 3 refers to the fact that people with BD frequently discontinue their medication. This poses a serious challenge for caregivers and patients. Estimates vary, but the consensus seems to be that **more than half** of those with BD stop taking their medications at some point in their lives. Accepting a programme of pharmacotherapy to treat BD is a long-term commitment and, thus, a very important personal decision (Miklowitz, 2011:135, 138). There is no way anyone can *force* a person to take responsibility for his or her treatment. Unless the patient makes the commitment to do so, no amount of love and support or even threats can make someone take this step (Mondimore, 2006:257). It was also previously pointed out that patients whose caregivers were more emotionally **overinvolved** were less adherent to medication (Perlick, et al., 2004:1033).

The researcher evaluated the respondents' opinion regarding the **compliance problem** that often features in the lives of BD patients. Again it can be stated that there were no right or wrong answers. The respondents were required to indicate if they thought a particular aspect exerted a **weak, moderate or strong** influence.

Table 8.22: Prioritised listing of the STRONG CATEGORY contributing to discontinuation of medication (pre- and post-test)

Pre-test			**Post-test**		
Factor	**Frequency (*f*)**	**Percentage (%)**	**Factor**	**Frequency (*f*)**	**Percentage (%)**
Lack of insight	20	74.07	**Denial of the illness**	23	85.19
Denial of the illness	16	59.26	**Lack of insight**	21	77.78
Side effects	13	48.15	**Miss the feeling of being manic**	17	62.96
Reasons for taking medication were not explained	11	40.74	**Side effects**	14	51.85
Lack of motivation	10	37.04	**Reasons for taking medication were not explained**	13	48.15
Miss the feeling of being manic	9	33.33	**Taking medication is a sign of personal weakness**	11	40.74
Pill fatigue	7	25.93	**Lack of motivation**	10	37.04

Pre-test			**Post-test**		
Factor	**Frequency (ƒ)**	**Percentage (%)**	**Factor**	**Frequency (ƒ)**	**Percentage (%)**
Taking medication is a sign of personal weakness	6	22.22	**Pill fatigue**	10	37.04

In the pre-test, respondents indicated that **lack of insight** into the illness was the strongest reason that a patient may stop his/her medication (74.07 %, 20, pre- versus 77.78 %, 21, in the post-test). The issue of **denial of the illness** rated 59.26 % (16) in the pre-test as a strong reason to stop medication and 85.19 % (23) in the post-test (refer to **Table 8.22**).

The pre-test and post-test did reveal a slightly different lists in the **strong category** contributing to discontinuation of medication. The post-test showed an increase in respondents thinking that the patient may miss the feeling of being manic. It might be the case that they never thought of this as a reason for poor compliance in the past.

- **Risk and protective factors**

The researcher‘s programme placed a strong emphasis on **risk** and **protective** factors in maintaining wellness and it was imperative that respondents should understand this concept. It was clear that they had grasped this truth even before the SEE-SAW programme, because 74.07 % (20) could say that risk factors must be minimised and protective ones maximised. After the SEE-SAW programme 85.19 % (23) knew the importance thereof.

- **Psychoeducation can empower caregivers**

Table 8.23: Psychoeducation can empower caregivers

	Pre-test		**Post-test**	
	Frequency (ƒ)	**Percentage (%)**	**Frequency (ƒ)**	**Percentage (%)**
Strong agree	24	88.89	23	85.19
Agree	2	7.41	4	14.81
Unsure	1	3.7	0	0
Total	27		27	

There was no disagreement concerning psychoeducation being able to empower caregivers - in the pre-test 96.3 % (26) of respondents agreed and strongly agreed with this statement and in the post-test 100 % (27) of respondents agreed and strongly agreed with this statement. This again pointed to the level of insight that respondents had, even prior to attending the programme (refer to **Table 8.23**).

8.3.2.8 Coping (Question 9)

- **Coping mechanisms to address difficult situations regarding the BD patient**

Respondents were asked to evaluate coping mechanisms that might help them to address difficult situations regarding the BD patient.

Table 8.24: Coping mechanisms that were rated as the most important by respondents

	Pre-test		Post-test	
Response	**Frequency (ƒ)**	**Percentage (%)**	**Frequency (ƒ)**	**Percentage (%)**
Yes, communication	27	100	26	96.3
Yes, problem solving	24	88.89	25	92.59
Yes, self-controlling	20	74.07	18	66.67

It was clear that respondents considered, both pre- and post-test, the SEE-SAW programme **communication** as the best coping mechanism, followed by problem solving and self-controlling (refer to **Table 8.24**).

It was mentioned in Chapter 4 that stable relationships are based on good communication. BD often robs a person of their ability to reason, which means the person with the illness often says and does things that are not part of their real behaviour or an honest reflection of their true and deeper feelings (Fast & Preston, 2004:115).

Relatives should be very aware of **how** and **what** they communicate to the patient. The relative may convey a direct or indirect message about how he/she liked the patient before he/she began medicine or therapy. This may make the patient ambivalent towards accepting treatment. Effective communication is a very important component of managing family or marital relationships and may even help facilitate recovery from an episode of illness. When a person is psychotic, communication becomes even more of a challenge (Miklowitz, 2011:283, 287). Having to deal with a psychotic person can be very traumatic for a caregiver, especially the first time.

Mondimore (2006:252) emphasises the importance of honest and open communication. One could ask the person with the illness about his or her moods, make observations about behaviours and express concerns in a caring, supportive way; accompany one's family member to doctors' appointments, and share one's observations and concerns during the visits in his or her presence. One should be supportive and constructively critical when criticism is warranted. Above all, one needs to be open, honest and sincere.

Table 8.25: Coping mechanisms that were rated as the least important by respondents

	Pre-test		**Post-test**	
Response	**Frequency (ƒ)**	**Percentage (%)**	**Frequency (ƒ)**	**Percentage (%)**
No, not blaming	19	70.37	23	85.19
No, not aggression	18	66.67	23	85.19
No, not denial	18	66.67	23	85.19
No, not avoidance	17	62.96	21	77.78

Most of the respondents indicated that **blaming, aggression, denial** and **avoidance** are not effective coping mechanisms to use (refer to **Table 8.25**). The fact that respondents realised that these reactions are not conducive to the situation pointed to their level of insight. Berk et al. (2008:272, 273, 267) (refer to Chapter 4) consider that maintaining healthy boundaries may relieve distress and prevent the build-up of anger. A caregiver may come to know that they are giving **too** much when they feel tired most of the time, feeling overwhelmed, irritable, depressed, resentful; or present with recurrent physical signs of stress, such as headaches (Last, 2009:139). Also refer to **Table 4.2: The evolution of family responses to mental Illness through time** (Terkelsen, 1987b:152-164) in Chapter 4 where the ways caregivers may react in the face of having a mentally ill relative were identified.

8.3.2.9 Legislation (Questions 10.1-10.3)

- **Act to admit patients to a government hospital**

It was mentioned in Chapter 7 that when someone refuses to acknowledge that they are mentally ill or refuses to take medication, it is important that the caregiver should consult with a health care professional. It might also be that the person has symptoms that exert a disruptive effect on their life, and they need time out to focus on getting well (Berk et al., 2008:16).

According to Baumann (2007d:795) **admission to a psychiatric hospital** is strictly defined in terms of the **Mental Health Care Act 17 of 2002** (South Africa) with regard to the patient's consent to admission, capacity to give consent, and the nature of the illness, which should be psychiatric in nature and not primarily due to a general condition.

The researcher included a discussion on the above mentioned Act in the programme, because she considered it as important knowledge that a caregiver should possess. The pre- as well as the post-test indicated that 85.19 % (23) of the respondents were aware of the fact that patients are admitted according to this Act.

- **Section of the Mental Health Care Act stating that the police must assist**

Zabow (2007:581) states that if a member of the SAPS has reason to believe that a person, owing to his/her mental illness or severe or profound intellectual disability, is likely to inflict serious harm on him/herself or on others, the member must apprehend the person and cause that person to be taken to an appropriate health establishment administered under the auspices of the state for assessment (**Art. 40 of Mental Health Care Act**) (refer to Chapter 7).

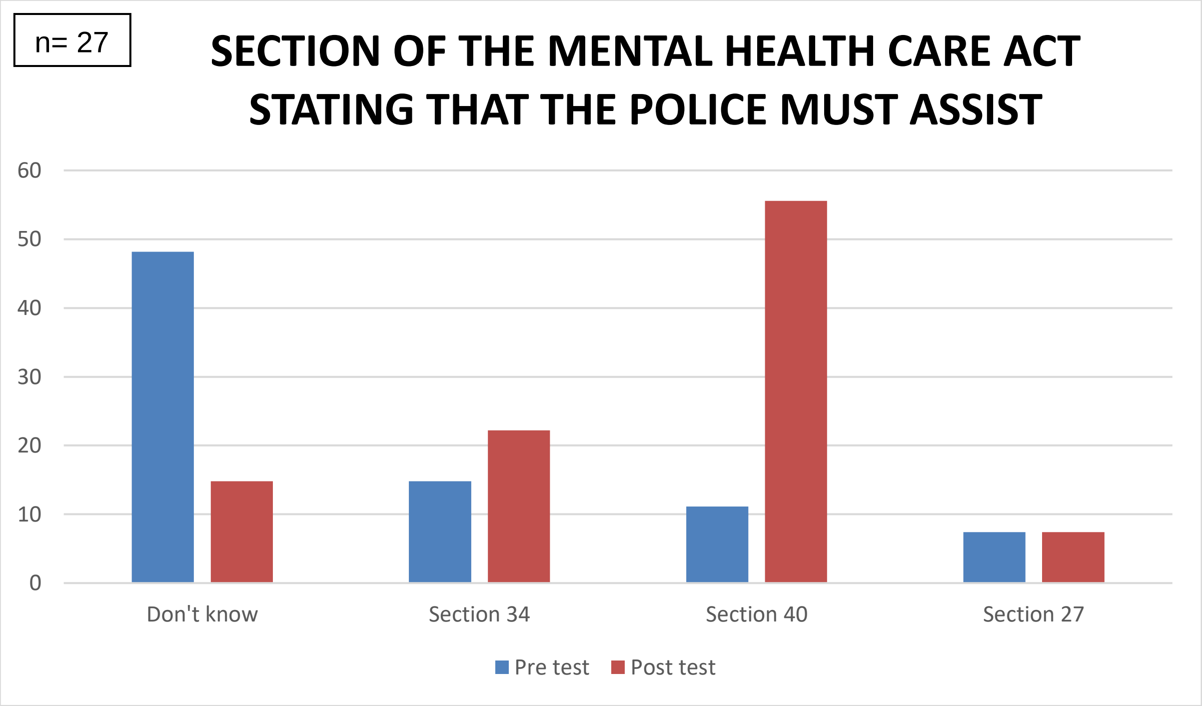


Figure 8.12: **Section of the Mental Health Care Act stating that the police must assist**

Pre the programme 11.11 % (3) respondents knew that article 40 instructs the police to help, whereas post the programme 55.56 % (15) respondents were aware of this fact (refer to **Figure 8.12**).

8.3.2.10 Application for involuntary admission to a psychiatric hospital

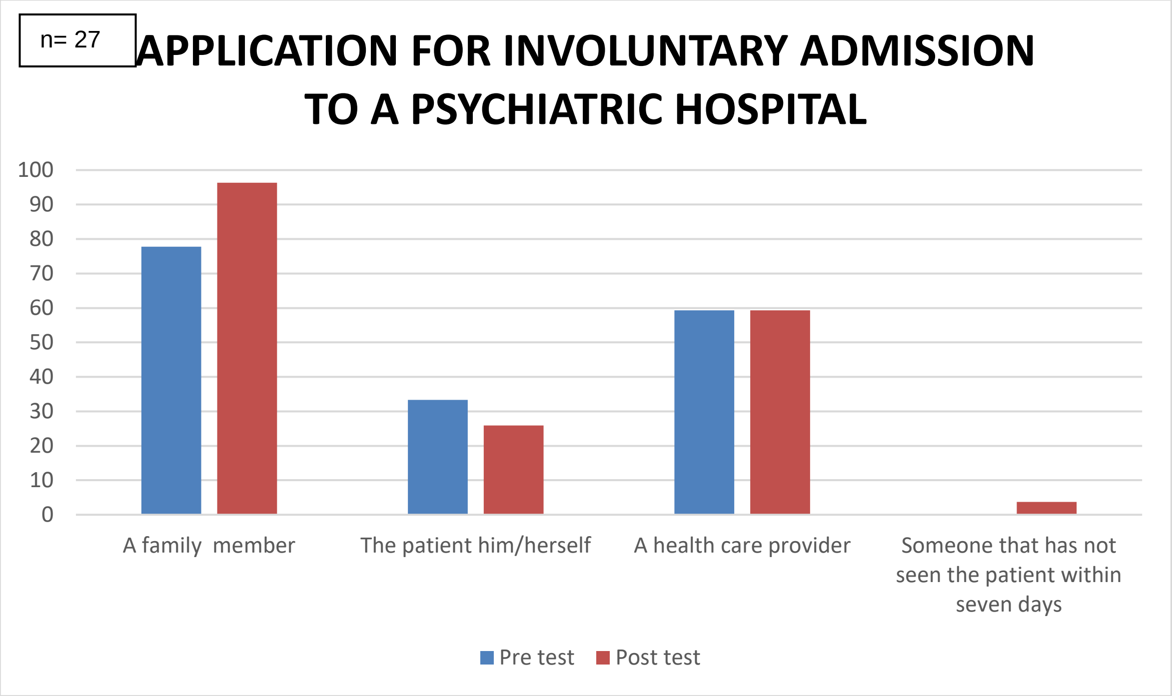


Figure 8.13: Application for involuntary admission to a psychiatric hospital

In the pre-test 77.78 % (21) of respondents said that a **family member** can have a patient admitted while 59.26 % (16) said a **health care provider** can have a patient admitted. The corresponding figures in the post-test were 96.3 % (26) and, again, 59.26 %. The researcher found it interesting that respondents said that a **patient** can have him/herself involuntarily admitted (33.33 %, 9, pre-test and 25.93 %, 7, post-test) (refer to **Figure 8.13**). One respondent (post-test) reported that someone who has not seen the patient within seven days of applying for admission can have a patient involuntarily admitted (the Mental Health Care Act states that only those persons who had seen the mental health care user (patient) within seven days prior to making the application may make the application). Respondents also indicated that the “guardian” of a patient can have him/her admitted, or a member of the police can do so. In their hand-outs respondents were provided with the MHCA (Mental Health Care Act) form 04 which is completed to apply for assisted or involuntary care, treatment and rehabilitation.

8.3.2.11 Caregiver (Questions 11.1-11.5)

- **Roles of caregiver**

In Chapter 4 the **role o**f the caregiver was discussed. It is possible that, when a person married, neither member of the couple had any illness and this relationship was entered as a partnership, but as the one partner has become ill, the other one has ended up in the **caretaker-type** role (Last, 2009:267). The role of the family includes **support, understanding** and **encouragement** of the person who is ill (Mondimore, 2006:248, 252). If a person’s spouse is manic, that person may become a **buffer** between the patient and the community who might demand that the patient be controlled (CAMH, 2000:33).

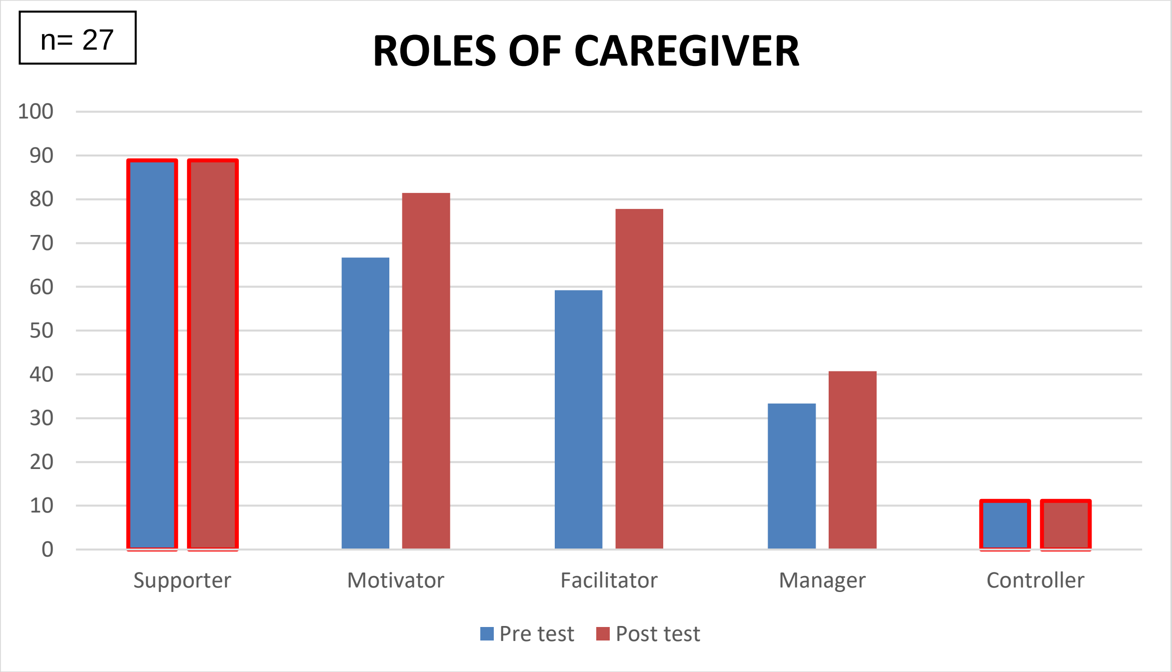


Figure 8.14: Roles of caregiver

Respondents were asked to reflect on their **roles** as a caregiver (refer to **Figure 8.14**). The orders in which they ranked the roles were the same in the pre- and post-test, as follows: **supporter** (pre- and post-test 88.89 %, 24), **motivator** (pre- 66.67 %, 18 and post-test 81.48 %, 22), **facilitator** (pre- 59.26 %, 16 and post-test 77.78 %, 21), **manager** (pre- 33.33 %, 9 and post-test 40.74 %, 11) and **controller** (pre- 11.11 % and post-test 11.11%, 3). It was therefore clear that caregivers thought that their role is mainly to support the patients and that they realised that they cannot control the patients.

- **Rights of caregiver**

In Chapter 4 the researcher referred to certain rights of caregivers that are important, e.g. the right to be treated with respect by the patient, MDT and the community; the right to information about the illness and skills regarding how to approach it; the right to feel safe and not tolerate any threats from the patient; the right to ask for help and the right to be recognised and acknowledged. This rights were also discussed during the SEE-SAW programme.

There were 85.19 % (23) of respondents who indicated in the pre-test that they have rights versus 100 % (27) afterwards. It was important that the researcher could empower the caregivers and that they could acknowledge their own worth.

- **Challenges of caregivers**

The caregiver is exposed to **challenges** on an ongoing or intermittent basis throughout the caregiver's and patient's lifetime together. It was mentioned in Chapter 4 that even when they are not experiencing mood episodes, bipolar individuals can be very "**high maintenance**"; they repeatedly impose both large and small **demands** on their spouses (Last, 2009:141). Last (2009:2, 260) refers to both the patient and spouse/partner when she mentions that: "Whether it's meeting expectations at work, keeping up with friends and family, pursuing hobbies and interest, and, at times, even just taking care of the basics of sleeping, eating, and grooming, BD makes day-to-day life a challenge".

In the SEE-SAW programme the researcher attempted to address some of the challenges that caregivers face and it seemed that after the programme they were better equipped to handle the demands, although the researcher would have preferred better results. A number of respondents indicated their answers as being "Neutral" whereas the researcher would have liked a "Yes" to prove to her that they had really benefitted by attending the programme. The challenges that they face do, however, require skills and the one day programme could not really provide an opportunity for caregivers to practice these.

In terms of the **understanding** of BD 44.44 % (12) said in the pre-test that they disagree that they do not understand the illness versus 70.37 % (19) respondents afterwards. Before the programme 44.44 % (12) of respondents agreed that they do not know **how to act** when the patient relapses versus 25.93 % (7) afterwards. In terms of dealing with **stigma** 33.33 % (9) respondents said in the pre-test that they could not deal with it versus 14.81 % (4) afterwards. In the pre-test 44.44 % (12) of respondents disagreed that they did not know **how to tell** people about the illness whereas in the post-test 59.26 % (16) disagreed with this statement. In the pre-test 55.56 % (15) of respondents agreed that they often feel **hopeless and helpless** while in the post-test 48.15 % (13) still felt this way. There were 37.04 % (10) of respondents that indicated “neutral” on this question. While 85.19 % (23) of respondents said in the pre-test that they often feel **emotionally drained**, 70.37 % (19) indicated this state of mind after the programme (refer to **Figure 8.15** & **Figure 8.16**).

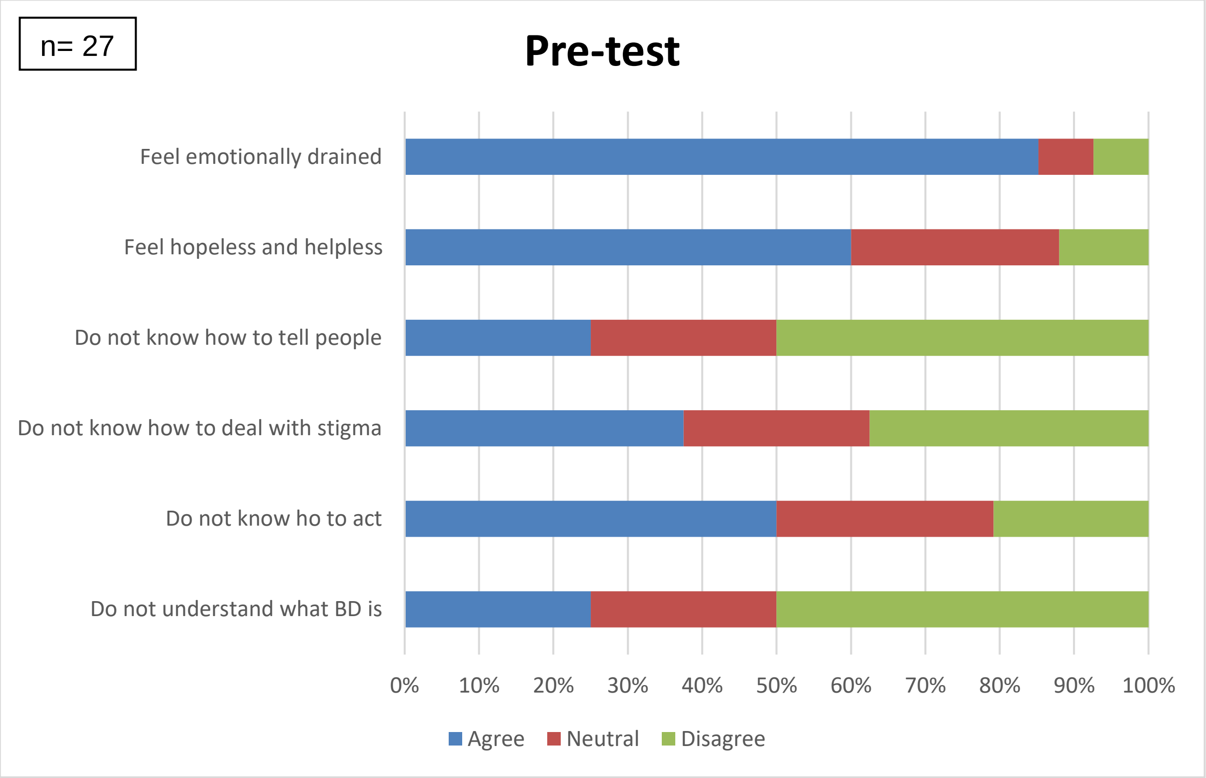


Figure 8.15: **Challenges of caregivers (pre-test)**

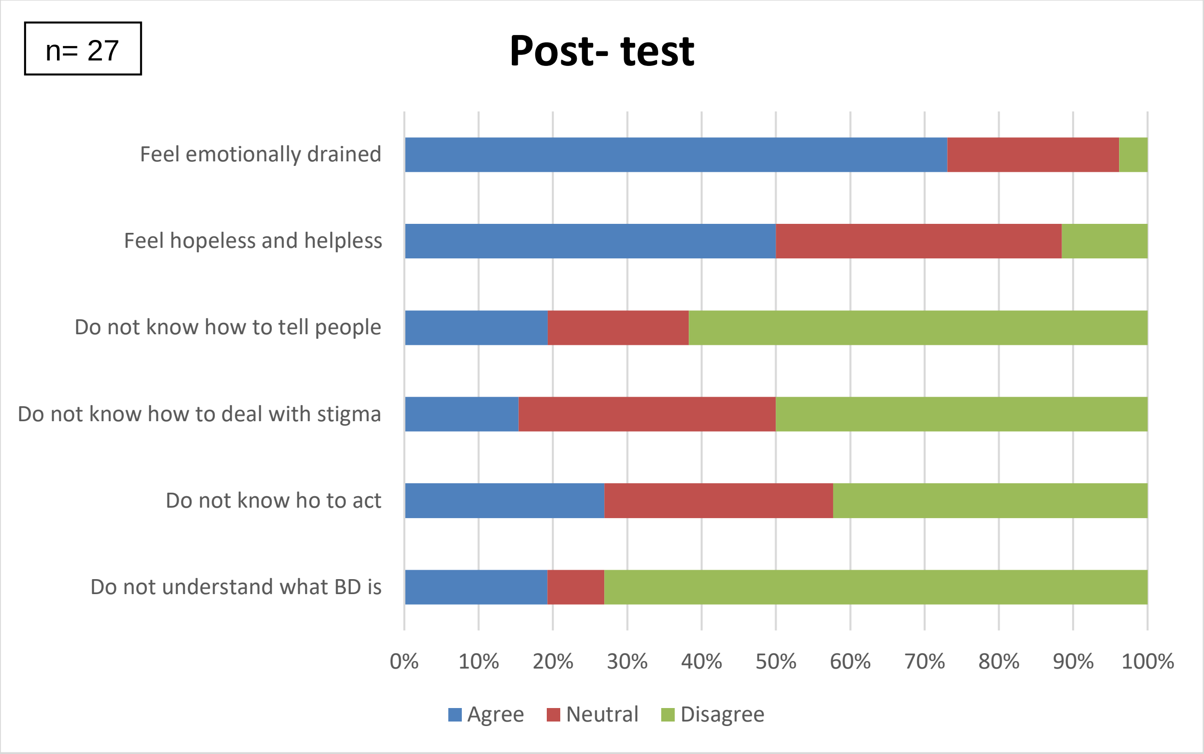


Figure 8.16: **Challenges of caregivers (post-test)**

From analysing these results, it is the researcher's opinion that caregivers would probably not change their emotional stance within just one day. She was aware that some of the respondents were also receiving treatment for depression and anxiety and that, in the light of the stress and burden that they have endured for years it was not realistic that these feelings would disappear after a one day programme. In her view these results are trustworthy, because in her experience a state of mind does take time to "recover".

Respondents indicated that **some of their other challenges** included having to deal with aggressive patients, their own anxiety and depression as well as guilt feelings and the fact that they might have to take care of the patient forever. The one respondent also indicated that she felt angry because of the role reversal and that she was obliged to become her father's carer.

- **Depression or anxiety experienced by caregivers**

Reinforcing the argument of the researcher that respondents' own resilience has also often been depleted, 88.89 % (24) mentioned in the pre- and post-test that they disagree that caregivers would never become **depressed or anxious** themselves. Reinares et al. (2006:161) (refer to Chapter 4) reported that, regarding adverse effects on others, nearly 70 % of caregivers were distressed by the way the illness (BD) had affected their **emotional**

health and their life in general. Caregivers are confronted with a **spectrum** of possible emotions when their loved one is diagnosed with BD. As also stated by CAMH (2000:38) it is important that caregivers should **acknowledge** and **accept** their own feelings and also the fact that it is normal to experience conflicting emotions when a loved one is diagnosed with BD. Caregivers should be afforded the opportunity to work through their thought processes and emotional reactions through guidance dialogues (Tranvag & Kristoffersen, 2008:15).

- **Fears of caregivers**

After the SEE-SAW programme, the respondents still reported very real **fears** (refer to **Table 8.26**).

Table 8.26: Confirmed fears of caregivers

	Pre-test		**Post-test**	
Fears	**Frequency (*f*)**	**Percentage (%)**	**Frequency (*f*)**	**Percentage (%)**
Yes, patient may become psychotic and I cannot handle it	16	59.26	19	70.37
Yes, patient may become aggressive and I cannot handle it	18	66.67	19	70.37
Yes, patient may become suicidal and I cannot handle it	21	77.78	20	74.07

In the post-test more than 70 % (19) of respondents **still felt** that they would not know how to handle the patient if he/she is psychotic, becomes aggressive or suicidal; possibly because they were sensitised to think about these situations. Much of the information was in the hand-outs, but the respondents would probably only read and integrate it after the workshop and would then realise what options they have. Taking cognisance of these fears of the respondents, it becomes logical to **recommend** further training for caregivers in this regard. It is a specialised field, so that even many mental health care workers with years of experience often do not know how to handle, for instance, an aggressive, psychotic patient. In spite of their training and experience it happens that mental health care workers are abused (verbally and psychically). The advantage, however, for staff in a clinical situation is that they can access chemical restraint. If caregivers could receive specialised training, it would empower them and they may feel less helpless. One of the respondents also voiced the fear of not being able to reason with the patient. These fears can only be addressed **over a longer period**, including discussions, workshops and skills training.

8.3.2.12 Rights of patients (questions 12.1-12.2)

During the course of the programme the researcher did refer to the rights of the patients regarding the **Patients' Rights Charter** and the **Mental Health Care Act. Table 8.27** indicates that respondents did realise after the SEE-SAW programme that patients have rights.

Table 8.27: Rights of patients

	Pre-test		**Post-test**	
Rights of patients	**Frequency (ƒ)**	**Percentage (%)**	**Frequency (ƒ)**	**Percentage (%)**
Yes, I am aware of the Patients' Rights Charter	7	25.93	25	92.59
Yes, I am aware of the fact that the Mental Health Care Act. Refers to patient rights	16	59.26	26	96.3

The concept of quality of life (QoL) was introduced in Chapter 4. The researcher feels that there is a connection between rights of patients and QoL. It has been mentioned that when asked to prioritise the areas they thought most important in determining QoL, the majority of participants in a study (Michalak et al., 2006:25) ranked **social support** as most important. Most of the affected individuals reported that BD exercised a profoundly negative effect upon their quality of life, particularly in the areas of education, vocation, financial functioning as well as social and intimate relationships. Having more rights may improve QoL and vice versa.

8.3.2.13 Resources (Questions 13.1-13.2)

Another area where there was no improvement was that of the respondents' skills to approach the MDT. The relationship between the caregiver and the patient's doctor is very individualistic and in retrospect it is the researcher's opinion that it was not within the scope of this programme to **change** it. The private sector is also quite different from the public sector. Respondents were however encouraged to reach out to the patient's MDT. Suggestions were also made on how to approach confidential matters.

Van der Voort et al. (2007:684) (refer to Chapter 4) state that there is little research on the need for professional support for caregivers of patients with BD. The researcher can nevertheless mention that it has been her experience that caregivers desperately need the support from and an "open door" to the professionals treating the patient.

8.3.2.14 SEE-SAW survival suitcase (Question 14)

In the programme the researcher referred to the fact that respondents should be given certain tools that can be used when confronted with BD. **Before** the SEE-SAW programme the concept had not yet been explained, but some respondents guessed what it was and mentioned some items for the survival suitcase. Items that were mentioned in the pre-test included knowledge and books, knowledge of the patient, the correct medication, communication, professional help, motivation, support and care, determination, patience and endurance, the caregiver team, support groups, skills and remaining positive. The fact that respondents could mention these items showed the researcher their resourcefulness and that they had applied many of these problem solving plans in the past (refer to **Table 8.28**).

Table 8.28: **Items respondents mentioned after the SEE-SAW programme (post-test)**

Item	Frequency (*f*)	Percentage (%)
Knowledge and books	10	37.04
Respect, love and understanding	7	25.92
Compile a file for the patient with his/her history and important documents	7	25.92
Correct diagnosis	6	22.22

Item	**Frequency (ƒ)**	**Percentage (%)**
Importance of a resource list	6	22.22
Use of mood chart and lifestyle chart	6	22.22
Sense of humour	5	18.50
Correct medication	3	11.11
Support group	3	11.11
Relaxation time	2	7.41

It is the researcher's view that the fact that respondents could identify "tools" which could help them to survive in the difficult battle which they fight against BD encouraged and empowered them.

She will now discuss the evaluation of the SEE-SAW programme by the respondents. This was very important, because the feedback that was received could help the researcher to improve the programme in future.

8.4 EVALUATION OF THE SEE-SAW PROGRAMME (Questions 15.1-15.8)

8.4.1 Short-term evaluation (post-test)

Respondents were requested directly after the SEE-SAW programme to provide a short-term evaluation. The researcher realised that some of the data collected from the questionnaires was more **qualitative** than **quantitative**, because it is difficult to measure aspects such as insight and attitude with a yes, no or maybe answer. This aspect was especially true for the evaluation of the SEE-SAW programme where the respondents wrote spontaneous comments. Some respondents left certain questions open, which made it difficult to know if in reality they intended to say no, or that they did not have an opinion regarding the particular question.

8.4.1.1 Improvement of knowledge

Figure 8.17 offers an indication of the respondents' improvement of knowledge.

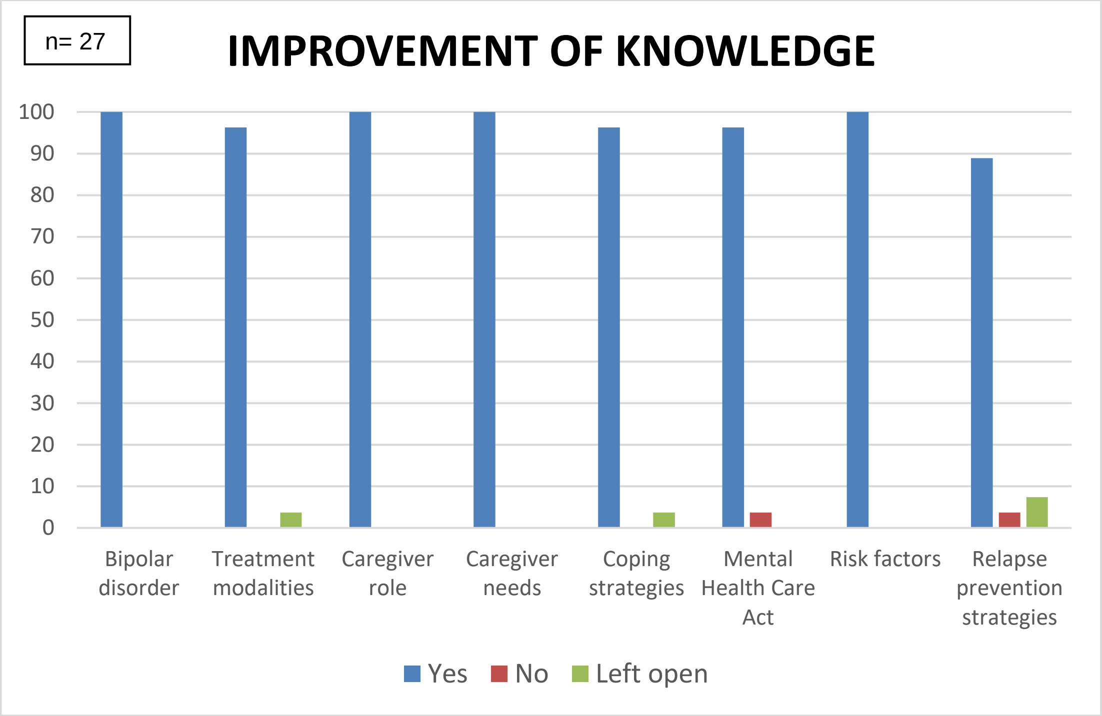


Figure 8.17: **Improvement of knowledge**

All 27 respondents indicated that by attending the SEE-SAW programme their **knowledge** of BD, their role as caregiver, the needs of caregivers, and their knowledge of risk factors for a BD relapse did improve. The questions on treatment modalities and on coping strategies received a positive answer from 96.3 % (26) of respondents – 2 left these open. The majority (96.3 %, 26) of respondents said their knowledge on the Mental Health Care Act had improved while 88.89 % (24) said they had learnt more about strategies to prevent a bipolar relapse.

The question was asked **what else** was learnt and the following was mentioned: “I have learnt about myself and my own capabilities to cope with this illness”, “I have learnt to be positive”, “I have learnt that BD is a biological illness that can be managed”.

8.4.1.2 Aspects that could have been included in the programme or excluded from the programme

Table 8.29: **Aspects that could have been included in the programme or excluded from the programme**

Aspects that could have been included in the programme as well as recommendations	Aspects that could have been excluded from the programme as well as recommendations
Communication skills	The list of medication was maybe too detailed (one respondent)

Aspects that could have been included in the programme as well as recommendations	Aspects that could have been excluded from the programme as well as recommendations
Telephone numbers of support groups	The DVD was not very relevant (one respondent)
Discussing financial aspects of caring for the BD patient	Everything was relevant
Programme could have been longer	
More time to share experiences	

The researcher posed the question what else could have been **included** in the SEE-SAW programme. The question was left open by 33.33% (9) of respondents whereas 37.04 % (10) respondents said nothing more could have been included (refer to **Table 8.29**). It is clear that the majority of respondents (70.37 %, 19) did not see the need to include anything more in the programme, because it did cover the most important aspects. During the second pilot the researcher did make sure that respondents were aware of the resources that are available. It had already been mentioned that when the SEE-SAW programme is presented again in future, more time will be allocated to communication skills and the sharing of experiences. The question of what could have been **excluded** from the programme was left open by 25.93 % (7) of respondents while 62.96 % (17) said they did not know or replied that nothing could have been. It is thus clear that 88.89 % (24) were satisfied with the content of the programme that was presented.

8.4.1.3 Content of the SEE-SAW programme

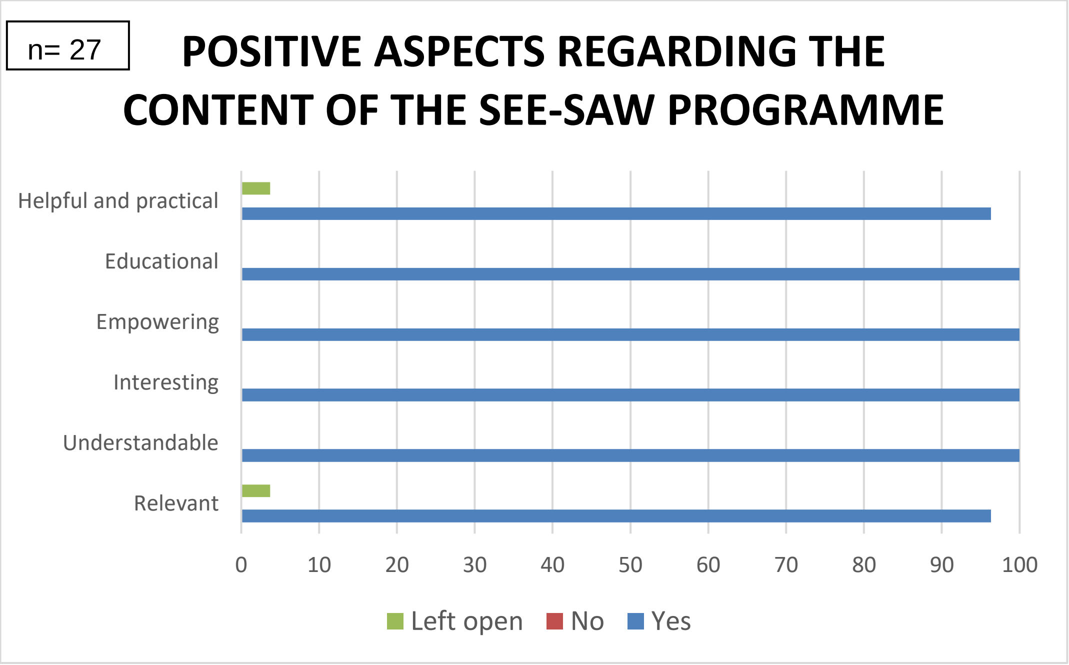


Figure 8.18: Positive aspects regarding the content of the SEE-SAW programme

It is clear from **Figure 8.18** that 100 % (27) of respondents experienced the programme as being understandable, interesting, empowering, and educational. Regarding its being relevant and helpful and practical 96.3 % (26) reported a positive answer (in both instances there was one respondent who did not answer the question). These results indicated to the researcher the value of the programme and that the respondents did find it worthwhile.

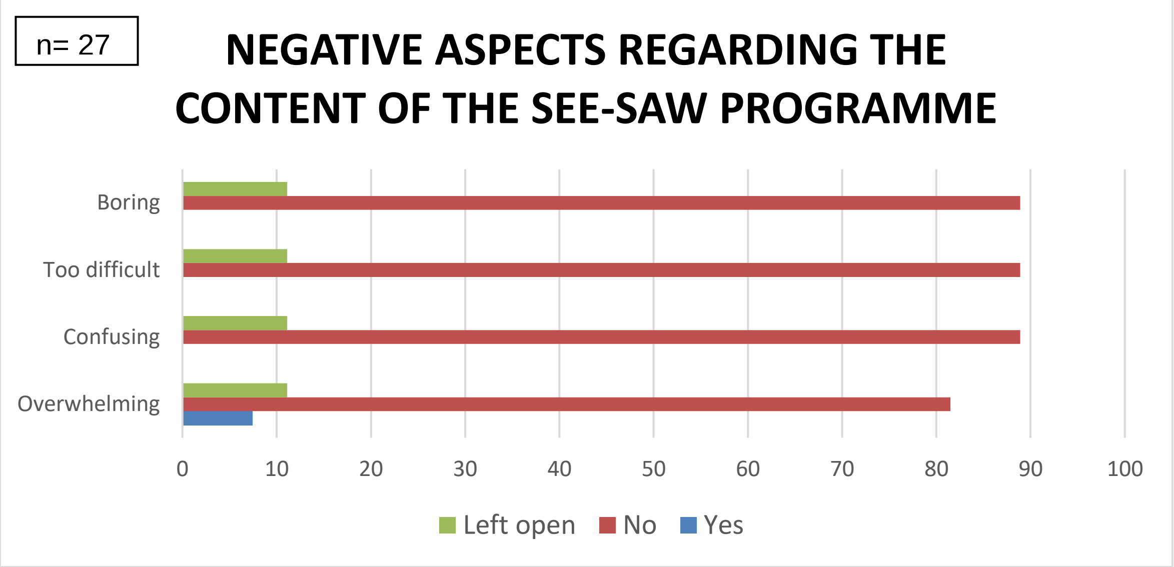


Figure 8.19: Negative aspects regarding the content of the SEE-SAW programme

Figure 8.19 indicates that the majority of respondents did not find the SEE-SAW programme overwhelming - 81.48 % (22); confusing – 88.89 % (24); too difficult – 88.89 % (24); or boring – 88.89 % (24). All of these four questions were left open by 11.11 % (3) respondents. There were 2 respondents (7.41 %) who indicated that the programme was **overwhelming**. This could be explained in the light of the fact that BD is a complicated illness to understand. In the researcher’s view this aspect also corresponded with the time aspect of the programme, as will be discussed in the next section.

8.4.1.4 Time aspect of the SEE-SAW programme

It was indicated by 29.63 % (8) of respondents that the programme was too **short** but by 7.41 % (2) respondents that it was too **long**. It was also indicated by 22.22 % (6) of respondents that the pace was **too fast** and that it was **too rushed**. The researcher was aware of the fact that she was very time conscious, because she had told the respondents the programme would finish at a certain time and she wanted to honour that agreement. She respected the fact that the programme was on a Saturday (also a long weekend in the first case) where people usually just want to relax and have the freedom to “do their own thing”. The respondents also took quite long to fill in the questionnaires. One respondent made the **comment** that the programme was a good investment in her life, while another said the programme should be presented over two Saturdays.

8.4.1.5 Most valued aspects of the SEE-SAW programme

Respondents were asked, in an open question, to mention the aspect(s) of the programme that they **valued** the most; the responses included the following:

- High standard of hand outs, study material provided - 22.21 % (6).
- Showed that we have much to learn -3.7 % (1).
- Presenter's in-depth knowledge of BD and the process of diagnosing and treatment - 3.7 % (1).
- Knowledge about the trigger factors, the possible causes of BD and how to prevent a relapse and coping skills - 18.5 % (5).
- Very good content of programme - 3.7 % (1).
- Realized that there are others in my situation, to know you are not alone, insight and comments of others, to be together -18.51 % (5).
- How to deal with situations, how to handle the BD patient - 7.4 % (2).
- That I have rights as a caregiver - 3.7 % (1).
- The programme was very personal and comfortable in all aspects - 3.7 % (1).
- Understanding - 3.7 % (1).
- Care and support from team for caregivers - 3.7 % (1).
- Building a file for the patient - 7.41 % (2).
- Knowledge about medication - 3.7 % (1).

8.4.1.6 Feedback regarding different aspects of the SEE-SAW programme

Table 8.30: Feedback regarding different aspects of the SEE-SAW programme

Item	**Good**		**Excellent**	
	Frequency (*f*)	**Percentage (%)**	**Frequency (*f*)**	**Percentage (%)**
Arrangements	6	22.22	21	77.78
Venue	6	22.22	21	77.78
Refreshments	2	7.41	25	92.59
Hand-outs	2	7.41	25	92.59
Audio-visual aids	7	25.93	20	74.07
Presenter	3	11.11	24	88.89
Information booklet			27	100

Item	Good		Excellent	
	Frequency (ƒ)	Percentage (%)	Frequency (ƒ)	Percentage (%)
Information	2	7.41	25	92.59

Respondents were asked to evaluate a variety of aspects concerning arrangements, venue etc. (refer to **Table 8.30**). It is the researcher's view that respondents were, overall, very positive about attending the SEE-SAW programme and also about the material that they received to take home to read and use for future reference.

8.4.1.7 Feedback regarding recommendations of the SEE-SAW programme

Some respondents used the opportunity to write general comments although they were asked for **recommendations**. Their responses follow:

- Everything was 5 star.
- Divide the programme in 2 days.
- Regular workshops for caregivers or for the caregivers and patients should be conducted.
- Do it again.
- It was a unique course.
- The programme is applicable to South Africa.
- Excellent resources were given.
- Caregivers are too often left to the mercy of doctors and hospitals, caregivers need to be empowered.
- A more in depth follow-up will be welcomed, impressed by the work that was done.
- The team of the day was great.
- Very informative, excellently organized.
- More time for interaction would have been good.

8.4.2 Medium-term evaluation (spontaneous feedback)

Qualitative research focuses on describing and understanding phenomena within their naturally occurring context, with the intention of developing an understanding of the meaning(s) imparted by the respondents – "seeing through the eyes of the respondents" – so that the phenomena can be described in terms of the meaning that they have for the respondents (Nieuwenhuis, 2007c:51). The researcher wishes to refer back to **Figure 5.1** (Chapter 5) where it was clear that a qualitative phase follows after the intervention where outcomes are explained.

After the programme the researcher received emails and sms's from respondents (giving her more of an understanding of their worlds) thanking her again for the SEE-SAW programme. This reflects the impact of the programme in the longer term, because even two months after the programme had been presented some of the respondents were still making comments in a spontaneous manner.

The researcher will report on this feedback (in the words of the respondents):

- Thank you so much for the information you shared to us. I am now fine emotionally and with the knowledge I have, I will be a better caregiver to my son and to anyone who needs support.
- Thank you very much for the informative workshop. It was organised very well. Please forward me the list of email addresses of the people who attended the workshop.
- "Ek wil net graag weer BAIE DANKIE sê vir Saterdag. Dit was 'n voorreg om daar te wees en bietjie van jou kennis te deel. Alles was so stylvol en professioneel, terwyl dit tog heerlik ontspanne en spontaan was. Ek het net Saterdag besef hoe swaar die 'caregivers' kry. K (one respondent) het vanoggend vir ons 'n lys met al Saterdag se mense se kontakbesonderhede gestuur. Ek hoop ons kan kontak hou en mekaar probeer bemoedig. Of dalk net luister…" (I want to thank you for Saturday. It was a privilege to be there and to share some of your knowledge. Everything was stylish and professional, but also relaxing and spontaneous**.** I realised on Saturday how difficult it is for the caregivers. K sent us a list with the contact details of all the people who attended on Saturday. I hope we can remain in contact and try to encourage each other).
- "Net om dankie te sê vir 'n puik geleentheid Saterdag. Uitstekende materiaal vir ons wat moet omsien na die bipolêre lyers. Mooi aangebied - die meditasie - pouse aan die begin werk nogal goed." (Just to say thank you for the excellent opportunity on Saturday. Excellent material for us who must take care of the BD sufferers. The presentation was good and the meditation in the beginning worked well).
- "Baie dankie vir 'n leersame, insiggewende, opbouende en interessante dag. Mensig maar ek het baie geleer. Baie dankie daarvoor. Ek waardeer dit baie. Hou my asseblief in gedagte vir enige programme, praatjies, studies, projekte of inligtingsessies in die toekoms." (Thank you for an informative, insightful, inspiring and interesting day. I have learnt a lot. Thank you very much. I appreciate it. Please keep me in mind for any programmes, presentations, studies, projects or information sessions in the future).
- "Ons moet vir jou baie dankie sê. Dit was 'n voorreg om deel te wees van hierdie projek en ek hoop regtig dit sal van krag tot krag gaan!" (We must thank you very much. It was

a privilege to be part of this project and I hope that it will still go from strength to strength in the future).

- "Dankie vir 'n mens wat soveel omgee, wat geen geld of moeite ontsien het om dit vir my moontlik te maak om in haar kennis en omgee te deel nie. Dankie dat ek kon beleef ander kry ook swaar" (Thank you for a person who cares and who went the extra mile to share her knowledge and caring. Thank you that I could experience that others also have difficulties).
- "Ek wil jou net bedank vir jul reëlings met die program van verlede Saterdag. Dit was 'n puik aanbieding, ons is trots op jou en wens jou alle sukses toe met jou studies. Dis ons voorreg om so 'n meelewende mens met soveel empatie te ken". (I would like to thank you for the arrangements regarding the programme of last Saturday. It was an excellent presentation, we are proud of you and wish you all the success with your studies. It is a privilege to know a person with so much empathy).
- "Dankie vir die geleentheid om deel te kon wees van die groep" (Thank you for the opportunity to have been part of the group).
- Just want to thank you for the programme and the materials and booklet provided - it was excellent. I went through it with my son during the holidays. It was so meaningful and we learnt a lot by reading through it together. If I did the post-test now, I would have scored better, because I have had time to read through the materials - comment received two months after the programme.

It is therefore evident that the programme added **quality of life** to the lives of the respondents and confirmed the hypothesis of this study (refer to Chapter one). More than simply imparting knowledge and skills, this programme validated the caregivers, gave them recognition for their suffering and gave them the opportunity to be together with others in the same situation. Hence respondents found the relationship they built up with the researcher and other respondents very meaningful and regarded it as an extended support system.

8.5 CRITICAL DISCUSSION OF AND REFLECTION ON THE SEE-SAW PROGRAMME

It was mentioned that the researcher utilised intervention research and as such, the SEE-SAW programme was the **intervention** that was developed. When reflecting on the programme that was presented, the researcher would like to make a few comments and share what she has learnt from this experience (even on a practical level). It should be recalled that **observation**, as a qualitative data gathering technique, is used to enable the researcher to gain a deeper insight and understanding of the phenomenon (in this case the caregivers and the programme that was presented) being observed. The researcher saw herself as a participant observer - working with participants to design and develop intervention strategies (Nieuwenhuis, 2007a:83, 85). This programme is therefore still evolving and will be improved with every presentation in the future.

8.5.1 Preparations before presenting the SEE-SAW programme

It was most important that every detail **had to be planned** to make the programme a success. The planning phase of the programme took months (even years) to complete – especially the information booklet that was prepared and given to respondents on the day of the presentation. A few important aspects of the preparations:

- A very detailed information booklet and other hand-outs were prepared for the respondents. A file consisting of the hand-outs and stationery was also prepared for them. A certificate of attendance was designed that each respondent received afterwards.
- Banners were made, in advance of the presentation of the programme, to display the content of the SEE-SAW programme in a nutshell. A wooden see-saw (painted blue on the one side and red on the other side) of about 1 meter long was also constructed to illustrate the importance of certain **risk** and **protective** factors in dealing with BD. The researcher prepared little bags - red for risk factors and blue for protective factors - that were hung on the see-saw during the presentation. The purpose was that respondents could see that if there are too many risk factors, there is no equilibrium and the patient might relapse. Afterwards each respondent also received a small see-saw to remind them always to strive towards a balance in their lives and in that of the patient.
- The researcher also prepared an example of a file that caregivers could create for the patient, which she showed to the respondents during the presentations. A patient should also be motivated to make his/her own file. Such a file should contain certain important documents e.g. clinical reports about the patient, dates of admissions to psychiatric units, medication prescribed, mood charts, as well as a relapse prevention plan.
- The researcher had to make sure that each respondent would receive an informed consent form and two questionnaires (pre-and post-test).
- The venue used at the university had to be booked at the department after permission was given by the HOD.
- The day before each programme presentation the researcher went to the venue to make sure that everything was in order.
- The researcher was in contact with the respondents to confirm their attendance and to obtain other details from them to arrange secure parking. University security needed to

be informed that the researcher was expecting people to attend her programme. A map was provided to the respondents to direct them to the venue.

- Refreshments were arranged.
- The researcher had to make sure that other visual aids used were in working order.
- The researcher arranged with an occupational therapy colleague to assist her during the presentation.
- The research supervisor was present to observe the programme on the first presentation and in order to evaluate it.

8.5.2 Observations of the researcher during the presentation of the SEE-SAW programme

- The two groups were both very attentive during the two programme presentations, but the group of the first Saturday was more responsive than the group of the next Saturday. The first programme was conducted in Afrikaans and the second in English - the material was, however, in English.
- The researcher met most of the respondents for the first time on the day of the programme and she needed to build rapport and a confidential group atmosphere within a short space of time.
- The researcher was more at ease during the second presentation, which might have contributed to the group being more relaxed.
- The programme was varied, an audio tape was used and a DVD was shown. Breaks were built into the programme. The respondents enjoyed the refreshments.
- Both groups had the need for more discussion and more time for questions.
- More time should have been allocated to do practical exercises during the programme in order to improve aspects such as communication and problem solving.
- During both the sessions the respondents spontaneously exchanged telephone numbers and email addresses, which demonstrated to the researcher that there was a need for mutual support amongst the caregivers. They did also verbalise that they did not feel so lonely any longer.
- Respondents were very understanding of each other.
- Respondents thought that this might be a programme offering all the quick and easy answers, but in reality it takes courage and perseverance from everybody involved to live with a chronic illness like BD; there is no miracle cure.

8.5.3 Researcher’s critical evaluation of the SEE-SAW programme

Despite the programme being presented in the middle of winter, with an early morning start, the response rate was still good. This indicated to the researcher that the respondents were motivated to attend the programme, because they did expect to learn something and to have a worthwhile experience. It helped that the venue was supplied with central heating - this contributed to its being very suitable. It was also equipped with a projector, tables and chairs and was private and quiet. It was big enough and refreshments could be served inside the venue.

- The preparation for the programme was thorough (practical aspects like the venue, audio visual material, aids to use during the presentation of the programme).
- The number of respondents per session was appropriate.
- The researcher was pressurised for time (having to include the informed consent and questionnaire during the day of the programme). This affected the time available and might have affected the respondents.
- The material that was prepared for the respondents was useful, but it might have been too much for one day. They had to take the responsibility to go and read it after the programme.
- The workbook was in easy to understand language and a graphic designer helped the researcher to make it user friendly.
- The researcher endeavoured to build in variety and to keep it interesting.
- Respondents needed more time for interaction during the presentation.
- It is the researcher's perception that the programme did not provide the full emotional support that she intended it to do.
- The programme is flexible and could therefore be presented to different cultural groups and also to other professionals. It will always be important that the presenter must adapt to the group for whom the programme is presented.
- The programme (or parts thereof) could be presented over different time periods, e.g. two days or a few days per month. This is however the ideal, and in practice difficulties may be experienced. Costs must be kept in mind – it will be more feasible if respondents are prepared to pay for the programme. Respondents will also have to commit themselves to attend for a longer period – something that can be very difficult when research is being done, because participation is voluntary. They may find it difficult to attend: travel costs and their availability of time are aspects to keep in mind. The researcher presented her programme on a Saturday, because most of the respondents are working.
- The programme contains charts, plans and tools that the patient and caregiver can use.

- More time to practice skills was needed, as it is complicated to know how to approach a psychotic, aggressive or a suicidal person. Time could have been allocated to communication skills and problem solving skills.
- The time allocated to the DVD could have been used for discussion or a shorter DVD could have been shown.
- The relaxation exercise worked well.
- The programme provided a framework, but it should always be presented according to the needs of the particular group.
- The content of the programme could also be used with individual BD patients or their families.
- It helped to have a colleague (also in the mental health field) present; during future presentations of the programme other MDT colleagues could be more actively involved.

8.5.4 Programme evaluation by occupational therapist who helped to facilitate the SEE-SAW programme

- Time management was well planned.
- The booklets that were given to respondents were of a very high standard and contained very detailed information.
- The researcher managed very well to convey the most important information to the group.
- Psychoeducation was successfully presented – not just on an academic level, but with respect and empathy.
- Both groups, although not to the same extent, showed a big need for emotional ventilation and support. Although it was not part of the planning, the researcher did give attention to this need, without neglecting the psychoeducation.
- In retrospect, perhaps the informed consent should have been finished before the programme material was given (respondents received a file at registration).
- All the aids (see-saw, books, power point, DVD, CD, example of a file) were excellently utilised.
- I think that the MDT approach is very important in the treatment of BD and can thus add value to a psychoeducational programme. The SEE-SAW programme is very holistic and covers all aspects of a person’s life and it can therefore involve different team members.
- I do not think the emotional support can be separated from the knowledge element and think that it is very important that it should remain a part of the programme.

- It was a privilege to be part of this programme. The researcher was very professional and very well prepared. A lot of effort went into preparation of the refreshments and other preparation for the particular days.
- Congratulations with an excellent programme.

8.5.5 Recommendations (refer to Chapter 9 as well)

The researcher refers the reader to Chapter 7 (Zipple & Spaniol, 1987:271-274) where suggestions for enhancing educational and supportive approaches were made. These included: to clarify mutual goals, to point out family strengths, to learn to respond to intense feelings, to encourage family enrichment, to provide information about psychiatric illness and medications, to provide practical advice, to provide information about community resources and to encourage involvement in local family support and advocacy groups.

Other recommendations include:

- Always be very well prepared when presenting this programme and take detail into consideration, e.g. the venue, refreshments and hand-outs.
- Attempt to make the group homogeneous in terms of language and age. A group should not have more than 15 members.
- Present the programme with the help of a colleague. Other presenters could also be invited, e.g. a psychiatrist to talk on medication.
- Do not try to cover too much material on one day. It has already been mentioned that the programme should rather be presented over a few weeks or months, although this approach may also create its own challenges.
- Provide time for interaction and allow participants to help each other, because that will empower them.
- The presenter should be knowledgeable about all applicable resources.
- The programme (or parts thereof) could be presented at the Outpatient clinic to either patients, caregivers or both.
- The programme should be accessible to lay people.
- The programme should be accessible to all cultures.
- Caregivers might also be involved in the presentation, especially if the programme is presented to students or colleagues.
- Some of the aspects of this programme (like the needs of the caregivers, relapse prevention strategies and aspects relating to the Mental Health Care Act) are also applicable to other psychiatric disorders.

- Mental illness is universal and therefore it can be recommended that this programme could also be presented internationally.
- Payment by participants is an issue worth considering.
- The approach being followed should be **informative, skills-training** and **supportive** orientated: being **comprehensive**.

8.6 SUMMARY

In this chapter data collection and data analysis were briefly reviewed; thereafter a profile of the respondents was provided. The empirical research findings stemming from the second phase of the study were presented - mainly a descriptive univariate analysis, with percentages and frequencies comparing pre and post-test results. Some bivariate analyses and statistical tests were also conducted. It was indicated that the results of the 54 questionnaires should be regarded in both a quantitative and also a qualitative light. The verbatim feedback of respondents provided a clear picture of their experiences and challenges.

The researcher also critically evaluated the SEE-SAW programme that she had designed and implemented and made some recommendations in this regard.

During the interpretation and analysis process the ecological systems perspective and the bio-psychosocial model was kept in mind as it was the theoretical framework of the study. It was clear that the respondents are sub-systems within bigger systems (e.g. family, community, mental health care providers, health system, environment and resources), but that every respondent and the way he/she fits in the bigger system (whole) is still unique and must be seen as such.

In Chapter nine, the overall summary, conclusions and recommendations based on the research are presented.

9. CHAPTER 9: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

9.1 INTRODUCTION

> **Participant 3**: So yes, I feel the **programme** that you want to do is going to be a wonderful thing for us who are the **supporters**. I think that it is a wonderful idea. I mean it is not just your husband who has got bipolar or depression per se, you feel it is not the people that work with you, they are in the street, I mean the person behind the till might also be a sufferer at that and it will make you so much more better to handle that person with grace and really handle them so that they know they are also very important.
> **Participant 5**: There is definitely a need for support for family. Even just sometimes to speak to someone and get some advice, maybe the person is hypo manic and not feeling well and you just need to know what can you do to stabilize her during this period. So it is very difficult on the **family**. For family living with someone like bipolar, that is **one of the hardest things**. The fact that you can't rely on this person for emotional support, you … the **basic thing** in life is to have someone **to share** joy with, to share sorrow, to share expressions. I mean that is the point of any relationship. Everything else is second, the clothing and the housing. So when you take that away, that really puts a strain on a relationship".
> **Participant 11:** I am very honest, I said many times I wish he would shoot himself so that it is over and done with, then we shall know that it is finished.

The quotes mentioned above indicate the extent to which BD can affect the lives of caregivers and the need for knowledge. This illness has an impact far beyond anyone's imagination. It is this need that the researcher saw in her work spanning, to date, 24 years of working with psychiatric patients and their families; it was also the driving force for this research that took place over a period of five years.

In this concluding chapter, the researcher considers whether the goals and objectives of the study were achieved. This is followed by conclusions and recommendations, with special reference to the role of the social worker in the MDT in practice.

The researcher did not want to design a psychosocial educational programme for caregivers without making sure what their **real** needs were. This was the rationale for first performing qualitative research to establish the caregivers' needs before embarking on the SEE-SAW programme design. A user-friendly programme was designed that was implemented and evaluated during the research process.

The term that is used in the literature is psychoeducation, but the researcher called her programme psychosocial educational, because it was devised from a social work perspective.

9.2 SUMMARY

9.2.1 Research goals and objectives

As previously discussed, the **first goal** of this research was to carry out an **exploratory descriptive study** on the **needs** of the caregivers of individuals diagnosed with BD (**phase one**) from an ecological systems perspective. It could even be said that the mental health of the individual is interdependent with the ecological health of the larger nationwide system (Smith, 2007:654). Social intervention is aligned to **systems theory**, specifically ecological systems models, which are consistent with biopsychosocial approaches. There is recognition that all health problems are multi-factorial and interrelated. It is the researcher's experience that the integrated **biopsychosocial model**, within an **ecological systems perspective**, is being used at the psychiatric institution where she has been working. This approach/framework therefore also served as the point of departure from which this research was conducted. It was clear that the needs of caregivers of people diagnosed with BD cover a very wide spectrum. During the first phase qualitative data were collected, analysed and interpreted.

A **second goal** was to develop, implement and evaluate a **psychosocial educational programme** based on the needs of the said caregivers (**phase two**). During this phase, quantitative data were collected, analysed and interpreted.

Understanding was expanded by means of a **mixed methods research approach**, which comprised both a qualitative and a quantitative component. The mixing of datasets provided a more complete picture of the research problem.

The researcher achieved these goals by accomplishing the following eight **objectives**:

- **Objective 1**: Describing the BD spectrum and the specific appropriate patient profile

In a literature study, discussed in **Chapter two,** the researcher mainly used the DSM 5 (2013) as a point of reference, but also consulted other relevant sources of information. It was essential that the researcher familiarise herself with the illness in order to include the relevant information in her psychosocial educational programme.

- **Objective 2**: Describing the treatment and intervention options available

A second literature study was performed on the treatment of BD and the intervention options available. This was presented in **Chapter three**. The biological treatment of BD (pharmacological and ECT) is a very important component of the regimen and the researcher therefore had to start this literature study considering these components. This was followed by research on different available psychosocial modalities, through which the researcher critically evaluated which aspects would be relevant for her programme.

- **Objective 3**: Identifying and exploring the needs and psychosocial challenges of caregivers of individuals diagnosed with BD

A literature study identifying and exploring the needs and psychosocial challenges of caregivers of people diagnosed with BD was presented in **Chapter four**. It should be noted that the literature that could be found was mostly international, pointing to the need for more literature that would specifically reflect on the South African population and needs.

Interviews with eleven caregivers were conducted according to an interview schedule and recorded, transcribed and analysed. The caregivers were selected according to predetermined criteria. This was the qualitative part of the research. The categories, themes and sub-themes that were identified are reflected in Chapter six of this research report.

As mentioned in Chapter four, it was the researcher's intention to alleviate the caregivers' burden and to do this in such a way as to improve the patients' prognosis.

- **Objective 4**: Describing and exploring any relevant psychosocial educational programmes for caregivers on a national and international level

A literature study on psychosocial educational programmes for caregivers on a national and international level was undertaken and was presented in **Chapter seven**. The researcher identified prominent experts that are renowned for programmes that they have developed, but it was found that these programmes usually focus on the patients and not the caregivers. Nationally, social work colleagues in other psychiatric hospitals were contacted, but although they recognised the importance of psychoeducation, they were not aware of such specific programmes for caregivers.

- **Objective 5**: Developing a psychosocial educational programme, relevant to South Africa, based on the possible needs and challenges of caregivers of individuals diagnosed with BD

The SEE-SAW programme was developed, as indicated in **Chapter seven**. It was devised over a few years, because the researcher wanted it to be applicable and user friendly. The programme is dynamic and will continue to evolve even more over time.

- **Objective 6**: Implementing a psychosocial educational programme for caregivers.

The SEE-SAW programme was implemented and presented to 27 caregivers on two consecutive Saturdays from 8.00 to 15.00.

- **Objective 7**: Evaluating the programme that was developed and implemented.

The respondents filled in questionnaires before the SEE-SAW programme (pre-test) was presented, as well as afterwards (post-test). They were also specifically asked to evaluate the programme; their responses comprised a valuable source of data. The results are presented in **Chapter eight**.

- **Objective 8**: Formulating recommendations regarding a psychosocial educational programme for caregivers of individuals diagnosed with BD in order to empower caregivers, as well as mental health-care providers

Objective 8 is addressed in **Chapter eight** and in this chapter.

It was anticipated that this study would give an indication of the possible **needs** of the caregivers of patients diagnosed with BD, and that a psychosocial educational **programme** would be specifically developed from the gathered data to address the needs of caregivers. Such a needs assessment and programme could provide general guidelines, in terms of other psychiatric conditions also. It could make a significant **contribution** locally, as well as nationally. The researcher would be able to make **recommendations** for practice, and develop a programme that is able to be universally applied, thereby increasing the value of the study.

It is clear that the researcher did achieve all the goals and objectives that were envisioned when she embarked on this research.

9.3 CONCLUSIONS BASED ON KEY FINDINGS

9.3.1 Conclusions based on literature review (Chapter 1 to Chapter 4, and Chapter 7)

This research conclusions are based on the literature review.

9.3.1.1 Chapter 1: General introduction

- BD may well create havoc in the lives of significant others and inflict emotional pain to the point where caregivers develop health and mood problems themselves. Their difficulties must be acknowledged. The caregiver is part and parcel of the patient's environment.
- In **South Africa** this disorder is also a very real problem. It is a **multicultural** country and all cultural groups are affected by this illness. The primary objective of South Africa's

mental health policy is the development of comprehensive **community-based** mental health services. While first world countries possess more resources (including mental health practitioners and community resources), South Africa has a severe **shortage** of skilled mental healthcare professionals and other resources.

- Caring for a relative with BD poses both **objective** burdens (such as increased expenditure of time and money) and **emotional** burdens (such as worry, tension and grief).
- The need for support for and education about BD amongst the caregivers of people diagnosed with BD is often neglected.
- Families' lack of understanding of the mental illness and how to deal with it, affects the **rehabilitation** outcome negatively. They should be assisted in taking an **active role** in dealing with their mentally ill relative, how to deal effectively with their roles in the family unit and how to respond to the patient being ill.
- Clinicians and researchers are increasingly recognising the value of **psychosocial interventions** as adjuncts to pharmacotherapy. It may be stated that, more perhaps than for virtually any other mental illness, there is a need for a **comprehensive and integrated approach** to the management of BD.
- According to the perspective of the **biopsychosocial model** behaviour is too complex to be understood from one perspective only. It takes the view that psychological disorders are caused by **multiple biological, psychological, and social factors** in interaction with each other.
- The 'life model' of ecological systems theory provides an account of how people impact on, and in turn are impacted upon, by their environment, and of the resultant **stresses** when there is **disequilibrium** in the system.
- The theoretical framework of this study was an integrated biopsychosocial model, within an ecological systems perspective.
- A **programme** that equips significant others of those people diagnosed with BD could reduce the treatment costs of an illness episode and even prevent admission. It may help caregivers to become less dependent on the healthcare system.
- It is important to take note of the **recovery** model which holds that hope and restoration of a meaningful life is possible, despite serious mental illness.

The researcher has come to certain conclusions, based on her experience of the field. This was integrated with her knowledge and enabled her to express an expert view on each of the literature chapters.

Researcher's **own integrative conclusion** regarding Chapter 1:

- BD is an international problem, but it is the researcher's opinion that it might have an even more profound effect in a third world country, like South Africa, which lacks the necessary resources. Therefore, a biopsychosocial model, within an ecological systems perspective, was chosen as the relevant theoretical framework of this study.

9.3.1.2 Chapter 2: Bipolar disorder spectrum and the specific patient profile

- Patients, their families and society tend to **oversimplify** BD and people even want to diagnose themselves as having this illness. It remains one of psychiatry's most **misunderstood** diagnoses. Inaccurate diagnosis may result in the implementation of inappropriate treatment, which can ultimately compromise long-term outcomes.
- BD **can be treated**, and people with this illness can lead full and productive lives.
- BD is not “only a brain disease” or “only a psychological problem.” It might be both of these. Therefore the biopsychosocial framework was deemed very relevant to examining these issues.
- Worldwide, more than 250 million people may have BD. It can be postulated that about 500 000 people in South Africa have this disease.
- Becoming pregnant can be very stressful for a woman with a mood disorder.
- There is a high divorce rate amongst bipolar patients (both male and female).
- The prevalence of mood disorder does not differ among races**.**
- People with BD are particularly vulnerable to changes in the sleep-wake cycle.
- Evidence indicates that patients with BD II are at greater risk of both attempting and completing suicide than patients with BD I and major depressive disorder. It is therefore most important always to monitor the BD population of patients extremely carefully, while the caregiver system should also be aware of the warning signs and risk factors.
- Symptoms such as changing moods, impulsive behaviour, and irritability are not limited to BD.
- Many people with BD, between 40 and 60 %, have a long-term **substance use disorder** as well.
- The idea that patients with BD in fact return to a fully functional state between mood episodes is no longer accepted as truth, and much of this is based on findings from the rapidly emerging literature on cognitive functioning in BD.
- It may be said that possibly the most important aspect of **comorbidity** in BD is **recognising its presence**.

- The majority of people with mental illnesses are not violent. Most people who are violent are not mentally ill, and most people who are mentally ill are not violent.
- Socrates thought that mental illness was a divine gift while Plato linked creativity to the inspiration derived from madness. Aristotle observed that eminence had something to do with the melancholic temperament and in some instances to diseases arising from “the black humour”.

Researcher’s **own integrative conclusions** regarding Chapter 2:

- The elderly psychiatric patient forms part of a very vulnerable group. It has been observed by the researcher that with aging, the time between episodes/hospitalisation becomes shorter.
- The researcher has noticed that in a controversial way, substance use/abuse can sometimes be considered a good prognostic factor, because if it is only the substance causing the psychiatric symptoms, the condition can still be reversed.
- It is sometimes difficult to distinguish between the person’s “normal self” and an episode of hypomania. The patient might even find the hypomanic episode enjoyable and family members may be relieved by what they perceive to be the disappearance of the depressive state that often precedes the energised one. This again may lead to poor compliance and the patient might go on to develop full mania.
- The researcher has observed that after a few relapses and hospitalisations, a patient is seldom able to resume his or her premorbid level of functioning. There is a decline of cognitive abilities and, frequently, a patient is unable to cope with a stressful job.
- It has been the researcher’s experience that there seems to be a relatively high incidence of HIV and AIDS among BD patients.

9.3.1.3 Chapter 3: Living with bipolar disorder – treatment and intervention

- There is a growing literature base suggesting that **cognitive impairments** (rather than insight alone) may adversely affect adherence.
- Non-adherent individuals with BD were more likely to be living with **family** members who were significantly less knowledgeable about BD and its treatment and were more critical of the patient than families of adherent subjects. The views of the patient’s significant others towards treatment are important, as these may influence the patient’s **beliefs** about their problems and/or attitudes towards proposed treatments.
- Successful maintenance treatment is the goal in BD.
- The management plan should be developed within a **biopsychosocial psychoeducational framework**. This model combines genetic and specialist

healthcare with assessment and therapeutic interventions in respect of the psychological and social underpinnings of mental health. It moves away from the compartmentalised, fragmented, traditionally medical-dominated model to more comprehensive care that focuses holistically on the person.

- Every good therapist is also a **teacher,** in the broad sense of the word.
- BD affects family relationships, and family relationships affect BD.
- **Caregiver group psychoeducation**, educating and supporting caregivers, could reduce the caregiver burden in BD.
- A spouse or parent who develops an **understanding** of the nature, course, triggers and treatment of the disorder may help create a milieu which helps protect the patient against recurrences.
- Genetic counselling for families affected by mental illnesses is important.
- Bipolar self-help groups can be very useful as an adjunct to skills-orientated psychological treatments. **Family support groups** are a suitable place to interact with other partners of bipolar people.
- Families have reported that service providers **are not always helpful** and may be negligent in encouraging families to be part of the treatment process. As a result, some families rarely turn to professionals for help, but seek support and guidance from self-help groups.
- The evidence base for social interventions that are at the disposal of mental health social workers is small, incomplete and disproportionate in size to that available to psychologists or psychiatrists.
- Social intervention within a developmental context in South Africa is increasingly focussing on how to use scarce resources to maximum effect.
- Evidence based practice has the potential to deliver more effective and efficient services to recipients of health and social care.
- Unfortunately, some people never receive the right treatment, while some never receive treatment at all.
- A major consequence of the failure to accurately identify and diagnose patients with BD is to worsen their long-term **prognosis**.
- **A change of paradigm** in the treatment of BD began a few years ago, when crucial findings on the impact of BD on the quality of life and social, cognitive and occupational functioning suggested that therapy **targets should be changed** from **symptomatic recovery to functional recovery**.

- The goal of treatment is to help people with BD live **symptom-free** for longer periods and to recover from episodes more quickly. Proper treatment helps most people with BD gain better **control** of their mood swings and related symptoms.

Researcher's **own integrative conclusions** regarding Chapter 3:

- In the South African context it is the reality that most psychiatric patients are treated in government hospitals where there are frequent changes from one doctor to the next (not allowing enough time to build a trusting relationship); it is the researcher's opinion that this factor also influences treatment adherence.
- It is essential that the mental health practitioner be aware of the South African National Mental Health Policy Framework and Strategic Plan 2013 to 2020. This document identifies key activities that are considered catalytic to further transforming mental health services and ensuring that quality mental health services are accessible, equitable, comprehensive and integrated at all levels of the health system, in line with the World Health Organization's (WHO) recommendations.
- The belief system of the significant others may have a positive or negative effect on the patient's compliance with treatment.
- Every episode **prevented** improves the subsequent course of the illness.
- The MDT should also include the **caregiver** whose **roles** might be to learn about BD, to stay in contact with the patient's therapists and to support the patient. The **patient**, too, must feel that he/she is part of the team and is able to take part in decision-making (this is also in line with a patient's rights). It is the **right** of the patient to be informed about his/her condition, management options and factors that may influence the outcome.
- **Discharge planning** begins immediately following admission to hospital.
- The experience of the researcher is that once a patient is admitted to a hospital, MDTs are under considerable pressure to **discharge quickly**; as a result the goals of proper psychoeducation and discharge planning are not always achieved. This may lead to a patient discontinuing his/her medication, **relapsing** and being **readmitted (revolving door)**.
- Psychoeducation does take place in psychiatric hospitals and all the members of the MDT provide it, but it is usually in an informal, unstructured way. Sometimes a patient is even educated about the "wrong" diagnosis, because the diagnosis at admission often alters after further assessments have been done.

- Psychiatric **aftercare** is a fundamental part of the recovery process but it is often neglected.
- BD is treatable, but, as yet, curative treatments or effective measures for primary prevention do not exist. The researcher therefore agrees that successful **maintenance treatment** is very important.
- In the researcher's experience, the **side effects** of medication that bother patients the most are weight gain, increased thirst (dry mouth), the effect on the libido and fatigue.
- In practice, it is found that patients may deny the abuse of benzodiazepines and will go to different doctors to obtain prescriptions. They also use these to self-medicate in order to feel better, but this does not provide a long term solution to their problems – on the contrary, it aggravates their problems.
- The researcher has observed that patients are often scared of **ECT**. When this treatment is considered, it is therefore very important that the patient and the caregivers should be well informed about the procedure and its possible side effects.
- There are still many patients and caregivers who do not have access to the potential internet help for psychiatric problems, while the researcher also has reservations about the reliability of some information accessible on the internet. In addition, the internet offers no therapeutic relationship.
- In the South African context, psychiatric services are still **fragmented** and it is often the social worker in the MDT who becomes the link to the community resources and even the coordinator of services within the MDT. If the rest of the team becomes "stuck", the patient's problem often becomes a "social" issue and other team members may become frustrated with the lack of progress.
- It is very clear to the researcher that the only approach that may be successful in the treatment of BD is that which is integrated and holistic.
- Collaboration between traditional healers and mental healthcare workers is likely to be beneficial. In practice it is found that there is still a substantial portion of patients and families who consult traditionally.
- The researcher believes and has experienced that treatment will be useless if the patient does not comply with the treatment regimen. She views treatment **adherence** and the **therapeutic relationship** as the basis of any treatment for the bipolar patient.

9.3.1.4 Chapter 4: Needs and psychosocial challenges of caregivers in relation to the individual with bipolar disorder

- The appearance of **mental illness** in a family member is invariably a **disaster** for the whole family, a disaster in which all become victims of the event and its sequelae.

- In the past, parents and siblings were thought to be responsible for many mental illnesses, during which time clinicians sought to explain these disorders solely in a behavioural context. As a consequence, **family members** felt demoralised and were blamed for their loved one's illnesses. Recently, however, neurobiological and genetic research findings have helped clinicians and researchers begin to understand the biological component of mental illness, particularly in terms of brain function and dysfunction, genetics, immunology, and endocrinology
- The ways in which different family members have **experienced** bipolar affective disorder have been investigated only to a limited degree in the past.
- Research has documented elevated levels of **burden** among family members caring for a relative with BD, which have been linked to poor physical and mental health and low levels of social support.
- Being **diagnosed** with BD really **is a beginning**: the start of **making sense** of the emotional roller coaster ride the patient (and family) has been and is on, and the beginning of obtaining help, the right kind of help, for the illness.
- There is a growing understanding that BD should be treated as a **family condition**. It is therefore important to take a broad view, as is being provided by the integrated biopsychosocial framework.
- One of the most difficult aspects of living with BD, both for the person who has the disorder and that person's significant other(s), is the **uncertainty surrounding the recurrence** of mood episodes.
- There is a need to **understand caregivers'** views and perceptions of the stresses and demands arising from caring for someone with BD in order to develop practical, appropriate, and acceptable interventions and to improve the training of professionals working with bipolar patients and their caregivers.
- The most important needs of caregivers are those of **knowledge and support**.
- The "**emic**" approach is central; that is, the outsider must learn to perceive the situation through the eyes of the subject, rather than superimposing his or her own external model of reality.
- The primary task of the mental health service is the **prevention** and **treatment** of mental disorders in the population. The biopsychosocial framework addresses biological and psychosocial predisposing, precipitating, perpetuating and protective factors.
- The caregiving role is associated with a considerable **burden**. It is more the exception than the rule that the mental health service has developed routines for taking care of the family, who often feel overlooked and forgotten. Available data suggest that the

caregiver burden is high and largely neglected in BD and is a matter of increasing clinical concern.

- Caregivers develop different kinds of **coping strategies** to deal with the burden.
- **Three groups of caregivers** may be identified: **effective** caregivers, **burdened** caregivers and a third group with high stress appraisal related to perceived stigma (**stigmatised** caregivers). This knowledge can be used to **prospectively** identify **caregivers** at **risk** for adverse health outcomes associated with caregiving and target them for a prevention-focused intervention.
- Clinicians should **assess symptoms** of caregiver distress. When this is noticed, efforts should be undertaken to support the caregiver and teach them skills to cope effectively with the consequences they experience, in order to stay well.
- BD **afflicts** one but **affects** many in the family.
- People who do not have BD have no concept of how terrible it is to suffer from it, while those with the illness have no concept of how terrible it can be to live with someone who has BD.
- A caregiver **should not be overprotective**, always stepping in, because, as a result, the patient does not use whatever skills he/she possesses, or develop ones for him/herself, and, consequently, becomes increasingly dependent and helpless.
- The **aftermath** of a mood episode may be as difficult to cope with as the episode itself.
- It is difficult to conduct a loving and intimate relationship when one partner is a caretaker and the other is a patient.
- **Men** whose wives have BD might need to make more of an effort to develop a support system. In general, women are more likely than men to devise a support system outside the nuclear family unit.
- **Parents** of adults with serious mental illness are at increased **risk** for poorer health and mental health and marital disruption.
- A child of someone with BD might experience a **role reversal** that leaves the child feeling more like the parent than the child.
- Siblings might think it is not their problem or responsibility to deal with the sick sister/brother.
- A situation becomes more challenging when more than one person in a family is afflicted with BD.
- Relatives should be very aware of **how** and **what** they communicate to the patient.
- **Stigmatisation** of individuals diagnosed as having serious mental illnesses has been globally observed, and the family members who help care for them report feeling

stigmatised themselves as a result of their association with the loved one who suffers from mental illness.

- People whose caregivers tend to be **overinvolved** exhibit poorer adherence to medication and are more likely to develop further episodes of illness. The caregiver's and patient's boundaries must be respected.
- One of the risk factors for committing suicide exists if a person is **isolated** from friends and family members. The emergence of self-destructive thoughts and impulses is frightening both to the patient and to those around him or her.
- Both the caregiver and patient should set coping strategies in place.
- Nearly 70 % of caregivers are distressed by the way the illness (BD) affects their **emotional health** and their life in general.
- Some caregivers become **frustrated with the professionals** and blame them for not doing enough, quickly enough, to "cure" the patient.
- Another issue arising is that not being understood by professionals may exacerbate the distress of families and unnecessarily increase their burden.
- Caregivers must remember their **own needs**, should share responsibilities with others and stop BD from taking over family life.
- An astute friend or family member who knows how to communicate observations in a caring, non-provocative manner upon noticing sustained changes in mood is one of the best **supports** a patient can have.
- The caretaker role does not have to be permanent. In fact, it needs to end at some point. A person with BD could take over a caregiver's life if the latter does not protect him/herself.
- Bipolar individuals can be very "**high maintenance**".
- BD poses many challenges that are difficult for anyone, except those suffering from it, to understand. It is said by patients that BD not only affects the way they live, it affects the way they see the world.
- A sufferer must remember that BD is a condition that they have, but **it is not who they are**. A person with BD is a complex human being with many more aspects to their character than the phrase "bipolar person" implies.
- Patients' **needs** in order to experience a good quality of life may include routine, independence, social support, the need to restore their sense of self-worth and identity.
- Patients might be **ambivalent** about the need for treatment.
- A person must **recognise** his/her **relapse signature** (an individual's personal warning signs of illness).

- Individuals with BD need to be alert to signs and symptoms of mood disorders in their **children** and to place them into treatment if such symptoms occur.
- Patients may **blame** their behaviour on people they might think have provoked them – typically, family members.
- Some **over-identify** with the illness, viewing all of their problems, emotional reactions, attitudes and habits as part of the disorder.
- People with BD face significant challenges in the **workplace**.
- Patients grieve their **past persona** before their BD diagnosis.
- Studies link a disordered family environment with a poor prognosis in BD.
- Expressed emotion (EE) studies focus on the discovery that psychiatric patients who have returned to live with their families, who express a high level of criticism and emotional over-involvement, tend to relapse and need hospitalisation more frequently than those families low in EE.
- Too often, professionals view the family as **unidentified patients** needing treatment rather than as **adult learners** attempting to deal with a major mental illness.
- The special **expertise** that families possess is relevant to quality care and the family's expressed needs must therefore be given priority.
- The **illness beliefs** of the caregiver have been found to strongly relate to the degree of experienced burden.
- **Burnout** is a serious consequence of caring for someone with a serious disease. The caregiver should establish his/her own limits and make time for himself or herself.

Researcher's **own integrative conclusions** regarding Chapter 4:

- The researcher has experienced that bipolar patients are frequently readmitted to hospital, even if they have been compliant with their treatment regime, perhaps demonstrating their vulnerability to stress in their lives.
- It is the researcher's opinion that if caregivers' needs could be recognised, patients will also benefit.
- In this study it was very important to discover the **real needs** of the caregivers, before starting a psychosocial educational programme.
- The researcher, in her day-to day work, finds that there is a tremendous lack of adequately equipped community **resources** to which mentally ill patients and their families may be referred, especially in the more remote areas.

- The **strengths** of caregivers and patients must be acknowledged; the focus should not always merely be placed on the pathology. Wellness, mental **health** and quality of life must be encouraged.
- The researcher concurs that caregivers are also influenced by the stigma which exists concerning mental illness.
- It has been observed that some mothers take over the sick child's life, even where this child might be an adult or married. It might be that this serves the function that the mother still feels important in her child's life.
- It has been the researcher's experience that violence towards others and the instability of the patient is very often the reason that caregivers refuse to take a patient home.
- The help of the **police** is sometimes needed to take an ill person to hospital. Family members often feel very guilty about having contacted the police. It has been the researcher's experience that the police are not always very helpful and they are often not able to handle psychiatric patients. It does seem that intensive training is needed to equip them.
- It has been the researcher's experience that twenty years ago patients were still kept in psychiatric hospitals for decades, but now the emphasis is on acute treatment, stabilisation and discharge. This too, puts more strain on the caregivers. Although hospitalisation can be traumatic for caregivers, **discharge** of a loved one can also challenge the caregiver and the patient.
- The researcher has found that if caregivers gain insight regarding the illness and treatment, this definitely improves the patient's prognosis. It also helps if the MDT have family meetings before discharge to stabilise family relationships and improve communication.
- The researcher supports a **collaborative approach** to managing the illness – one that includes the patient, the significant others and the MDT. The **patient** should be an informed and pro-active partner in treatment and wellness management
- It has been the researcher's experience that the significant other, whether the parent, child, spouse or other relative, also has to deal with the multiple **losses** that the illness implies.
- BD is an illness of mood, but it is still very important to observe the emotions "behind" the mood, for example that a manic person might still feel rejected or insecure.
- The researcher acknowledges that BD does seriously affect the patient and his / her life. However she does also deem it important that the patient should set **appropriate expectations** for him/herself and also take cognisance of his/her own **strengths** and, by doing so, build resilience.

- The researcher has observed that families are becoming more aware of the fact that they are also affected by their loved one being mentally ill.
- Families often begin their relationships with professionals with the expectation that **information** and **guidance** will be forthcoming. It is the researcher’s experience that this seldom happens.
- It has also become clear to the researcher that the professionals sometimes act from a position of feeling helpless and frustrated with the situation. Some caregivers are perceived as very demanding; requesting time, attention and information.
- As mental health care professionals we often emphasise the pathological and do not recognize the strengths of a family – the empathy and cohesiveness that still prevails within the system. A non-blaming stance broadens the possibilities of working with families as partners.
- For their BD patients’ families, who frequently have to provide support and care for them, the consequences of the illness may also be far-reaching and the rate of marital and long-term partnership breakdown is very high. This has also been the researcher’s experience in her practical interactions with BD patients and families.
- It is usually the parents who will persevere with supporting the patient in spite of everything he/she might do or say. It seems to be more difficult for the siblings to hold this non-judgemental attitude.
- Members of the MDT should become aware of the family’s **belief system** and even any rituals that they need to perform. Their beliefs should be respected. A thorough assessment needs to be done in this regard.
- In South Africa, illnesses such as HIV and cancer invariably receive financial assistance and attention, whilst the effect of a mood disorder illness (also affecting a large segment of society) receives hardly any recognition.
- Families of the mentally ill have become increasingly **vocal** about the need for the restoration of long-term hospital services, provision of community residences in adequate numbers and an increase in funding for day programming and case management services. This statement was made more than 25 years ago in the USA, but it is the researcher’s experience that it is still a desperate need in the current South African milieu. **Resources** to support caregivers are **seriously lacking**, which often results in them giving up, with families becoming less vocal – they just become silent.
- The biopsychosocial framework offers the opportunity to be aware of the caregiver as a cardinal part of the patient’s psychosocial context.

9.3.1.5 Chapter 7: Psychosocial educational programmes for caregivers and the SEE-SAW programme

- In the last decade, four main models of psychological interventions have evolved for bipolar disorders: cognitive behaviour therapy, interpersonal social rhythms therapy and family - focused therapy and the fourth model that was developed *de novo* by the **Barcelona** group, a psychoeducational programme.
- Psychoeducation fulfils a fundamental right of the patient and of any human being: **the right to know**. Recognition of the family as a valuable **asset** in the care of persons with mental illness has brought to the attention of mental health providers the need to support family caregivers in this demanding task.
- The following approaches are important – **informational** approaches, **skills-training** approaches, **supportive** approaches and **comprehensive** approaches.
- The biopsychosocial framework puts the emphasis more on prevention and rehabilitation than cure; this approach was also visible in the models that were assessed.
- The researcher’s own SEE-SAW programme was presented in Chapter 7 and was supported by appropriate literature.

Researcher’s **own integrative conclusions** regarding Chapter 7:

- There is an abundant amount of knowledge available on BD, but perhaps the challenge is to **reduce** this knowledge to make it **simple** and digestible for patients and caregivers.
- **Two groups** of researchers/clinicians have been developing programmes – Colom and Vieta (Barcelona, Spain) as well as Miklowitz (Los Angeles, USA).
- It is the researcher’s opinion that each and every patient as well as their caregiver/s has the right to know more about his/her disorder. In the biopsychosocial model the focus falls less on the pathology than on the affected individual in a particular social and cultural context. This framework is enabling and holistic and it should therefore be the point of departure for any psychoeducational programme.

9.3.2 Conclusions based on research methodology (Chapter 5)

- In this study, the researcher collected individual **qualitative** interview data (phase one) as well as **quantitative** survey data (phase two). The qualitative information was employed to develop a psychosocial educational programme that was tested. It is thus evident that a **mixed method** approach was used in this study. The **exploratory mixed methods design** was chosen.

- The study fell into the category of **applied research**, because its aim was to design a psychosocial educational programme in order to solve the problem of possible lack of knowledge and skills of caregivers of people diagnosed with BD. '**Intervention research**' is a type of applied research in the social sciences targeted to address the application of research in practice. The researcher directed the study according to the **intervention design and development model** (D&D). A primary goal of intervention research is to develop interventions that are effective in a variety of real-life contexts along with those who actually experience the problem. This was also the researcher's goal.
- In phase one, a **collective case study** design was used.
- The specific **experimental design** that was chosen as being the most appropriate for the study was a pre-experimental design, the one group, pre-test – post-test design.
- The criteria for the **selection** of respondents for this study (sample) were that they should be caregivers of adult people diagnosed with BD: who had been caregivers for at least three months; who were aware of the diagnosis; who were conversant in either English or Afrikaans; who expressed the need for more knowledge and skills regarding bipolar disorder. These caregivers could be male or female, a parent, child, sibling, spouse or partner, colleague or good friend of the patient.
- In **phase one** the researcher collected information concerning the caregivers' needs and challenges. The data collection instrument was a semi-structured interview.
- In **phase two** of this research, a psychosocial educational programme (the intervention) was developed and implemented for respondents who are caregivers. Respondents completed a pre and post-test to evaluate the programme.
- It was important that the researcher took note of issues of trustworthiness and ethical considerations when the research was planned and when it was executed.

Researcher's **own integrative conclusions** regarding Chapter 5:

- The mixed method research model provided a holistic view of the field of research.
- The intervention model did provide a guideline of steps that had to be followed in the research process.
- In the post-test, quantitative as well as qualitative feedback was received, but the qualitative feedback was of a richer nature.
- The researcher was able to adhere to the ethical considerations that are important in research.

9.3.3 Conclusions based on the empirical study (Chapter 6 and Chapter 8)

9.3.3.1 Chapter 6: Empirical research findings of the qualitative phase of the study

This chapter focused on the **first phase** (qualitative) of the study. The researcher will provide an overview of the key findings of the twelve categories, as well as the themes, that were highlighted in **Chapter 6**, and briefly comment on each category **(**See **Table 9.1)**.

Table 9.1: Overview of the twelve categories based on the interviews with participants

Category	**Theme**
1. Needs	Needs of participants Needs of patients
2. Burden	Objective burden Subjective burden
3. Relationships	Type Characteristics Communication Family-healthcare staff dissonance
4. Illness	Symptoms of being ill Triggers Diagnosis Hospitalisation Treatment Belief system of patient and family members
5. Protective factors	Insight Concordance to treatment Resources and support
6. Risk factors	Lack of insight of caregiver Suicide/homicide Comorbid conditions Lack of treatment, resources and support Mental illness in family High expressed emotion
7. Emotions of participants and patients	Emotions of participants Emotions of patients
8. Participant’s and other family member’s response to mental illness	Participant’s response Extended family members’ responses to mental illness
9. Roles and qualities of a caregiver and the patient’s roles	Roles of caregiver Qualities of a caregiver Roles of patient

Category	Theme
10. Psychosocial challenges for caregiver	Fear of being spontaneous and of the unexpected - creating uncertainty Expectations placed on the caregiver Dealing with stress Losses and limitations The challenge of acknowledging the positive in a difficult situation
11. Psychosocial challenges for patients	Work Losses
12. Recommendations from participants' practical experience of what works for them	Different strategies

- **Needs**

It is necessary to **understand caregivers'** views and perceptions of the stresses and demands arising from caring for someone with BD, in order to develop practical, appropriate, and acceptable interventions. Participants felt that the patient always receives all the attention and that the caregiver is often ignored. Participants' need for initial and ongoing psychoeducation on a practical, understandable level was indicated. Participants were aware that the patients also have needs. In fact, both caregivers and patients have needs that the other often ignores.

- **Burden**

BD definitely has a financial impact on the lives of caregivers. The participants also reported a level of stigmatisation in their lives and even within their own families and communities. Identifying and modifying burdensome aspects might reduce the level of burden and its negative effects on both caregivers and patients' outcomes. In practice, the researcher has experienced that caregivers also become depressed and anxious.

This illness may lead to the carer losing his/her social life, which in turn might make him/her feel extremely lonely and isolated. It is evident from the quotes that caregivers need support on different levels. Families need opportunities to relate to persons with similar experiences.

- **Relationships**

Parents may provide decades of extended caregiving for their adult son or daughter with BD during those times when debilitating symptoms are obstacles to social and occupational functioning and independent living. Parents of adults with serious mental illness are at increased **risk** for poorer health and mental health and marital disruption. Participants caring for a parent reported their fears and insecurity stemming from growing up with a mentally ill parent. These emotions did continue, even in adulthood. It was clear that although these children no longer live with the patients, they still experience the impact of having a mentally ill parent.

The sensitive area of sexuality (in marital relationships) was mentioned during the interviews. Some people become **overinvolved in their role as caregivers** and feel the need to step in and **take over**, even when their loved one is relatively well. Relationships across a wide spectrum are very important in the world of the BD patient and caregiver.

- **Illness**

It is clear that the caregivers could identify when different **episodes** were occurring. The experiences of aggression and psychosis were the aspects that were especially difficult to handle. It has been the researcher's experience that a diagnosis offers relief to caregivers, because there is something definite that they can study and they are able to empower themselves. They can start to accept it. Participants revealed that it is difficult to gain **admittance** to a government hospital. Emotionally it is also a difficult step to take.

- **Protective factors**

The importance of protective factors was discussed above; it was evident that insight, compliance with treatment and support contributed towards a better outcome to handle the illness.

- **Risk factors**

The researcher observed that suicide attempts or ideation of suicide were experienced as very disturbing by participants. Participants emphasised the serious **lack of** resources – especially affordable rehabilitation centres. More than half of the participants reported that other family members had also been diagnosed with a mental illness.

- **Emotions of participants and patients**

Caregivers reported a wide range of emotions regarding their interaction with the patients. It has been the researcher's experience that patients frequently focus just on their own emotions and are surprised that the caregiver might also be frustrated or hurt. The key findings of this category are that both the caregiver and patient experience a variety of emotions when confronted with BD. The importance of recognising this and processing the emotions cannot be emphasised enough.

- **Participants' and other family members' responses to mental illness**

In this category it was clear that participants and extended family members exhibit certain **responses** in relation to the patient's mental illness. Participants reported that they would typically first deny, hide or suppress their reaction, also reacting in a "fed-up" manner, before reaching a place of acceptance of, and adapting to, the situation. From this it may be understood that acceptance and adaptation is clearly a process.

- **Roles and qualities of a caregiver and the patient's roles**

It could perhaps be argued that women fit better in the role of caregiver, although this would be a generalisation. Children are severely affected by a mentally ill parent – even when they are adults. This was clear when the children reflected on their lives. The parents were mothers and their unconditional love for their children was clear.

It did seem that some of the participants were doing too much for the patients. The caretaker role does not have to be permanent. In fact, it needs to end at some point. A number of participants noted that it is important to be patient and caring, but also to be assertive and set boundaries. Some of the patients (in the views of the participants) were not able to fulfil their roles of parenthood, spouse and breadwinner. It was also clear that some roles overlapped. It should however be remembered that there are no rights or wrongs, and roles are performed according to the ability to face certain situations.

- **Psychosocial challenges for caregiver**

Participants felt they were obliged to adapt to the patient's needs and could not be themselves.

It was clear that expectations (from the patient as well as other sources) were sometimes overwhelming for the caregivers. Participants indicated that there were times when they did not think they would be able to carry on. Financial issues and lack of security were experienced on different levels by the various participants. They experienced losses of different kinds.

Caregivers should be challenged to see the positive in the midst of a very difficult situation, because this will empower them.

The researcher found that most of the participants reported on the challenges they face. Some even felt that their own well-being was threatened and that the expectations and stresses they are exposed to could become unbearable.

- **Psychosocial challenges for patients**

In the researcher's opinion it must always be remembered that the patient also faces challenges. During the interviews it was reported that the issue of work is a concern. It was also mentioned that patients experience losses, such as having no friends.

- **Recommendations from participants' practical experience of what works for them**

During the interviews participants also reviewed what they find helpful in dealing with this difficult situation. It was clear that the participants also possessed **strengths** that they could utilise. Different **strategies** were reported by the participants. The researcher was able to use these recommendations as part of the tools for the SEE-SAW survival suitcase.

The biopsychosocial framework allowed the researcher to explore the social context of the caregiver. It was mentioned earlier that the ecological systems model is consistent with biopsychosocial approaches and that ecological systems theory provides an account of how people impact on and in turn are impacted upon by their environment, and of the resultant stresses when there is disequilibrium in the system. The individual functions within a family who functions within a larger community system. This system might be supportive or comprise pathologies. It was important that the researcher had to become aware of the needs and challenges in the system to address these in the psychosocial educational programme that was designed.

9.3.3.2 Chapter 8: Empirical research findings of the quantitative phase of the study

This chapter focused on the **second phase** (quantitative) of the study.

- A quantitative data gathering instrument (questionnaire) was developed and implemented in a pre-test and post-test before and after the presentation of the SEE-SAW programme to the caregivers. This chapter dealt with the results of the questionnaires, being quantitative as well as qualitative.

The researcher did notice that the respondents' **knowledge** gain was less than she expected and hoped for. It is her opinion that the following **factors** could have played a role in this regard:

- Most of the caregivers had already been in this role for years and therefore had attained a certain level of knowledge, experience and insight before attending the programme.
- The caregivers who volunteered to attend the programme were mostly people who had tried to improve their knowledge on their own by reading, and or attending support groups and talks on the subject.
- Seventy percent of the respondents possessed a tertiary qualification and were knowledgeable.
- BD is a complicated illness to understand.
- The researcher might have tried to cover too much in the one day programme.
- Insight may take years to develop.
- People do not change their belief system overnight.
- Some of the questions in the questionnaire might have been too difficult to understand.
- The researcher‘s goal for the SEE-SAW programme was not only to convey knowledge, but also to provide support and hope for caregivers.

9.3.4 Conclusions based on comments from MDT colleagues

The researcher concludes this section with written **comments** that were made by colleagues (all experts in the field) who attended the Doctoral seminar that she presented about the research findings at a psychiatric hospital. Feedback could have been given **anonymously**, but **some colleagues** did write down their names. The researcher is including this feedback, as it can be regarded as a qualitative phase that followed after the intervention (see **Figure 5.1**) regarding the evaluation of the SEE-SAW programme. The following remarks were received:

- Excellent work. Very relevant and necessary (Registrar in Psychiatry).
- Well presented. Cover all the themes. Excellent work.
- Excellent programme (Social Worker).
- Amazing (Social Worker).
- The work presented to us is excellent. The researcher has really worked hard and put in a lot of effort. I am very much encouraged after hearing and seeing her work. Keep it up, well done! (Psychiatrist).

- The exploratory mixed methods design was very appropriate for the research, and represents cutting-edge social science research methodology. The research was clearly conducted very thoroughly in an accountable way. The potential value of the research for the community affected by bipolar disorder is far-reaching. The research also offers a model for research in other psychiatric disorders (Professor of Psychiatry and in charge of psychiatric research at the academic psychiatric hospital where researcher is working).
- Very relevant research regarding the management of the illness most successfully. Psychoeducation of the patients and caregivers is critical for optimal illness course management. Illness with “insight lacking aspects” puts more burden, responsibility and involvement on the caregiver. Therefore it is important to have open communication channels between the family/caregivers and mental health care providers. Congratulations, well done (Psychiatrist in private practice).
- Very informative and useful. You put in years of hard work and dedication to come up with such an excellent end product. Suggest that things like the mood chart can possibly also be implemented at the hospital. More workshops are needed on this research and the implementation of the programme.
- Thank you for your inspiring work – a special gift to our mental health community (Psychiatrist).
- Well done, very practical, user friendly intervention to patients and caregivers.
- This was very informative. If possible, arrange for more seminars.
- Interesting and thorough research. The programme developed is necessary and user-friendly for caregivers.
- I agree with functional outcomes. Wonderful to support caregivers as lack of supervision and family support is one of the major reasons for relapse (Psychiatrist).
- Very good quality. The book is great. Importance of MDT getting involved in the support groups and help not just the patient but also the caregivers. Stress management and problem solving skills for caregivers (not therapy, but aspects that can help them cope).
- Very good research. A lot of information given and research done well. We can see a lot of time and effort has gone into this research and opened up many doors for future research.
- This is a neglected, but extremely important topic in bipolar disorder research. The research question was well structured and research methodology is sound. The participants’ response emphasizes the needs of caregivers of people diagnosed with bipolar disorder. The broad cover of the literature regarding this topic is impressive. I find the signature of relapse very interesting. This should be emphasized – it can be

extremely important in relapse prevention. Comments of caregivers is so powerful. Congratulations on innovative, scholarly research that was excellently done (Professor of Psychiatry).

- Very well done. Lots of work and ideas went into the research. Seems to cover all aspects of bipolar disorder. Posters very good (Social Worker).
- The research indicates how much work went in.
- Excellent work. This is an excellent presentation and you really put a lot of time and effort in it.
- Congratulations. I think this is amazing work done. Very impressive. Well done. Have you considered having the programme done on a regular basis? (Psychiatrist).
- Extremely excellent research, presentation. Well done!
- "*Daar is ongelooflik baie werk al hier in, kan mens sien en die kwaliteit van navorsing, dink ek, is baie goed. Ek stem saam met W… om nie die fokus te veel op die kwantitatiewe deel te maak ten koste van die kwalitatiewe nie, omdat die waarde van die studie meer gaan oor die insette ook t.o.v. ondersteuning en erkenning binne die verhoudingskonsep, as bloot net feite-oordrag. Ek dink die boek/handleiding (by gebrek aan my kant van beter word daarvoor) is ongelooflik en ek hoop iemand publiseer dit Die groot vraag vir families van waar om hulp te kry, impliseer ook waar gaan die hulpverleners opleiding kry. Ek moet jou eintlik net baie geluk sê met ongelooflike studie en sterkte met die opskryf en samevatting van alles".* (A person can see that you have done an unbelievable amount of work and I think that the quality of your research is very good. I agree with some of the other feedback that the focus should not be so much on the quantitative part of the study at the cost of the qualitative, because the value of the study is more about the input regarding support and recognition in terms of relationships – more than just the conveying of facts. I think your book/manual is amazing and I hope someone will publish it. The big question where the caregivers will get help also implies where they will get training. I must just say congratulations with your wonderful study and good luck with the writing up and summarizing of everything) (Psychiatrist).
- I found the programme very helpful, very clear and practical. I also liked the indications of risks and management thereof (Social Worker).

The feedback received from colleagues in the mental health field confirmed to the researcher that she has managed to achieve her goals and objectives in undertaking her research.

9.4 RECOMMENDATIONS

Recommendations will be made as follows: for social work **practice** and from **MDT** colleagues.

9.4.1 Recommendations for social work practice

Recommendations will be discussed in terms of **themes** that the researcher considers to be important. The focus of this research was obviously on the **needs** of the caregivers and the development of a psychosocial educational **programme**, but the recommendations will also touch on other applicable areas. It is important to consider these areas if the social worker is wanting to develop a plan to manage a path to wellness for patients and caregivers. The researcher will thereafter refer to social work in a psychiatric hospital. Although some recommendations may sound idealistic, the researcher does believe they are possible.

9.4.1.1 Important themes

- **Biopsychosocial treatment**

Every patient should receive comprehensive care that focuses on the person as a whole (biopsychosocial model). Treatment should be continuous. Monitoring is very important to prevent relapse. Each patient that is admitted to a psychiatric hospital should receive a proper discharge plan, involving his/her significant others. The significant others' recommendations, capabilities, and resources for their relative's rehabilitation programme should be considered, if the discharge plan is to be viable.

- **Location of treatment**

It should be the goal that the place of treatment (hospital or when at home) is conducive to healing. It may well be difficult for a caregiver to see their loved one in a "lock-up" facility; staff should therefore prepare caregivers and explain why this is necessary. The atmosphere should be friendly and helpful and patients should feel safe. The noise factor in wards should also be taken into consideration.

- **Tools**

At each follow-up visit, the patient's clinical status should be determined and recorded in a systematic manner. In view of time-constraints, it could be very helpful if patients complete a **self-report form** in the waiting room, as well as **daily mood charts** that they bring to the consultation. Active patient collaboration with routine assessment not only increases the time available for more unstructured talk, but also improves rapport by providing documentation of the patient's subjective experience.

The clinician would also benefit from using **graphical charting**, since knowledge of an individual patient's **disease course** is perhaps the most useful guide to planning treatment. These practices do not seem to be followed in the government sector and the researcher strongly recommends that these aids be implemented.

The "**social rhythm**" chart may be a valuable tool; it is something concrete to use when discussing a complex situation. Patients and caregivers should be encouraged to continue monitoring the patient's rhythms and patterns of daily activity when he/she is at home; if any disturbance to the pattern is noticed, they should report it to the MDT.

Each patient should be encouraged to devise a **wellbeing plan**. This may range from a private decision by an individual to adopt a certain strategy, through to a formal document drawn up by an individual to consult family, friends and health professionals. The researcher is of the opinion that **suicide prevention** should form part of the wellbeing plan. It is also important to develop an advance directive/relapse plan. This could empower caregivers and may help them to feel less guilty should the patient relapse, because it has been decided in advance that the patient should also take responsibility for his/her own life.

Caregivers could help patients to build their **own file** containing valuable documents (e.g. ID, CV, previous clinical reports). When patients relapse they tend to lose everything.

A **guideline** provided to the patient or caregiver may help them to compile their own history of the mental illness and could save them from the frustration of always being obliged to repeat it during new admissions.

- **Change of paradigms**

The evolution in the treatment of BD began a few years ago, when crucial findings on the impact of BD on the quality of life and social, cognitive and occupational functioning suggested that therapy **targets should be changed** from **symptomatic recovery to functional recovery**.

Another paradigm that needs to be challenged is that the focus should not always be on the pathology. Clinicians should actively look for **strengths** within a system and build on the resilience of patients and caregivers. Wellness should be the goal.

- **MDT**

It is a given that the **MDT** is very important and if there should be any tension amongst team members it should be addressed. Sometimes roles of team members overlap, which might cause role conflict. The care team should ensure regular follow-ups, with defined tasks for different team members. The role of **significant others** should be acknowledged by the MDT. The MDT should be sensitive to the real needs of patients and caregivers and offer ongoing support. Members of the MDT should try to understand the caregivers' views and perceptions of the stresses and demands arising from caring for someone with BD.

The training of professionals working with bipolar patients and their caregivers should be continuous.

- **Psychoeducation**

This should be an integrated part of a BD patient's treatment plan, but in an organised, well planned, ongoing manner. The SEE-SAW programme (or parts thereof) may be implemented while a patient is still in hospital or at the out-patients' clinic for the benefit of patients and significant others. Short discussions might be more practical, because patients and caregivers might not follow up if a programme is presented over a longer period. Educationally relevant DVDs, followed by group discussions, can benefit the patient system.

Caregivers do experience a need for **skills**, such as how to communicate with the ill BD patient, what to do if the patient becomes suicidal or aggressive, as well as other coping skills. Family members do not always know what to do when the relative with BD reacts negatively to their attempts to help. The researcher recommends that stress management and problem solving skills should also be included in psychoeducation (of patients and caregivers).

Counselling on the **genetic** aspects of psychiatric disorders should receive more attention. The significant others should be taught the difference between a psychiatric illness and anti-social behaviour. Should a patient be uncontrollable and aggressive, they should know when to bring the patient back to hospital and when to lay a charge.

It is good to have a co-therapist when presenting a psychosocial educational programme.

It is thus important that psychoeducational programmes should be presented on an ongoing basis to patients, significant others and other professionals. One should allow enough time for **interaction**, because people usually learn from others in the same position, and incorporate other team members to talk about their speciality, e.g. the psychiatrist about medication and the occupational therapist about vocational rehabilitation. Psychoeducation must be provided in a pragmatic, user friendly way and be on the level of the target group. It is important that it addresses the needs of the specific group.

Psychoeducation to patients and caregivers should be about more than exchanging knowledge – it should concern the **experience** of being heard and being able to tell their stories.

Psychoeducation should also be provided to schools, other professionals, church groups, shelters for homeless people and to traditional healers. Communication media, such as the radio, TV, newspapers and cell phones should be utilised. In this regard an organisation such as SADAG is very active, promoting such days as mental health day, bipolar day and world suicide prevention day.

A comment from the feedback after the Doctoral presentation was that pamphlets could be distributed at the outpatient clinic to caregivers, and it was agreed that it is a good idea to show educational DVD's.

- **Community resources**

Hospitalisation has become shorter, due to the changing health system, and it is therefore important that caregivers must be informed about resources in the community and that proper **referrals** should take place. There is a need for greater **community care**, an increase in adequate housing and better employment support.

The researcher would like to recommend **mobile treatment teams** to assist patients and families at home when a **crisis** arises, because families must often call on the help of the police who are not equipped to handle psychiatric emergencies. Incidentally, Akeso Clinics have recently (August 2014) launched the Psychiatric Intervention Response Unit in Gauteng and Kwa-Zulu Natal. This was done to fill the gap for emergency response units in the mental health arena, and consists of a hotline coupled with a vehicular response unit for people in a psychological crisis. It is a free service for all South Africans.

There should also be wraparound services such as early intervention programmes when a patient starts relapsing, thereby **preventing** admission to psychiatric hospitals.

Day clinics which patients can attend may contribute to alleviating stress amongst caregivers. Feedback was given at the Doctoral seminar that the audience agreed with the idea of day care/respite care. Adult foster care should be initiated and supported.

Patients and caregivers should be encouraged to attend relevant support groups. **Support groups for caregivers alone** should also be considered**,** because their needs differ from those of the patients.

Police (perhaps especially at grassroots level) should receive adequate training in handling the psychiatric patient. In Section 40 of the Mental Health Care Act (17 of 2002) it is stated that the police should take a patient with mental illness to the nearest health establishment.

In practice, many psychiatric patients are referred to **shelters** for homeless people, because those are the only places they can afford on a disability grant and often families refuse to let them come home. Most shelters are managed by lay people who need to be empowered with knowledge and skills. These staff members should be taught about mental illness and signs of relapse, to enable them to establish when to bring a patient back to the hospital or when to consult with a member of the MDT. At the psychiatric hospital where the researcher works, open days are held for these facilities.

- **Significant others**

Improving the quality and quantity of **social support** to significant others is a primary recommendation. Their rights should be respected and their opinion should be asked when decisions are made. They should be able to express dissatisfaction. At the psychiatric hospital where the researcher is working there is a complaints procedure in place and all complaints are discussed on a weekly basis.

The significant others should feel part of the MDT. It is important to **contract** with the caregivers in terms of their roles and responsibilities. They should be involved in the process from admission to discharge and during aftercare as well. None of the participants mentioned that they saw themselves in this role, indicating that they are not always invited to become part of the team.

Ideally a family meeting should take place with every family during every admission. Caregiver support groups can take place at OPD.

Feedback from a participant after the presentation of the SEE-SAW programme was that it is important to assist caregivers with financial difficulties that might occur as a result of patients' behaviour. This may be done by implementing preventative measures such as teaching the patient budgeting skills; not giving him/her access to bankcards; monitoring his/her psychiatric condition and being aware of any manic symptoms indicating an episode during which the patient may overspend. Caregivers may also be advised about the procedure to follow in applying for an Administrator at the Master of the High Court.

- **Bipolar Disorder Unit**

The researcher wants to recommend a **Bipolar Disorder Unit** at the hospital where she is working, consisting of people having a special interest in this field. Already there is a specific MDT working with BD I patients, but by expanding on the current work of the MDT, more of an impact could be made.

- **Maintaining health of the health care provider**

Working with psychiatric patients can be very emotionally draining and it is therefore important that professionals should look after their own health. They should also be working in a safe environment and be protected against aggressive, abusive, psychotic patients.

9.4.1.2 Social work in a psychiatric hospital

It should be noted that such a social worker should have resilience, empathy, perseverance, patience and passion. He/she should possess self-knowledge and be sure that the psychiatric setting is an area of interest before starting to work there. He/she should be assertive and not allow abuse by others, e.g. just to handle practical problems, such as applying for grants and identity documents and finding accommodation. Activities like these could also be carried out by an auxiliary social worker and patients should be empowered to do things for themselves. A social worker should never encourage dependency. The following bullet points reflect the researcher's recommendations based on her experience:
It is important that the social worker should recognise that when people develop illnesses, mind and body are involved. Health problems are multi-factorial and interrelated, hence social work in a psychiatric hospital should follow a **biopsychosocial** approach.

The social worker should focus on work with individuals, groups and communities, but education and guidance to other professionals and students could also be added. **Research** is another area that is much neglected, and social workers should be encouraged to publish articles and to make presentations at national and international conferences. By doing this, their valuable knowledge will be retained and disseminated.

The social worker should **equip** her/himself with knowledge of the relevant psychiatric conditions, treatment, risk and protective factors and resources.

The social worker must know his/her **role within the MDT and be visible**. It has been the researcher's experience that the social worker forms a very important part of the team, although this position and the respect of others must be earned by hard work (i.e. it is not a given). The social worker is often the glue keeping the team together and the team member who negotiates with the caregivers and other resourceful people. Communication with the rest of the team is of paramount importance. He/she should always be aware of the **climate** within the team and address any conflict or tension, so that the team is able to provide quality patient care.

The social worker should follow patients up at the outpatient clinic and work **preventatively** so as to curb the revolving door syndrome. The social worker also plays an important role in the admission unit and her/his intervention can often prevent an unnecessary admission.

Social workers can initiate **support groups** for patients and/or caregivers, but then these should not depend on the social worker – they should "belong" to the patient system.

The multi-disciplinary team (MDT) focuses mainly on the patient, whereas the partners, families or **caregivers** are often **neglected**. An important role of the social worker in a psychiatric hospital is to reach out specifically to the significant others, because they are the secondary sufferers of the mental illness. If their needs can be addressed, the patient will also benefit. The person with BD should be respected and he/she should make it clear to professionals if they want their family to be involved. The person can even put this in writing so it can be kept on the file. This is an important aspect of the relationship when the social worker contracts with the patient.

The **history** taken from the patient and his/her relatives is essential to make the correct diagnosis. The social worker can play an important role in this regard by obtaining collateral information from family members and others and in compiling a psychosocial report.

It is important that the social worker take cognisance of the **reasons** for high readmission rates, and work in a proactively preventative manner. The reasons for readmission may include a lack of knowledge and insight, substance abuse, violence and high-risk behaviours, lack of support, lack of resources, inadequate or disorganised care pathways and non-adherence to treatment. Psychosocial stressors also play an important role.

Vocational training and **occupational support** may require addressing; they are important needs. In the context of the researcher's workplace, this is a significant responsibility with which the occupational therapist is tasked. However, the social worker does also play a coordinating and facilitating role as regards the patient's employer.

Another role that falls to the social worker is that of resource manager (e.g. community networker). It is very important that he/she should know about the **resources** available in the community in order to be able to exploit them. Consultation with other community and/or social welfare programmes involved, such as residential services/treatment may be needed. The social worker has an important **referral** role in assisting a patient to access community resources, but also to support such resources, should readmission become necessary or should their personnel need any consultation. He/she should liaise with the **community resources** such as the community clinics, mental health organisations, halfway houses and, where applicable, even the patient's private psychiatrist, to ensure continuation of care and rehabilitation. The social worker also plays an important role by involving and coordinating **volunteers** to offer support to the patients.

The social worker is an encourager, educator, developer, facilitator and therapist. Regarding the BD patient, it has been emphasised that CBT could be implemented, and also interpersonal and social rhythm therapy (IPSRT) as well as family and couple therapy.

The researcher wishes to argue that the social worker in the psychiatric hospital can be creative and the role provides a very wide scope. Nonetheless, making the most of the assigned role will depend on the individual social worker.

9.4.2 Recommendations for future social work research

There are a number of possibilities for further research in this and similar populations:

- Investigating and evaluating the psychosocial reasons for readmission to a psychiatric hospital – especially where there are more than three admissions of a particular patient per year.
- A qualitative study of the mother/father and adult child's dynamics where the child is the patient.
- The effect on the parents' relationship if a child is diagnosed with BD.

- An evaluation of the “bipolar marriage” (where one or both of the spouses are diagnosed with BD) and the reasons for the high divorce rate in this population.
- A retrospective study regarding the effect on an adult child who has been obliged to grow up with a bipolar parent.
- Exploring the caregiver’s perceptions regarding the genetic aspects of BD and the impact it has on the lives of the next generation.
- Action research to improve the present SEE-SAW programme.
- An assessment of the needs, fears and frustrations of the different members of the MDT in treating the BP patient system.

9.4.3 Recommendations from MDT colleagues

During the Doctoral research seminar that was presented to MDT colleagues they were requested to give input regarding suggestions for future research. Some also provided general recommendations. Some of the colleagues wrote in cryptic style and simply indicated a possible area of research and thus their recommendations/suggestions are reported as such.

9.4.3.1 Recommendations from MDT colleagues – in general

- In future, maybe also with other diagnoses, maybe a general programme similar to the SEE-SAW programme. Also maybe therapeutic programme in future that will incorporate the knowledge aspects of SEE-SAW programme.
- Write a book for general use. You have all the information. Centres with activities for bipolar people.
- Close interaction with the MDT can enhance and improve the quality of life of both the caregiver and the patient. The caregivers and patients should be persuaded to observe for any changes in their functionality and cognition.
- My suggestion for future is that the programme could be translated in one of the African languages so that it will be applicable to all caregivers of our service beneficiaries (Social Worker).

9.4.3.2 Recommendations from MDT colleagues – future research

- Understanding patients’ and caregivers’ fears and expectations regarding the illness.
- A future follow-up study involving in-depth individual interviews with some of the people who attended the programme, at some point, e.g. 1 year after attending the programme, or 2 years afterwards – to evaluate the effect that the programme has had on them, beyond increasing their knowledge maybe, e.g. how their experiences may have changed. Such a project might also elucidate new needs that they may have become

aware of. The listed recommendations (given during the presentation) are very comprehensive and very practical and useful (Psychiatrist).

- With the amount of young females diagnosed with “Bipolar type illness” and placed on mood stabilizers, psychoeducation should include the safety of medicines in pregnancy/planned pregnancies. The aspect of breastfeeding is also important. A plan for the possible relapse intra and postpartum is necessary (Psychiatrist).
- The research can be adapted to study other diagnoses. The programme could possibly be translated into other languages. A follow-up questionnaire implemented after a longer period when respondents have implemented what they have learnt from the programme, can also be useful (Psychiatrist).
- Further research could involve a follow up to see how caregivers have found the experience of implementing the contents of the SEE-SAW programme. This would help to further develop the programme with the help of the caregiver. Maybe involving the patients in the process of implementing the programme to ensure buy-in from both the caregivers and the patients.
- How different cultures experience the stress that an illness like bipolar imposes on families. Reaction of patients when the programme is being implemented – attitude towards the programme.
- Further validation of this instrument in practice. How can this programme be adjusted for other cultural groups and caregivers who are less literate? Caregiver support groups at OPD can become a registrar research project (Psychiatrist).
- Explore the role of witchcraft in bipolar disorder. Explore cultural differences – how do African people understand bipolar?
- Follow up with the research participants in a year’s time. To find out how the programme was, negatives/positives. To find ways on how to improve on it. Go to schools to present the programme because there are many children whose parents have bipolar and they also don’t know how to cope.

It was clear that colleagues did see the need for follow up studies and the researcher agrees with them, but that is beyond the scope of this specific study.

9.5 CONCLUDING REMARKS

In 2012, in the U.K., Labour leader, Ed Miliband addressed the Royal College of Psychiatrists on mental health and stated that mental ill-health is a “cradle to grave” problem, but with nothing like a “cradle to grave” service. According to the World Health Organization, one in four of us will have a mental illness at some point in our lifetime. The WHO predicts that by 2030, depression will be the leading cause of disease around the world. Good mental health does not start in hospital or the treatment room. It starts in our workplaces, our schools and our communities (Miliband, 2012; http://www.newstatesman.com).

The researcher identifies with what this politician has said and is of the opinion that good mental health starts at home; it is therefore essential to involve the whole family in treatment.

BD can be a devastating illness, seriously affecting not only the person with BD but also their children, partners, parents, family and friends. While most people are familiar with the terms “manic depressive” and “bipolar disorder”, there remains a lack of real understanding about the illness so that many sufferers and their families can feel helpless, alone and misunderstood. In spite of this, many people living with BD have written books or made DVD’s regarding their experiences with this illness. This was indicated throughout the study. These are stories of hope and courage that can be used to create hope for BD sufferers.
It is hoped that this research has improved, and in future will still improve, the lives of many living with BD.

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General

The researcher here includes **seminars** that she has been attending over the last few years to improve her knowledge on bipolar disorder and also **experts** that she has consulted:

Seminars:

A morning of reflection on bipolar disorder. 2010. Lecture presented by Stella Street Dutch Reformed Church. 17 April, Pretoria.

Bipolar mood disorder. A seminar for patients and families. 2008. Presented by Dreyer, H. & Colin, F. September. Pretoria.

Deconstructing bipolar mood disorder, 2013. Presented by Aspen. 20 July, Benoni.

Depression seminar. 2012. Hana Event Solutions. 15 September. Pretoria.

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Ladikos, A., Winter, C., Venter, A., Rademeyer, M. & Redelingshuys, S. 2009. *Perspectives on bipolar disorder in South African children and adolescents.* Child Trauma Clinic Seminar. 13 March, Pretoria, South Africa.

Seminar on mood disorders. 2011. Presented by the South African Society of Clinical Hypnosis. 7 May, Pretoria.

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Experts consulted

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Grobler, I., Senior Occupational Therapist, Weskoppies Hospital. 2010. Interview by researcher. 10 January. Pretoria.

Kleyn, J., Statistician, University of Pretoria. 2014. Interview by researcher. 9 September. Pretoria.

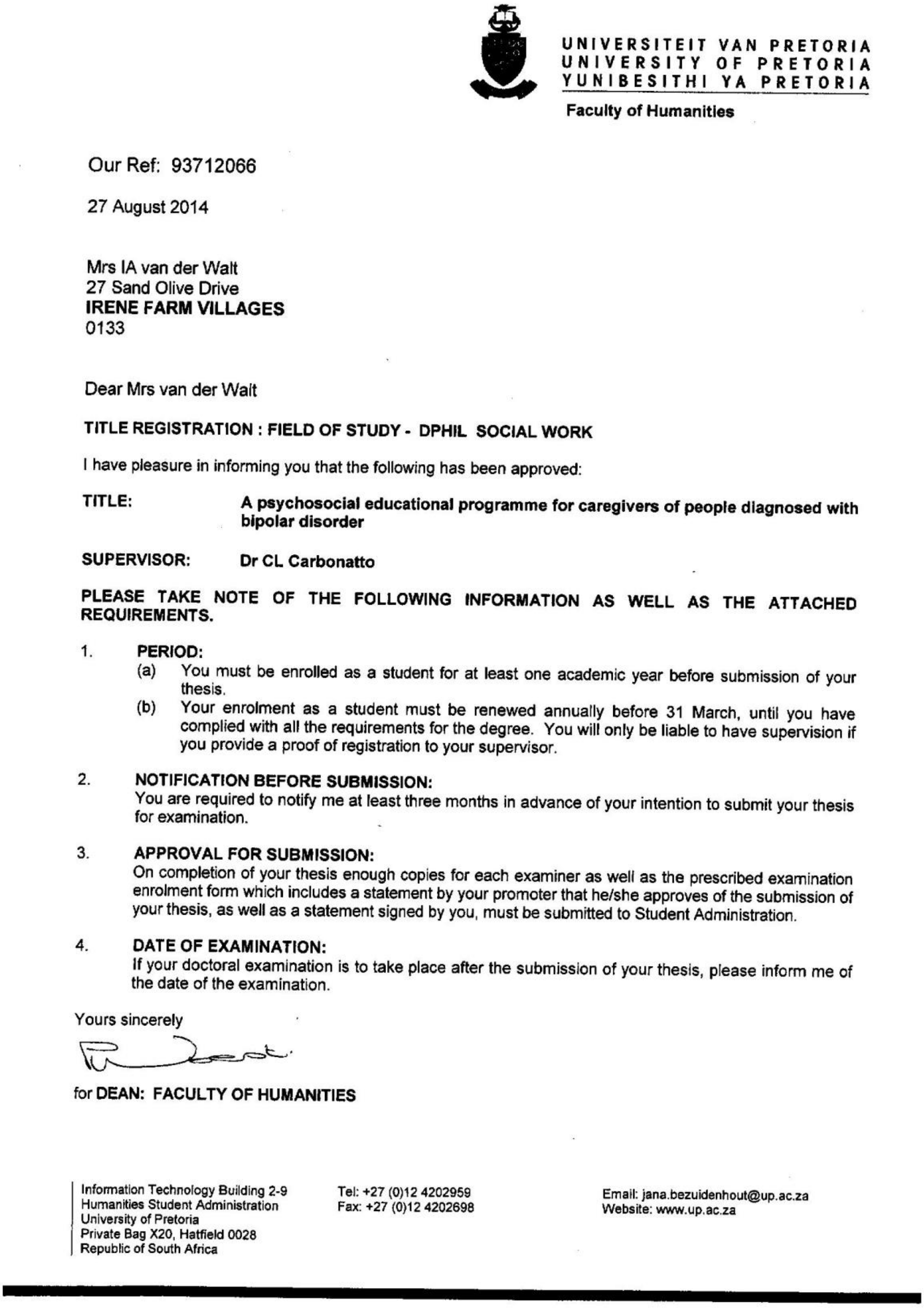
Krüger, C., Professor of Psychiatry, Weskoppies Hospital. 2010. Interview by researcher. 16 January. Pretoria.

Roos, J.L., Professor of Psychiatry, Weskoppies Hospital. 2010. Interview by researcher. 29 January. Pretoria.

Van Staden, C.W., Professor of Philosophy and Psychiatry, Faculty of Health Sciences University of Pretoria. 2011. Interview by researcher. 7 April. Pretoria.

11. APPENDICES

Appendix 1.1: New Title of Study



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

Our Ref: 93712066

27 August 2014

Mrs IA van der Walt
27 Sand Olive Drive
IRENE FARM VILLAGES
0133

Dear Mrs van der Walt

TITLE REGISTRATION : FIELD OF STUDY - DPHIL SOCIAL WORK

I have pleasure in informing you that the following has been approved:

TITLE: **A psychosocial educational programme for caregivers of people diagnosed with bipolar disorder**

SUPERVISOR: **Dr CL Carbonatto**

PLEASE TAKE NOTE OF THE FOLLOWING INFORMATION AS WELL AS THE ATTACHED REQUIREMENTS.

1. **PERIOD:**
   (a) You must be enrolled as a student for at least one academic year before submission of your thesis.
   (b) Your enrolment as a student must be renewed annually before 31 March, until you have complied with all the requirements for the degree. You will only be liable to have supervision if you provide a proof of registration to your supervisor.

2. **NOTIFICATION BEFORE SUBMISSION:**
   You are required to notify me at least three months in advance of your intention to submit your thesis for examination.

3. **APPROVAL FOR SUBMISSION:**
   On completion of your thesis enough copies for each examiner as well as the prescribed examination enrolment form which includes a statement by your promoter that he/she approves of the submission of your thesis, as well as a statement signed by you, must be submitted to Student Administration.

4. **DATE OF EXAMINATION:**
   If your doctoral examination is to take place after the submission of your thesis, please inform me of the date of the examination.

Yours sincerely

for **DEAN: FACULTY OF HUMANITIES**

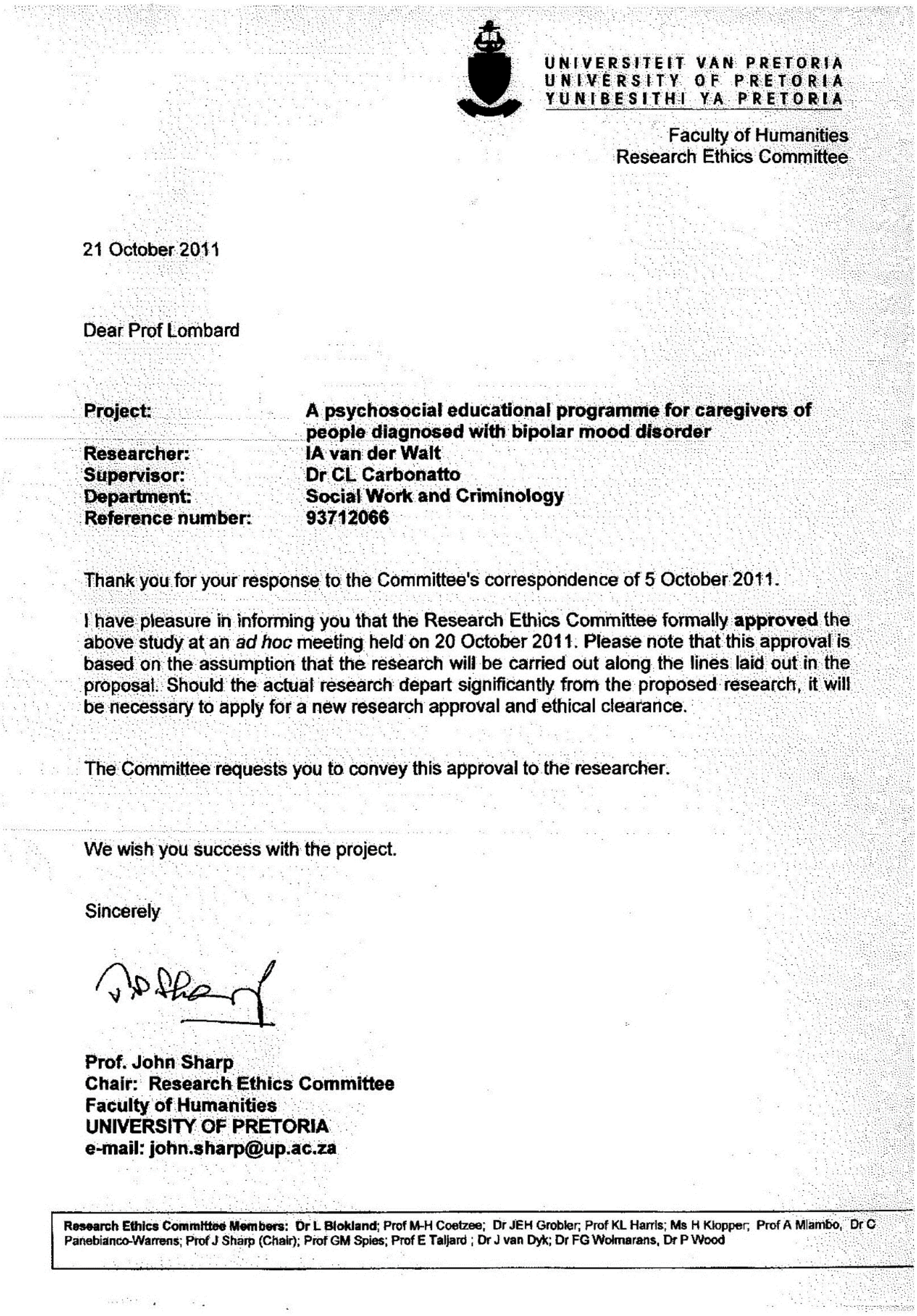
Information Technology Building 2-9
Humanities Student Administration
University of Pretoria
Private Bag X20, Hatfield 0028
Republic of South Africa

Tel: +27 (0)12 4202959
Fax: +27 (0)12 4202698

Email: jana.bezuidenhout@up.ac.za
Website: www.up.ac.za

Appendix 1.2: Ethical Approvals

Appendix 1.2.1: Faculty of Humanities



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

21 October 2011

Dear Prof Lombard

Project:	**A psychosocial educational programme for caregivers of people diagnosed with bipolar mood disorder**
Researcher:	**IA van der Walt**
Supervisor:	**Dr CL Carbonatto**
Department:	**Social Work and Criminology**
Reference number:	**93712066**

Thank you for your response to the Committee's correspondence of 5 October 2011.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 20 October 2011. Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. John Sharp
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za

Appendix 1.2.2: Faculty of Health Sciences

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences
Research Ethics Committee

17 August 2011

The Chairperson
Research Ethics Committee
Faculty of Humanities
University of Pretoria

Dear Professor

RE: Confirmation of submission for ethics approval by I van der Walt – 93712066 – DPhil (Social Work)

I hereby confirm that the above student submitted her application for ethics approval at the Faculty of Health Science Research Ethics Committee as required by the National Health Act regarding health-related research. Her application is currently being considered.

Please do not hesitate to contact me should you want to discuss the submission.

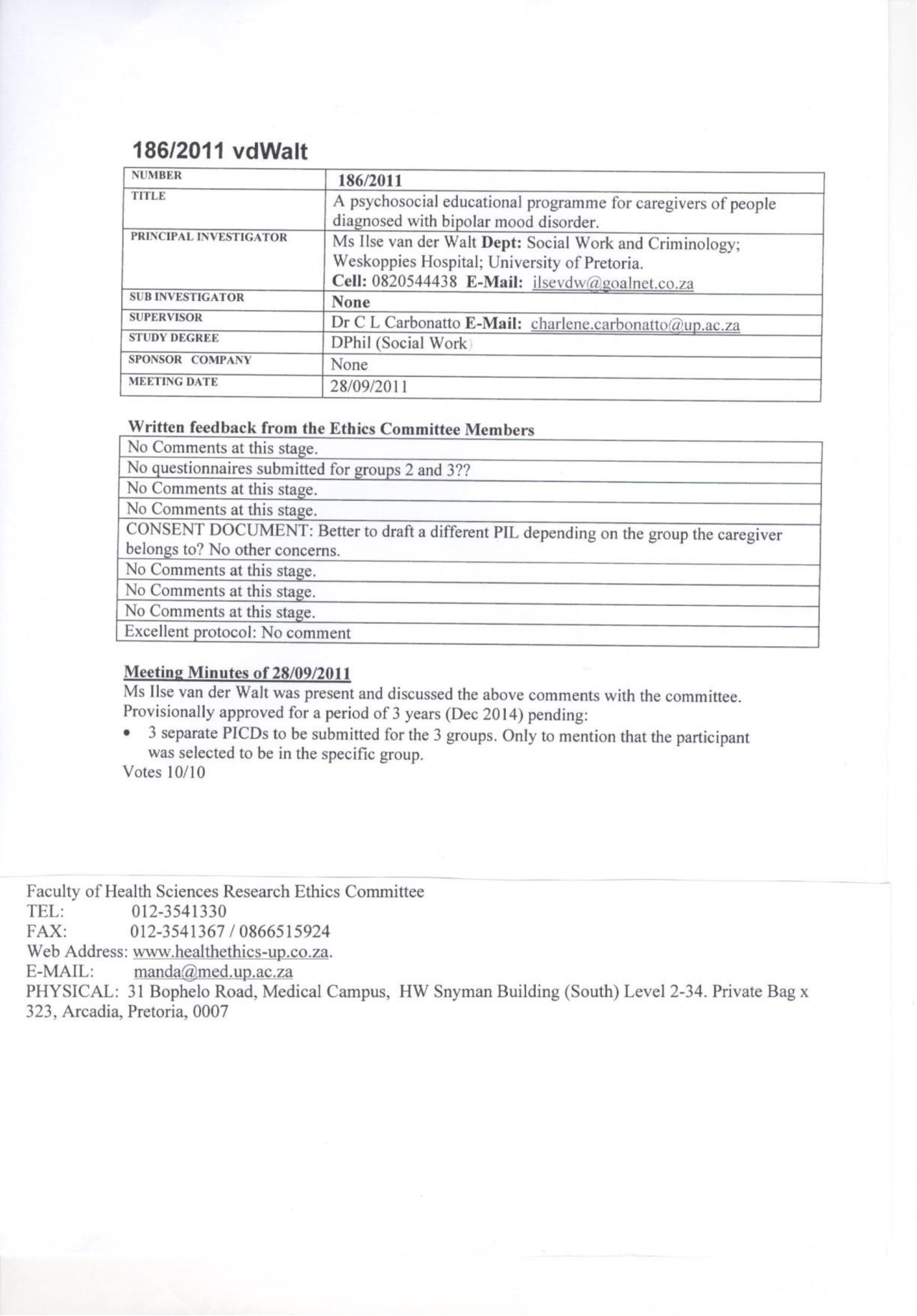
Yours sincerely

Professor Werdie (CW) Van Staden
Chairperson

Chairperson: Research Ethics Committee
Faculty of Health Sciences
University of Pretoria
Pretoria 0020 South Africa

Tel +27 (0)12 319 9748
Fax +27 (0)86 593 0500
Mobile +27 (0)82 934 4668

e-mail: werdie.vanstaden@up.ac.za



186/2011 vdWalt

NUMBER	**186/2011**
TITLE	A psychosocial educational programme for caregivers of people diagnosed with bipolar mood disorder.
PRINCIPAL INVESTIGATOR	Ms Ilse van der Walt **Dept:** Social Work and Criminology; Weskoppies Hospital; University of Pretoria. **Cell:** 0820544438 **E-Mail:** ilsevdw@goalnet.co.za
SUB INVESTIGATOR	**None**
SUPERVISOR	Dr C L Carbonatto **E-Mail:** charlene.carbonatto@up.ac.za
STUDY DEGREE	DPhil (Social Work)
SPONSOR COMPANY	None
MEETING DATE	28/09/2011

Written feedback from the Ethics Committee Members

No Comments at this stage.
No questionnaires submitted for groups 2 and 3??
No Comments at this stage.
No Comments at this stage.
CONSENT DOCUMENT: Better to draft a different PIL depending on the group the caregiver belongs to? No other concerns.
No Comments at this stage.
No Comments at this stage.
No Comments at this stage.
Excellent protocol: No comment

Meeting Minutes of 28/09/2011

Ms Ilse van der Walt was present and discussed the above comments with the committee. Provisionally approved for a period of 3 years (Dec 2014) pending:

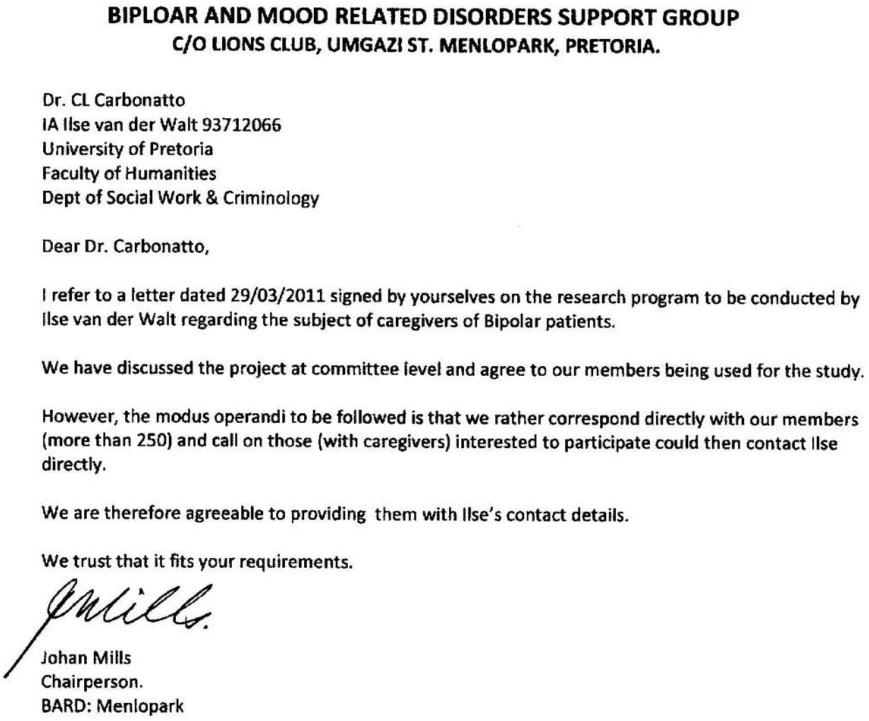
- 3 separate PICDs to be submitted for the 3 groups. Only to mention that the participant was selected to be in the specific group.

Votes 10/10

Faculty of Health Sciences Research Ethics Committee
TEL: 012-3541330
FAX: 012-3541367 / 0866515924
Web Address: www.healthethics-up.co.za.
E-MAIL: manda@med.up.ac.za
PHYSICAL: 31 Bophelo Road, Medical Campus, HW Snyman Building (South) Level 2-34. Private Bag x 323, Arcadia, Pretoria, 0007

Appendix 1.3: Letters of Permission

Appendix 1.3.1: Bipolar Support Group



BIPLOAR AND MOOD RELATED DISORDERS SUPPORT GROUP
C/O LIONS CLUB, UMGAZI ST. MENLOPARK, PRETORIA.

Dr. CL Carbonatto
IA Ilse van der Walt 93712066
University of Pretoria
Faculty of Humanities
Dept of Social Work & Criminology

Dear Dr. Carbonatto,

I refer to a letter dated 29/03/2011 signed by yourselves on the research program to be conducted by Ilse van der Walt regarding the subject of caregivers of Bipolar patients.

We have discussed the project at committee level and agree to our members being used for the study.

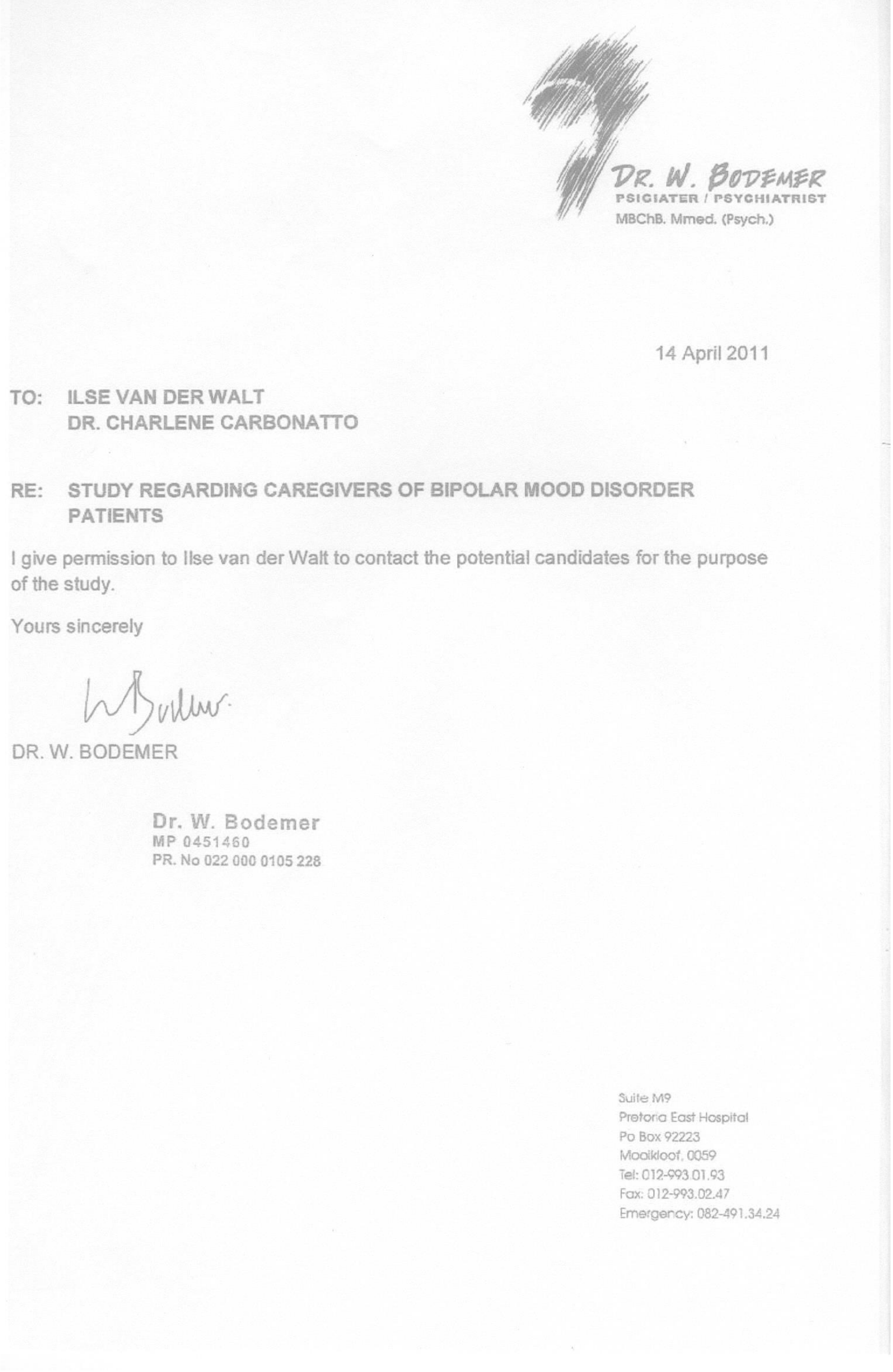
However, the modus operandi to be followed is that we rather correspond directly with our members (more than 250) and call on those (with caregivers) interested to participate could then contact Ilse directly.

We are therefore agreeable to providing them with Ilse's contact details.

We trust that it fits your requirements.

Johan Mills
Chairperson.
BARD: Menlopark

Appendix 1.3.2: Private Psychiatrist



DR. W. BODEMER
PSIGIATER / PSYCHIATRIST
MBChB. Mmed. (Psych.)

14 April 2011

TO: ILSE VAN DER WALT
DR. CHARLENE CARBONATTO

RE: STUDY REGARDING CAREGIVERS OF BIPOLAR MOOD DISORDER PATIENTS

I give permission to Ilse van der Walt to contact the potential candidates for the purpose of the study.

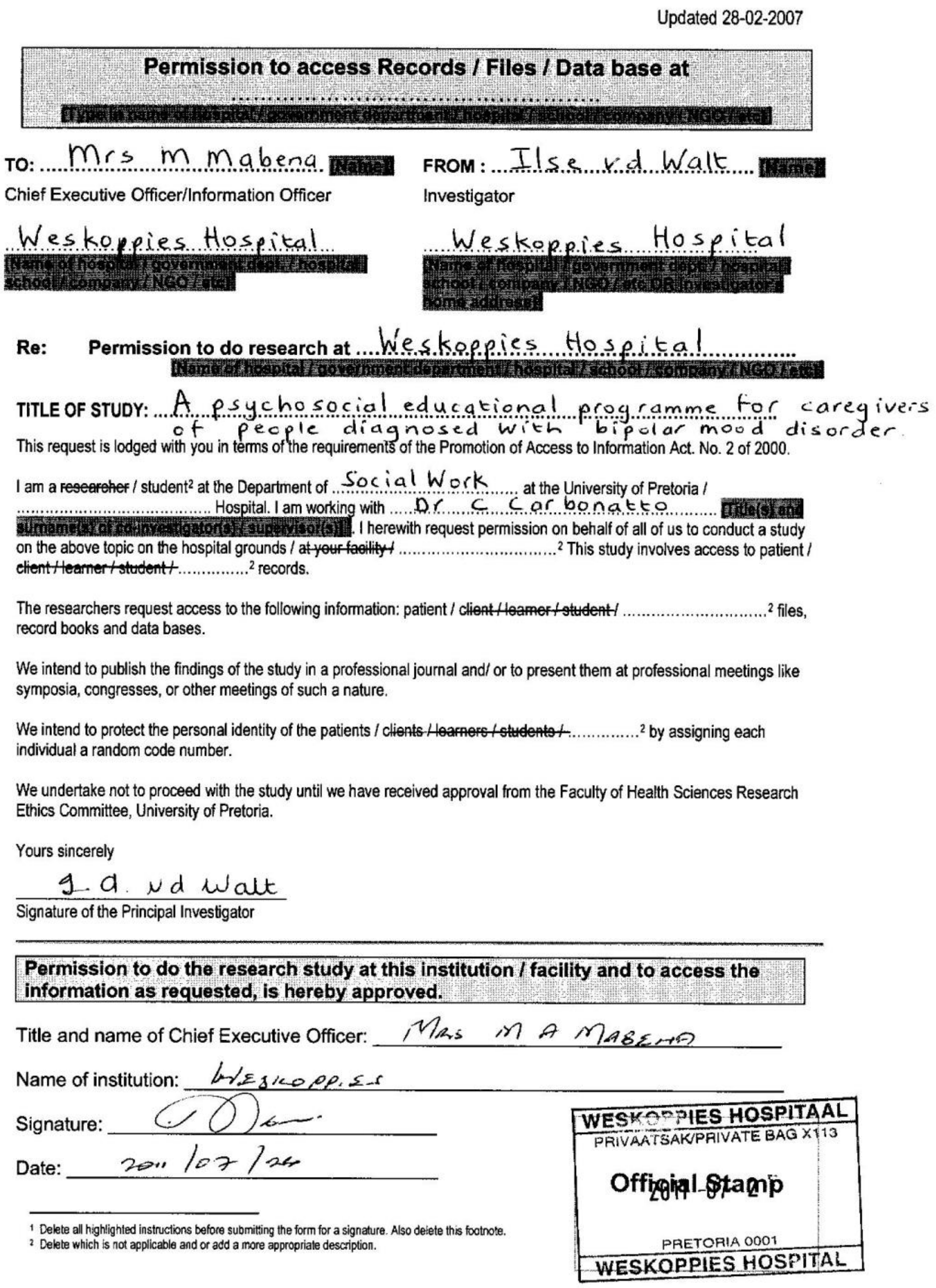
Yours sincerely

DR. W. BODEMER

Dr. W. Bodemer
MP 0451460
PR. No 022 000 0105 228

Suite M9
Pretoria East Hospital
Po Box 92223
Moolkloof, 0059
Tel: 012-993.01.93
Fax: 012-993.02.47
Emergency: 082-491.34.24

Appendix 1.3.3: Permission to Access Records – CEO of Hospital



Updated 28-02-2007

Permission to access Records / Files / Data base at

....

[Type in name of hospital / government department / hospital / school / company / NGO / etc]

TO: Mrs M Mabena [Name]
Chief Executive Officer/Information Officer

Weskoppies Hospital
[Name of hospital / government dept. / hospital / school / company / NGO / etc]

FROM : Ilse vd Walt [Name]
Investigator

Weskoppies Hospital
[Name of hospital / government dept / hospital / school / company / NGO / etc OR investigator's home address]

Re: Permission to do research at Weskoppies Hospital
[Name of hospital / government department / hospital / school / company / NGO / etc]

TITLE OF STUDY: A psychosocial educational programme for caregivers of people diagnosed with bipolar mood disorder.

This request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

I am a ~~researcher~~ / student[2] at the Department of Social Work at the University of Pretoria / .... Hospital. I am working with Dr C Carbonatto [Title(s) and surname(s) of co-investigator(s) / supervisor(s)]. I herewith request permission on behalf of all of us to conduct a study on the above topic on the hospital grounds / ~~at your facility /~~ ....[2] This study involves access to patient / ~~client / learner / student /~~ ....[2] records.

The researchers request access to the following information: patient / ~~client / learner / student /~~ ....[2] files, record books and data bases.

We intend to publish the findings of the study in a professional journal and/ or to present them at professional meetings like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of the patients / ~~clients / learners / students /~~ ....[2] by assigning each individual a random code number.

We undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely

I. a. vd Walt
Signature of the Principal Investigator

Permission to do the research study at this institution / facility and to access the information as requested, is hereby approved.

Title and name of Chief Executive Officer: Mrs M A Mabena

Name of institution: Weskoppies

Signature:

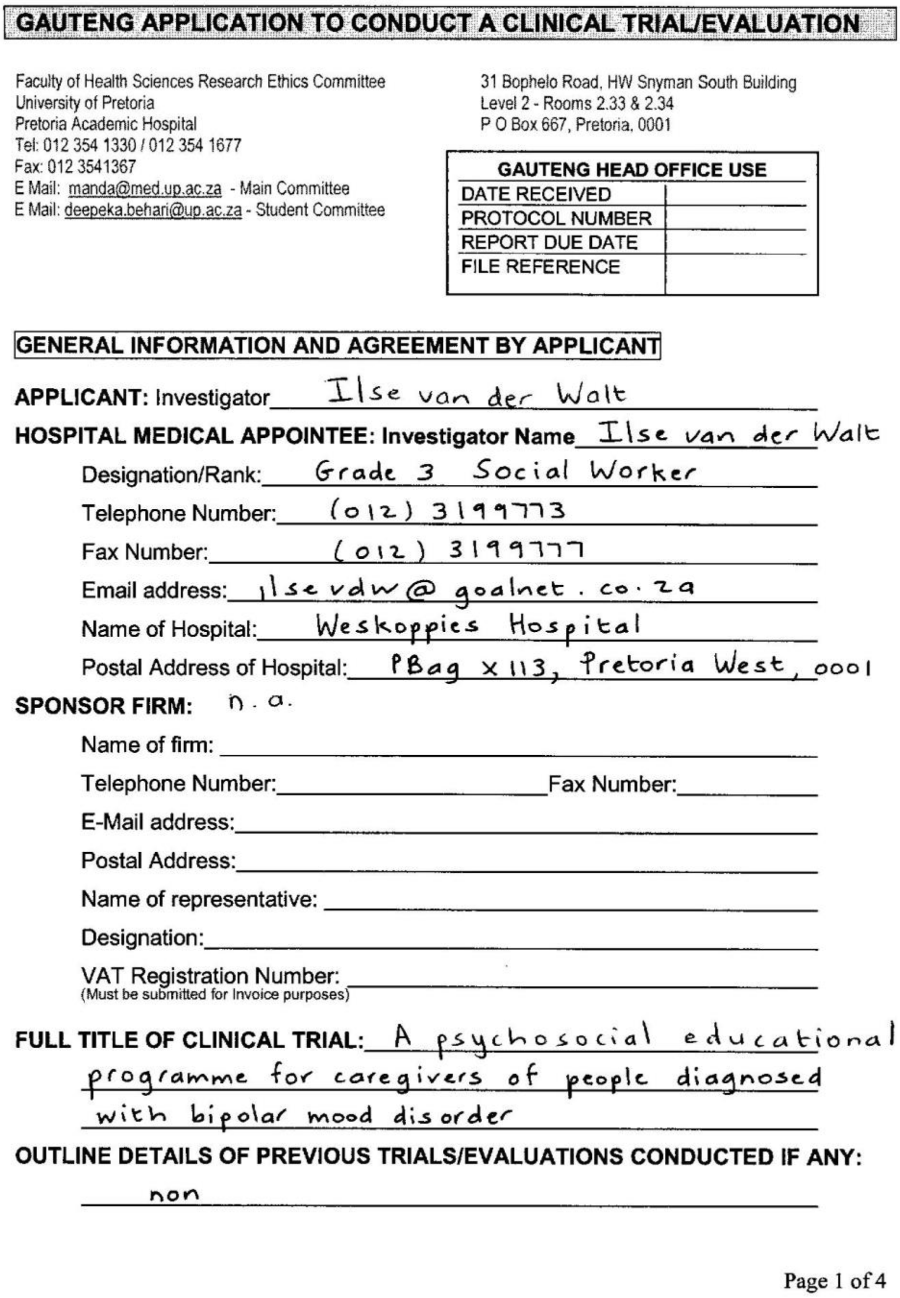
Date: 2011/07/26

WESKOPPIES HOSPITAAL
PRIVAATSAK/PRIVATE BAG X113
Official Stamp
2011 -07- 2
PRETORIA 0001
WESKOPPIES HOSPITAL

---

[1] Delete all highlighted instructions before submitting the form for a signature. Also delete this footnote.
[2] Delete which is not applicable and or add a more appropriate description.

Appendix 1.3.4: Gauteng Application to Conduct a Clinical Trial/Evaluation



GAUTENG APPLICATION TO CONDUCT A CLINICAL TRIAL/EVALUATION

Faculty of Health Sciences Research Ethics Committee
University of Pretoria
Pretoria Academic Hospital
Tel: 012 354 1330 / 012 354 1677
Fax: 012 3541367
E Mail: manda@med.up.ac.za - Main Committee
E Mail: deepeka.behari@up.ac.za - Student Committee

31 Bophelo Road, HW Snyman South Building
Level 2 - Rooms 2.33 & 2.34
P O Box 667, Pretoria, 0001

GAUTENG HEAD OFFICE USE	
DATE RECEIVED	
PROTOCOL NUMBER	
REPORT DUE DATE	
FILE REFERENCE	

GENERAL INFORMATION AND AGREEMENT BY APPLICANT

APPLICANT: Investigator Ilse van der Walt

HOSPITAL MEDICAL APPOINTEE: Investigator Name Ilse van der Walt

Designation/Rank: Grade 3 Social Worker

Telephone Number: (012) 3199773

Fax Number: (012) 3199777

Email address: ilsevdw@goalnet.co.za

Name of Hospital: Weskoppies Hospital

Postal Address of Hospital: PBag x113, Pretoria West, 0001

SPONSOR FIRM: n.a.

Name of firm:

Telephone Number: Fax Number:

E-Mail address:

Postal Address:

Name of representative:

Designation:

VAT Registration Number:
(Must be submitted for Invoice purposes)

FULL TITLE OF CLINICAL TRIAL: A psychosocial educational programme for caregivers of people diagnosed with bipolar mood disorder

OUTLINE DETAILS OF PREVIOUS TRIALS/EVALUATIONS CONDUCTED IF ANY:

non

Page 1 of 4

TRIAL/EVALUATION PRODUCT (S) Name the product(s) and state the mode of application(s)

____

REGISTRATION ______________________________

PHARMACEUTICAL

State MEDICINE CONTROL COUNCIL registration number: ______________
If not registered state MCC trial approval number and attach officially approval letter.

____

NON-PHARMACEUTICAL

State registration/code number : ______________________________

What is the estimated cost of these investigations? ______________________________

Who will be responsible for these costs? ______________________________

What other equipment will be required for the trial? ______________________________

____

What arrangements have been made for those investigations and with whom?

____

ARE ANY SPECIAL PRECAUTIONARY MEASURES TO BE TAKEN AND BY WHOM?

____

____

INDICATE EXPECTED DATE OF TRIAL / EVALUATION REPORT :

DAY	MONTH	YEAR
Start	September	2011
end	August	2012

INDICATE NUMBER OF PATIENTS INVOLVED : zero, only caregivers

THE NAME OF THE HEAD OF THE DEPARTMENT:

Mrs J Skosana

WILL SUFFICIENT TRIAL/EVALUATION MATERIAL BE SUPPLIED? (✓) ☐ Yes ☐ No

INVESTIGATIONS

WHAT LABORATORY AND OTHER INVESTIGATIONS WILL BE REQUIRED OVER AND ABOVE THOSE NORMALLY REQUIRED.

____

AGREEMENT BY APPLICANT

- The applicant(s) agree(s) as follows
- To conduct the trial/evaluation recorded in and under the conditions set out in this application form.
- To conduct this trial/evaluation at no additional expense to the Gauteng Department of Health whatsoever.
- To accept full responsibility for any or all-possible harmful effects on a patient using my/our/ the product recorded in his application form.
- To exonerate the Gauteng Department of Health from all liability of damages, legal,financial or otherwise, including my claim instituted by a patient using my/ our/ the product recorded in this application form, but excluding negligence on the part of the medical officer and/ or employee of the Gauteng Department of Health using the said product on the patient's concerned: provided that the medical officer and/ or employee is not the applicant.
- To inform the Superintendent General: Gauteng Department of Health and other relevant authorities should it be deemed necessary to deviate from protocol or stop this trial/ evaluation.
- To make available without delay all the results of this trial/ evaluation to the Superintendent General: Gauteng Department of Health.
- I/ We understand that the Superintendent-General: Gauteng Department of Health having allowed this trial/ evaluation to be conducted places himself or herself or the Gauteng Department of Health under no obligation whatsoever and to leave the final choice of the institution where the trial/ evaluation will be conducted to the Superintendent- General: Gauteng Department of Health.

THE APPLICANT MUST SIGN HERE

APPLICANT- INVESTIGATOR			**DATE**		
Signature	**Initial(s)**	**Surname**	**Day**	**Month**	**Year**
I. a. vdWalt	I. A.	Van der Walt	25	July	2011

Designation/ Rank:

SPONSOR FIRM - IF THERE IS A FIRM INVOLVED- THEY MUST SIGN HERE n. a.

MANAGING DIRECTOR OR REPRESENTATIVE			**DATE**		
Signature	**Initial(s)**	**Surname**	**Day**	**Month**	**Year**

Designation/ Rank:

IT IS VERY IMPORTANT THAT 2 WITNESSES MUST SIGN IF A FIRM IS INVOLVED! n. a.

WITNESSES			**DATE**		
Signature	**Initial(s)**	**Surname**	**Day**	**Month**	**Year**
1.					
2.					

Page 3 of 4

INITIAL CONSENT BY DEPARTMENTAL HEAD

I Jane Maud Mokgaetji Skosana head of Social Work department of Weskoppies hospital in consultation with the Chief Executive Officer / Superintendent of this Hospital grant permission to submit an application to conduct a clinical trial/evaluation to the Chairperson (s) of the relevant Ethics, Research and Therapeutic Committees of this Hospital.

The officer conducting the trial/evaluation will be Mrs Ilse van der Walt

Designation / Rank Grade 3 Social Worker

THE HEAD OF THE DEPARTMENT MUST SIGN HERE!

HEAD OF DEPARTMENT			DATE		
Signature	**Initial(s)**	**Surname**	**Day**	**Month**	**Year**
JSkosana	J.M.M.	SKOSANA	21	07	2011

THE APPLICANT MUST SIGN HERE

TRIALIST-INVESTIGATOR			DATE		
Signature	**Initial(s)**	**Surname**	**Day**	**Month**	**Year**
I. A. v d Walt	I. A.	Van der Walt	21	07	2011

THE APPLICANT THAT APPLY FOR THIS STUDY MUST SEE TO IT THAT THE SUPERINTENDENT / C.E.O. OF THE HOSPITAL WHERE THE STUDY WILL BE DONE - SIGN HERE BEFORE THE ETHICAL COMMITTEE RECEIVE THIS APPLICATION FORM.

APPROVAL BY HOSPITAL CHIEF EXECUTIVE OFFICER:

I Mrs M A MABENA Chief Executive Officer / superintendent of WESKOPP. EJ Hospital, hereby agree that this trial / evaluation be conducted in the PSYCHIATRIC Department of this hospital.

The officer conducting the trial will be : ______________________

The officer controlling supplies will be: ______________________

HOSPITAL C.E.O. / Superintendent			DATE		
Signature	**Initial(s)**	**Surname**	**Day**	**Month**	**Year**
	M A	MABENA	26	07	2011

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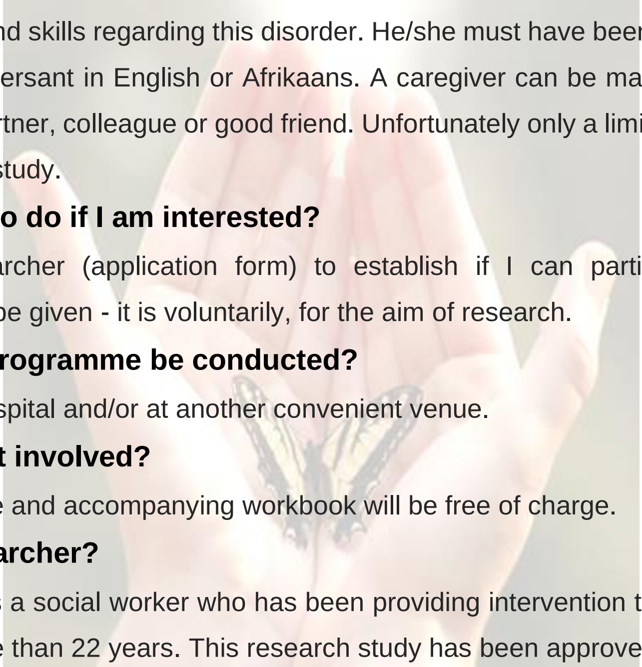
Appendix 1.4: Pamphlet about the Research

A study is being conducted about the needs of caregivers of people diagnosed with BD and a one day subsequent programme will then be available. In an effort to better understand the needs of caregivers of people diagnosed with BD, they will be interviewed and will then be invited to attend the SEE-SAW programme. The title of the study is: “A psychosocial educational programme for caregivers of people diagnosed with bipolar disorder”. We are inviting interested caregivers to join in the study.

Can I participate?



We are looking for caregivers of adult people with confirmed diagnosis of BD interested in gaining more knowledge and skills regarding this disorder. He/she must have been a caregiver for 3 months or longer and conversant in English or Afrikaans. A caregiver can be male/female, a parent, child, sibling, spouse, partner, colleague or good friend. Unfortunately only a limited number of people can be included in the study.

What do I have to do if I am interested?

Contact the researcher (application form) to establish if I can participate in the study. No compensation will be given - it is voluntarily, for the aim of research.

Where will the programme be conducted?

At Weskoppies Hospital and/or at another convenient venue.

Is there any cost involved?

No, the programme and accompanying workbook will be free of charge.

Who is the researcher?

Ilse van der Walt is a social worker who has been providing intervention to psychiatric patients and caregivers for more than 22 years. This research study has been approved by the Faculty of Health Sciences Research Ethics Committee and the Faculty of Humanities Research Ethics Committee, University of Pretoria.

Bipolar Mood Disorder Programme

Application Form

Please tick if applicable

Yes, I am interested in participating in this research.☐

I would like more information about the research.☐

I am a caregiver of a person with a confirmed diagnosis of bipolar disorder.☐

I may be contacted by the researcher.☐

Name:___________________________________

Address: _________________________________

Telephone numbers:______________________

Cell number: ____________________________

E-mail: __________________________________

The researcher will contact you after receiving your details:

Name:	Ilse van der Walt
Address:	PO Box 61232, Pierre van Ryneveld, 0045
Telephone numbers:	(012) 319 9773 (Work); 082 05 444 38 (Mobile)
E-mail:	ilsevdw@vodamail.co.za

Shared joy is double joy;
shared sorrow is half a sorrow.
Swedish proverb

If you want to have a happy and stable relationship, you have to treat bipolar first
Fast & Preston (2004)

Appendix 1.5: Information Consent

Appendix 1.5.1: Information Leaflet and Informed Consent for Non-Clinical Research No. 1

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work & Criminology

INFORMATION LEAFLET AND INFORMED CONSENT FOR NON-CLINICAL RESEARCH

A. INFORMATION LEAFLET nr 1

TITLE OF STUDY: A psychosocial educational programme for caregivers of people diagnosed with bipolar disorder.
RESEARCHER: **Ilse van der Walt**
DEGREE: **DPhil (Social Work)**

Dear Participant

1) INTRODUCTION

We invite you to participate in a research study, because you have been identified as a caregiver of a person being diagnosed with bipolar disorder. This information leaflet will help you to decide if you want to participate. Before you agree to take part, you should fully understand what is involved. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask the researcher, Ilse van der Walt, a doctoral research student of the University of Pretoria, Department of Social Work and Criminology.

2) THE NATURE AND PURPOSE OF THIS STUDY

The purpose of this research is to do a study on the needs of the caregivers of people diagnosed with bipolar disorder. Furthermore, based on identified needs, a one day psychosocial educational **programme** will be developed, implemented and evaluated to assist caregivers to live better with this illness. You as a caregiver are a very important source of information to make sure that this research will be relevant.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

If you agree to participate, the following will occur:

The researcher will interview you in order to explore your **experiences** and your **needs**, being a caregiver of a person diagnosed with bipolar disorder.

You will be required to participate in an audio taped semi-structured interview. You will be asked to respond as honestly as possible to all the questions asked. If you are interested you will be able to attend the one day psychosocial educational programme, based on the needs of caregivers of people diagnosed with bipolar disorder, at a later stage.

The **contact session** (about your needs or your knowledge) will take place at a private, convenient place. You will be contacted to arrange a time and date. The procedure will take approximately one hour of your time. Demographic information concerning your age, gender, race and background will be required. The content of the psychosocial educational **programme** will still be developed because it will be based on the said needs of caregivers. The programme will be conducted at a convenient venue and no costs will be involved.

4) RISK AND DISCOMFORT INVOLVED

You may feel sad, somewhat uncomfortable or angry sharing your feelings, needs and experiences. You can stop the interviewer or leave at any time should you not want to continue with the interview. You can be referred for counselling if you have the need.

5) POTENTIAL BENEFITS OF THIS STUDY

Although you will not benefit directly from the study, it will give you an opportunity to voice your experience and needs. You might gain more insight into your own ways of coping. You will also help clinicians to obtain a better understanding of caregivers and their challenges.

6) WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time during the study or interview without any negative consequences.

7) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committee of the Faculty of Health Science and the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria. Copies of the approval letters are available if you wish to have one.

8) INFORMATION AND CONTACT PERSON

The contact person for the study is Ilse van der Walt. If you have any questions about the study please contact her at telephone (012) 3199773 or cell 082 05 444 38. Alternatively you may contact my supervisor at telephone (012) 4202410.

9) COMPENSATION

Your participation is voluntary. You will not receive financial benefits by participating in this study.

10) CONFIDENTIALITY

All information that you give will be kept strictly confidential. Your research records, which include the demographic information and tape-recordings, will be stored in a secure place and will also be kept a further 15 years thereafter at the University of Pretoria. Any information derived from this research study that personally identifies you will only be seen by the researcher and will not be voluntarily released or disclosed by the researcher without your separate consent. Your identity will remain anonymous and a pseudonym or false name will be used for your data. Should you withdraw from the study for any reason, your data will be destroyed. Research reports and articles in scientific journals will not include any information that may identify you or the hospital.

Should you require more information about the study you may contact the researcher on:
Mobile: 082 05 444 38 Work: (012) 3199773 Home: (012) 662 5708
E-mail: ilsevdw@goalnet.co.za
Kind regards.

Ilse van der Walt	Dr Charlene Carbonatto
RESEARCHER	**SUPERVISOR**

B. CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about the nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (information leaflet and informed consent) regarding the study. I am aware of what is required of me as a participant. I have read and understand how the research process will be followed. I am aware that the results of the study, including personal details, will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study.

Please complete the form below:
I have read and understood the purpose of this study and agree to participate voluntarily. I have received a signed copy of this informed consent agreement.

Participant
Name and Surname:………………………………….………………………………………(please print)
Signature:………………………………………..…………………………………………...
Date:…………………………………………………………..…………………………………

I have explained the study to the participant and provided him/her with a copy of the participant information sheet.
Researcher
Name and Surname: Ilse van der Walt

Signature: ..…………………………………………………………………………………....

Name in print: ……………………………………………………………………………...

Date:…………………………………………………………………………………………….

Appendix 1.5.2: Semi–Stuctured Interview Schedule for Caregivers of People Being Diagnosed with Bipolar Disorder

TITLE OF STUDY

A psychosocial educational programme for caregivers of people diagnosed with bipolar disorder.

INTRODUCTION

Thank you for agreeing to participate in my study. Before we begin I would like us to go through the informed consent form so that you can get a better idea of why I am doing the research and also about your rights as a participant in my study. (This will be done in case it has not been done prior this interview). If you have any questions at any time, please feel free to ask and interrupt if necessary.

Do you have any questions before we begin?

QUESTIONS

1. **Can you tell me a little bit about yourself? Just give me a brief description of who you are and anything else that you think I might want to know about you.**

- Your relationship with the patient?
- Family context/ background.
- Mental illness within your broader family.
- Your future aspirations.

2. **Do you consider yourself to be a caregiver of the person suffering from bipolar disorder?**
3. **Tell me more about yourself as caregiver.**

- Understanding and clarifying role definition from caregiver’s point of view.
- Limitations and/or benefits it puts on your life.
- Life style changes you had to make since the patient has been diagnosed.
- Losses or gains you have had because of the patient’s illness.

4. **Tell me more about your needs in your role as a caregiver.**

- Understanding bipolar disorder (symptoms, triggers).
- Understanding the treatment for bipolar disorder/ biopsychosocially.
- Being able to accommodate behaviour coupled with this disorder (aggressiveness, suicidal tendencies, substance abuse, psychosis, promiscuous behaviour, spending money and impulsiveness).
- Need to be informed about possible resources available.
- Need to be more involved with the patient’s treating team and to be informed.

5. **Share with me any feelings/ emotions you experience as a result of caregiving.**

- Possible feelings could include: depression, anger, irritation, frustration, worry, fear, emotional pain, feeling guilty or resentful, feeling hopeless, feeling overwhelmed, feeling out of control and burnout.

6. Share with me any challenges or the most common thing you face daily regarding this illness when the patient is ill?

7. How do you deal with these challenges?

- Lack of knowledge and skills to handle the patient.
- Lack of coping mechanisms and/or survival strategies.
- Lack of support.
- Compromising your social life.
- Concerns about your children.
- Concerns about your own future.
- Living with the stigma attached to mental illness.
- Lack of recognition for your sacrifices.

8. Can you identify anything that will make it easier for you to be a caregiver?

9. Discuss what strengths and weaknesses you have identified in yourself that have helped you to cope to be a caregiver?

10. What are personality characteristics or skills you think a caregiver needs to be an efficient caregiver?

11. Would you like someone to help you with the caregiving and to make turns in order to have one day off? Motivate. Do any family or friends help you in this role?

12. Would it help you in any way to attend a psychosocial educational programme, based on the needs of caregivers, to offer support and to improve your skills? What day and time would suite you?

Yes/No:………………………………………………………………………………………..
Day of the week:……………………………………………………………………………..
Time of the day:……………………….………………………………………………………...

13. Do you perhaps have any questions or concerns?

Thank you for your time.
We have come to the end of our interview.
Your contribution is much appreciated.

Appendix 1.5.3: Information Leaflet and Informed Consent for Non-Clinical Research No. 2

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work & Criminology

INFORMATION LEAFLET AND INFORMED CONSENT FOR NON-CLINICAL RESEARCH

A. INFORMATION LEAFLET nr 2

TITLE OF STUDY: A psychosocial educational programme for caregivers of people diagnosed with bipolar disorder.
RESEARCHER: **Ilse van der Walt**
DEGREE: **DPhil (Social Work)**

Dear Participant

1) INTRODUCTION

We invite you to participate in a research study, because you have been identified as a caregiver of a person being diagnosed with bipolar disorder. This information leaflet will help you to decide if you want to participate. Before you agree to take part, you should fully understand what is involved. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask the researcher, Ilse van der Walt, a doctoral research student of the University of Pretoria, Department of Social Work and Criminology.

2) THE NATURE AND PURPOSE OF THIS STUDY

The purpose of this research is to do a study on the needs of the caregivers of people diagnosed with bipolar disorder. Furthermore, based on identified needs, a one day psychosocial educational **programme** will be developed, implemented and evaluated to assist caregivers to live better with this illness. You as a caregiver are a very important source of information to make sure that this research will be relevant.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

If you agree to participate, the following will occur:

You will be required to fill in a questionnaire to assess your **knowledge and skills** about being a caregiver for someone being diagnosed with bipolar disorder. You will participate in a one day psychosocial educational programme and then complete the questionnaire again. You will participate in the programme between the two times that the questionnaire be administrated to be able to evaluate the impact of the programme. The programme will be conducted at a convenient venue and no costs will be involved.

Demographic information concerning your age, gender, race and background will be required.

4) RISK AND DISCOMFORT INVOLVED

You may feel sad, somewhat uncomfortable or angry sharing your feelings, needs and experiences. You can be referred for counselling if you have the need.

5) POTENTIAL BENEFITS OF THIS STUDY

Although you will not benefit directly from the study, it will give you an opportunity to voice your experience and needs. You might gain more insight into your own ways of coping. You will also help clinicians to obtain a better understanding of caregivers and their challenges.

6) WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time during the study without any negative consequences.

7) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committee of the Faculty of Health Science and the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria. Copies of the approval letters are available if you wish to have one.

8) INFORMATION AND CONTACT PERSON

The contact person for the study is Ilse van der Walt. If you have any questions about the study please contact her at telephone (012) 3199773 or cell 082 05 444 38. Alternatively you may contact my supervisor at telephone (012) 420 2410

9) COMPENSATION

Your participation is voluntary. You will not receive financial benefits by participating in this study.

10) CONFIDENTIALITY

All information that you give will be kept strictly confidential. Your research records, which include the demographic information, will be stored in a secure place and will also be kept a further 15 years thereafter at the University of Pretoria. Any information derived from this research study that personally identifies you will only be seen by the researcher and will not be voluntarily released or disclosed by the researcher without your separate consent. Your identity will remain anonymous and a pseudonym or false name will be used for your data. Should you withdraw from the study for any reason, your data will be destroyed. Research reports and articles in scientific journals will not include any information that may identify you.

Should you require more information about the study you may contact the researcher on:

Mobile: 082 05 444 38 Work: (012) 3199773 Home: (012) 662 5708

E-mail: ilsevdw@goalnet.co.za

Kind regards.

Ilse van der Walt	Dr Charlene Carbonatto
RESEARCHER	**SUPERVISOR**

B. CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about the nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (information leaflet and informed consent) regarding the study. I am aware of what is required of me as a participant. I have read and understand how the research process will be followed. I am aware that the results of the study, including personal details, will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study.

Please complete the form below:

I have read and understood the purpose of this study and agree to participate voluntarily. I have received a signed copy of this informed consent agreement.

Participant

Name and Surname:……………………………….……………(please print)

Signature:……………………………………..………………………………...

Date:…………………………………………………..………………………………

I have explained the study to the participant and provided him/her with a copy of the participant information sheet.

Researcher

Name and Surname: Ilse van der Walt

Signature: ………………………………………………………………………..

Name in print: ………………………………………………………………………

Date:…………………………………………………………………………………

Appendix 1.6: Questionnaire

QUESTIONNAIRE: Pre and post SEE-SAW programme – Doctoral study	**For office use**

Respondent number: ____________________ V0a ☐

Dear Caregiver

Thank you kindly for your cooperation to complete this questionnaire to establish the value of the SEE-SAW programme. It is appreciated. Please write your answer to a question in the shaded space provided or indicate your answer with a circle around the appropriate number in a shaded box. Please answer all questions.

This questionnaire will be filled in twice – therefore please indicate if it is the 1st or 2nd time.

First	**Second time**	V0b	
Today's date		V0c	

Section 1 to section 14 will be filled in before the programme and section 2 to section 15 will be filled in after the programme.

1. BIOGRAPHICAL INFORMATION

1.1 Indicate your **gender:**

Male	**1**	Female	**2**	V1.1	

1.2 Indicate your **age:** years

	V1.2	

1.3 Indicate your **marital status:**

Never married (single)	**1**	V1.3	
Married	**2**		
Separated	**3**		
Divorced	**4**		
Widowed	**5**		
Living together/cohabiting	**6**		

1.4 Indicate your **race:**

White	**1**	V1.4	
Black	**2**		
Indian	**3**		
Coloured	**4**		

1.5 Indicate your **highest** educational qualification**:**

Grade 10 – grade 12	**1**	V1.5	☐
Diploma obtained at a FET training institute or college	**2**		
Degree obtained at a university	**3**		
Post graduate qualification	**4**		

For office use

1.6 Indicate your **relationship** to the patient**:**

Spouse	**1**	V1.6	☐
Child	**2**		
Sibling	**3**		
Friend	**4**		
Other (specify)			

1.7 **Diagnosis**

a. Which year was your family member first diagnosed with a mental disorder?		V1.7a	☐
b. Which year was your family member diagnosed with bipolar disorder?		V1.7b	☐

2. BIPOLAR DISORDER IN GENERAL

2.1 How would you rate your **knowledge** of bipolar disorder?

Excellent	**1**	V2.1	☐
Good	**2**		
Average	**3**		
Poor	**4**		

2.2 A diagnosis of **Bipolar I** disorder can be made when (choose one):

A manic episode (excessive cheerfulness and increased activity) lasting a week was present	**1**	V2.2	☐
The patient is just severely depressed and not manic	**2**		
The patient has dementia	**3**		
The patient is using substances on an on-going basis	**4**		
Mood symptoms are caused by HIV	**5**		
A hypomanic episode (a mild degree of mania) lasting 4 days was present	**6**		
I do not know	**7**		

2.3 A diagnosis of **Bipolar II** disorder can be made when (choose one):

A manic episode (excessive cheerfulness and increased activity) lasting a week was present	**1**	V2.3	☐
The patient is just severely depressed and not manic	**2**		

The patient has dementia	3
The patient is using substances on an on-going basis	4
Mood symptoms are caused by HIV	5
A hypomanic episode (a mild degree of mania) lasting 4 days was present	6
I do not know	7

For office use

2.4 Indicate if you think the following **statements** about bipolar disorder are true or false (answer all questions):

	True	**False**		
a. Bipolar disorder and schizophrenia are two different disorders	1	2	V2.4a	
b. Bipolar disorder is a modern illness	1	2	V2.4b	
c. It is easy to diagnose bipolar disorder	1	2	V2.4c	
d. It can take long to receive the correct diagnosis	1	2	V2.4d	
e. Mood swings of bipolar disorder are character flaws	1	2	V2.4e	
f. There is no cure for bipolar disorder	1	2	V2.4f	
g. St. John's Wort (herbal anti-depressant) may cause a switch to mania in some people with bipolar disorder	1	2	V2.4g	
h. Bipolar disorder does have a genetic/ hereditary component	1	2	V2.4h	
i. Interpersonal/ family conflict cannot lead to a patient's relapse	1	2	V2.4i	
j. Lack of family support is a risk factor	1	2	V2.4j	

2.5 Does bipolar disorder occur over and over again? (choose 1):

Yes	1	V2.5	
No	2		
Maybe	3		
I do not know	4		

2.6 In your opinion people being diagnosed with bipolar disorder:

	Yes	**No**		
a. Are just lazy	1	2	V2.6a	
b. Must "pull themselves together"	1	2	V2.6b	
c. Brought this illness upon themselves	1	2	V2.6c	
d. Can help themselves to get better	1	2	V2.6d	
e. Are just looking for sympathy and attention	1	2	V2.6e	
f. Are sometimes misdiagnosed	1	2	V2.6f	
g. Are not really ill	1	2	V2.6g	
h. Are always violent	1	2	V2.6h	

2.7 According to which document do psychiatrists make diagnoses? (choose one):

Diagnostic and Statistical Manual of Mental Disorders (DSM)	1	V2.7	
The Bipolar Survival Guide	2		
Mental health policy documents	3		
Medical dictionary	4		

For office use

3. DEPRESSION

3.1 **Symptoms** of depression (answer all questions):

	Yes	No		
a. More talkative than usual	1	2	V3.1a	
b. Loss of interest in almost all activities	1	2	V3.1b	

For office use

c. Sleep too little or too much nearly every day for two weeks	1	2	V3.1c	
d. Significant weight loss when not dieting	1	2	V3.1d	
e. Increased activity level	1	2	V3.1e	
f. Racing thoughts	1	2	V3.1f	
g. Suicidal thoughts and / or actions	1	2	V3.1g	
h. Fatigue or loss of energy nearly every day	1	2	V3.1h	
i. Buying/ spending sprees	1	2	V3.1i	
j. Other (specify)			V3.1j	

4. MANIA

4.1 Choose a **word** that can help you to remember the symptoms of mania:

SEE-SAW	1	V4.1	
Digfast	2		
Swing	3		
Do not know	4		
Other (specify)			

5. PSYCHOSIS

5.1 Identify **signs** of psychosis (when a person loses touch with reality) (answer all questions):

	Yes	No		
a. Delusions (fixed false beliefs)			V5.1a	
b. Sleeping too much			V5.1b	
c. Substance abuse			V5.1c	
d. Anxiety			V5.1d	
e. Hallucinations (false perception of something that is not there)			V5.1e	
f. Other (specify)			V5.1f	

6. RELAPSE IN BIPOLAR DISORDER

6.1 Evaluate the following factors in terms of their contribution towards **triggering a relapse** of bipolar disorder:

	Weak	Moderate	Strong		
a. Stressors like lack of finance or relationship problems	1	2	3	V6.1a	
b. Use of any substance/drugs/alcohol	1	2	3	V6.1b	

c. Overinvolved family	1	2	3	V6.1c	
d. Lack of supportive multi-disciplinary team	1	2	3	V6.1d	
e. Poor compliance to treatment (medication and psycho social treatment)	1	2	3	V6.1e	
f. Lack of family support	1	2	3	V6.1f	
g. The patient does not take responsibility	1	2	3	V6.1g	

For office use

6.2 Who is the major role player to prevent a relapse of bipolar disorder? (choose one):

Multi-disciplinary team	1	V6.2	
Extended family	2		
The caregiver	3		
The patient	4		
Other (specify)			

6.3 Alcohol, dagga or other drugs are commonly used by bipolar people to (answer all questions):

	Yes	No		
a. Escape			V6.3a	
b. Self-medicate			V6.3b	
c. Relax			V6.3c	
d. Treat their bipolar episodes			V6.3d	
e. Other (specify)			V6.3e	

7. SUICIDE

7.1 Evaluate the following factors in terms of their **contribution** towards possible **suicide risk** for bipolar patients:

	Weak	Moderate	Strong		
a. Being a male				V7.1a	
b. Having a specific suicide plan				V7.1b	
c. Being isolated from friends and family members				V7.1c	
d. Being prone to impulsive acts such as driving recklessly				V7.1d	
e. Having a family history of suicide attempts				V7.1e	
f. Having previous suicide attempts				V7.1f	
g. Having a relapse of bipolar disorder				V7.1g	

7.2 Select factors that can **prevent** suicide:

a. Adherence to treatment	1	V7.2a	
b. Ignorance about bipolar disorder	2	V7.2b	
c. Frequent contact with the multi-disciplinary team	3	V7.2c	
d. Blaming the patient for being ill	4	V7.2d	
e. Hospitalization	5	V7.2e	

7.3 Should you ask a patient if he/she is suicidal when you see **warning signs**? (choose one):

Yes	**1**	V7.3	
No	**2**		
Do not know	**3**		

For office use

7.4 What should **you do** if your family member is suicidal?

	V7.4a	
	V7.4b	
	V7.4c	

8. TREATMENT

8.1 Choose the one medication that is the **oldest** that is used for bipolar disorder:

Lithium	**1**	V8.1	
Ativan	**2**		
Painkillers	**3**		

8.2 Are anti-depressants always **safe** for bipolar patients?

Yes	**1**	V8.2	
No	**2**		
Do not know	**3**		

8.3 Rate your feelings regarding your viewpoint about **ECT** (shock treatment):

Positive	**1**	V8.3	
Neutral	**2**		
Negative	**3**		
Do not know	**4**		

8.4 Choose any other **relevant** treatment apart from medication or ECT for bipolar disorder (you may indicate more than one):

a. Psychoeducation	**1**	V8.4a	
b. Sleep therapy	**2**	V8.4b	
c. Cognitive behavioural therapy	**3**	V8.4c	
d. Alternative treatment	**4**	V8.4d	
e. Indigenous/ traditional treatment	**5**	V8.4e	
f. Other (specify)	**6**	V8.4f	

8.5 Evaluate the following factors in terms of their contribution towards possible **reasons** patients may **stop their medication:**

	Weak	**Moderate**	**Strong**		
a. Miss the feeling of being manic	**1**	**2**	**3**	V8.5a	
b. The reasons for taking medication were not explained	**1**	**2**	**3**	V8.5b	
c. Lack of insight into their illness	**1**	**2**	**3**	V8.5c	
d. Cannot cope with side effects	**1**	**2**	**3**	V8.5d	
e. Denial of the illness	**1**	**2**	**3**	V8.5e	
				For office use	
f. Taking medication is a sign of personal weakness	**1**	**2**	**3**	V8.5f	
g. Lack of motivation	**1**	**2**	**3**	V8.5g	
h. Pill fatigue	**1**	**2**	**3**	V8.5h	

8.6 Complete

Maintaining wellness means minimizing ……………………… factors and

maximizing…………………… factors

V8.6a

8.7 Psychoeducation for caregivers can empower them. Do you:

Strongly agree	**1**	V8.7	
Agree	**2**		
Unsure	**3**		
Disagree	**4**		
Strongly disagree	**5**		

9. COPING

9.1 Evaluate **coping mechanisms** that might help you to address difficult situations regarding the bipolar patient

	Yes	**No**		
a. Aggression			V9.1a	
b. Problem solving			V9.1b	
c. Communication			V9.1c	
d. Denial			V9.1d	
e. Blaming			V9.1e	
f. Self-controlling			V9.1f	
g. Escape or avoidance			V9.1g	

10. LEGISLATION

10.1 According to which legislation/Act do patients get admitted to a government hospital?

Criminal Procedure Act	**1**	V10.1	
Mental Health Care Act	**2**		
National Health Act	**3**		

Prevention of and Treatment for Substance Abuse Act	4		
Other (specify)			

10.2 Which section of the Mental Health Care Act states that the Police must assist in the case of a psychiatric patient?

Section 34	Section 40	Section 27	V10.2	

For office use

10.3 **Admission** to a government psychiatric hospital:

10.3.1 Who can apply to have a patient involuntary admitted to a psychiatric hospital?

a. A family member	1	V10.3.1a	
b. The patient him/ herself	2	V10.3.1b	
c. A health care provider	3	V10.3.1c	
d. Someone that has not seen the patient within **seven days** of making the application for admission	4	V10.3.1d	
e. Other (specify)		V10.3.1e	

11. **CAREGIVER**

11.1 Indicate the roles you can play to help your family member with bipolar disorder:

a. Motivator	1	V11.1a	
b. Manager	2	V11.1b	
c. Supporter	3	V11.1c	
d. Controller	4	V11.1d	
e. Facilitator	5	V11.1e	
f. Other (specify)		V11.1f	

11.2 Rights of caregiver

I also have rights when dealing with the family member with bipolar disorder.

Yes	Maybe	No	V11.2	

11.3 What are your biggest challenges as a caregiver? (choose all the applicable):

	Agree	Neutral	Disagree		
a. I do not understand what bipolar disorder is	1	2	3	V11.3a	
b. I do not know how to act when the family member relapses	1	2	3	V11.3b	
c. I do not know how to deal with the stigma attached to the illness	1	2	3	V11.3c	
d. I do not know how to tell other people about the illness	1	2	3	V11.3d	

e. I often feel hopeless and helpless	**1**	**2**	**3**	V11.3e	☐
f. I often feel emotionally drained	**1**	**2**	**3**	V11.3f	☐
g. Other (specify)				V11.3g	☐

11.4 Caregivers will never become depressed or anxious themselves:

Agree	**1**	V11.4	☐
Unsure	**2**		
		For office use	
Disagree	**3**		

11.5 My biggest **fears** are (choose all applicable):

	Yes	**No**		
a. The patient may become psychotic and I cannot handle it			V11.5a	☐
b. The patient may become aggressive and I cannot handle it			V11.5b	☐
c. The patient may become suicidal and I cannot handle it			V11.5c	☐
d. Other (specify)			V11.5d	☐

12. RIGHTS OF PATIENTS

12.1 Are you aware of the Patients' Rights **Charter**?

Yes	**No**	V12.1	☐

12.2 Are you aware that the Mental Health Care **Act** also refers to the rights of the patient?

Yes	**No**	V12.2	☐

13. RESOURCES

13.1 Do you know your family member's psychiatrist and team?

Yes	**Some of them**	**No**	V13.1	☐

13.2 Do you know how to approach your family member's psychiatrist and team?

Yes	**Sometimes**	**No**	V13.2	☐

14. SEE-SAW survival suitcase

14.1 Name any three items in the SEE-SAW survival suitcase:

a.	V14.1a	☐
b.	V14.1b	☐
c.	V14.1c	☐

15. **EVALUATION OF THE PROGRAMME** (Fill in after the programme)

Your input regarding the evaluation of the programme will be appreciated:

15.1 Today I have learnt more about:

	Yes	No		
a. Bipolar disorder			V15.1a	
b. Treatment modalities			V15.1b	
c. My role as caregiver			V15.1c	
d. The needs of caregivers			V15.1d	
		For office use		
e. Strategies to cope with the illness of my family member			V15.1e	
f. The Mental Health Care Act			V15.1f	
g. Risk factors for a bipolar relapse			V15.1g	
h. Strategies to prevent a bipolar relapse			V15.1h	
i. Other important aspects (specify)			V15.1i	

15.2 What other aspects could have been i**ncluded** in the programme?

	V15.2a V15.2b V15.2c	

15.3 What other aspects could have been **excluded** from the programme?

	V15.3a V15.3b V15.3c	

15.4 The **content** of the programme was:

	Yes	No		
a. Relevant			V15.4a	
b. Understandable			V15.4b	
c. Interesting			V15.4c	
d. Empowering			V15.4d	
e. Educational			V15.4e	
f. Helpful and practical and I can apply what I have learnt			V15.4f	
g. Overwhelming			V15.4g	
h. Confusing			V15.4h	
i. Too difficult to understand			V15.4i	
j. Boring			V15.4j	

15.5 Recommendations regarding the **time aspect** of the programme:

	Yes	No		
a. It was too short			V15.5a	
b. It was too long			V15.5b	
c. The pace was too fast			V15.5c	
d. It was too rushed			V15.5d	
e. Other comments			V15.5e	

15.6 Mention the aspect of the programme that you **valued** the most:

V15.6 ☐

For office use

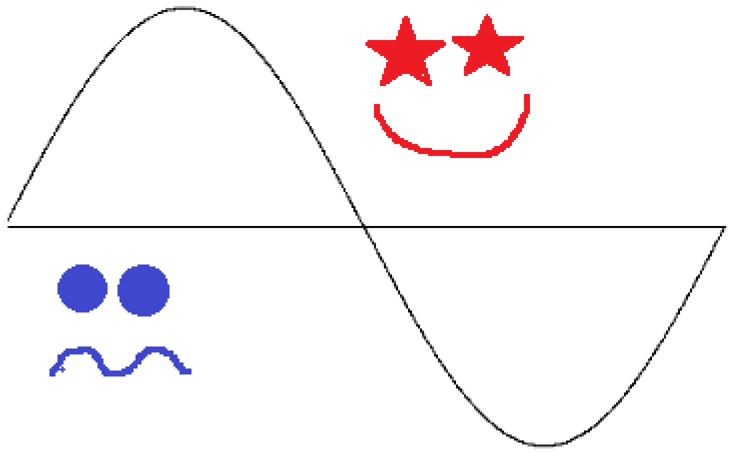
15.7 Feedback regarding the:

	Bad	**Good**	**Excellent**		
a. Arrangements				V15.7a	☐
b. Venue				V15.7b	☐
c. Refreshments				V15.7c	☐
d. Hand-outs				V15.7d	☐
e. Audio visual aids				V15.7e	☐
f. Presenter				V15.7f	☐
g. Information booklet				V15.7g	☐
h. Information				V15.7h	☐

15.8 Any other recommendations?

V15.8a ☐
V15.8b ☐
V15.8c ☐

Thank you for your time and co-operation in answering this questionnaire



Chapter 2: Appendix 2.1: Bipolar Symptoms: A Self-Administered Checklist

(Miklowitz, 2011:38, 39). This checklist is a tool that might be given to the patient to fill in or the therapist can also fill it in with the patient and it might help him/her to gain insight.

DEPRESSION

Has there ever been a period of time lasting two weeks or more when you were not your usual self and you experienced five or more of the following:

	Yes	No
Felt sad, blue, or down in the dumps?	____	____
Were uninterested in things?	____	____
Lost or gained more than 5% of your body weight?	____	____
Slept too little or too much?	____	____
Were slowed down or sped up in your movements?	____	____
Felt fatigued or low in energy?	____	____
Felt worthless or very guilty about things?	____	____
Were unable to concentrate or make decisions?	____	____
Thought about killing yourself or making plans to do so?	____	____

MANIA OR HYPOMANIA

Has there been a period of time when you were not your usual self and you:

	Yes	No
Felt so good or so hyper that other people thought you were not your normal self or you were so hyper that you got into trouble?	____	____
Were so irritable that you shouted at people or started fights or arguments?	____	____
Felt much more self-confident than usual?	____	____
Got much less sleep than usual and found you didn't really miss it?	____	____
Were much more talkative or spoke much faster than usual?	____	____
Had thoughts racing through your head or couldn't slow down your mind?	____	____
Were so easily distracted by things around you that you had trouble concentrating or staying on track?	____	____
Had much more energy than usual?	____	____
Were much more active or did many more things than usual?	____	____
Were much more social or outgoing than usual, for example, telephoning friends in the middle of the night?	____	____
Were much more interested in sex than usual?	____	____
Did things that were unusual for you or that other people might have thought were excessive, foolish, or risky?	____	____
Spent excessive money that got you or your family into trouble?	____	____
If you checked yes to more than one of the above, have several of these ever happened during the same period of time?	____	____

How much of a problem did any of these cause you-like being unable to work; having family, money, or legal troubles; getting into arguments or a fight? Please check one response only.

No problem ____________________ Minor problem____________________

Moderate problem ______________ Serious problem ______________

Chapter 3: Appendix 3.1: Confidential Psychiatric Social Work Assessment

CONFIDENTIAL PSYCHIATRIC SOCIAL WORK ASSESSMENT: BIPOLAR AND RELATED DISORDERS. GUIDELINE FOR FIRST INTERVIEW WITH PATIENT and with *SIGNIFICANT OTHERS*

Goal: *To establish patient's own unique clinical profile and set of priorities and to assess the broader context*

Date of interview with patient:……………………… Place of interview:……………… Starting time of interview:………… Duration of interview:……………… Interpreter needed: Yes/No…………….

1. DEMOGRAPHICS

Name:	Reference number:	Currently in or out patient:
Referred to social worker by:	Date of referral to social worker:	Reason for referral:
Date of admission to hospital:	Referred to hospital by: Status of admission:	Ward:
Address:	Telephone numbers:	
Date of Birth:	Age:	Gender Identification:
Ethnic origin:	Refugee? Yes/No	Country:
Marital status:	Name of spouse:	Address and telephone numbers:
Significant others Names:	Significant others Telephone numbers:	Significant others Addresses:
Religious Denomination:	Involved member? Yes/No	Name of pastor: Telephone number:
Occupation:	Employer: Permission to notify employer about admission Yes/No	Telephone numbers:
Name of private psychiatrist or traditional healer:	Telephone numbers:	

2. MAIN COMPLAINT

2.1 Patient's view on index episode

Social worker's observations of patient during the interview (psychotic, appearance, eye contact, level of aggression, irritability, restlessness, inappropriate behaviour, mood, cooperation, emotional labile, withdrawn):

What happened that you were NOW brought to the hospital? (Precipitating factors, triggers)

Were there any family conflicts or life events that precipitated the episode? (Evaluation of prodromal period)

Did any life events disrupt your sleep-wake cycle (e.g. changing job hours, transatlantic flights)?

What manic, depressive or psychotic symptoms dominated the picture? (magnitude, duration, intensity)

Substance abuse prior admission (in the last month):
Yes/No……………………………………………………………………………………………….
Name of substance and quantity/duration…………………………………………………………….

Do you think you are ill? (Evaluating insight)

Did the illness start suddenly or gradually?

If you could get the perfect treatment, what would it do for you? What symptoms would get better?

Are you currently on any treatment? If yes, do you take it or why not?

2.2 View of *significant other* (may be more than one)

Social worker's observations of significant other *during the interview (appearance, eye contact, level of aggression, irritability, emotional reactions, cooperation):*

Name:………………… Address:…………………………….. Tel:………………………….................
Date of Interview (s):………………………. Personal or Telephonic interview…………………………..

What happened that you NOW brought him/her to the hospital? (precipitating factors, triggers)

History of *present* Illness episode - symptoms (magnitude, duration, intensity)

Substance abuse prior admission:
Yes/No *Name of substance and quantity/duration*

Were there any family conflicts or life events that precipitated the episode?

Did any life events disrupt the patient's sleep-wake cycle (e.g. changing job hours, transatlantic flights)? (Assessment of the family context)

Are you afraid of the patient?

Is the patient compliant towards treatment?

Risk factors

3. FAMILY HISTORY OF PSYCHIATRIC PROBLEMS (e.g. mood disorder, substance abuse, suicide attempt)

First degree relative:

Name…..………………..Illness…………………………Treatment…………………………………

Second degree relative:

Name…..……………….Illness…………………………Treatment………………………………….

Information from significant other

4. PERSONAL HISTORY

4.1 Family (genogram, eco map, including family of origin and current family system)

Record family background (ages, occupations, illnesses, family dynamics, relationships, resources and strengths, cultural beliefs and attitudes towards mental illness)

Identify the **primary** caregiver

Comment

4.2 Childhood/adolescence

0-6 years (birth, milestones, behavioural problems):

Patient	***Significant Other***

7-13 years: (primary school, friends, sport, hobbies, behavioural problems):

Patient	***Significant Other***

14–18 years: (high school, friends, sport, hobbies, behavioural problems):

Patient	***Significant Other***

Failed any grades?

Year, age and grade when patient left school?

Ever expelled from school?

Ever a time when performance unexpectedly declined?

Were there any significant early life events, such as long periods of separation from a parent, instances of physical or sexual abuse or deprived economic conditions?

Tertiary Education

Name of institution	Name of Course and year enrolled	Completed Yes/No

Employment History

Name	Duration	Problems

At Present: employed/unemployed?

Receiving a disability grant? Yes/No

Financial status

Personal income per month/week **Contract/permanent worker……………………..**

Family Income **Expenditure………………………………………**

Information from employer

Name **Company** **Date of contact**

Any relevant information regarding functioning at work

Marital history/psychosexual relationships

Date of marriage/cohabiting	Name of spouse	Quality of relationship	Date of divorce

Information from significant other regarding the marital aspects

---

Support from the partner?

Legal history

Present	Past

Information from significant other regarding legal history

____

Medical illness (epilepsy, head injuries, HIV, other)

Information from significant other regarding medical illness (epilepsy, head injuries, other):

____

Substance abuse history

Name of substance………………………… Duration ………………………………………………

When last used……………………………………………………………………………………

Frequency………………………………………..Blackout……………………………………...................

Withdrawal/seizures?…………………………...Rehabilitation……………………………………………

Problems (marital, work, legal) because of substance abuse?

____.

Information from significant other

Adherence to treatment:	Subjectively	Objectively
Insight:	Subjectively	Objectively

Information from significant other

Religion and culture

____

Social circumstances

____

4. ETHICAL ASPECTS

Permission to contact family/friends: Yes/No

Name:………………………………….Date: ……………………………………………………………

Signature: ……………………………..Witness:…………………………………………………………..

Permission to contact others e.g. employer/ pastor/social worker/psychiatrist: Yes/No

Name:………………………………….Date: ……………………………………………………………

Signature: ……………………………..Witness:…………………………………………………………..

5. RELEVANT INFORMATION FROM PATIENT CONCERNING PAST PSYCHIATRIC ILLNESS

Premorbid functioning (socially, occupationally)

Symptoms according to FIND – frequency, intensity, number, duration

Admissions to hospitals for psychiatric reasons

Name of hospital/doctor	**Date of admission Duration of admission**	**Reason for admission Voluntarily/in-voluntarily**	**Type of medication administrated Compliant Yes/No**

6. RELEVANT INFORMATION FROM ANY CAREGIVERS OR *SIGNIFICANT OTHERS* CONCERNING PAST PSYCHIATRIC ILLNESS

Premorbid functioning (socially, occupationally)

Admissions to hospitals for psychiatric reasons

Name of hospital/doctorr	**Date of admission**	**Duration of admission**	**Reason for admission**

Family Background (mental illness, relationships)

When did any mental illness first start?

Can you describe the main symptoms of that episode?

Chronological history of past psychiatric history - symptoms (magnitude, duration, intensity)/ can use life chart, medication history table, treatment, hospitalizations, suicide attempts, violence towards others

How would the patient spend a typical day prior to the episode?

How would you describe him /her as a person?

What about him/her do you find attractive/enjoyable?

What aspects of his/her behaviour do you find most disturbing? Report symptoms

Most Important concerns (e.g. suicidal ideation, aggression, will abscond, no insight)

Patient's report on general health maintenance (when euthymic)

Diet:

Exercise:

Sleep pattern and quality:

Stressors:

Hobbies:

Daily plan

Information from significant other

Stressors (acute and chronic)

Coping:

Strengths	**Weaknesses**
•	•
•	•
•	•
•	•

Support system:

Name	**Relationship**	**Contact Details**

User's priority needs and expectations from social worker (contract)

Discharge Plan

7. EVALUATION

Is this a high-stress, high-EE (critical, hostile, emotionally overinvolved) family? What family conflicts can be anticipated during the post episode period?

Current *risk factors* (e.g. lack of support, lack of insight, aggressive, suicidal) and *protective factors* (e.g. support, compliance to treatment and absence of substance abuse)

Strengths and *weaknesses* within the system.

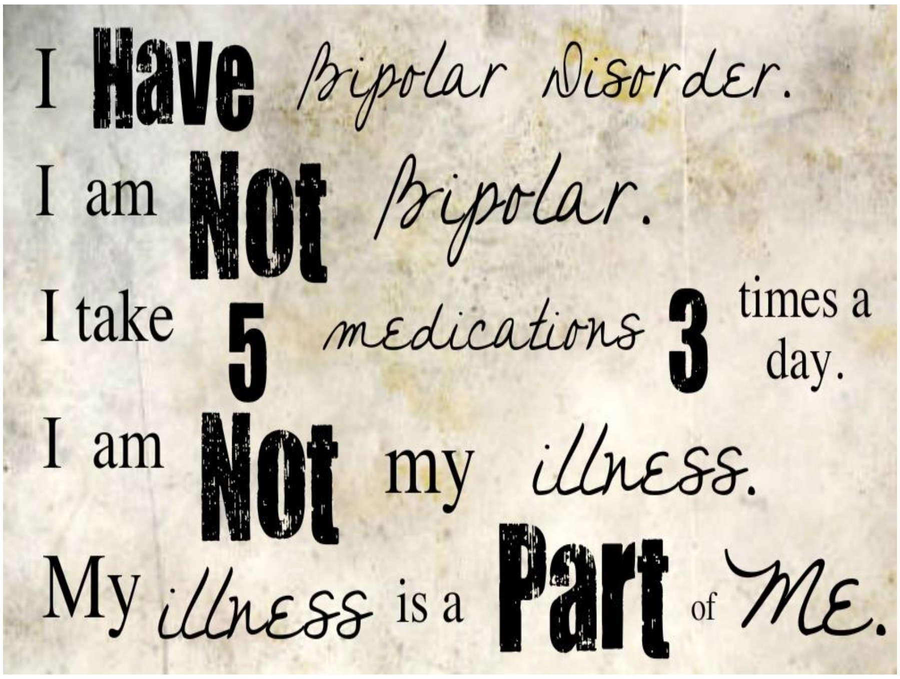
8. PLAN OF ACTION

(Include *discharge plan)*

Name of social worker: ______________________________Date: ___________________________
Registration number of social worker:____

Chapter 7: Appendix 7.1: See-Saw Programme for the Day

BIPOLAR DISORDER SEE-SAW programme	1.	Registration and welcoming to programme	08:00-09:00
	2.	Fill in consent form to participate in research	
	3.	Fill in questionnaire (pre-programme)	
	4.	Presentation of programme	09:00-10:30
		S1	
		E1	
	5.	Refreshment break	10:30-10:45
	6.	Presentation of programme	10:45-11:45
		E2	
		S2	
	7.	Video: The secret life of the Manic Depressive	11:45-12:45
	8.	Lunch	
	9.	Presentations of programme	13:15-14:15
		A	
		W	
	10.	Fill in questionnaire (post-programme)	14:15-14:45
	11.	Certificates	



Chapter 7: Appendix 7.2: See-Saw Life Style Chart

How to use the Life Style Chart

- Record your number of meals and number of snacks.
- Check the spaces next to the things that affected you that day, such as relaxation time. Add some of your own if you want to.

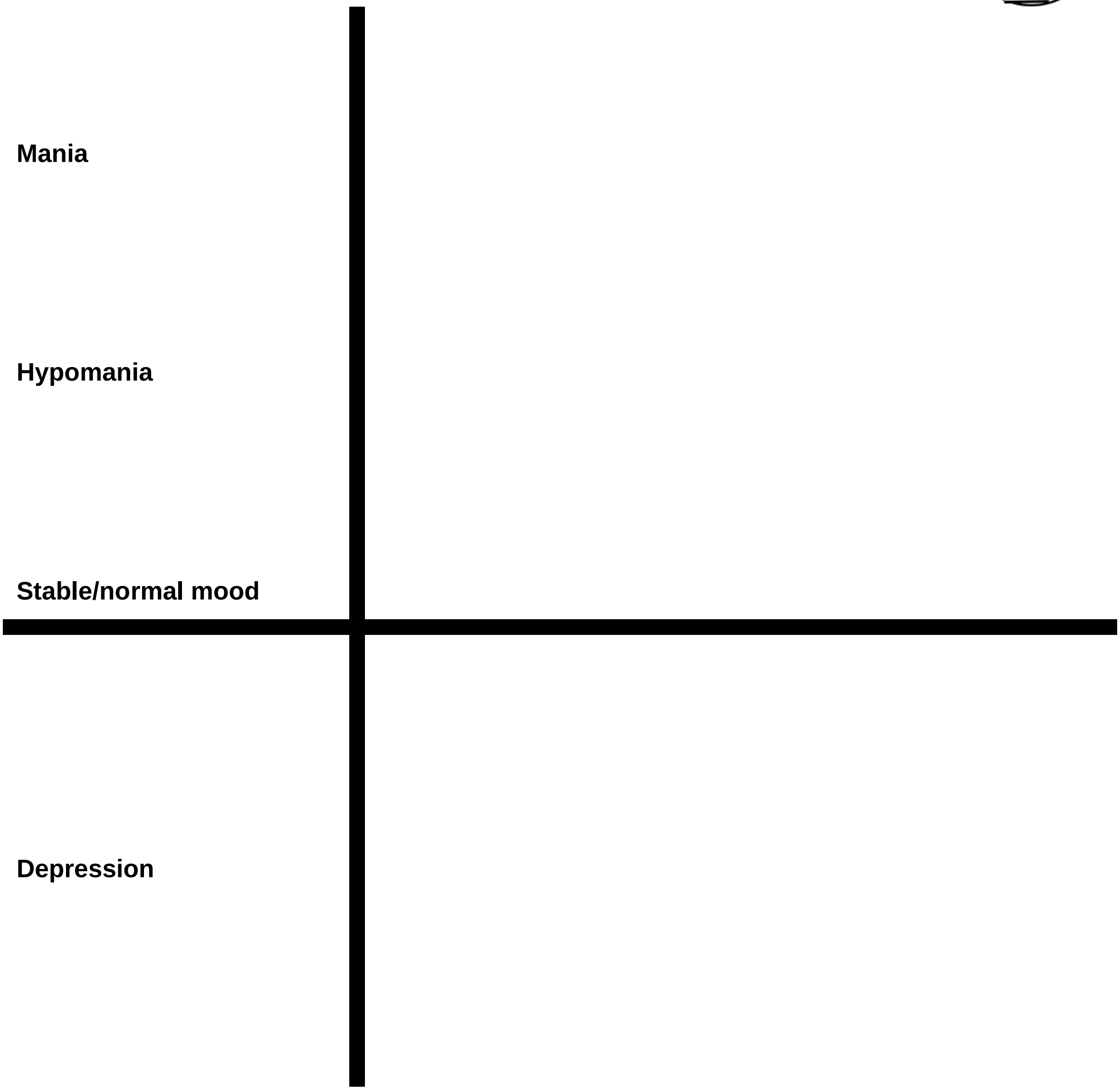
DAY	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
NUMBER OF MEALS																															
NUMBER OF SNACKS																															
IF YES √																															
PHYSICAL ACTIVITY?																															
RELAXATION TIME?																															
WENT TO SUPPORT GROUP?																															
SPENT TIME TALKING WITH A PROFESSIONAL PERSON?																															
HAD APPOINTMENT WITH A SUPPORTIVE PERSON?																															
PSYSICAL ILLNESS?																															
MENSTRUAL PERIOD?																															
MAJOR LIFE EVENT?																															
TRIGGERS? Name them:																															

Name____ Month/Year____

Adapted from DBSA (2004)

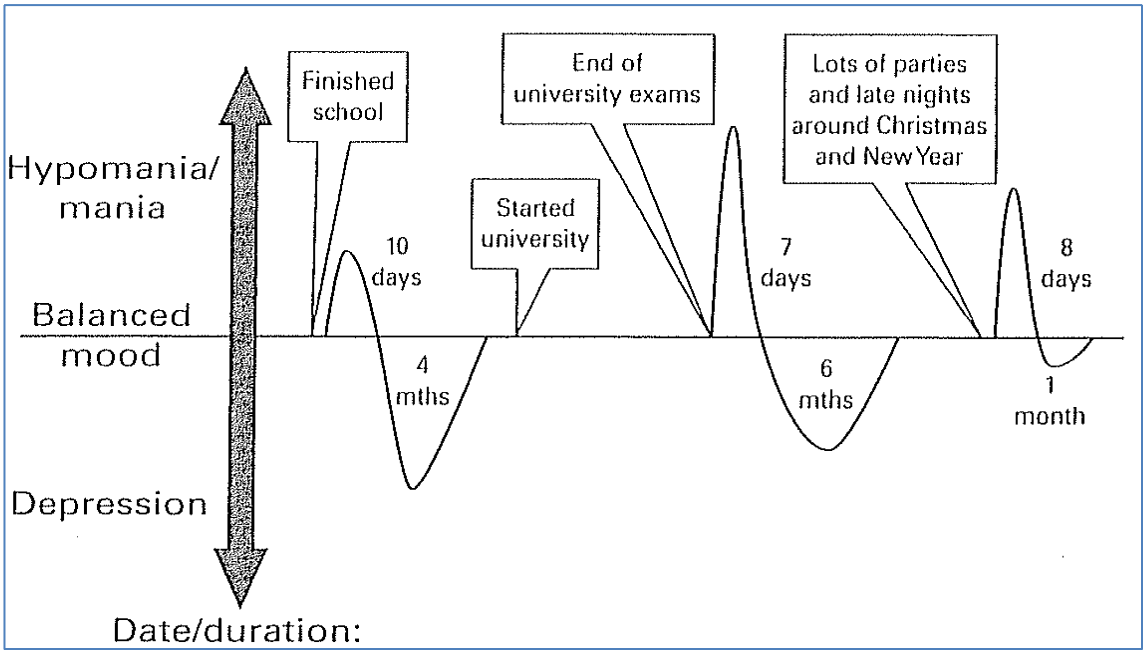
Chapter 7: Appendix 7.3: Life chart to indicate episodes of illness

Life chart to indicate episodes of illness



Date:	**Duration:**
Triggers that caused instability:	
Pattern that is observed:	

Chapter 7: Appendix 7.4: Example of a life chart to indicate episodes of illness (Berk et al, 2008: 117, 119)



Chapter 7: Appendix 7.5: A Crisis Plan for the Patient

Write a personal crisis plan to be used if your symptoms become so severe and/or dangerous that you need others to take over responsibility for your care (SADAG – Bipolar Disorder Treatment and Referral Guide). The researcher is of the opinion that your crisis plan may also be seen as a **contract** between the patient and caregiver. It must be made while the patient is stable. Although it is important that each patient's and caregiver's crisis plan/contract is unique, it may include:

1. Support system:

Name of caregiver	**Telephone number**
Names of multi-disciplinary team members	**Telephone numbers**

2. People you do not want to be involved:

____

3. List of all medication you are taking and information on why they are being taken:

Name of medication	**Reason for taking it**	**Dosage**

4. **Symptoms that indicate your need for caregivers to make decisions for you and take over responsibility for your care may include the following**: (these are also usually signs of relapse)

- Severe, agitated depression
- Psychosis
- Uncontrollable pacing
- Inability to stop compulsive behaviours
- Self-destructive behaviour
- Abusive or violent behaviour
- Substance abuse
- Threats of suicide
- Clash with the law
- Leaving home without the caregiver knowing where you are
- Significant changes in sleep patterns (also difficulty getting out of bed)
- Refusal to eat
- Signing contracts that you are not able to take responsibility for
- Over spending of money
- Any risk taking behaviour (e.g. speeding, sexual inappropriate behaviour)

5. **If I relapse, I would like my caregiver/ give my caregiver permission to do the following:**

Action to be taken	**Yes**	**No**
Supervise my medication		
Contact my doctor		
Accompany me to the doctor		
Take my bankcards, ID and other valuable documents for safekeeping		
Restrict or monitor internet use, because it may lead to online shopping and gambling		
Inform my employer that I am not well		
Make me aware that I am showing symptoms of relapse and that I should urgently make an appointment with my doctor		
Take care of my young children while I am too sick to do it		
Take my cell phone when I make unnecessary phone calls		
Take my car keys if I am not well enough to drive		

Action to be taken	**Yes**	**No**
Encourage me and give me hope		
Do not ignore me		
Do not nag me		
Do not judge me		
Accept me		
Stay with me		
Take away any weapons I may hurt myself with		
Stress that my life is important to others		
Take me to hospital and apply to have me admitted if there is no alternative		
Listen to my needs		
Other		

6. I would like to state that I feel very strongly about the following aspects (e.g. to be respected and that I also have rights):

____

____

____

Signed at: ____
Date: ____
Name of patient: ____
Signature of patient: ____
Name of caregiver: ____
Signature of caregiver: ____
Witness: ____

Chapter 7: Appendix 7.6: Relapse Prevention Plan for the patient

It is important to develop and maintain a plan to prevent relapse. If the patient or caregiver notice triggers or warning signs it can help to reduce the severity or duration of an episode if it occurs. Strategies need to be practical and realistic, a few core strategies may be better that a lot of complicated ones. Make sure to keep all contact details up to date and update plans as you learn more about the illness and what works for you. It can be helpful if those people involve can all have a copy of this plan (Berk et al., 2008, Haycock, 2009, Miklowitz, 2010, Colom & Vieta, 2008).

1. Useful information

Health care details

List Medicare, health insurance, pension card or any other numbers that may be useful to you when you need to obtain treatment:

Clinicians' contact details

List more than one name if possible in case your doctor is unavailable or you wish to contact any other member of the multi-disciplinary team.

Doctor's name:	Phone number:
	Emergency number:
Other clinician's name:	Phone number:
	Emergency number:
Hospital emergency department	Phone number:

Key support people

Name:	Phone number:
Name:	Phone number:
Name:	Phone number:

2. Managing triggers

Triggers to monitor

List the high-risk situations or triggers that might lead to or worsen symptoms.

Ways to manage triggers

List the things that you can do to manage these triggers and how others can support your strategies.

Things not to do

List the ways you may sometimes manage triggers that are not helpful or make things worse.

3. Managing warning or early symptoms

Warning/early symptoms to monitor

List your typical warning symptoms/early symptoms of this type of mood episode so you can intervene early.

Ways to manage warning or early symptoms

List the things that you can do to prevent or reduce relapse if you notice warning or early symptoms and ways key people can support your strategies.

Things not to do

List the things that you may sometimes do to cope with warning or early symptoms that may make your symptoms worse.

4. Being prepared if things get worse

List what you or others can do if your symptoms get worse.

5. **Reasons for wanting to reduce relapse** (why you want to get well so it is easier to stick to your plans to prevent relapse when you are developing mood symptoms). Have this list handy to help you to go against what your illness is telling you to do when you are relapsing.

Reasons for wanting to reduce relapse. It is important to consider the cost versus the benefits.

The cost to me of being ill are….	The benefits of me being well are….

Chapter 7: Appendix 7.7: Suicide Risk Preventin Plan for the patient

This plan must be completed when the patient is well. Check items that are relevant to the patient and add those that apply to the personal situation. The plan can also be developed over time. The caregiver should have a copy of the prevention plan and can also sign it (Berk et al., 2008 & Miklowitz, 2011).

1. Contact details

Therapists' names and telephone numbers:
Emergency Department phone number:
Close family or friends' numbers:

2. Early warning signs that I may become suicidal

List warning signs that you may be becoming suicidal:

3. What can I do about warning signs?

List ways of dealing with your warning signs, for example contact your doctor or key support people, activate relapse prevention plans to reduce symptoms, enlist support with challenging hopeless thinking or deal with a problem that may be triggering your suicidal impulses and consider treatment and your safety:

4. Consider safety and getting treatment

What do you need to do to ensure your safety and access to treatment? (For example):

- Phone your clinician (s) and let them know your are suicidal
- Book an emergency appointment to discuss treatment
- Go to an emergency department

- Enlist the help of your support system to temporarily look after your weapons, pills and other means of committing suicide
- Spent time with family or friends so you are not alone
- Let family or friends know that you feel suicidal and help you access the appropriate treatment like contacting your doctor or taking you to hospital
- Abstain from drugs or alcohol
- Contact suicidal hotline

5. Other strategies I can use and ways others can assist me (For example):

- Plan soothing or distracting activities to get through the next hour or day
- Talk things through with a trusted person to try and gain a new perspective on old problems
- Remind yourself that suicidal symptoms are temporary symptoms and that you will feel differently in the future
- Tell yourself that you are not going to make any decisions about your life until you have been better for a while
- Prioritise and delegate stressful demands
- Consult your reasons to live list

Signature of patient: ____
Signature of caregiver: ____
Date: ____

Chapter 7: Appendix 7.8: Sample Contract for Suicide Prevention (Last, 2009:254)

Sample Contract for Suicide Prevention

If having thoughts of self-harm, my partner will:

Share suicidal thoughts or plans with me and the doctors (s)
Turn over any weapons
Give me his pills
Abstain from drinking or abusing recreational drugs
Seek counsel with his pastor, priest, rabbi, etc.
Go to the hospital (if hospitalization is necessary).

If my partner is having thoughts of self-harm, I will:

Stay with him
Call the doctor(s) to arrange emergency appointments
Remove alcohol and weapons from the home
Take possession of all pills
Drive him to the hospital (if hospitalization is necessary).

Our signatures below indicate that we agree to the above:

Date:________________________ Signed:________________________

Patient

Caregiver

Chapter 7: Appendix 7.9: Support and Activity Strategies when becoming depressed (for patient and caregiver)

Set small short term goals doing something that will give a sense of pleasure or achievement. Use this chart when feeling depressed or down (Berk et al., 2008).

Date	My goal is to do this pleasurable or achievement focused activity:	The sense of pleasure it gave me on a 0 (no pleasure) to 5 (a lot of pleasure) was:	The sense of achievement it gave me on a 0 (no achievement) to 5 (a lot of achievement) was:

Chapter 7: Appendix 7.10: Certificate of Celebration

CERTIFICATE OF CELEBRATION
SEE-SAW PROGRAMME

CAREGIVERS OF BIPOLAR PATIENTS

THIS CERTIFICATE OF ATTENDANCE AND PARTICIPATION IS AWARDED TO:

PRESENTED BY:

ILSE VAN DER WALT

SOCIAL WORKER

SIGNATURE ____________________ **DATE** ____________________

SACSSP Registration number: 10-05100

Chapter 7: Appendix 7.11: Glossary: User-friendly terms/programme

Akathisia	Restlessness in the legs (Colom & Vieta, 2006:119)
Anhedonia	A person's inability to enjoy any activity (Colom & Vieta, 2006:87)
Anticholinergic effects	Dry mouth etc. (Colom & Vieta, 2006:119)
Antipsychotic medication	Also called neuroleptics. Medication effective against psychoses (Lundbeck, 2005:28)
Bipolar I	A category of bipolar disorder characterised by episodes of mania. People with this type of bipolar disorder may or may not also experience periods of depression (Berk et al., 2008:280). For a diagnosis of bipolar I disorder, it is necessary to meet the criteria for a **manic** episode (DSM 5, 2013:123).
Bipolar II	A category of bipolar disorder characterised by episodes of hypomania and depression. (Berk et al., 2008:280). For a diagnosis of bipolar II disorder, it is necessary to meet the criteria for a current or past **hypomanic** episode *and* criteria for a current or past major **depressive** episode (DSM 5, 2013:132).
Comorbidity	Experiencing two or more disorders at the same time, for example bipolar disorder and social phobia (Berk et al., 2008:281).
CT	(Computerized tomography) scan: Takes thousands of thin x-ray pictures from different angles and then uses computer software to create a 3D image of the brain (Haycock, 2010:57).
Delusions	More or less absurd or unfounded beliefs that go against all reason, that is, believing that you are fluent in a language you have never studied or believing you are being pursued by the KGB (Colom & Vieta, 2006:84). Personal convictions which do not correspond with the patient's intelligence and level of education. (Lundbeck, 2005:28). False but firmly held beliefs (Haycock, 2010:23).
Depot medication	Antipsychotic medicine given as a long-acting injection. One injection is effective for 1-4 weeks (Lundbeck, 2005:28).
Diagnosis	The identification of a disease or disorder, based on a series of symptoms and signs, which accord with a particular disorder **(**Berk et al., 2008:281).
Dopamine system	The system of nerve cells in the brain where dopamine is the messenger chemical from one cell to the next (Lundbeck, 2005:28).
ECT (electroconvulsive therapy)	A treatment for severe depression and occasionally for puerperal psychosis and mania. A convulsion is produced by passing an electric current through the brain (Oxford Concise Colour Medical Dictionary, 2010:236).
Expressed emotion	Critical, hostile, or overinvolved attitudes and behaviours that family members may exhibit toward the ill individual (Last, 2009:121).
EEG (electroencephalogram)	A technique for recording the electric activity from different parts of the brain and converting it into a tracing called an EEG (Oxford Concise Colour Medical Dictionary, 2010:236).

Euthymic	A normal (i.e. nondepressed) mood state, often referred to in mental state examinations. The term also refers to a neutral mood state in a person with bipolar affective disorder (Oxford Concise Colour Medical Dictionary, 2010:260).
Hallucinations	False sensory perceptions with no influence from the outside. Patients might hear voices (auditory hallucinations) or perceive smells (olfactory hallucinations) that a healthy person would not hear/smell. The hallucinations might appear as tactile hallucinations where the patient feels that he/she is touched (Lundbeck, 2005:28). Hearing or seeing things that don't exist (Haycock, 2010:23).
Hypersomnia	Oversleeping (Colom & Vieta, 2006:91)
Intramuscular injection	Injection of a medication into the muscle where it is then released into the blood stream (Lundbeck, 2005:28).
Intravenous injection	Injection directly in the vein (Lundbeck, 2005:28)
Labile moods	Quickly changing moods (Berk et al., 2008:283)
Life charting	A tool that involves reflecting on times of wellness and illness and working out whether particular episodes were sparked off by particular triggers. Episodes are recorded on a timeline that roughly indicates the date and duration of the episode as well as the type of relapse (Berk et al., 2008:116).
Maintenance treatment	On-going treatment designed to reduce the recurrence of an episode of illness (Berk et al., 2008:283).
Major depression	Significantly lowered mood and/or a loss of interest or pleasure in things, plus at least five other symptoms of lowered mood, that last at least **two weeks** and affects your daily life (Berk et al., 2008:283).
Mania	An abnormally elevated or irritable mood, plus at least three or four other symptoms of mania, that lasts at least a **week** and affects your daily life (Berk et al., 2008:283).
Mood	A conscious state of mind that lasts longer than a fleeting emotion and includes feelings, thoughts and behaviour (Berk et al., 2008:283).
MRI	(Magnetic resonance imaging) Records the magnetic properties of atoms in the brain after they have been exposed to electromagnetic waves. Computer software transforms the information into a revealing picture (Haycock, 2010:57).
Neurotransmitters	Substances in charge of carrying information in the brain (Colom & Vieta, 2006:71).
Oral	Pertaining to the mouth (Lundbeck, 2005:28).
Paranoid	Suffering from delusions of persecution. Believe others are trying to harm one (Lundbeck, 2005:28).
Predispositions	It means that some people are susceptible to having manic or depressive episodes because of a factor within themselves, like the genes they inherit or the particular chemistry of their brains (Miklowitz, 2010:135).
Prodromes	Signs and symptoms that precede and lead up to the point at which an episode of illness is at its most severe (Berk et al., 2008:121). Warning signs (Colom & Vieta, 2006:156).

Prophylactic	An agent that prevents the development of a condition or disease (Oxford Concise Colour Medical Dictionary, 2010:598).
Psycho education	Education about an illness combined with information on helpful management strategies (Berk et al., 2008:283).
Psychosis	A loss of contact or break with reality (Fast & Preston, 2006:22).
Racing thoughts	Fast ideas (Colom & Vieta, 2006:81)
Recovery	A term used to describe "a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness. Rather than being an end point that the person achieves, recovery may be an on-going and very personal process of finding ways to manage the illness and live well (Berk et al., 2008:29).
Relapse	A recurrence of an episode of illness (Berk et al, 2008:284).
Relapse signature	An individual's personal warning signs of illness **(**Berk et al, 2008:284). A person may have his/her own pattern of how warning signs and symptoms develop into a specific type of episode (mania, hypomania or depression). This is called a **'relapse signature'** (Berk et al., 2008:121).
Schizophrenia	A psychotic disorder characterised by a loss of contact with reality. This results in the experience of delusions and/or hallucinations, confused thoughts and speech, and unusual behaviour (Berk et al., 2008:284).
Schizoaffective disorder	This disorder occurs when symptoms of a mood disorder (either depression, mania or a mixed episode) and schizophrenia occur together, but psychotic symptoms are present for at least two weeks without mood symptoms (Berk et al., 2008:284).
Self-medication	Seeking to alleviate some of their symptoms (Colom & Vieta, 2006:148).
Serotonin system	System of nerve cells in the brain where serotonin works as a chemical messenger from one cell to the next (Lundbeck, 2005:29).
Substance abuse	Recurrent significant negative consequences from repeated use of substance; does not meet criteria for substance dependence.
Substance dependence	Repeated use of the substance results in the development of tolerance, withdrawal, and compulsive drug-taking/drug-seeking behaviour (Last, 2009:192).
Social rhythms	Those patterns of everyday activity – falling asleep, waking up, having meals and social interaction – that structure daily life and set your body clock. Doing some things routinely may help regulate sleep/wake cycles. People with bipolar disorder are sensitive to changes in social rhythms, which can act as stressors to trigger symptoms (Berk et al., 2008:107).
Symptoms	From the Latin *symptoma,* meaning 'chance, accident, mischance'. Symptoms refer to a change from what is usual (Berk et al., 2008:285).
Tardive dyskinesia (TD)	NIMH (2010:12) states that this condition causes muscle movements that commonly occur around the mouth. A

	person with TD cannot control these movements. TD can range from mild to severe, and it cannot always be cured.
Trigger	Stressors that increase the risk of the person developing symptoms. Recognizing a trigger provides the opportunity for the person to either reduce the stressor or find helpful ways to cope with it (Berk et al., 2008:12).
Warning symptoms	Changes that indicate that an episode of illness is brewing (such as changes to usual sleep pattern) (Berk et al., 2008:285).

Chapter 7: Appendix 7.12: Relevant resources for caregivers (national and international)

DVD

Barnard, S (dir). & Rijnen, A.Heyns, K. (prods). 2009. *Living with Bipolar Disorder*. [Documentary]. Medihelp

Websites to contact for information

Black Dog Institute www.blackdoginstitute.org.au The Black Dog Institute offers specialist mood disorders assessment, treatment and information. It contributes to research in the area and offers education programmes.

bpkidssa@mweb.co.za / bpkidssouthafrica.co.za. Offers support and guidance for parents with children who are bipolar. Contact Lee: 083 227 2304

Department of Social Development Substance Abuse Line: 0800 12 13 14 SMS 32312

Dreyer, H. [sa]. Dr Hans Dreyer for stress related illnesses. [Online]. Available: www.drhansdreyer.com.

http://helpguide.org/mental/bipolar disorder family friends support.htm

http://supportsabda.co.za (SABDA) Mental health support/ advocacy group for caregivers and clients affected by schizophrenia and bipolar and other mental illnesses.

http://www.encyclopedia.com/topic/bipolar disorder.aspx

http://www.health24.com

http://www.manicdepressive.org/moodchart.html. To download a mood chart.

http://www.nimh.nih.gov National Institute of Mental Health (USA)

http://www.pendulum.org/bpcoping.htm

info@schizophrenia.co.za Schizophrenia Foundation of South Africa

Narcotics anonymous: 083 900 6962

SADAG www.sadag.co.za (The South African Depression and Anxiety Group) Mental Health Line: (011) 262-6396; Fax: (011) 262 6350. Free telephone counselling, 365 days per year, 8 am to 8 pm.

SADAG Suicide crisis line: 0800 567 567 SMS 31393

www.allenandunwin.com/livingwithbipolar charts that can be off load (Berk et al., 2008:114)

www.bipolar.co.za has a list of support groups

www.bipolarhappens.com Managing Bipolar Disorder

www.bipolar-lives.com (also find “The Bipolar Toolkit – Taking Charge of Your Own Recovery” by Sarah Freeman at this website).

www.bipolarworld.net provides information e.g. on bipolar diagnosis, treatments, stigma and family support.

www.bpkids.org. A parent-led organization provides information and support to family members, health care professionals, and public concerning bipolar disorders in the young (Miklowitz, 2011:315).

www.cgmhs.co.za Central Gauteng Mental Health society is a non-profit organisation providing services to persons affected by mental illness, intellectual disability and those experiencing life crises.

www.dbsalliance.org (Depressive and Bipolar Support Alliance, DBSA, USA). This site offers information on bipolar disorder, support groups, and help for people with bipolar disorder as well as for friends and family members (Fast & Preston, 2006:264).

www.drada.org (Depression and Related Affective Disorders Association). This site offers information on bipolar disorder and on support groups for consumers and their friends and family members (Fast & Preston, 2006:264).

www.fda.gov (FDA website) Information on medication (Haycock, 2010:70).

www.isbd.org (**International** Society for Bipolar Disorders) aims to promote awareness of bipolar conditions in society at large, educate mental health professionals, foster research on bipolar disorder, and promote international collaborations. Its journal, *Bipolar Disorders: An international Journal of Psychiatry and Neurosciences,* is becoming a primary outlet for new research on the diagnosis, aetiology, and treatment of bipolar conditions.

www.jan.wvu.edu/media/Bipolar.html The Job Accommodation Network provides recommendations for accommodating workers with bipolar disorder.

www.manicdepressive.com

www.mcmanweb.com This site presents information on bipolar and related topics in a unique and interesting way. It makes the latest research in the area easy and enjoyable to read and has a number of useful resources.

www.mdf.org.uk (MDF the bipolar Organization) is a user-led charitable organization that offers self-help groups, publications, and other practical information for those living with bipolar disorder.

www.mentalhealth.com (Internet Mental Health) is an informational website. It is a good site for new research on medications.

www.mentalhealthsa.org.za Mental Health Information Centre (MHIC) 021- 938-9229 (University of Stellenbosch).

www.mhfa.com.au (Mental Health First Aid) this website offers members of the public well research guidelines about how to help a person who is developing a mental health problem or in a mental health crisis to the point where they get appropriate treatment or the crisis resolves.

www.moodswing.org

www.nami.org (National Alliance on Mental Illness) This site offers help where to find local branches of NAMI, and provides information on NAMI's services for consumers as well as for friends and family members (Fast & Preston, 2006:263).

www.nlm.nih.gov/medlineplus/bipolardisorder.html (Medline Plus Health Information) offers links to National Institute of Mental Health publications and clinical trials.

www.pendulum.org (Pendulum Resources) offers information e.g. about the DSM diagnostic criteria, medical treatments and articles on how to cope with depression or bipolar disorder in yourself or a loved one.

www.safmh.org.za South African Federation for Mental Health.

www.supportsabda.co.za (Schizophrenia and bipolar disorders alliance, 011- 326 0661)

www.survivorsofsuicide.org.za Survivors of suicide

Remember BIPOLAR DAY every year on 26 May