

The experiences of caregivers of mental health care users with bipolar disorder in Harare,  
Zimbabwe.

A mini-dissertation

by

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## ACKNOWLEDGEMENTS

One saying goes like, *“whenever you see a turtle sitting on top of a fence post, you know the turtle didn’t get there by itself!”*. This turtle wants to acknowledge the phenomenal support and guidance he got from his supervisor Dr C.L. Carbonatto throughout this research.

I also want to thank my parents Charles and Shumirai Mavingire and all my siblings John, Susan, Fadzai, Joe, Sandra and Mufaro for making my life so full, so complete, and, most important, so peacefully happy - that it has allowed me to sit down and think beyond my current circumstances.

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## ABSTRACT

**Student Name:** Fanuel Mavingire  
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**Topic:** The experiences of caregivers of mental health care users with bipolar disorder in Harare, Zimbabwe.

Zimbabwe has an estimated population of 14 million people and the capital city is Harare, which has a population of 1.6 million. Just like many other developing countries Zimbabwe is faced with multiple social, economic and political challenges. As such mental health is a low priority, as issues of food shortages and HIV and AIDS have taken the priority. With the move towards deinstitutionalisation of mental health services, family members are expected to provide care to their relatives with mental health conditions. Nevertheless, there is limited research on the experiences of caregivers in Zimbabwe.

Therefore, the rationale for this study was to address this gap in research and provide recommendations to improve intervention and support to caregivers of persons diagnosed with bipolar disorder in Zimbabwe. The goal of the study was to explore and describe the experiences of family caregivers of mental healthcare users diagnosed with bipolar disorder in Harare, Zimbabwe.

This qualitative study used an instrumental case study research design to explore the lived experiences of caregivers of mental health care users with bipolar disorder. The ten caregiver research participants were purposively sampled, using the following selection criteria: participants had to be caregivers of patients diagnosed with bipolar disorder at the unit; the bipolar patients had to be consistently receiving treatment from this institution for the past 12 months; bipolar patients had to be staying with their families (nuclear or extended), who are their caregivers in Harare; participants had to be adult males or females above eighteen years; and had to be primary caregivers, for at least one year, appreciating that they had adequate experience in caregiving for bipolar patients. The ten caregivers were interviewed at Parirenyatwa Annex Psychiatry Unit in Harare, using a sem-structured interview guide.

The research findings reflect that caregivers experienced physical, psychological, emotional, social stigma and financial challenges. Subsequently, caregivers adopted varied coping mechanisms that included acceptance, faith and religion and family. The study also revealed that caregivers of mental health users need financial and emotional support. It was also identified that there are inadequate community mental health care services.

Recommendations include capacity building for caregivers of mental healthcare users through providing them with ongoing emotional and psychoeducation support; developing community awareness programmes that educate families and communities on bipolar disorder and other mental illness to address the high stigma and discrimination associated with mental illness.

## **KEY WORDS**

Bipolar disorder

Caregiver

Experiences

Mental health care

Mental health care users

Biopsychosocial

Social work

Zimbabwe

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## CHAPTER 1

### GENERAL INTRODUCTION AND ORIENTATION TO THE STUDY

#### 1.1 Introduction

Bipolar disorder is a severe mental disorder that is characterised by a persistent fluctuation of moods. A central identifying feature of bipolar disorder is the oscillation of moods from manic to depressive episodes (Bressert, 2016:1). The Diagnostic and Statistical Manual of Mental Disorders 5 (DSM 5) identifies a manic episode as a period of abnormal and persistent elevated, expansive, or irritable mood with increased goal-directed activity, lasting at least one week and present most of the day, nearly every day (or any duration if hospitalization is necessary) (American Psychological Association, 2013:124). A depressive episode is characterised by sadness, lack of hope and lack of energy (APA, 2013:125). Individuals exhibiting manic and depressive episodes (bipolar) exert emotional, physical pressure on caregivers' lives, compromising their quest to attend to other productive socioeconomic activities (Pratima, Bhatia, & Jena, 2011:211).

Zimbabwe, like most developing countries, grapples with a myriad of social and economic challenges. These challenges affect families and individual members of society. One of these challenges arises when a family member is diagnosed with a severe mental illness such as bipolar disorder. Estimations indicate that, worldwide, about 29.5 million people have bipolar affective disorder (World Health Organization, 2017:14). Significant studies have been conducted globally on bipolar disorder, however little has been done on the experiences of caregivers of bipolar patients in the Zimbabwean context. Studies have been carried out in the United States of America and Europe, but the findings cannot be generalised across all societies. Wintersteen, Mupedziswa, & Wintersteen, (1995:89) indicate that most of these studies reflect on the situation of developed countries, which can be anecdotal and might not represent an attempt to understand the experiences of families in developing countries such as Zimbabwe.

Traditionally, the care for persons with mental illness in Zimbabwe is the responsibility of the extended families. However, the colonisation of Zimbabwe by Britain led to the development of some psychiatric hospitals, by the then government of Southern Rhodesia (Wintersteen et al., 1995:90). Post-independence has mostly limited the involvement of government in the continuation of these hospitals, even though there has been a surge in community service programmes (Chikara & Manley, 1991:944). Presumably, the continuation of care of bipolar patients is a burden placed on the shoulders of families. Tan, Yeoh, Choo, Huang, Ong, Ismail and Ang (2012:24) posit that modern trends in mental health care is moving away from institutionalisation to community care, leaving the family responsible for caring for their mentally ill patients.

Globally, caregivers to persons with severe mental illness experience severe challenges. Tan et al. (2012:24) observe that caring for bipolar patients places a heavy burden on the caregiver's shoulders. Family caregiving to persons with mental illness such as bipolar disorder can cause disruption to daily living and brings limitations on things such as individual freedom, reduced leisure time, missing work, challenges in interpersonal relationships with other

(friends, family), as well as induced feelings of shame, guilt and worry (Chang, Chiou, & Chen, 2010:14). Chang et al, (2010:14) further asserts that families living with family members with bipolar disorder provide support in various ways, for instance case management (assessment of patient functioning, and identification of patient needs) and serving as a link with the treatment team (in terms of encouraging and supporting, and monitoring patient compliance with medication and recommended activities). The study attempts to explore the lived experiences of family caregivers of persons living with bipolar disorder to identify their responsibilities and needs to provide recommendations for social work practice related to caregivers to bipolar patients. Subsequently, the key concepts of this study are as follows:

## 1.2 Definition of terms:

- **Bipolar disorder:** Bipolar disorder I refers to classic manic-depressive disorder or affective psychosis (APA, 2013). The APA (2013, p. 123) states that “bipolar disorder II requires a lifetime experience of at least one episode of major depression and at least one hypomanic episode.” The diagnosis of cyclothymic disorder is given to adults who experience at least 2 years (for children, a full year) of both hypomanic and depressive periods without ever fulfilling the criteria for an episode of mania, hypomania, or major depression (APA, 2013:123). Substances abuse, some prescribed medications, and several medical conditions can be associated with manic-like phenomena (APA, 2013:123).
- **Caregiver:** refers to a family individual who provides unpaid assistance and support to one of the family members who have been diagnosed with bipolar disorder (Chang et al., 2010:3).
- **Experiences:** personal knowledge about the world gained through direct, first-hand involvement in everyday events (Oxford Dictionary, 2013).
- **Mental health care users:** refers to persons receiving care, treatment and rehabilitation services (Mental Health Care Act 17 of 2002:6).
- **Compassion fatigue:** is a state of physical or psychological distress in caregivers, which occurs as a result of ongoing support for a person with a mental illness (Nimmo & Huggard, 2013:39).
- **Mental wellness:** is a state of wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (WHO, 2004).

## 1.3 Theoretical framework

General systems theory holds that a family is a system and that every action will subsequently produce a reaction (Kaplan et al., 1994:846). It focuses on understanding context and looking for connections between the parts, actors and process of the system personnel communication (Shiell & Riley, 2009:269). Holden (2005:654) defines a system as a complex adaptive entity that self-organises, adapts and evolves with time. It is complex because of the interconnectedness of the parts of the system and adaptive because of its ability to communicate and change based on experience.

Understanding the relationships that exist within given systems is key to help design and evaluate system-level interventions (Golden & Martin, 2004:67). In this regard it is fundamental to tackle the interaction that exist between a family caregiver and a bipolar patient. The systems theory seeks to explain how family caregivers strive for meaningful interactions with the bipolar patient. In this family system, effective communication forms the backbone of all interactions within the system.

The social worker's responsibility in this context is to help the caregiver adapt to the burden of caring for a bipolar patient. It is fundamental for caregivers to make decisions on the best way to adapt.

The study is guided by the biopsychosocial approach as it seeks to explore and describe the biopsychosocial experiences and challenges of caregivers caring for a person living with bipolar disorder.

### 1.3.1 Biopsychosocial approach

The biopsychosocial approach has its roots in the systems theory, which was formulated by the German philosopher Georg Friedrich Hegel (1770–1831). He believed that when it comes to the nature of systems that the whole is greater than the sum of its parts (Deacon 2013:846). It is the whole that defines the nature of the parts and the parts are dynamically interrelated or interdependent (Skyttner, 2001:36). Proponents of the systems theory strived to overcome a mechanistic model of biology in the 1920s. Experiments by biologist Weisse with butterflies led him to believe that biological phenomena have to be understood at a systems level (Drack, Apfalter & Pouvreau, 2007:351). Deacon (2013:846) argues that the systems theory's emphasis is on holism. It has contributed to the move away from the traditional medical model that suggests exclusively physiological causes for illness and disease.

The biopsychosocial (BPS) approach was then developed in 1977 by Dr George Engel and Dr John Romano. This approach is an integrative approach that embraces biology, psychology and social aspects as part of health care (Dogar, 2007:10). The approach thus considers biology, psychology, and social factors and their complex interaction in understanding health, illness and health care delivery (Cohen et al., 2010:64). The BPS approach recognises that biological, psychological and social forces act together to determine an individual's health and vulnerability to disease. Dogar (2007:10) posits that the biopsychosocial approach (BPS) provides a holistic, broader, integrated approach to health and disease. It provides a basis for understanding the determinants of disease and arriving at rational treatments and patterns of health care. This integrated approach is key to understanding psychiatric conditions such as bipolar disorder, its treatment and caregiving. Subsequently, the three components, namely biology, psychology and social factors, and how they relate to health outcomes are discussed.

#### 1.3.1.1 Biological context

Proponents argue that all behaviours, including states of health and illness, occur in a biological context. Every thought, mood and urge is a biological event made possible because of the characteristic anatomical structure and biological function of the person's body (Dogar,

2007:11). Genes provide a guideline for our biological mechanisms that predispose our behaviour; healthy and unhealthy, normal and abnormal. This explains for example how alcohol dependency can run in families, just like cancer or diabetes (Borrel-Carrio Suchman & Epstein, 2004:68). Biology and behaviour constantly interact, for instance bipolar from a biological lens shows elements of severe depressive aspects.

#### 1.3.1.2 Psychological context

The psychological component of the biopsychosocial approach looks for potential psychological causes for a health problem such as a lack of self-control, emotional turmoil, and negative thinking (Cohen et al., 2010:65). Health and illness are subject to psychosocial influences. These influences are key factors in how well caregivers of patients with bipolar disorder cope with a stressful life experience of caregiving. Caregiving for bipolar patients is as overwhelming, pervasive and beyond their control and takes a toll on their physical and psychological functioning (Cohen et al., 2010:65). Psychological factors also play an important role in the treatment of chronic conditions. Psychological interventions can help users in managing the everyday stresses of life, which seem to exert a cumulative effect on the immune system. Dogar (2007:11) observes that negative life events such as bereavement, divorce, job loss or relocation, has been linked to decreased immune functioning and increased susceptibility to illness. Therefore, teaching users about more effective ways of managing unavoidable stress may help users' immune systems combat diseases (Cohen et al., 2010:65).

#### 1.3.1.3 Social context

The social part of the biopsychosocial approach investigates how different social factors such as socioeconomic status, culture, poverty, technology, and religion can influence health (Dogar, 2007:12). Socio-cultural perspectives consider how social and cultural factors contribute to health and disease. Dogar (2007:12) argues that socio-cultural forces play an important role in variations in health-related beliefs and behaviours, for instance a gender perspective that focuses on gender-specific health behaviours, problems and barriers. In the context of this study, family caregivers are social entities (constructs) that contribute to health outcomes by caring for bipolar patients.

The BPS model provides a clear lens through which social workers can view health care outcomes. The BPS model underpins this study.

### 1.4. Rationale and problem statement

Several studies worldwide have shown that the caregivers of mental health care users diagnosed with bipolar disorder face a plethora of psychosocial challenges. This affects all the dimensions of their lives, such as the biological, psychological and social dimensions. Challenges can include the disruption of individual freedom, reduced leisure time, missing work, challenges in interpersonal relationships with other (friends, family) as well as induced feelings of shame, guilt and worry (Chang et al., 2010:267).

Even though numerous studies have given great attention to the burden of bipolar disorder patients, very little has been done on the impact of caring for bipolar patients, specifically in Zimbabwe. As a result of the move away from institutional care in Zimbabwe, mental healthcare users have become the responsibility and burden of their families and the community.

Therefore, the aim of this study is to address this gap in research by exploring the experiences of caregivers of mental health care users diagnosed with bipolar disorder in Harare, Zimbabwe. Recommendations from this study can help improve interventions and support to the caregivers of persons diagnosed with bipolar disorder.

**Research question:** What are the experiences of caregivers who care for mental healthcare users with bipolar disorder in Harare, Zimbabwe?

### 1.5. Aim and objectives

The aim of the study is to explore and describe the experiences of family caregivers who care for mental health care users diagnosed with bipolar disorder in Harare, Zimbabwe.

In order to meet this aim, the objectives of this study are:

- To explore, describe and contextualise bipolar disorder from a systems theory perspective, making use of the biopsychosocial approach;
- To explore and describe the biopsychosocial experiences and challenges of family caregivers caring for a person living with bipolar disorder;
- To ascertain the challenges and responsibilities of caregivers in caring for a person living with bipolar disorder;
- To explore the level of intervention and support provided by professionals to the family caregivers of a person living with bipolar disorder; and
- To suggest the role of social workers in service delivery intervention with caregivers of mental health care users with bipolar disorder.

### 1.6 Overview of research methods

The study followed a qualitative research approach. According to Babbie and Mouton (2012), qualitative research seeks to study things in their natural setting by making sense of a matter or phenomenon by exploring the meanings that people attach to it. The research design was a instrumental case study and the study population were caregivers who care for mental health care users with bipolar disorder in Harare. The researcher used a semi-structured interview as a method to gather data. Chapter 3 provides a more detailed description of the research methodology as well as the ethical considerations applicable to this study.

### 1.7 Lay-out

The following content is discussed in this report:

#### Chapter 1

General orientation and research methodology

## Chapter 2

Literature review on experiences of family caregivers of mental health care users diagnosed with bipolar disorder.

## Chapter 3

Empirical findings, analysis and interpretation of data.

## Chapter 4

Conclusions and recommendations.

The following chapter will focus on the literature review.

## CHAPTER 2

### LITERATURE STUDY

This chapter provides an in-depth review of the available literature.

#### 2.1 Introduction

Mental health is a state of wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (World Health Organization, 2011:8). Bipolar disorder is a mental health disorder which affects one's mental health state (WHO, 2004:2). This study focuses on caregiving of family members with bipolar disorder.

This chapter provides the contextualisation of bipolar disorder, its nature, symptoms, causes and the experiences of caregivers of persons with bipolar disorder. In order to understand all the concepts used in this chapter, they are defined below:

#### 2.2 Contextualising bipolar disorder

Bipolar disorder is a recurrent severe mental illness that is characterised by frequent oscillation between manic and depressive symptoms, which may be intense and last anywhere from one day to months, with a prevalence ranging from 1.3% - 1.6% to 3.8% (Pompili et al., 2014:2). It was first diagnosed in 1851 in France by Jean-Pierre Farlet, who identified the disorder in patients who represented with depression and manic episodes. Previously in the DSM-IV, bipolar was classified under mood disorders. However, it has been given a separate category in the DSM-5. Clinical diagnosis of bipolar disorder is presented with manic and depressive moods in the DSM 5 as discussed below:

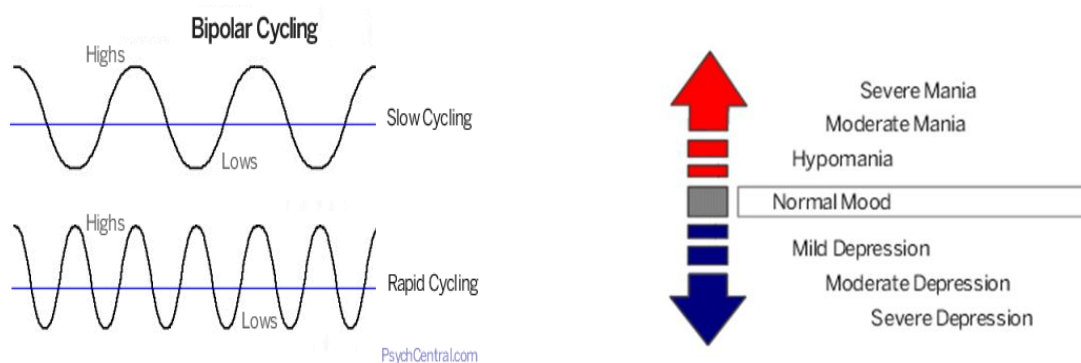
##### 2.2.1 Manic episode

This is a distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy (APA 2013:124). The manic episode is characterised by the following, inflated self-esteem or grandiosity, decreased need for sleep, more talkative than usual or pressure to keep talking, flight of ideas or subjective experience that thoughts are racing, distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli), as reported or observed, increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation (i.e., purposeless non-goal-directed activity), excessive involvement in activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments (APA, 2013:124).



## 2.2.2 Depressed mood

This manifest in the following; depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, or hopeless), diminished interest or pleasure in activities most of the day, significant weight loss when not dieting or decrease or increase in appetite nearly every day, insomnia or hypersomnia nearly every day, psychomotor agitation or retardation nearly every day, fatigue or loss of energy nearly every day, feelings of worthlessness or excessive or inappropriate guilt, diminished ability to think or concentrate, or indecisiveness, nearly every day, recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt (APA:125)



**Figure 2.1: Bipolar cycling, from severe depression to severe mental illness (Bressert, 2016).**

Ostensibly, persons with bipolar become impulsive and act aggressively during manic episodes, leading to high-risk behaviours, such as frequent intoxication, excessive spending and risky sexual behaviours.

## 2.3 Types of Bipolar

The DSM-5 classifies bipolar disorder into seven categories as a result of different occurrence and interval of manic and depressive symptoms. These include bipolar I disorder, bipolar II disorder, cyclothymic disorder and substance/medication-induced bipolar and related disorder, bipolar and related disorder due to another medical condition, other specified bipolar and related disorder, and unspecified bipolar and related disorder (APA, 2013:123).

### 2.3.1 Bipolar I disorder

Bipolar I disorder refers to the classic manic-depressive disorder or affective psychosis (APA, 2013:123). An indispensable feature of bipolar I is the experience of one full manic episode, nevertheless, hypomanic or severe depressive episode may precede the manic episode (Medina, 2016:4). Also central to the manic episode is abnormal, obstinate elevation, irritable mood and persistently increased activity or energy that prevails almost daily, lasting for at least one week (Medina, 2016:4), often accompanied by at least three other manic symptoms.

### 2.3.2 Bipolar II disorder

Bipolar II is characterised by historic occurrence of one or more major depressive episodes and at least one hypomanic episode (Medina, 2016:4). The amount of time individuals with this condition spend in depression and ostensibly, the instability of mood experienced by individuals with bipolar II disorder is typically accompanied by serious impairment in work and social functioning (APA, 2013:123). Medina (2016:4) reiterates that, in both bipolar I and II, persons can have an episodic mood, which is manic or depressed, in which a manic/hypomanic episode have significant depressive symptoms, and in a depressive episode there are also aspects of manic/hypomanic symptoms.

### 2.3.3 Cyclothymia

The diagnosis is given to adults who experience at least 2 years (for children, a full year) of both hypomanic and depressive periods without ever fulfilling the criteria for an episode of mania, hypomania, or major depression (APA, 2013:126). The symptoms are not better explained by schizoaffective disorder, schizophrenia, schizophrenic form disorder, delusional disorder, or other specified or unspecified schizophrenia spectrum and other psychotic disorders. The symptoms are not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition (e.g., hyperthyroidism). The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

### 2.3.4 Substance/medication-induced bipolar and related disorder

Several substances of abuse, some prescribed medications, and several medical conditions can be associated with manic-like phenomena. This fact is recognised in the diagnoses of substance/medication-induced bipolar and related disorder and bipolar and related disorder due to another medical condition (APA, 2013:123).

### 2.3.5 Bipolar and related disorder due to another medical condition

This category is identified as the clinical presence of a prominent and persistent period of abnormal elevated, expansive or irritable mood and abnormally increased activity of energy predominantly that is attributable to another medical condition (APA, 2013:146). The following include the most common medical disorders that are associated with this type of bipolar; traumatic brain injury, stroke, multiple sclerosis and Cushing's disease (APA, 2013:146).

### 2.3.6 Other specified bipolar and related disorder

The category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for any specific bipolar and related disorder (APA, 2013:148). The APA (2013:148) give examples of presentations that can be specified using the "other specified" designation including the following;

- Short-duration hypomanic episodes (2-3 days) and major depressive episodes,
- Hypomanic episodes with insufficient symptoms and major depressive episodes,
- Hypomanic episode without prior major depressive episode,
- Short-duration cyclothymia (less than 24 months).

### 2.3.7 Unspecified bipolar and related disorder

Specific to this, is the symptoms which characterise 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 (APA, 2013:149). “This category is used in situations in which the clinician chooses not to specify the reason that the criteria are not met for a specific bipolar and related disorder, and includes presentations in which there is insufficient information to make a more specific diagnosis (e.g., in emergency room settings)” (APA, 2013:149).

### 2.4 Symptoms of Bipolar Disorder

The following serve as information on signs and symptoms of bipolar at different stages (Parikh Parikh, S.V., Zaretsky, A., Beaulieu, S., Yatham, L.N., Young, L.T., Patelis-Siotis, I., Macqueen GM, Levitt A, Arenovich T, Cervantes P, Velyvis V, Kennedy SH, & Streiner DL., 2012:5).

- **Exaggerated self-esteem:** At this stage a person feels powerful and motivated, they will have a strong belief that they can save anything in the world and have a deep understanding of the world’s problems, as they feel like they have a special life mission and tend to confuse reality and fiction.
- **Less sleep:** A person with bipolar disorder may feel that there is less need for sleep and can have short time of rest and in extreme circumstances may not sleep at all for a few days or even weeks.
- **Increased Talking:** Individuals with bipolar became more talkative and very louder than usual. They can get very angry if they are interrupted when talking. The speech lacks coherence and may jump from one topic to the other using rhyming words. This makes it difficult for individuals to be able to converse properly with other people around. Their social skills are limited and distorted in this state.
- **Racing thoughts:** the individual is also easily distracted and may be very impatient with the people that cannot keep up with the racing thoughts which keep on changing ideas and conversation topics.
- **Poor judgement:** one’s ability to exercise control or plan is lost as the patient becomes more prone to engaging in risky activities without realising the possible harming consequences. In this state the patient will require constant watch by caregivers.
- **Psychotic behaviour:** patients can also exhibit signs of psychosis in the form of delusions and hallucinations.
- **Depressed mood:** Individuals also experience depressive episodes which can be manifested in slow speech, thinking and movement and response to the environment around them. This causes individuals diagnosed with bipolar disorder to be at risk of becoming incapacitated to carry out daily tasks. In some scenarios the reactions are very opposite as they exhibit signs of being easily agitated and tormented by an inner lack of rest as they just continuously pace around.

In this light of the above, bipolar disorder symptoms are erratic and can present from manic to depressive moods. It is the view of the researcher that caregivers of bipolar disorder patients should be able to understand the presentation of these episodes to provide the needed care for patients.

## 2.5 Causes of bipolar disorder

There has not been clear explanation as to the exact cause of bipolar disorder, however, researchers have pointed to genetic, neurochemical and environmental factors as having a bearing in the development of bipolar disorder. Medina (2016:5) posits that currently most researchers agree that bipolar is a predominantly neurobiological disorder, that occurs in a specific part of the brain and is due to a malfunction of certain brain chemicals (that occur both in the brain and the body). Three specific brain chemicals have been implicated, namely serotonin, dopamine and noradrenaline. As a neurobiological disorder, it may lie dormant and be active spontaneously or it may be triggered by stressors in life (Medina, 2016:5). Although the causes may not be clearly laid out (Van Zyl, 2017:29), categorised them into social, psychological and biological possible risk factors that may cause bipolar.

### 2.5.1 Biological causes

Milkowitz (2010:41) describes bipolar as a disorder of genetic and biological origin and hence needs a host of treatment solutions. Children who are born of parents with bipolar are at a higher risk of developing the disorder and about 72% of children conceived by mothers with bipolar disorder are also at a higher risk of developing other mental illnesses in their lifetime (Milkowitz, 2010:41). The neurotransmitters such as serotonin, norepinephrine, dopamine, gamma-aminobutyric acid and norepinephrine are all linked to the diagnosis of bipolar disorder (Van Zyl 2017:29). As such therapy linked to the above neurotransmitters is seen as a critical factor in the treatment of the bipolar disorder (Van Zyl, 2017:29). The use of substances and alcohol also increases the risk of developing bipolar disorder and inhibits the effectiveness of treatment as individuals with high nicotine levels also have high prevalence of suicidal ideation, mixed episodes when they have bipolar (Frye & Perugi, 2010:34). Persons under such circumstances are said to respond slowly to medication. Considering the above, the use of illicit substances and alcohol abuse places individuals at the risk of triggering bipolar and other psychiatric disorders.

### 2.5.2 Psychological causes

Bender and Alloy 2011 in (Van Zyl, 2017:230) are of the assertion that between 40% to 76% of people who are diagnosed with bipolar disorder can be linked to a highly stressful event in life. Current studies have found that patients exposed to childhood trauma such as sexual or physical abuse, neglect, traumatic events and losing someone very close like a parent, have a higher likelihood of developing bipolar disorder than those who are not exposed to childhood trauma (Andrade et al., 2014:2). Significant stressful life events such as relationship breakdown, money worries, poverty and experiencing a traumatic loss, are often linked to the causes of bipolar disorder. This demonstrates that the causes of bipolar disorder are multifaceted and is a combination of both biological and psychological factors. Therefore Van Zyl (2017:30) emphasises becomes important to show the risk factors that are associated with the disorder, which are listed as follows:

- Low levels of education.
- Being in a high-income country.

- Being a person of low social and economic standing.
- Divorced, widowed or separated persons.
- Diagnosed with other psychiatric illnesses.
- Having an eating disorder.
- Being diagnosed with sleep or anxiety disorders in adulthood.
- Being diagnosed with attention deficit hyperactivity disorder in childhood.
- Substance abuse.
- Having a physical disorder like diabetes.

Many people who are diagnosed with bipolar are reported having experienced it in their childhood and adolescence (Van Zyl, 2017:31). The following risk factors are identified in the diagnoses of bipolar disorder (Van Zyl 2017:32):

- Being aggressive and moody in childhood.
- Struggling to show sympathy towards others.
- Having a high concern of the parent's emotional state.
- Being diagnosed with ADHD in childhood.
- Showing symptoms of mania.
- Having a family history of bipolar.

### 2.5.3 Socioeconomic causes of bipolar

In an environment with social and economic challenges, the prevalence of mental health illness is likely to be high due to stressful life circumstances. Van Zyl (2017:34) mentions that individuals and families in such circumstances are stressed by challenges like poverty, political instability, family violence and idleness. This increases the likelihood of risk among individuals who already have exhibited some signs of depressive behaviours. In Zimbabwe, the current challenges increase people's susceptibility to bipolar disorder. Zimbabwe's poverty datum line for an average family of five rose by 15,18 percent as the cost of living continues to rise on the back of unrestrained price increases (Zimbabwe National Statistics Agency 2019:2). Considering this, the prevalence of mental health conditions has high chances of rising as the mental wellbeing of many people is at risk. This is further worsened by the already limited and debilitating mental health care services in the country. As a result, the treatment process become compromised, as there are not enough resources and facilities to cater for those that would have been diagnosed.

In a nutshell, the state of the social and economic stability of a given country has a direct bearing on the mental health illness of a country. Therefore, more resources must be directed at mental health awareness and treatment support.

## 2.6 Treatment of bipolar disorder

The treatment of bipolar disorder relies on wide range of biological, psychological and spiritual methods. Achambeault (2009:36) posit that because bipolar is classified as a persistent mental illness, there is a need to involve a host of methods in order to obtain the desired outcomes. This therefore confirms Milkowitz (2009:57), who asserts that the biopsychosocial approach

is the most suitable way to deal with bipolar disorder. This is because it becomes important to put focus on other aspects like psychosocial aspects, as they are the stress inducers and hence become triggers as well. Van Zyl (2017:35) mentions that there has been support for a multipronged approach for effective treatment. Treatment should focus on the following three areas:

### 2.6.1 Biological

Van Zyl (2017:36) is of the view that there is a need to ensure that there is an accurate and timely diagnosis for treatment of bipolar and thus there should be a reasonable time between the actual diagnosis and the prescription of medicine. Therefore, early medicinal treatment soon after noticing symptoms and diagnosis is of paramount importance to the recovery of the patients. Milwokitz (2010:300) is of the view that the doctors should also trace the family history when it comes to a proper diagnosis.

In the biological treatment, the patient will be taking mood stabilising medication, anti-depressant medication and antipsychotic medication as well. Van Zyl (2017:36) is of the view that non-adherence to medication leads to the development of side effects. On the other hand, adherence may also lead to stigma from the society members. Thus Van Zyl, (2017:37) states that family members of the diagnosed patient should be well educated on the biological aspects of the disorder so that they understand the patient's behaviour. The multidisciplinary team should work towards providing information to caregivers of bipolar patients to ensure that patients take in their dosages correctly and improve on the quality of care for patients

### 2.6.2 Psychological treatment

Therapeutic interventions are essential for dealing with bipolar disorder, by equipping a mental health patient learn how to cope with difficult, repair patient relationships, management of stress, and mood regulation. Miklowitz (2009:577) acknowledges that emotional, behavioural and cognitive therapies need to be introduced as treatment interventions for individuals diagnosed with bipolar disorder. Psychological methodologies are fundamental to addressing behavioural issues, therefore specialist services are required to complete the individual's psychiatric history. Smith, Segal and Segal (2019:6) identify that the specialist will ask the individual about their symptoms, the history of the problem, if there is any treatment previously received and the family history of mood disorders. as they firstly, need to adjust to their lives without manic symptoms or the precipitation thereof, and secondly, need to develop effective ways of coping with new challenges on a practical and emotional level. The importance of psychological intervention in the form of therapy is significant, as the therapeutic relationship can mean the difference between adherence and non-adherence to treatment (Scott & Tacchi, 2010:276).

Psychological treatment interventions mainly utilise the cognitive behavioural therapy to address challenges faced by bipolar patients. The cognitive behavioural therapy addresses negative thinking patterns and behaviours into more positive ways of responding. With regard to bipolar disorder, the thrust of the cognitive behavioural approach is on managing symptoms, avoiding triggers for relapse and problem solving (Smith et al., 2019:7).

### 2.6.3 Social and cultural level

Psychiatry was developed as part of Western medicine, thus the influence of culture, for example, African culture, did not play a significant role when mental health care (diagnosis and treatment) was defined and developed (Allott, cited in Archambeault, 2009:27). In this regard, treatment is often avoided by patients and their families because they fear the stigma related to their own or family member's diagnosis, especially in societies where other cultural and religious opinions regarding psychiatric disorders are present (Archambeault, 2009:117). The withdrawal from families poses additional concerns, as Yatham et al. (2009:2) warn that symptoms associated with bipolar disorder are very common in other disorders and thus families should be included from assessment to ensure that the correct diagnosis is made, more so when manic symptoms are present.

The nature and origin of mental health care created a need for psychoeducation with patients and their families, as this has a direct impact on relapse rates, especially in families where criticism, hostility and over-involvement are common (Miklowitz, 2009:577). Families and significant others should thus be educated on bipolar disorder to enable them to understand and recognise warning signs and to inform them of how they can support their relative (Miklowitz, 2010:26). Muzina et al. (2009:117) believe that when families are involved in treatment, they will not only gain knowledge, but they will be able to determine and report whether treatment is effective or not. The role that families play in the treatment of bipolar disorder is also important in identifying possible risks factors associated with the onset of future mood episodes; for example, the use of substances, non-adherence to medication, or severe family conflict (Miklowitz, 2010:26). Families should also be included in setting realistic treatment goals in terms of resuming psychosocial responsibilities, to ensure that the family or the individual diagnosed do not assume too much or too little responsibility in an unreasonable amount of time (Miklowitz, 2010:27). The risk of not including family members, means they will not understand bipolar disorder and become less supportive and often disregard the seriousness of the disorder, leading to more instances of non-adherence among patients (Scott & Tacchi, 2010:277).

## 2.7 Global mental health policy

Mental health policy is an essential and powerful tool to improve the mental health of a country (Zhou, Yu, Yang, Chen & Xiao., 2018:117). The European Ministerial Conference on Mental Health, Facing the Challenges, Building Solutions held in Helsinki, Finland in 2005, recognised that mental health and mental wellbeing are key to the quality of life and productivity of individuals, families, groups, communities and nations, enabling people to experience life as meaningful and to be creative and active citizens (WHO, 2011:1). Member states resolutions addressed that policy and practice on mental health should work on prioritising the following:

- prognosis, of mental health disorders;
- foster awareness of the importance of mental wellbeing;

- collectively tackle stigma, discrimination and inequality, and empower and support people with mental health problems and their families to be actively engaged in this process;
- design and implement comprehensive, integrated and efficient mental health systems that cover promotion, prevention, treatment and rehabilitation, care and recovery;
- address the need for a competent workforce, effective in all these areas;
- recognise the experience and knowledge of service users and carers as an important basis for planning and developing mental health services (Article7:2) (WHO, 2011:2).

In a nutshell, the global have policies and strategies that member states can adopt to address global mental health challenges. However, there are existing gaps between policy development and implementation in most countries, consequently family caregivers of mental health patients have the burden of care due to limited support services.

## 2.8 Epidemiology and burden of bipolar disorder in Africa

Bipolar disorder impacts negatively on the psycho-socio and economic life of the patient, the family and the society at large. Esan and Esan (2016:93) posit that, bipolar disorder taxes the health care services, owing to a combination of the illness and associated medical conditions, as well as psychiatric comorbidities. A study on the global burden of disease of 2010, revealed that, the burden of disease related to mental illness and substance use disorders in terms of disability adjusted life years was 7.4 % worldwide (Whiteford, Degenhardt, Rehm, Baxter, Ferrari & Erskine 2013:75). Out of this, bipolar disorder alone accounted for 7 % of the disability adjusted life years caused by mental and substance use disorders (Whiteford et al., 2013:75). This implies that more healthy years in life are lost to psychological, behavioural and mental disorders, than to diseases like cancer and heart related diseases. Statistics have demonstrated that despite the severity of mental health as a global health concern, mental health issues only make up of less than one percent of health expenditures in low income countries (Murray 2010:12).

An assessment on the expenditures for mental health care by employers, showed that bipolar disorder compared to other mental health diagnoses was found to be the more expensive mental health care diagnosis (Peele, Xu & Kupfer, 2003:86). The same study also established that bipolar disorder caused huge financial burden on employers, costing more than twice as much as depression per affected employee (Peele et al., 2003:86). Ae-Ngibise, Korley Doku, Asante & Owusu-Agyei, (2015:5) observes that there has been a growing public health burden in the health systems of the world as a result of mental health issues which has been estimated to be at 14%, with developing countries having to bear the bulk of the burden.

Mental health illnesses in the year 2010, accounted to almost nine hundred billion in low income countries (WHO 2011:15). The cost is expected to rise well over the two hundred-billion-dollar mark by the year 2030, due to an increase of mental health issues and their symptoms that have long-term health care costs (Murray 2010: 14). More so, most people



who are diagnosed with mental disorder in most cases become incapacitated economically and hence must be taken care of. Interventions that are specifically designed for mental health issues can improve the economic circumstances in low income countries and this has been proven in multiple controlled trials and studies (Bloom, Cafiero, Jané-Llopis, Abrahams-Gessel, Bloom, Fathima, Feigl, Gaziano, Mowafi, Pandya, Prettner, Rosenberg, Seligman, Stein & Weinstein, 2011). Mental health illnesses are one of the top five causes of disease burden in Africa (Murray, 2010:5). Zimbabwe has developed progressive mental health policies and facilities for services delivery; however, Zimbabwe's health care system is underfunded and limited resources to provide proper diagnosis and care services are available (Murray 2010:5). There is a paucity in the knowledge and burden of bipolar disorder in Africa, the most available researches are from Europe, United States and other developed countries.

## 2.9. Zimbabwe National Policy Framework on mental health

In Zimbabwe mental health issues are addressed by several frameworks that have been laid out by the government which are as follows: The Mental Health Act (1996); Mental Health Policy (2004) and the Mental Health Strategy (2014:18).

The Mental Health Policy (2004:6-14) policy stands guided by the Mental Health Act of (1996), the provision of mental health care services in Zimbabwe is guided by the following principles:

- Quality care in providing mental health services
- Access to mental health services is a fundamental human right to all citizens
- Professional and ethical standards should be upheld to the highest level when treating clients
- Decentralisation and integration of mental health services to enable accessibility and sustainability
- Multidisciplinary approach to care systems
- Multi-sectoral approach to interventions should be a strong belief for the improvement of the client's quality of life
- Community involvement in the caring of mental health care users and delivering client focused solutions

There has been slow progress in implementing these principles to date, community based mental health institutions have not been established and hence there is a need to look at how this may be affecting caregivers of bipolar patients (Kushinga, 2016:10).

## 2.10 Cultural interpretations of mental illness

Often in Africa, mental illness is attributed to demon possession or black magic and usually the first treatment option is with the traditional healer and even faith healers, as it is largely regarded as a spiritual matter which requires a corresponding spiritual solutions (Ae-Ngibise et al., 2015:5). In this view it is critical to understand that experiences of caregivers of bipolar patients in the Zimbabwean context are interwoven in the cultural and spiritual beliefs.

Hewson (1998:1029) provides some of the traditional African understanding of mental illness. Hewson (1998:1029) further affirms that there may be a belief that mental illness derives from psychological conflicts or disrupted social relationships which may cause imbalance. This imbalance manifests itself through mental and physical problems. Thus, these psychological or spiritual factors may threaten the wellbeing of the person (Hewson, 1998:1029). While mention is made of the psychological, mental and physical, the emphasis is generally on the supernatural and the spiritual. The meaning attributed to behaviour is generally attributed to bewitchment, social relationships and ancestry and may be nonspecific (Shoko, 2008:506).

Shoko (2008:507) further classifies the supernatural framework of mental illness and categorises causation as being mystical, magical or animistic. Magical refers to being in a state of pollution, where one is no longer protected from negative forces. Animistic causation occurs when one has displeased the ancestors. Magical causation is linked with witchcraft and curses. Robertson (2006:87) reflects that indigenous healers generally abide by the following diagnostic categories in their explanations of mental illness.

In the African context real concept of nature covers the physical world and the social environment of the living and the dead together with the metaphysical forces in the greater universe (Muchinako, Mabvurira & Chinyenze 2013:2). In the African context everything is interpreted in the eyes of the dimensions and mental health issues are not an exception. Moleko (2012:163) postulate that, people's way of life, belief systems, perspectives, attitudes behaviour and traditions are shaped by culture. Thus, culture can be better explained as a system of beliefs and values that a group of people hold to be of high esteem and abide to. Smith (2015:126) is of the view that cultural standards are the ones which greatly determine thresholds between health and sickness and thus the common and shared notions determine how support is rendered to a sick person within a community. In this aspect, the focus is not only on the disease but more on having knowledge of the individual diagnosed with the disease and their environment (Muchinako, et al., 2013:2). In the African context the environment comprises of spiritual beliefs that are tied to the ancestors, God and other objects that may be viewed as mystical or of spiritual significance. Mental sickness in this aspect is usually associated with spirituality and sometimes is believed to be a symbol of curse or bad spirit that can be contagious and hence leads to stigma and discrimination of people with mental ailments (Muchinako, et al., 2013:2).

A study by Altweeck, Marshall, Ferenczi & Lefringhausen (2015:34) at Brunel University in London found that mental health literacy in African cultures was at very low levels compared to North America and Asia. Stigma in African culture was regarded as high due to the negative beliefs that are associated with having a mental illness (Altweeck et al., 2015:34).

## 2.11 Mental health care knowledge and family caregiver

Mental health care users of bipolar disorder face challenges in accessing treatment in Zimbabwe due to centralisation of services to major hospitals. In this purview, mental health patients are attended at home due to the lack of adequate facilities to accommodate them, with only those who are severely affected being admitted (Izibeloko & Felicia, 2016:2). Jidda, Rabbebe, Omeiza, Wakhil and Ibrahim (2012:3) contends that in mental health, the family

members have the substantial role to provide care for an ill relative. The role of caregivers is mainly because of closer family ties and relationships that exist in African societies. Nevertheless, most of the caregivers do not have the requisite knowledge, skills and support to provide quality care for persons diagnosed with bipolar disorder and other related mental health conditions, despite being in the matrix of daily care and recovery process (Jidda et al., 2012:352). This can also be attributed to the low number of rehabilitation professionals available to provide community awareness in the mental health sector (Jidda et al., 2016:355). There is also lack of priority and lack of adequate infrastructure and the funds to support this aspect of health care in developing countries (Chadda, Singh & Ganguly 2007:924).

The nuclear family members maintain and support their member diagnosed with mental illness, provide shelter, financial, emotional and spiritual support, as well as source and secure treatment (Onwumere, Kuipers, Dunn, Fowler & Freeman 2008:462). Mental health care users of bipolar disorder are isolated, lose their employment and friends as a result of myths and prejudice that surrounds mental disorder (Jack & Uys, 2013:170). In a study carried out to explore the lived experiences of people living with mental illness in rural areas, it was observed that the families' psychosocial and emotional support have been found to be of considerable value and an important factor in the recovery process (Robinson, Springer, Bischoff, Geske & Backer 2012:55). However, with a paucity in the knowledge of bipolar disorder, Jack and Uys (2013:178) argue that it is critical for mental health care providers to offer education awareness to families about mental disorders such as bipolar. Robinson et al. (2012:56) further attest that mental health care should zero on improving communication with and education for family caregivers to warrant appropriate quality of care for mental health care users.

The lack of adequate knowledge and requisite caregiving skills among most family caregivers affect the quality or amount of care provided to mental health care users (Shinde, Desai & Pawar, 2014:521). Considering this, caregivers require to have a basic level of understanding about mental disorders and how to access health care services. It is quite significant that, caregivers with knowledge of mental disorder can together with the health care professionals, form an effective partnership in the continuum of care for persons with mental disorders (Sin & Norman, 2013:23). Jack and Uys (2013:178) concurs that, knowledge is a fundamental building block to the development of skills essential to manage mental health disorders when patients are being taken care of outside the health facility. Mohamad, Zabidah, Fauziah and Sarnon, (2012:1911) posit that, basic skills are key to assist caregivers to maintain a healthy lifestyle, identify early warning signs of relapse, and respond swiftly to manage the prevailing stressful situation.

A significant number of mental health care users get maximum assistance from their nuclear or extended families for support, on their daily activities. As such, it is critical for the caregivers to understand bipolar disorder. Ibrahim, Pindar, Yerima, Rabbebe and Shehu (2015:31) observe that, the inclusion of families in the care planning of mental health care, strongly impacts on mental health, as their involvement improves health and recovery, reduces the risk of a relapse and improves the wellbeing of the family. According to the findings of a study by Rugema, Krantz, Mogren, Ntaganira and Persson (2015:251), ignorance of mental illness among caregivers was directly associated with the low use of coping strategies and numerous

resignations. It is therefore, important for mental health professionals to collaborate with families in the treatment process for mental health care users in order to achieve positive outcomes (Koolae & Etemadi, 2010:635).

The researcher is of the view that` general limited knowledge on mental health illness in most African communities and its association with outcast and avenging spirits increases likelihood of stigma and discrimination of families with a mental health patient.

## 2.12 Mental health facilities in Zimbabwe

There are six public institutions in Zimbabwe with psychiatric beds: Harare Hospital Psychiatric Unit, Parirenyatwa Hospital Annexe, Ingutsheni Hospital, Mpilo Hospital psychiatric unit, Ngomahuru Hospital and Mutare Hospital Sakubva Unit. In addition, three facilities provide forensic psychiatry services: Mlondolozhi Special Institution, Harare Central Prison and Chikurubi Special Institution (Mangezi & Chibanda 2010:93). Parirenyatwa Hospital Annexe and Harare Hospital Psychiatric Unit are the only institutions with a psychiatrist. The main organisation is the Zimbabwe National Association for Mental Health (ZIMNAMH), which represents the interests of people with mental illness which was founded in 1981. It has been the main vehicle for advocacy for mental health services.

## 2.13 Mental health and the family: Experiences and challenges of family caregivers of bipolar disorder

In many African countries it is usually the family members that serve in the capacity of informal caregivers to sick relatives who will be receiving treatment for chronic mental illnesses or other diseases (Adewuya, Owoeye & Erinfolome 2011:418). The demands may be substantially affecting their financial, personal and social resources, as the role of caregiver is demanding, consequently leading to a burden being exerted (Adewuya, et al., 2011:418). There is stress, anxiety, resentment, depression, hopelessness, sense of entrapment, disruption in family life and relationships, financial difficulties restrictions in social and leisure activities and above all a decrease in the quality of life for the whole family.

### 2.13.1 Biological experiences

The following section explores the biopsychosocial experiences and challenges of family caregivers caring for a person living with bipolar disorder.

#### 2.13.1.1 Sleep depravity

One of the notable biological challenges of caregiving for individuals living with bipolar is sleep deprivation (Bland & Darlington, 2002:38). The caregivers may not get enough sleep due to the manic episode of the bipolar patient. In some cases, the caregiver is always anxious on what would happen if they slept and forgot about the patient. This leads the caregiver to be awake most nights, trying to ensure best of care for the patient. A study by Chentsova-Dutton et al., (2000:19) revealed that some care givers avoid sleeping at night to watch over the bipolar individual and ensure that they get a good sleep. This exposes the caregiver to physical harm where not sleeping makes them mentally exhausted and fatigued. The caregiver has no

energy to perform some of the tasks during the day. This affects the day to day running of the household.

#### 2.13.1.2 Physical health

Caregivers of mental health care users such as those with bipolar disorder, may also suffer physically. More research has been done on psychiatric and emotional effects of caregiving and less research about the physical problems experienced by caregivers (Chang et al., 2010:3). Most studies conducted about the physical effects of caregiving, speak to the challenges presented for caregivers of patients with chronic illnesses, such as cancer and Alzheimer's disease, rather than the challenges of mental health. Chang et al., (2010:268) cited various studies that found that "caregivers often experience several physical problems, including back injuries, arthritis, high blood pressure, gastric ulcers and headaches" (Chang et al., 2010:268). Other literature suggests caregivers may experience sleep deprivation, frequent diarrhoea, and weight changes (Lynch & Lobo, 2012:254).

#### 2.13.1.3 Physical harm

Caregivers can be exposed to physical harm through the violent outbursts of the bipolar patient during an uncontrollable manic episode (Shibre, Kebede, Alem, Negash, Deyassa, Fekadu, Fekadu, Jacobsson & Kullgren, 2003: 16). In some cases, where biological parents have heightened behaviours children may be upset and traumatised. One must note that physical harm can also be ascribed to the caregiver intentionally hurting themselves. Shibre et al., (2003: 17) revealed that some caregivers intentionally hurt themselves to feel alive. The belief is that constantly taking care of the patient can make one feel numb to life. Thus, inflicting pain on themselves makes them feel something which is better than what they go through every day. Johnson et al., (2003: 12) supports such finding where they revealed that some caregivers opt for suicide when the burden stress is overwhelming. A study in Zimbabwe by Mudzingwa (2007:9) revealed that, most caregivers in are willing to go the extra mile in ensuring that the patient is well looked after. However, there are cases reported of caregivers who have attempted to hurt themselves, (Nkomo, 2003:6). Such results show that caregivers are at a vulnerable position where the intense stress can lead them to inflict self-harm and be suicidal.

#### 2.13.1.4 High blood pressure

High blood pressure has been linked with the experiences of family caregivers caring for a person living with bipolar disorder. Research by Jonsson et al., (2003:13) shows that the demands of taking care of a bipolar individuals can be physically strenuous. The study highlights that the caregiver has a demanding role that may lead to high blood pressure especially in aged caregivers. Chang et al., (2010:3) observe that in most cases the caregivers of individuals with bipolar are elders who are mature enough and patient with the individual, however, the experience can thus be overwhelming at times. This exposes the caregiver to high blood pressure which can consequently result in a heart attack or a stroke if left unmonitored. The caregiver may end up frustrated constantly as he/she tries to figure out how to take care of the individual in isolation (Lynch & Lobo, 2012:254). Succinctly, the demands of looking may be stressing out on the caregiver who might also as a result of some

medical conditions such as blood pressure end up having high blood pressure often. This increases the risks of sudden death for that given caregiver.

### 2.13.2 Psychological

#### 2.13.2.1 Stress and depression

One of the notable experiences associated with caring for a person living with bipolar disorder is stress and depression. According to a study in Canada by Jonnson et al., (2003:8), caregivers are prone to the exposure of stress due to the constant worry about the manic episodes. Johnson et al. (2003:10) observe that most caregivers are uncertain on the onset of the manic and the caregiver must be able to calm the atmosphere throughout the different mood swings. Undoubtedly this situation can be overwhelming to someone and may struggle to keep up to the needs of the individual with the bipolar disorder. In research conducted on spousal caregivers, it emerged that there was relatively high level of service-related stress (Awad & Voruganti, 2008:150). This explains the stress that is caused by the caregiving role, when available community services that were supposed to assist them in their role caused additional stress (Awad & Voruganti, 2008:150). Marimbe, Cowan, Kajawu, Muchirahondo and Lund (2016:20) posit that caregivers who do not attain help in coping with their stressful events, are at risk of suicidal ideation. The individual may soon fail to realise the meaning of and become suicidal. In this purview, taking care of a bipolar patient can lead to stress, depression and consequently suicide.

#### 2.13.2.2 Emotional

Several studies subscribe to the fact that family caregivers of persons with chronic and severe mental illness such as bipolar are faced with a myriad of challenges, which include emotional stress (Chang et al., 2010:4). A study conducted in the USA with caregivers of schizophrenic patients, had emotion as a central aspect, mentioned by many caregivers. Goldenberg and Goldenberg, (2008:8), hold that if a patient returns home to where expressed emotion is high, especially expressed in negative and hypercritical comments about the patient's overtly disturbed behaviour, then it is likely that a patient's symptoms might return, resulting in relapse. On the other hand, if a family has low expressed emotion, when concerned about the disturbed behaviour of their relative, they may not be overly anxious in their response to the patient's condition, allowing the individual more psychological space (Goldenberg & Goldenberg, 2008:8), then the patient will do better. Subsequent studies have also found that living with a person with severe mental illness increases the emotional level within the family, epitomising that the relationship may be reversed or bidirectional (Milliken, 2001:159). While living with bipolar patients raises the emotional level within a family, it is comprehensible that caregivers experience a range of emotions such as guilt, grief, exhaustion, stress, depression, anxiety, and anger (Lynch & Lobo, 2012:8). It is therefore key to state that caregivers of bipolar disorder patients are faced with a myriad challenge.

#### 2.13.2.3 Compassion fatigue

Compassion fatigue is defined as a state of exhaustion and dysfunction; biologically, psychologically, and socially, as a result of prolonged exposure to compassion stress and all

that it evokes (Lynch & Lobo, 2012: 253). Like any other kind of fatigue, compassion fatigue reduces our capacity or our interest in bearing the suffering of others (Lynch & Lobo, 2012: 2127). Of late, the concept has only been referred to by health care professionals such as nurses, social workers, doctors, psychologists and other mental health workers. Lynch and Lobo (2012:9) argue that, given that families assume more responsibility of caregiving, they subsequently experience high levels of stress with a limited number of individuals in families being able to provide 24-hour care. Several studies have found out that caregivers may experience their own mental health issues, with high rates of depression among caregivers estimated between 38% and 60% (Berg-Weger, Rubio & Tebb, 2000:162). Additionally, caregiver depression may be correlated with a caregiver's sense of competency, which implies that, as the caregiver's perception of his/her competence improves, so does the caregiver's ability to perform tasks to meet his/her basic needs (Berg-Weger et al., 2000:170).

#### 2.13.2.4 Development of psychotic behaviour

The major adverse challenges of caring for a person living with bipolar disorder is developing a psychotic disorder (Nehra, Chakrabarti, Kulhara, Sharma, 2006:10). A research by Lund et al., (2013:12) depicts that prolonged stay with a person with bipolar disorder may induce some psychotic behaviour on the caregiver. The caregiver can begin to normalise the psychotic behaviour display by the bipolar patient. With time, the caregivers can adopt the similar trait of behaviour as they would have conformed to the existing situation (Nehra et al, 2006:10).

#### 2.13.2.5 Anxiety of patient violent behaviour

Caregiving a bipolar patient can be faced with anxious feelings about the violent behaviour of the mentally ill individuals. Freedberg (2011:10) observes that persons with bipolar are prone to violent episodes which can be disruptive to all the family members. In the early days of manic episodes manifestation caregivers often have reported to be unsettled and irritated by the patient's behaviour (Nehra et al., 2006:10). Sandhya (2010:14) observes that individuals with bipolar can unknowingly irritate the other family members with demanding control that reduces the ability of the caregiver to meaningfully engage with others. Mudzingwa, (2007:8) also argues that persons with bipolar can overreact during conversations and can cause fear that could be traumatising to the primary caregiver, and children. In the same sentiments Ajibade et al. (2016:10) reiterate that manic and major depressive episodes can contribute to divorce, instability and abandonment of the caregiver by significant family members.

### 2.13.3 Socioeconomic challenges

#### 2.13.3.1 Stigmatisation

Stigmatisation is one of the notable burdens that caregivers in most communities are faced with. In India, Nageswar Rao Nallapaneni, Prabhakar Yendluri, Chandra Bhanu Gupta Paritala, Bhupal Naidu Racharla (2015:19) revealed that caregivers of bipolar patients are stigmatised within their communities. The caregivers are tainted and viewed as potential carriers of the mental health condition. The people around the caregiver distance themselves from anything to do with the caregiver. These findings are complimented by Abdulkareem et al. (2009:11)

who noted that in Nigeria, families with individuals affected by mental illness are isolated and the people around that community avoid contact with the caregivers of the bipolar patient. This underscores that beliefs and values in cultural spheres have a huge bearing to the occurrence of stigmatisation against family caregivers of bipolar patients.

#### 2.13.3.2 Disconnection from friends and family

One of the notable challenges faced by caregivers of bipolar disorder is the disconnection with friends and family. The caregiver's relatives are likely to withdraw themselves from the situation prevailing on the mentally affected individual. Ritu et al., (2006:12) in India, reveal that families and friends usually distance themselves upon discovery of a mental illness case in the family. The caregiver is left isolated and lonely with a huge responsibility and lack of support. Indisputably, such experiences increase the likelihood of depression and suicidal ideation among caregivers.

The disconnection of the family is also associated with the perceptions on the causes of the mental illness. In developed nations, mental health is better funded and resourced than in most developing nations (Nwoywe 2015:6). In African mental disorders are associated with spirituality where people believe that mental disorders are a punishment for not appeasing the ancestral spirits or a sin committed by the affected family member or their forefathers, (Idemudea 2013:12). Hence when the caregiver has a child or spouse affected with bipolar, the rest of the relatives will distance themselves in fear of contaminating the same evil spirit possessing the mentally ill individual. This exposes the caregiver to carry the burden of caring for the affected individual alone.

In Zimbabwe, research by Nkomo (2003:13) revealed that most of the caregivers are isolated from the rest of their families. The families do not want their children to visit the households with the mentally ill individual. In agreement, (Sandhya 2010) also notes that the family where there is an individual with a mental illness is disassociated from the rest of the community. The children in the neighbourhood are conditioned to avoid contact with the family of the patient. Given that children can also be caregivers to the bipolar individual, the researcher notes that the children are also affected at school and during play as they will be treated as social outcasts, (Marimbe, et al., 2016:20). The children are treated as contagious. The caregiver is thus disconnected from friends and family who are expected to be the form of social support.

Different interpretations have been put across to ascertain the meaning and responsibilities of caregivers in psychiatric spheres. This study focuses on the family caregiver and attempt to explore their experiences in rendering care to bipolar patients.

#### 2.13.3.3 Isolation

Many studies have indicated that family caregivers may increasingly become isolated (Erlingsson, Magnusson & Hanson, 2012:643). Severe mental illness is associated with stigma and stress, which makes it difficult for families to maintain relationships with significant others (Chang, Chiou, & Chen, 2010:267). Most importantly, caregivers' personal lives may be restricted in some sense, due to their caregiving responsibilities. Some areas of restriction or



disruption may include neglecting friends or other family members, conflicts within the family, reduced leisure time and absenteeism from work or school (Tan et al., 2010: 152).

#### 2.13.3.4 Financial

Financial challenges have been a central issue on the caregiver's face. Given that family caregivers are responsible for the day to day care responsibilities, they may have trouble keeping a job (Tan et al., 2012:154). As Miliken (2000:156) found in her qualitative interviews with Canadian caregivers, supporting someone with a mental illness can be very expensive. In Canada, basic health insurance covers most costs; however, there are certain aspects of a patient's treatment that may not be covered, such as medications or psychotherapy (Miliken, 2000:156). The researcher also takes into cognisance the increased poverty due to unemployment in the Zimbabwean context. Some of the financial strains acknowledged by caregivers in Miliken's (2000:157) study, were extra expenses due to damaged furniture and clothing, smoking and drugs, cleaning apartments, deposits on new apartments, clothing, food, insurance, telephone charges, and periodic handouts. The financial burden on the care giver is not easy because they must ensure the total cost cover all the house and everyday expenses (Chadda 2014:7). Therefore, given the current economic situation in Zimbabwe, most caregivers are bound to struggle sustaining their livelihoods.

In a study conducted in Ethiopia by Shibre (2003:22) found that female caregivers comprise of much of the population providing care. This is linked to the culture and gender dynamics that exist in most patriarchal society. As Kambarami (2006:4) states that, in patriarchal societies the provision of care to mental health patients or children is dominated by females. Some males have been found to be at risk of deserting their families in the event of tragedy and mental illness (Mudzingwa, 2007:5). Lund et al., (2013:10) posits that single parent households are most affected as they may lose their jobs, subsequently, become unable to meet the financial expenses for basic needs and medical health services for patient. In this regard the quality of life for a family living with a bipolar patient is reduced especially for the caregiver.

In a nutshell, most studies have found out that the burden of caregiving for mental health care users is mostly implicated by the following, emotional stress, compassion fatigue, isolation, deteriorating physical health and financial stress. This study seeks to understand the experiences of caregivers of persons diagnosed with bipolar disorder in Harare.

### 2.14 Caregiver burden and coping strategies

Coping can be described as both cognitive and behavioural strategies that people use to adapt to excessive demands that trigger stress responses (Akanni et al., 2012:2). Caregiving burden can be categorised into subjective and objective burdens (Akanni et al., 2012:4). Akanni et al. (2012:4) observe that objective burden as the experiences on account of the patient's behaviour, symptoms, household routine changes social or family relations, time of leisure, work and health. Subjective burden is conceptualised as a scenario where the mental health and psychological distress among family members and the emotional reactions of the caregiver in the form of stress, anxiety, fatigue, frustration and consistent worry (Akanni et al., 2012:4).

Lazarus and Folkman (1985: 10) coping is a behavioural mechanism developed by individuals to better manage the stressful environment they live. This may relate to responses to external challenges in life to avoid the emotional distress may result from caregiving a mental health patient and the caregiver stays clear on the likelihood of harm (Shulz et al., 2007:9). Notably, caregivers are individuals and have different coping strategies that may range from problem focused coping mechanisms to emotion focused coping mechanisms (Shulz et al., 2007:9).

Providing care for mental health care users is not a matter of choice but a task that one unexpectedly assumes as a result of the unfortunate circumstances. Kuipers & Bebbington (2005) provides that the role of a caregiver in any situation is not an equal role as the one who provides the care is left with the task of shouldering responsibility which often becomes a burden as the one receiving the care often is wholly dependent on the caregiver for everything because of they became unable to make decisions. This triggers stress which will require the caregiver to deal with daily by developing coping strategies in order to live quality life.

The use of denial, resignation and avoidance are identified to be the most common coping strategies adopted by caregivers (Akanni et al., 2012:193). In some instances, making use of available social support systems and acceptance of the circumstance are typical coping strategies. This study seeks to identify coping strategies used by caregivers of bipolar patients in Harare, Zimbabwe.

According to the National Institute Mental health (NIMH 1989:1) in America, practical coping strategies can be summed up according to the following:

- Getting a better and deeper understating of the mental illness, services required and resources that are needed to obtain the services
- Developing stress Management skills
- Joining support groups for families
- Identifying and sharing feelings with friends and other family members
- Recognising and accepting mental illness as a disease
- Finding solace in spirituality and religion.

There are basically two types of types of coping strategies according to (Ashok et al 2015:354-356), which are conscious and unconscious strategies.

- Unconscious: describes how people make use of their defence mechanisms. Ashok et al. (2015:250) state that a caregiver's emotions are distorted as a way of protecting the self from the stressing situation for instance excessive use of drugs and alcohol. This results in denial, repression and displacement by carers.
- Conscious strategy: caregivers may occupying themselves with other things, accept the situation, seek solace in religion, families, community support or withdrawal from social activities (Akanni et al., 2012:193). In a problem focused coping, people deal with the stressful situation by confronting the problem head on and increasing their resources to engaging in social network and participating in economic activities (Lazarus 2006:30).

Caregivers of patients attending psychiatry hospitals in Zimbabwe carry a significant burden of caring for a family member with a mental disorder. Quality support is needed from the multidisciplinary team to enhance caregivers and patients coping capacity (Muchirahondo

2016:1). Therefore, it is important for a multidisciplinary team to be able to coordinate and provide quality support systems for mental health care users of bipolar disorder. Bazondile et al., (2016:1) caregivers of mental health care users experience burdens that affect their emotional, physical, financial and social wellbeing as well as spheres of life. Caregivers of mental health care users are at risk of common mental disorders that may be as a result of the burden taking its toll on their psychological wellbeing and as such, they require psychosocial support for them to cope with the burden of caregiving.

Overtime a plethora of research has highlighted the significance of a caregiver's wellbeing and many of these studies have highlighted the importance of providing relevant interventions to support the wellbeing of the caregivers of persons diagnosed with mental illness (Reihhard et al 2008:1). There is however a dearth in the support of caregivers of mental health care users in Zimbabwe to help caregivers cope with the caregiving burden, notwithstanding the increase in the prevalence of mental health issues.

In a study conducted in India by (Dijkxhoon et al., 2018:68) identified the following phases through which caregivers of patients with mental disorders experience, Phase 1. Manifestations of symptoms, Phase 2. Seeking help, Phase 3. Helplessness and attribution, Phase 4. Relative control and insights, Phase 5. Loss and Worries, Phase 6. Finding new meaning. It is important to observe that caregivers have different experiences however the mentioned phases capture what caregivers go through from the onset of mental illness.

## 2.15 Responsibilities of caregivers in caring for a person living with bipolar disorder

Caregivers of mental health care users perform significant task to ensure that patients receive quality care services as shall be demonstrated as follows.

### 2.15.1 Supervises treatment

One of the most important roles played by caregivers of bipolar patients is the overarching supervisory to ensure that patients attend regular medical appointments and are consistent in taking their medication. The caregiver can understand the appropriate time for taking in the medication for the patient and assess if the medication levels are low and ensures that they get a refill on time. Treatment for mental health bipolar patients might not be limited to medication, but at times psychotherapy for bipolar patients, support groups and mental health reviews (Ajibade et al 2016:12). The caregiver has shown to be the responsible individual to take care of the treatment offered to the patient (Marimbe, et al., 2016:20).

### 2.15.2 Emotional support

Bipolar caregivers also ensure that the patient has emotional and psychological support. Freedberg (2011:407) observes that an integral part of the patient's wellbeing is vested on providing emotional support. This research provides that emotional support is a critical role that the caregiver must play in order to help the bipolar patient feel supported. Srinivasa, Kumar, Chisholm, Thomas, Sekar and Chandrashekari, (2005:13) reiterate that, without emotional support some mental health patients have a high likelihood of committing suicide

because they might assume that life is meaningless living with a mental health condition. Emotional support involves listening to the views of the patient, talking to them about their daily routines, involving them in case planning, involving them in family decision making (Jevne & Nikolaichuk 2013:14). It is apparent that a strong emotional support can help the patient deal with mental health behaviours associated with bipolar disorder.

### 2.15.3 Provides financial needs

The provision of financial support is one of the critical roles played by caregivers of mental health care users of bipolar disorder. In most cases individuals affected with bipolar cannot work for themselves to sustain their livelihoods, thus the persons providing care for the bipolar patient sees to it that get the financial needs to support their medical requirements and dally needs (Shibre et al., 2003:9) The caregiver in some instances also supply the patient with money to attend medical reviews, therapy and other psychosocial support activities for bipolar patients.

## 2.16 Stigma and mental illness

Social stigma is a compounding factor given the problems that most of the caregivers of people living with mental illness face. Stigma is presented with challenges of knowledge, values, attitudes and behaviours regarding an individual's life circumstances (Thorncroft, Rose, Kassam, & Sartorius, 2007:10). It is regarded as a social cognitive aspect that involves the following; stereotypes, prejudice and discrimination (Corrigan, Watson, & Ottati, 2006:8). Stereotypes are shared beliefs about personality traits and behaviours of members of a social group. Stigma related to mental health impacts on several life domains of those afflicted including interpersonal relationships, housing, employment and recovery illness (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001:5). This is because stigma often causes social exclusion and isolation for those afflicted. Thus, an important goal of mental health research is to important establish strategies to reduce stigma (Lauber & Rossler, 2007). However, before this can be done it is fundamental to establish and understand the contributing factors to stigma in communities.

## 2.17 Multidisciplinary intervention and support provided by professionals to the family caregivers of a person living with bipolar disorder

### 2.17.1 Psychologists

World Health Organization (2016: 5) asserts that, one of the most significant recommendation to support family caregivers of persons living with bipolar disorder is to offer psychological services. Psychologists play an important role in helping caregivers living with bipolar patients learn effective coping strategies with the situation, educate the caregiver on the best method of ensure a sustained wellbeing for the individual living with bipolar disorder and consequently the caregiver's wellbeing that promotes functionality daily activities, (WHO 2016:6). Importantly, psychologists are directly involved with the bipolar patients which put them in a better position to provide ongoing psychological support services for caregivers of the bipolar patient. Nallapaneni, et al (2015:10) postulate that psychologists play a pivotal role in assisting caregivers of mental health care users of bipolar patients to cope with the

emotional, psychological, social and physical strains of taking care of a bipolar patient. Similarly, in Nigeria, Ajibade, Ajao, Fabiyi, Olabisi & Akinpelu (2016:12) found that psychologists indeed help the caregivers in understanding that mental illness is also like any other illness and one can live a fruitful life with the disorder. The study revealed that the caregivers were informed on the expectations of behaviour change and the possible causes of the illness. This strategy helps the caregivers to identify with the mentally ill individual thus being able to give the adequate care to the bipolar individual while sustaining their wellbeing. In Zimbabwe, Psychological services are limited in aiding caregivers living with bipolar patients, (Fulton et al 2011:11). The resources needed to affect such strategies are limited and at times unavailable. However, caregivers are helped through psychoeducation and counselling when they attend hospital visits or when the care giver is going to collect medication, and through community engagement programs (Mutamba et al, 2013:14). This enables the care givers to have knowledge on how to live with the bipolar individual and the applicable strategies to their everyday problems to living with a bipolar individual.

#### 2.17.2 Psychiatrist

Previous studies have noted that psychiatric services play a critical role in supporting caregivers of persons diagnosed with bipolar disorder. Psychiatric medical practitioners are effective in the provision of pharmacological interventions, (WHO 2016:5). Most caregivers have little understanding of the prescriptions and the treatment given to the patient. The psychiatrists are therefore a means of intervention in helping the caregiver to be informed on the proper treatment, dosage, benefits and potential side effects of the treatment, (WHO, 2016:4). In Chile, Srinivasa et al, (2005:18) highlighted that psychiatric services are a paramount intervention strategy because the caregiver needs to be fully aware of the situation and understand the physiological aspect of the illness. The study noted that psychiatrists are effective in ensuring the repression of the effects of bipolar, this is done through the reviews and drug monitoring, Srinivasa et al, 2005:10). In relation to the Zimbabwean situation, Marimbe et al, (2016:14) discusses the impact of psychiatrist, observing that psychiatrist have a significant role in ensuring that the caregiver understand the disorder and what it means to their life. The study revealed that much of the psychological support is enacted from the psychiatrist where the doctor`s word holds water. The belief in tangible solutions within the African context, (Idemudia, 2015:8), gives the psychiatrist a chance to help the caregiver because he or she has to explain the treatment to the caregiver, thus also counsel, educate and psychologically prepare the caregiver on the management of bipolar disorder.

#### 2.17.3 Clinical nurses

Health care nurses are also integral professionals in the multidisciplinary model who play a significant role in the support of caregivers of bipolar patients. Jevne and Nikolaichuk (2013:12) reiterate that the nursing profession has the responsibility to inspire and promote hope on the care givers of people living with bipolar disorder. The nurses are believed to have more contact time with the care giver as they attend doctor`s review or through community engagement programs. A similar research in Canada by Jonsson et al, (2010:9) posit that nurses play a crucial role by being friendly and accommodative to the caregivers, which will

enable the caregivers to ask them questions which might be hindering their effectiveness in taking care of the bipolar patient. The nurse in a sympathetic character should encourage the caregiver to unburden and gain a source of psychological support that ensure their comprehensive wellbeing, (Bland & Darlington 2002:30). Hence forth the nursing profession carries adequate impact in assisting the caregivers to better take care of the people living with bipolar.

#### 2.17.4 Traditional healers and faith healers

In the African context, the interconnectedness of mental health to spirituality have led to families of people with mental health conditions to sought spiritual intervention. Idemudia (2015:7), maintains that people perceive mental illness as a spiritual warfare and as a result of bad spirits occupying the mentally ill individual. A study by, Chadda Singh and Ganguly (2007:1) revealed that caregivers of people living with bipolar mostly sought spiritual assistance through traditional healers and faith healers because the individual believe that the disorders are a form of witchcraft compelling the affected to act psychotic. To add on, most African psychologist have noted the high levels of belief in spiritual possession as a cause of mental disorder (Schuster, 2005:8). Families seek answers from ancestral spirits whom they believe to guide the caregivers to an appropriate solution (Idemudia 2015:7). Traditional healers help the caregivers by giving them a peace of mind where the problem is believed to be spiritual and out of the hands of the affected, thus the caregiver leaves all the worries to the spiritual rituals and ceremonies (Chadda Singh & Ganguly, 2007:1). Such beliefs are commonly shared among the different Shona cultures in Zimbabwe (Marimbe et al., 2016:30). Shibre et al. (2003:8) observe that, caregivers chose to depend on prayers and other Christian practices. Within the contemporary Zimbabwe, the Christian practices are dominating as a solution to most spiritual problems, (Marimbe et al., 2016:30). Hence, one should note that traditional healers and faith healers have a significant contribution to mental health management.

#### 2.18 Roles of social worker in service delivery

The social worker is an active member of the multidisciplinary team. Hudson (2018:28) reiterates that social work practice in mental health, is embedded in the need for interdisciplinary and collaboration in the multidisciplinary team to achieve efficient and effective care. Social workers play an important role in providing care for mentally ill patients and their families, through case management, providing therapy, crisis counselling, policy and administration (Hudson, 2018:31). The role of the social worker does not focus on the client only but tries to improve patient outcomes through strengthening the family environment. In this purview, the social worker assesses the client's impairment in his/her social environment bearing in mind the individual's previous mental state and social functioning.

##### 2.18.1 Educating the caregiver of the disorder

Social workers have helped people though out history by educating the community on the aspects that contribute to the daily live hoods and wellbeing. A study in Ethiopia by Shibre et al (2003:31) revealed that social workers play an important role in educating the community

about the effects, treatment and the coping strategies that can be practical and applicable to the care giver. The study notes that the caregiver needs information on the disorder so that he/ she can have the adequate expects on helping the affected individual. To support such findings, Gitterman and Germain (2008:5) maintains that educating the caregiver enables them to address some of the misconceptions which can be problematic to the effective care of the bipolar patient. In Zimbabwe social workers engage in community outreach programs which aim to support the de-institutionalisation of mental health patients. The social workers attend to the families who need the assistance, thus conduct the education on the entire household to curb any problem proactively. In educating the caregiver, the social workers focus on training the caregiver on how to treat the bipolar patient and respect their needs despite their psychological illness. The primary aim is to desensitise the care giver to the disorder (Cakir & Ozerdem 2010:7). This will ensure that the caregiver is familiar with the disorder and can figure out solution to the adverse problems associated with the disorder.

### 2.18.2 Counselling services

Social workers can also engage in counselling of the caregivers of mental health care users. A study by Gregory (2014:17) counselling is an effective strategy that helps the caregiver to decompress and unburden. It should be notable that, due to social isolation and stigmatisation, the caregivers might not have people to free talk to about the effects of the illness to them. Chentsova-Dutton, Shucter, Hutchin, Strause, Burns, and Zisook (2000:8) contents that some caregivers tend to neglect their wellbeing and thus putting themselves at a risky position of being psychotic as well. The pressure and needs of taking care of a bipolar patient can be overwhelming, therefore the caregiver needs to be able to talk to someone who will help them cope with the situation. In this case a social worker would be adequate in helping the caregiver sustain their psychological wellbeing. Counselling the caregivers can also be applied through group counselling and support groups. Cakir and Ozerdem (2010:76) revealed that the social worker is at a position where they can initiate support groups within the community which will benefit more individuals. The support groups need to be managed by the community members so as to give them a sense of ownership of the initiative which will motivate them to attend support group because the group is theirs and the social work is there ensure the smooth running of the programme. One should note that support groups are effective because the caregivers will be helping each other according to their past experiences and they can relate to each other`s contextual solutions, (Van Breda & Du Plessis, 2009:6). The caregivers are helping each other at the same level thus creating an active dialogue. Hence, the study notes that social workers can assist the caregivers of bipolar patients by offering them with counselling.

### 2.18.3 Community awareness campaigns

Social workers can organise and execute community awareness campaigns as a method of assisting care givers living with bipolar patients. The rational is that educating the care givers and their immediate family will not necessarily curb the cycle of stigmatisation and discrimination, (Johnson, Lundström, Aberg-Wistedt & Mathé 2003:7). A research by Gitterman and Germain (2008:4) revealed that social workers should incorporate a comprehensive solution that will also cater for the individual around the caregiver. The

community campaigns aim to educate the community members on the psychological disorders, their causes, treatment and the importance of supporting families of mental health care users (Gitterman & Germain 2008:7). Community awareness will ensure that the people around the care giver understand what it means to take care of a mentally ill individual. This strategy is an endeavour to bring unite and fellowship within the community (Van Breda & Du Plessis, 2009:256). According to Johnson, Lundström, Aberg-Wistedt and Mathé (2003:5) educating the community at large empowers the caregivers to be able to debrief and share their burdens. It creates an environment that accommodate mental illness as a condition like any other illness. Hence, social workers can use advocacy as strategy to raising community knowledge and understanding of mental health.

In summary the social worker plays the following fundamental roles:

- Working with individuals, families and groups to provide counselling and psychotherapy;
- Helping caregivers of mental health care users enhance and more effectively use their own problem solving and coping capacities;
- Strengthening and building relationships between mental health care users with resource system available in their community; and Advocating on behalf of mental health care users to lobby for friendly and progressive policy frameworks for mental health care users.

## 2.18 Summary

In a nutshell, this chapter explored the bipolar concept, types, causes and treatment. Literature on global mental health policy, epidemiology of bipolar in Africa and national mental health policies peculiar to the Zimbabwean context were exhaustive. Additionally, literature on the knowledge and cultural views of mental health care users as well as caregivers' experiences and coping strategies are also put into light. Finally, literature on the role of caregivers, roles of the multidisciplinary team and the social worker's role in mental health is discussed.

The succeeding chapter will present the research methodology of this study.



## CHAPTER THREE

### RESEARCH METHODOLOGY AND FINDINGS

#### 3.1 Introduction

This chapter discusses the research methods that were implemented in this study, namely research approach and type, research design, study population, sampling methods, data collection, data analysis, data verification, pilot study and ethical considerations. The research findings are then discussed using a thematic analysis.

#### 3.2 Research Approach

This study used a qualitative research approach. Qualitative research involves studying things in their natural setting, by attempting to make sense of or interpret phenomena in terms of the meanings people bring to them (Babbie & Mouton, 2012; Denzin & Lincoln, 2005). The qualitative research methodology was used in this study, to enable the researcher to explore and understand the in-depth experience of caregivers of bipolar disorder patients in their natural setting, with a substantive exploration of the reality from the caregivers' perspective (De Vos et al., 2011:308).

#### 3.3 Research type

The study explored the experiences of caregivers of bipolar disorder patients. To this effect, the study was applied in nature, which attempted to provide practical means of solving problems by adopting empirical methods on caregiving for bipolar patients (De Vos et al., 2011:94). Applied research utilises empirical theoretical knowledge, methods and techniques (Neuman: 2011:23) for understanding the experiences of caregiving mental healthcare users in the context of bipolar disorder.

#### 3.4 Research design

A research design can be conceptualised as a way in which participants are chosen and how the information will be gathered from them. The study adopted an instrumental case study research design. Case study research involves an exploration of a bounded system, or single or multiple cases over a period through detailed, in-depth data collection (Creswell, 2014:73). The case study design was used for this study, to immerse the researcher in the activities of caregivers, to familiarise with their experiences (De Vos et al., 2011:320). In-depth data collection methods and tools were employed in the case study design, which enabled the researcher to obtain a broader understanding and a holistic picture of the experiences of caregivers. This study used the instrumental case study method (Mills, Durepos, & Wiebe, Eds. 2010:127; Stake, 2006:89). This method allowed for exploration of caregivers' experiences by examination of a case to answer why and how questions. Instrumental case study explores the richness of the phenomenon in the context of real life (Yin, 2009:19) and does so through an in-depth exploration of a bounded system (Creswell, 2014:47). Case studies rely on multiple sources of evidence in an exploration of the phenomenon to illuminate a set of decisions (De Vos et al., 2011:320). In this study the multiple sources of evidence were interview 10 (participants) and literature documents. Therefore, the researcher used the instrumental case study to identify and explore the experiences among caregivers of mental health care users of persons diagnosed with bipolar disorder.

### 3.5 Research methods

The research methods to follow include the study population, sampling method and sample, as well as the methods of data collection, data analysis and data quality.

#### 3.5.1 Study population and sampling

##### 3.5.1.1 Study population

Zimbabwe has an estimated population of 14 million people and the capital city is Harare, which has a population of 1.6 million. Harare was targeted as the site for the study because researcher resides there and it has a well-established psychiatric health centre, namely Parirenyatwa Annex Unit, which is a psychiatric unit that provided the researcher access to research participants for this study. According to Zimstats (2012:280) over 200 families are living with bipolar disorder in Harare. This informed the population of this study. The target population for the study was caregivers of bipolar patients in Harare, Zimbabwe.

##### 3.5.1.2 Sampling Methods and sample

A sample is a subset of the population that is considered for actual inclusion in the study, or a subset of the measurements drawn from the population in which the researcher is interested in (Unrau et al., 2008:279).

Non-probability sampling was utilised to select 10 family caregivers who participated in this study. In this respect participants for this study were selected purposely, to inform an understanding of the research problem (experiences of caregiving bipolar patients) (Creswell, 2014:125). Purposive sampling involved the researcher using his own personal judgment when choosing caregivers of the population to participate in the study (Creswell, 2014:125). Researcher purposively identified participants who had been providing a caregiving role to patients diagnosed with bipolar disorder in Harare. The researcher provided the matron at the Psychiatric Unit with an information letter, to explain the study to participants. Those who were interested provided their contact details to the matron to give to the researcher. Researcher collected the details from the matron. Those who met the following inclusion criteria were contacted:

- Participants had to be caregivers of patients diagnosed with bipolar disorder at the unit;
- bipolar patients who had been consistently receiving treatment from this institution for the past two years;
- bipolar patients had to be staying with their families (nuclear or extended), who are their caregivers in Harare;
- Participants had to be adult males or females above eighteen years; and
- Had to be primary caregivers, for at least one year, appreciating that they had adequate experience in caregiving for bipolar patients.

Once selected an appointment was made and the letter of informed consent was firstly discussed with them. Once they signed the letter of informed consent, the interview commenced.

### 3.5.2 Data collection

The researcher used in-depth interviews to collect information from participants. A semi-structured interview was conducted using an interview schedule was used to guide the interviews with family caregivers and allow them to share their feelings and experiences in caring for a relative with a severe mental illness such as bipolar disorder.

The researcher conducted interviews with caregivers of bipolar patients as a data collection technique, to explore the experiences of caregivers of bipolar patients. The data collection technique enabled the researcher to gain a detailed picture of the lived experiences of caregivers of bipolar disorder (De Vos et al., 2011:351). All interviews were audio-recorded with the permission of the participants and transcribed. The researcher had one interview with each participant lasting at least 30 minutes; thus, the researcher completed the data gathering exercise within two weeks.

The researcher took consideration of the biographical data of each participant. Questions in the interviews included, but were not limited to the following: Tell me when was the patient first diagnosed with bipolar? Tell me about the role you play in the daily care of the patient? Explain your caregiving responsibilities? Tell me about the challenges you are facing as a caregiver? What are your needs as a carer? Tell me about any form of support from the community? The researcher conducted interviews until data saturation has been reached.

### 3.5.3 Data analysis

Data for this study was analysed using the thematic framework. The thematic approach is a search for themes that emerge as being important to the description of the phenomenon (Babbie & Mouton, 2012:187; Neuman, 2011:245). Data analysis involves an iterative process of moving from general to more specific observations (Creswell, 2007:151). Data analysis started informally during the initial stages of the research (Yin, 2004), as the researcher wrote field notes of his observations and impressions. Data was transformed into findings by bringing order, structure and meaning to the data collected from caregivers of bipolar patients (Schurink, Fouché & De Vos, 2011:397). The analysis of data was not a linear fixed approach, rather it followed a spiral image, that is the researcher moved in circles while analysing data (Creswell 2014:324).

The researcher applied Braun and Clarke (2006) six-phase framework data analysis.

**Step 1: Become familiar with the data:** The researcher firstly impeded himself thoroughly reading the transcripts, listened to audio-recordings and wrote notes of observations from the entire body of data collected from the interviews with caregivers of bipolar disorder patients, before going any further. The researcher interview caregivers in Shona and translated the field notes into English.

**Step 2: Generate initial codes:** Data started to be organised in a meaningful and systematic way. Coding allowed lots of data gathered to be reduced to small meaningful chunks and the different ways to code and the method are determined by the researcher's perspective and

research questions (Maguire & Delahunt 2017:33). The researcher coded each section of data that was relevant to the research question and did not code every piece of text.

**Step 3: Search for themes:** This was arrived at through reading the transcripts to identify themes reflected by participants. The researcher identified and label relevant features of the data. This was done to identify patterns in the data, thereby putting together similar data segments, the researcher clustered codes to identify key patterns in the data. Themes were reviewed to check whether the developed themes had a good fit with the data already coded and the entire data set (Braun & Clarke 2006:92). This helped the researcher to find out whether the codes have an organised central concept. The researcher then interpreted the codes into a maximum of six categories to reduce the data into small manageable themes for the final report

**Step 4: Review themes:** The researcher reviewed, modified and developed the preliminary themes that he identified in Step 3. This was done to find out whether the themes made any sense and he put together all the data that was relevant to each theme. The researcher scanned the data associated with each theme and considered whether the data really was supportive and checked on whether the themes were working in the context of the entire data set. Themes were checked for coherency and whether they were distinct from each other.

**Step 5: Define themes:** Themes were finally refinement to identify the essence of what each theme was about (Braun & Clarke, 2006:92). The researcher was guided by the following prompts in mind; what the theme said, subthemes and how they interacted and related to the main theme and to each other.

**Step 6: Write-up:** Finally, the findings were presented in a table format for the generated themes. The data on the experiences of caregivers was presented through the verbatim question in the report.

#### 3.5.4 Data verification

Data verification is the process of checking, confirming, making sure and being certain on the quality of data (Morse et al., 2002:9). This was done to correct and prevent errors during the research process. The researcher ensured the trustworthiness of data by closely representing the perspectives of the participants into the research findings.

#### 3.8.1 Trustworthiness

This refers to the neutrality of the research findings and decisions which are credible, transferable and dependable (Babbie & Mouton, 2012:174). The researcher ensured the trustworthiness of the data by considering the following constructs that are credibility, transferability, dependability, and confirmability as defined by Lincoln and Guba (1985 Lietz and Zayas, 2010:191).

- Confirmability

Refers to the process of ensuring that the findings of the study are the results and experiences of caregivers of bipolar patients and not the researcher's preferences. An audit trail was

compiled to promote the dependability and confirmability of the study (Lincoln & Guba, 1999:132). The researcher also increased confirmability by providing findings to the supervisor to evaluate and confirm the research procedure (Lietz & Zayas, 2010:197).

- Credibility

Credibility is the degree to which the research findings represent the meanings of the participants (Lincoln & Guba, 1985 in Lietz and Zayas, 2010:191). The researcher ensured a prolonged engagement and persistent observation with participants to promote the credibility of the study (Lincoln & Guba, 1999:132). The study also involved the use of multiple methods of data collection, from different secondary sources (research journals and textbooks), and participants at different events, for triangulation purposes (Babbie & Mouton, 2012:174), contributing to credibility. Reflexivity was also observed by the researcher to ensure credibility. Berry (2011:169) argues that reflexivity involves critical questioning of the methods that have been used, testing the validity of results that have been obtained, the ability to accept several meanings that have been generated and a clear understanding of the research process, including the role of the researcher and the participants. Throughout the research process, the researcher kept a reflexivity journal in which to record his own observations, reactions, feelings and thoughts in response to his immersion in the lives of the caregivers of mental health care users of bipolar patients. This enabled the researcher to guard against bias resulting from spending extensive time with caregivers. The researcher also developed a case study protocol and case study database of participating caregivers during the data collection process (Rose & Cainheto, 2015: 152).

- Transferability

Transferability is the degree to which the results of qualitative research can be transferred to other contexts or settings with other participants. Transferability relate to the aspect of applicability (Lincoln & Guba 1985 in Lietz and Zayas, 2010:454). The researcher provided with a rich description of the participants and the research process, including the following the study setting, sample size, sample strategy, socio-economic demographic information, inclusion and exclusion criteria, interview procedure and topics, changes in interview questions based on the iterative research process, and excerpts from the interview guide. This process was done to enable the reader to assess and make own transferability judgement.

- Dependability

Dependability includes the aspect of consistency and to achieve dependability, the researcher ensured that the research process is logical, traceable, and clearly documented (Tobin & Begley, 2004). The researcher documented the research design and implementation, including the methodology, the details of data collection for example field notes (Streubert 2007:47). This will enable an external auditor to examine the research process, as they are better able to judge the dependability of the research (Lincoln & Guba, 1985 in Lietz & Zayas, 2010:454).

- Member checking

Member checking is a process that allows participants to review findings from the data analysis in order to confirm or challenge the accuracy of the work (Creswell 2003; Horsburgh,

2003; Johnson and Waterfield, 2004 in Lietz & Zayas, 2010:453). The researcher sent transcripts of the interviews to the participants for feedback. Additionally, the researcher had a meeting with all the participants, allowing them to reflect and challenge the interpretations the researcher had made. In response to this task, the 3 participants were able to complete their member check by writing a final journal entry that would discuss their reactions to the findings. Finally, the findings were shared with participants in order to check with the caregivers of bipolar disorder the trustworthiness of what was found (Lietz & Zayas, 2010:454). The researcher collected additional data and spend more time with the participants to increase the ability for a qualitative researcher to reach saturation of the data.

### 3.6 Pilot Study

The researcher conducted a pilot study before undertaking data collection for the main study. A pilot study is a small study conducted before a larger piece of research, to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate (Bless Higson-Smith & Kagee, 2007:184). In this case, the pilot study was done with two participants (caregivers of bipolar patients) in Harare, merely to ascertain certain trends (De Vos, 2011:394). The pilot study enabled the researcher to determine whether the relevant data on the experiences of family caregivers of bipolar patients can be obtained from the participants and whether the questions were relevant. The family caregivers involved in the pilot study did not participate in the main inquiry (Rubin & Babbie 2017: 219; Unrau et al., 2007:179). Additionally, the pilot study was done to test the nature of questions in the developed interview schedule, which were subject to modification to ensure quality interviewing during the main study (De Vos, 2011:395). Relationship building by gaining permission and introducing himself to the staff at the Parirenyatwa Annex Unit was also central to the pilot study, for the researcher to obtain permission to conduct the study.

### 3.7. Ethical Considerations

Ethics can be conceptualised as preferences influencing behaviour in human relations conforming to rules, principles, responsibilities and standards of conduct for a given profession (Rubin & Babbie, 2017:62). This study applied ethical issues such as confidentiality, written informed consent, the right to dignity and respect, the right to participate, the principle of no harm, no compensation and benefits.

#### 3.7.1 Confidentiality and protection of identity

Strydom (2011:119) emphasizes that “confidentiality can be viewed as a continuation of privacy, which refers to agreements between persons that limit others’ access to private information.” Data must not be released in such a way that identifies specific individual’s responses (Neuman, 2012:78). In terms of maintaining confidentiality, the researcher ensured participants of confidentiality during the interview. Their real names were not used in the research report, instead, pseudonyms were given to each participant to protect their identity and were used when reporting the findings, to protect their identity and ensure confidentiality (Rubin & Babbie 2016:364).

The researcher also confirmed to participants (caregivers) that the results of the study were not going to be published or shared in any way that might bring them harm. It was also made clear to the caregivers regarding who will have access to the data and what will happen to the

data once the research is completed, namely, that it will be stored for 15 years at UP. The real names of the participants were not used in the research report, instead, pseudonyms were given to each participant to protect their identity and were used when reporting data to ensure confidentiality (Rubin & Babbie 2016:364).

### 3.7.2 Informed Consent:

The researcher sought permission to conduct the study from the Department of Mental Health, Director of Mental Health, Parirenyatwa Annex Unit, using a research permission letter (De Vos et al., 2011:117). The participating caregivers were asked to sign an informed consent letter after accurate and complete information of the study had been fully comprehended (Babbie 2017:64). The researcher ensured that informed consent was given by caregivers of bipolar patients prior to the commencement of the interviews. It was the right of the individual caregiver to consent to participate. The researcher provided information to the family caregivers to understand the goal of the investigation, nature, duration, procedure, possible benefits and risks of the study, before the inception of the study (Royse 2004:52-54). The consent forms were provided in English and the vernacular language of the participants, namely Shona. The consent forms also informed participants that the interview will be recorded with their permission, that they may withdraw without any consequences, that the data will be stored for 15 years at UP and that they will not be remunerated in any way. The researcher also shared with participants (De Vos et al., 2011:117) that permission to conduct the study had been obtained from the Medical Research Council of Zimbabwe, Patron Parirenyatwa Annex Unit, as well as the Joint Research Ethics Committee (University of Zimbabwe)

### 3.7.3 Right to Autonomy/ Voluntary participation.

Ostensibly, the researcher did not coerce, entice or persuade the participation of the caregivers (Grinnell & Unrau, 2008:36) and their participation was voluntary (Rubin & Babbie 2017:71). The importance of the research was carefully explained to participants, and any refusal to consent was accepted and respected (De Vos et al., 2011:121). The participants were allowed to ask questions during and after their participation in the research (APA, 2010:7). The research was conducted "with caregivers rather than on caregivers" (Woodhead & Faulkner, 2000:12).

The participants had the right not to answer questions they feel uncomfortable with. This is an essential ethical concern when working with vulnerable groups such as caregivers of mental healthcare users, as unequal power relationships are addressed (Young & Barret, 2010:132). Participants were assured to withdraw from the research process if they so wish and were assured that their non-participation would not disadvantage them.

### 3.7.4 Deception of subjects

Corey, Corey and Callanan (1993:230), as mentioned in Strydom (2011:119), state that "deception involves withholding information, or offering incorrect information to ensure the participation of subjects when they would otherwise possibly have refused it." The researcher was aware of the consequences of deliberately withholding information or offering incorrect

information to ensure the participation of participants when they would have otherwise refused. Therefore, the researcher always avoided deception by informing the participants exactly what the research entailed at each stage of the research process.

#### 3.7.5 Right to respect and dignity.

The participant's views were respected throughout the research process. They were treated with dignity and they were not involved in processes that negatively affect their wellbeing. They were informed on the information, the purpose, nature and the methodology to be used. Their consent was obtained before their participation in the study. The participants were informed that they have the right to access the research findings and the study report.

#### 3.7.6 Avoidance of Harm

The researcher should be aware of all types of potential harm, which include legal, physical, psychological harm as well harm to a person's career, reputation or income and as a result take specific actions to minimize the risk to participants at all times (Neuman, 2012:71,72). The researcher protected caregivers from physical, social and emotional harm during and after the research process (Creswell, 2014:64). In this endeavour the researcher, thoroughly inform caregivers beforehand, the potential impact of the study (De Vos et al., 2011:115). Additionally, the researcher eliminated participants with possible vulnerability during the investigation (De Vos et al., 2011:115), by debriefing them after the interview. In cases where the participants are distressed or traumatised with their experiences, the researcher referred them for counselling to a social worker with whom prior arrangements were made.

#### 3.7.7 Compensation and Benefits

The researcher made it clear to the participants that they will not receive any incentive for participating in the study. The offering of the incentives was avoided, as it would influence participation (Royse, 2004:59), as this constitutes personal or pressure on participants (Alderson & Morrow, 2004:324)

#### 3.7.8 Actions and competence of researchers

Strydom (2011:124) highlights that researchers have an ethical obligation to ensure that they are adequately and competently skilled to undertake the study. The researcher is a qualified Social Worker and has conducted a research study as partial fulfilment of his Bachelor of Social Work degree and has also completed a module on postgraduate level on Research Methodology. The researcher has four progressive years of experience working with children, young people and families from vulnerable backgrounds. The researcher was guided by her University of Pretoria (UP) supervisor during the present study. The researcher is aware of the implications of plagiarism and therefore referenced all sources within the text and in the reference list used in the study.

#### 3.7.9 Release of publications or findings

The importance of making the publication or findings public in a written form is highlighted by Strydom (2011:126). A copy of the mini-dissertation is held at the UP's Academic



Information Centre in a hard copy format as well as at the Medical Research Council of Zimbabwe (MRCZ). Additionally, the researcher will write and submit an article for possible publication.

### 3.8 SECTION 2: RESEARCH FINDINGS AND DATA INTERPRETATION

In the following section the researcher presents an overview of the biographical information of the research participants and give an analysis of the findings obtained from the research.

#### 3.8.1 Biographical information

The research in question focused on caregivers of persons diagnosed with bipolar disorder, who are currently receiving mental health services at Parirenyatwa Annex Psychiatry in Harare, Zimbabwe. Data was collected from ten caregivers of bipolar disorder patients who had two or more years of experience as carers.

##### 3.8.1.1 Caregiver Biographical data

The biographical data is presented in the table given below. Eight of the participants are married except 2 who are single, having never been married before. Out of the 10 only 1 caregiver was male, giving one the impression that more women are involved in the daily care of mental health care users.

Table 3.1: Biographical data of participants

	Caregiver 1	Caregiver 2	Caregiver 3	Caregiver 4	Caregiver 5	Caregiver 6	Caregiver 7	Caregiver 8	Caregiver 9	Caregiver 10
Age	40	39	48	32	56	44	46	39	37	38
Marital status	Married	Married	Married	Single	Divorcee	Married	Married	Married	Married	Divorced
Sex	Male	Female	Male	Female	Female	Female	Female	Female	Female	Female
Number of children	5	1	2	Nil	2	2	4	2	2	3
Religion	Christianity	Christianity	Christianity	Christianity	African Traditional	Christianity	Christianity	Christianity	Christianity	Christianity
Home language	Shona	Shona	Shona	Shona	Shona	Shona	Shona	Shona	Shona	Shona
Highest qualification	O level	O level	O level	University degree	Diploma	Degree	Degree	Diploma	O level	O level

Occupation	Unemployed	Student	Self-employed	University student	Accounts clerk	Unemployed	Unemployed	Self-employed	Self-employed	Unemployed
Relationship to patient	Child	Wife	Husband	Sister	Mother	Daughter	Daughter	Daughter	Sister	Mother
Does the patient live with you?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
If so who else lives in the household	Lives with 15 other household members	Lives with their child	No other people	Parents and 2 other siblings	Other children	Husband and other children	Husband	Husband and sister	Husband and brother	Siblings

Table 3.2: Patient Biographical Information

Patient	1	2	3	4	5	6	7	8	9	10
Age	65	37	41	21	22	16	15	18	25	20
Sex	Female	Male	Female	Male	Male	Female	Female	Male	Female	Female
Race	African	African	African	African	African	African	African	African	African	African
Occupation	Unemployed	Unemployed	Unemployed	Unemployed	Student	Student	Student	Student	Unemployed	Unemployed
Educational status	Not educated	O level	Form 2	O level	Primary	Form 3	Form 2	Primary	O level	O level

### 3.8.1.2 Religion of participants

Information gathered during the interviews showed that of the ten caregivers nine of them were Christians and only one identified as African traditional religion. In this research faith and religion are identified as fundamental aspect in mental health concerning the prognosis and treatment of mental illness. Religion has since time immemorial provided the basis through which individuals get spiritual support and answers to the problem of mental health in Africa.

### 3.8.1.3 Summary of participants' background information

The following subsection gives a glimpse into the background information of the participants and their families.

*Participant 1:* is a married 40-year-old male. He is unemployed and his highest level of education is Ordinary Level. He has five children; speaks Shona and he takes care of a bipolar patient who is 65 years old.

*Participant 2:* is a 39-year-old married female who is playing the role of caregiver to a 37-year-old bipolar patient. She is not yet employed and is still a student and she has one child

*Participant 3:* is a 48-year-old male who is also married and has a 41-year-old patient under his care. His highest level of education is Ordinary Level and has three children in the household. He is self-employed.

*Participant 4:* is a 32-year-old female university student who takes care of 21-year-old patient. The caregiver is still a university student and the patient is her sister.

*Participant 5:* is a 56-year-old divorced female who takes care of a 22-year-old male bipolar patient. The caregiver is on part-time employment as an Accounts clerk.

*Participant 6:* is a married 44-year-old female. She is unemployed and his highest level of education is a university degree. She has two children; speaks Shona and he takes care of a bipolar patient who is 7 years old patient.

*Participant 7:* is a 40-year-old married female who is playing the role of caregiver to a 15-year-old bipolar patient. She is not yet employed and is still a student and she has four children.

*Participant 8:* is a 39-year-old female caregiver and is also married and has a 41-year-old patient under her care. His highest level of education is a diploma and has two children in the household. She is self-employed.

*Participant 9:* is a 37-year-old female who is married and has two children. She takes care of 25-year-old patient. The caregiver is still a university student and the patient is her sister.

*Participant 10:* is 38-year-old divorced female who takes care of a 20 year old male bipolar patient. The caregiver is unemployed.

### 3.8.2 Thematic analysis of the study

Data was analysed using thematic frameworks, major themes and subthemes were developed from the interviews which were conducted with the research participants. Further, verbatim quotes were extensively used to support the data presented with concrete evidence that is crucial to the understating of the research. In the use of verbatim quotations, supporting literature was also utilised to substantiate the findings. Table 3.1 summarises the themes and subthemes:

Table 3.3: Themes and sub-themes

Themes	Subthemes
1. Knowledge of mental illness	Subtheme 1.1 Causes of bipolar disorder Subtheme 1.2 Medication
2. Psychological emotional	Subtheme 2.1 Misery Subtheme 2.2 Stress
3. Physical experiences	Subtheme 3.1 Physical Illness Subtheme 3.2 Lack of Sleep
4. Social experiences	Subtheme 4.1 Stigma and discrimination Subtheme 4.2 Isolation and exclusion Subtheme 4.3 Negative community attitudes
5. Economic experiences	Subtheme 5.1 Unemployment Subtheme 5.2 Finances
6. Support systems	Subtheme 6.1 The family Subtheme 6.2 Community Support
7. Coping strategies	Subtheme 7.1 Faith and religion Subtheme 7.2 Traditional healers Subtheme 7.2 Emotionally cutting off and ignoring
8. Caregiver needs	
9. Lack of local services	

#### 3.8.2.1 Theme 1: Knowledge of mental Illness

Most of the responses from research participants indicated that the larger number of caregivers had a basic knowledge of bipolar disorder and were able to explain the clinical

presentation of bipolar disorder and treatment. However, there is little knowledge of the causes of bipolar disorder among primary caregivers of mental health care users. It was gathered that all the participants had no idea of bipolar disorder before, they knew it as a result of caregiving experience.

*Participant 1: "I understand that bipolar is a mood disorder whereby one frequently changed their mood from being happy to sad and the opposite, however, I am not aware of its causes."*

*Participant 3: "Bipolar is a disorder of the mind where the patient may be depressed and feels bad....if the patient feels excited they are prone to do extreme things that may not be pleasant to those who are around."*

However, there was one participant showed a lack of knowledge of the disorder by observing that she only understands it as a mental health condition.

*Participant 4: "I only know that my child sometimes gets mentally disturbed which leads to destructive behaviour in her conduct."*

It is key for caregivers to know mental health care users of bipolar disorder to be able to identify appropriate needs, treatment and referral to appropriate health care services. Importantly, knowing the mental health condition, empowers the caregiver to be able to help the patient during the different emotional and behavioural state, which is mostly the case in patients with bipolar disorder. Additionally, knowledge and understanding of bipolar disorder condition is critical in helping acceptance of the illness by the caregivers that help in coping with the burden of caregiving. In support of the above analysis Chadda et al., (2007:1) is of the view that mental health ailments like bipolar and schizophrenia are associated with a considerable degree of a perceived burden by caregivers.

#### Subtheme 1.1 Cause of bipolar disorder

The knowledge and understanding of the causes of bipolar disorder were varied *among the participants*.

*Participant 1: "I think bipolar is genetically inherited and follows that blood line, as I understand one of our great grandfathers had a mental health condition of like"*

*Participant 2: "Some of these things are spiritual and demonic, witchcraft is also among the causes of bipolar and other mental health disorders"*

*Participants 6: "It is not clear but it's something that can just happen, its mainly biological factors at play"*

*Participant 7: "Some of these mental conditions are caused by abuse of drugs and substances among these youth"*

In the current study genetics, environmental factors, physical illness, and substance are viewed as important components causing bipolar disorder within the biopsychosocial approach.

### Subtheme 1.2: Medication

All the caregivers highlighted that the patients under their care were receiving medication for bipolar and related disorders. Four of the participants observed that they were also getting alternative medicines and spiritual help for treatment.

The following quotes are examples that confirm the claim above:

*Participant 4: "The patient has been on prescribed medication ever since diagnosis and I have been making sure that I monitor him in adhering to the doctor's instructions."*

*Participant 7: "I am not sure of the name of the medication, but the patient is on prescribed medication"*

*Participant 9: "My patient has been put on treatment, and I come at this place every month for health check-ups or collecting his medication, which helps in mood regulation"*

The participants showed the researcher the medication as she had already collected on the day of the interview. All the participants interviewed knew the medication that their patients are taking, and this knowledge was gained through their experience in providing care for bipolar patients. During heightened episodes of people with bipolar, where a patient at times becomes elated mental health professionals often prescribe medication only to control the heightened behaviour. It is fundamental for alternative treatments to be explored as medicines may also have side effects that may harm the patient. As observed in the following sentiments by some of the participants.

*Participant 1: "I come to get medication every month but that isn't enough I will then go and have him prayed for by the pastor"*

*Participant 5: "I know the medication from the doctors is good and I help my patient to take the treatment, but at times you need to consult the n'anga to get some traditional medicines"*

As opined by the participants, it is important to observe that caregivers sought alternative medicines for treatment. Traditional medicines and spiritual interventions are at the core of mental health treatment with some caregivers. This is closely related to the observed causes of mental health. This is buttressed by Muchinako, et al., (2013:2) who observed that the use of both traditional medicine and Western medicine is prevalent in Africa and the socio-cultural issues cannot be divorced from mental health disorders and their management. Considering the above, the use of medication may be taken as a biological factor and the use of spiritual intervention can be viewed as a social component of the biopsychosocial approach (Walsh, Cohen, Ursano, Gifford, Fullerton, & Galea, 2013:14)

#### 3.8.2.2 Theme 2: Psychological and emotional

The responses from the participants on the emotional experiences encountered by caregivers of bipolar patients identified mixed emotions that were being experienced by these caregivers



as a result of the role they were playing. Participants indicated positive coping strategies notwithstanding a bundle of negative experiences in the caregiving role.

#### Subtheme 2.1: Misery

All the participants reported having undergone some form of misery at some stage in their journey of taking care of a bipolar patient. The following sentiments provide examples of depression and misery experienced in the caregiving role:

*Participant 2: "It's tiring me as I have to make sure that I plan everything around my sick daughter. I cannot leave her at home alone as I have to go with her everywhere I go. Sometimes I even plan my things, but I end up cancelling if her mood changes suddenly."*

*Participant 5: "It is draining and exhausting me... I no longer enjoy the freedom I used to have every day as I must constantly be on the watch for her. I have to cook for her, feed her and bath her on a daily basis and I cannot even leave her alone as she can sometimes have destructive behaviour that may harm her or even the children in the house."*

*Participant 7: "Sometimes I feel like crying because I am busy taking care of my mother all by myself. None helps out and it has been taking its toll on me as sometimes I think I may not survive it alone."*

*Participant 9: "I have to monitor him for the greater part of my time. I must ensure that I monitor all his movements as he is sometimes prone to destructive behaviour which is not good for his safety and wellbeing."*

A study by Chadwick, Harrington, Iriate, Lower, Mannan, MckConkey and O'Brien (2012:124), found out that, caregivers usually experience negative feelings and emotions of life as a result of the role of caring for those with mental challenges. Almost all the caregivers who participated in the study experienced isolation, exhaustion and despair. The experience of being a caregiver is subject to considerable stress and burden as it needs help in keeping up with the demands of providing care. Thus, the caregiver needs to develop different coping strategies to managing it well. For a long time, the family caregiver role has been neglected and sometimes looked down upon to an extent that many people do not want to be associated with such a role. However, this key aspect cannot be continuously ignored by or be taken for granted by social workers and other significant mental health professionals (Chadda, et al., 2007:1). Therefore, there is a need to adopt a holistic approach which does not overlook the roles, experiences and challenges of caregivers who are responsible for mental health care users.

#### Subtheme 2.2: Stress

Caregivers sometimes undergo a lot of stressful experiences when the bipolar patient becomes aggressive or even sometimes abusive to them or visiting friends. This becomes a cause for concern, especially when new friends who will be visiting are targeted:

*Participant 1: Every time I get new friends to visit my house, my mother starts to be aggressive and sometimes she will be disturbing the visitors and I*

*always have to plead with her and also with the visitors to understand her condition... Sometimes she starts to pick the visitors' things and it always gets to me as I am afraid that no one will like to visit my house again because of my mother's condition.*

A Shona idiom "kufungisisa" being repeated in the responses that were being given by most of the caregivers in their responses. This Shona idiom can be loosely translated as thinking too much and according to (Patel et al., 1977) is heavily associated with depression.

The following participants said:

*Participant 3: "I am always thinking too much every day of my life as I always wonder about how long I am going to be in this situation. I am looking after an adult who under normal circumstances should be able to sufficiently take care of himself without any help and it is stressing me. It has also affected even our happiness as a family as we cannot be happy while my father is suffering like this."*

*Participant 5: "It pains me as at one point my daughter was growing up so well and she was like any other child as she reached all of her milestones at the right time. However, all of a sudden she just changes and it is very hard for me to accept that it is happening to the innocent child as she doesn't know anything. She has never done anything wrong to deserve this? She deserves a better life.... I am really at in pain every day when I think about this situation (starts crying)"*

Caregivers seem to be psychologically affected by the burden of taking care of the sick and it ends affecting their wellness. The psychological wellbeing of the caregiver is under threat and thus it also hinders their effectual functionality.

### 3.8.2.3 Theme 3: Physical experiences

#### Subtheme 3.1: Physical illness

Caregivers described the physical problems that they attributed to the burden of caregiving

*Participant 9: "Since I started taking care of my mother; I have undergone a lot of stress and diagnosed with depression. The burden is now unbearable for me. I have to do everything and daily some fewer people are willing to help me."*

*Another participant explained how she had developed high blood pressure which she also attributed to the burden she had in providing care:*

*Participant 8: "His behaviour got me stressed especially when we would go to places with people as sometimes he would threaten to harm people around. This would stress me until I developed high blood pressure as I could not have peace of mind because of his behaviour."*

### Subtheme 3.2: Lack of sleep

Six of the participants shared the same view and reported how they were unable to sleep sometimes because of the behaviour of their patients were in a manic episode:

*Participant 8: "When she starts, ummh..., we cannot even afford to sleep, as she will be crying for the whole night. I am afraid when she behaves like that because I don't know about what will be happening to her. Sometimes I feel like I don't even really know how to manage her condition as it becomes overwhelming for me to handle"*

*Participant 10: "It hurts me to see her like that. Every time I sleep, I always think about my sister's condition. Sometimes I even think that it would be better if she could just rest from this trouble as she cannot be on her own. There must be someone to watch her wherever she is."*

Caregivers are thus at great risk of developing sleeping disorders due to the lack of adequate sleep that may be brought about by the lack of adequate sleeping time.

### 3.8.2.4 Theme 4: Social experiences

#### Subtheme 4.1: Stigma and discrimination

Participants reported that they experienced stigma from family members and community members as a result of having mentally ill patients under their care. The following quotes provide examples of hurt and stigma when caring those with bipolar disorder:

*Participant 4: "People in our community tend to associate mental sickness with bad things and no one wants to be around my child in the community. Whenever I take my child to social gatherings, none wants to be around me especially when she is displaying unusual behaviour. As a parent, it pains me, and I sometimes end up staying at home."*

*Participant 6: "You cannot have a conversation when my son is around as sometimes, he ends up screaming and shouting she drives people away from me. I am sometimes told to go outside when I attend social gatherings with."*

In most African societies, mental illness is associated with bad omen and negative spiritual connotations. In this regard, families with mental health patients are thus stigmatised and it also takes its toll on the caregiver as he/she is isolated. The findings in this instance are in line with Chang et al, (2010:14) who observe that caregiving for adults with mental illness can hurt the wellbeing of the caregivers.

Stigmatising attitudes may also prevent seeking help and increase psychological distress. Thus, an important goal of mental health research is to reveal ways to reduce stigma (Lauber & Rossler, 2007). Therefore, with a paucity in the knowledge of bipolar disorder, (Jack & Uys, 2013:178) posit that it is critical for mental health care providers to offer education awareness to families about mental disorders such as bipolar.

Social beliefs that include lack of knowledge, negative attitudes and perceived stigma about mental illness, may keep those who suffer from mental illness away from treatment. Mental illness stigma is a serious concern, due to its impact on patients' willingness to seek treatment, their quality of life and the discrimination that mentally ill individuals face Thornicroft, et al., (2007:809). By activating uninformed and negative responses from members of society and threatening individuals' self-esteem and self-efficacy, stigma thwarts the growth and potential of individuals and families suffering from mental illness (Corrigan, Larson & Ruesch, 2009:46). Thornicroft, et al., (2007:809) noted that stigma extends to the institutions, health care workers and even mental health specialists who provide treatment. One result is that "stigma makes the community and health decision-makers see people with mental illness with low regard, resulting in a reluctance to invest resources into mental health care" (Sartorius, 2007:810). Numerous empirical and narrative accounts look at the negative impact of stigma on help-seeking intentions, help-seeking behaviour, self-esteem and discrimination (Corrigan et al., 2006:47). Specifically, stigma has been found to contribute to discrimination from others and internalised negative self-perceptions in the form of self-stigma, both of which make people avoid treatment and hide their symptoms. Beliefs about the cause of mental illness often include the entire family, who may also suffer stigma, prompting them to hide their family member's illness.

#### Subtheme 4.2: Isolation

Caregivers reported being isolated and ostracised by community members. They reported that there was a lot of stigma mostly from the community and it was attributed to a lack of knowledge as even some people within the community or even close family members believed that mental illness is a sign of a curse or a sin.

One caregiver explained how her husband's relatives had blamed her for her child's mental sickness and accused her of bringing it into the family:

*Participant 5: "When my child developed the condition, some of my husband's relatives were saying this was from my family side as they had never had anyone in their side of the family who had suffered from such a condition or any mental illness. They were accusing me of bringing a curse into the family"*

*Participant 6: "I had my child out of wedlock and people are now saying that my child's sickness is now a punishment from God because I had sex before marriage which is not acceptable in our church. Some even blame causing punishment to an innocent child as it causes me to think too much and get stressed."*

There seems to be much ignorance on the issues of mental health in Africa at large due to preconceived beliefs and doctrines that are associated with issues of mental health. This creates a gap in the provision of a strong social support structure for families of patients with mental illness as they are isolated due to ignorance and lack of knowledge among the community and even other family members

### Subtheme 4.3: Community attitudes

Some participants reported that some people in the community would stare and make nasty or inappropriate comments. Some of the participants reported that at times you are given names because of having someone with mental illness. The following quotes are examples of community reactions towards the caregivers of bipolar patient disorder:

*Participant 3: "They are the worst because I don't say I want sympathy, but they do not understand at all, like if you go to community gathering together with the patient and when he starts such behaviours they easily become very annoyed and at times may ask you to leave with your patient."*

*Participant 6: "Some people refuse even to shake hands and sit together close to the patient even when she looks fine"*

Chang, Chiou, & Chen, (2010:267) opine that people with mental illnesses or disabilities are often negatively affected by stigma, especially by public stigma, "which refers to the attitudes of the general population towards stigmatised persons." The author suggests that public stigma is harmful and hurts the individuals' inclusion in community life. A study conducted in 2015 at Brunel University London has revealed that mental health literacy levels are higher in the Western world, namely North America and Europe when compared to African and Asian cultures. Social factors refer to family relationships, socioeconomic status and social support (Goldenberg & Goldenberg, 2008:13). Community reactions resort under the social factors in the biopsychosocial approach.

### 3.8.2.5 Theme 5: Economic experiences

#### Subtheme 5.1: Unemployment

Five participants highlighted that they had given up full-time jobs due to difficulties that were being brought about as a result of playing the role of caregiver. Three participants reported that they were self-employed and had resorted to doing so due to the inflexibility of a formal working environment which does not afford them the time to properly execute the role of caregiver.

The quotes below are evidence of the challenges that are faced by caregivers:

*Participant 2: "It has been 15 years since he was first diagnosed, and I have never been able to hold a stable job since then as the role of caregiving is demanding and I have to be watching him most of the time... Now, I can no longer provide all the patients' needs as my ability to earn a living has been severely affected."*

*Participant 7: I had to leave my job ultimately as my patient needed me to be around on a full-time basis. Now with the hard economic environment, I cannot provide for my child.*

*Participant 9: "My work is now under threat because I cannot function effectively any more at the workplace as I am constantly needed at home to take care of the patient. As a result, I constantly give excuses for being late"*

*at work and sometimes I have to take time off the job more than usual and my employer is beginning to complain."*

Tan et al., (2012:154) is of the view that caring for people with mental illness may substantially increase the likelihood of the caregiver adjusting in the hours of work or stopping the work altogether. More so from the information given above it is evident that the greater responsibility of a caregiver is to provide for the patient's financial needs. In most cases individuals affected with bipolar cannot work for themselves to sustain their livelihoods, thus the individual caring for the patient sees to it that they get all the financial needs, (Shibre et al, 2003:9). The financial needs are inclusive of medication expenses, food, clothing and other basic needs. The caregiver must also supply the patient with money to attend to the reviews, therapy and other social activities designed for bipolar patients. The financial strain is not easy on the caregiver, but he/she must see to the fact that the patient gets the needed supplies. In Zimbabwe, this is a challenging role, given that most of the people in Zimbabwe are not formally employed. The caregiver thus struggles with the demands of the patient and their expenses.

In a study that can be used to further support the analysis and data collected. Miliken (2000:156) observe that it is not the caregiver only that may struggle in this instance but rather the patient as well. According to the study, the physical health of mentally challenged patients is even vulnerable to influences that may arise from the work schedules that are not friendly or flexible and the overlapping stressing demands of the workplace as well that may extend to affect the functionality of a family.

In the perspective framework of this study, employment is seen as an important social factor in the component of the biopsychosocial approach.

#### Subtheme 5.2: Finances

Most participants reported going through financial difficulty since at some point as the needs for mental health patients are increasingly becoming expensive in a harsh economic environment that is prevailing in Zimbabwe. They reported incurring extra costs that are being precipitated by the rising inflation in the county.

The following are the quotes from the caregivers of bipolar patients:

*Participant 4: "It is now about 15, 18 years I started taking care of her, but with the state of things in Zimbabwe, it is daily becoming more difficult and challenging. The cost of the medication and therapies is becoming unbearable."*

*Participant 6: "I only get \$600 a month and I can no longer afford to meet my daughter's needs. When she gets violent, she sometimes cries for expensive things that are beyond my reach and it frustrates me financially. On top of that, I have to pay for her medication and transport her for all the doctor's appointments."*

*Participant 7: "The medical aid is failing to cover for all his medication and related needs due to the financial crisis and continuous rise in the cost of living. The prescribed medication is not cheaply available as it is the medicine that you don't just buy every day. It's now becoming a bit of a challenge and we are feeling it as a family."*

As Miliken (2000:156) mentions that most families cannot manage to satisfy the financial needs of their mentally ill persons and of the whole family. Parents or caregivers, caring for adults with mental or intellectual disabilities suffer greater levels of stress, may experience loss of earnings from having to give up work or face additional costs from clothing, bedding, special equipment and medical bills Tan et al., 2012:154).

### 3.8.2.6 Theme 6: Support systems

All the caregivers who participated in the interviews pointed to the family as the main support system in their roles of providing care for bipolar patients.

#### Subtheme 6.1: The family

The members of the immediate family included spouse, siblings and children and a majority of the participants reported having extremely supportive family members. The following quotes are examples of the evidence of the kind of support they are receiving from their families.

*Participant 5: "Of course the support from my family has always been shown from the very first day of diagnosis. My husband is very protective of our daughter whenever we go out and she has heightened behaviours. When we go to gatherings and she starts to shout, he tries to talk to people not to overreact and explains her condition for better understating and acceptance..."*

*Participant 6: "I can rely on my husband as he has always been there in there for me throughout the situation. I would want to go with him whenever I go out with the patient."*

*Participant 7: "My son and daughter help out in taking care of their brother as they take turns to assist in the day to day needs of the patient. My son drives us to therapy session every time and my daughter helps with the medicines."*

*Participant 8: "My youngest daughter does everything for me and I can always count on her support in every situation."*

A social support system is mostly a multi sectoral and multidimensional approach and is thus determined or rather defined by the availability of a network of people that can be easily relied on during times of need and difficulty (Walsh, Corcoran, Crooks, Cooke & Cummings, 2016:16). Thus, the special support from the immediate family members forms a part of the social factors of the biopsychosocial approach. The availability of this network of people on

whom one can rely on is thus what is referred to as a social support system (Walsh, et al., 2016:16)

#### Subtheme 6.2: Community support

From the data collected, there was not enough support for the caregivers of mental illness as a whole as the only mentioned support was for the patients themselves and not the caregiver as the role of the caregiver and the burdens that go with it seem to be largely ignored.

All the participants were unanimous on the lack of support, especially from the community in taking care of the mentally ill. Some of the participants reported that:

*Participant 2: "I need assistance in taking care of my father so that the heavy burden I have is reduced. No one in the community is willing to understand or even help"*

*Participant 10: "There are no services that are available close by as I always have to travel for a long distance to get to Harare with my child so that she gets what she needs from the hospital."*

The caregivers must travel long distances to even get the medication for the sick patients which sometimes is in erratic supply and henceforth it becomes costly for them in the long run. This also shows a gap in the provision of community based mental health services in Zimbabwe. The unavailability of community based mental health services are exacerbating ignorance and stigmatisation of mental illness in local communities as the aspect of mental health remains an alien to them. Thus, the provision of community based mental health facilities will lead to even greater awareness on mental health issues as some of the stigma may be attributed to ignorance.

#### 3.8.2.7 Theme 7: Coping strategies

##### Subtheme 7.1 Faith and religion

Over half of the caregivers who were interviewed openly pointed to their faith as a source of strength as they had a feeling of a higher power stepping in to assist.

*Participant 4: "My faith has kept me going despite all the challenges I have been facing since I started to take care of my sick mother....It has been God all the way..."*

When asked about what helped her cope, another caregiver said:

*Participant 6: "Going to church has been my source of courage as I always get messages of hope and God's love and care to my problems"*

In African society, different families interpret mental illness in different ways and thus they respond according to how they see it and according to what they fundamentally believe in (Johnson 2000: 5). This is consistent with the findings in a study by (Savage & Bailley 2004:1) where it was found out that caregivers resort to religion for comfort as a coping strategy. According to (Ozanne 1994:5) most caregivers rely on faith healers as they hope that the



patient's condition will eventually improve through the prayers they will be receiving from the faith healers. This, therefore, shows the extent to which religion may play a major role in people's perceptions on mental health issues.

#### Subtheme 7.2: Traditional healers

Another strategy that was commonly used by some caregivers was seeking spiritual assistance from churches and traditional healers. This can be attributed to the common belief in the African societies that mental health problems are spiritually rooted, and can be thus dealt with using spiritual means

*Participant 7: "We looked for help from N'angas (traditional healers) as we succumbed to pressure from my husband's relatives who strongly believed that my child's mental illness is a sign of spiritual curse in the family. It led us to visit many N'angas (traditional healers) although my child's situation did not improve."*

*Participant 8: "My family has a strong Christian background and we believed that the mental illness was a spirit that was tormenting my child. We went to many prophets who prayed for my mother and she continues to be prayed for as we pray and believe that she will be well very soon."*

Marimbe, et al., (2016:4) mental illness in African societies is commonly linked to witchcraft and bad spirit possession. It can also be said that all this was done to manage the symptoms of the patient and allay anxieties concerning the causes and progression of the mental illness.

In a study by (Tan et al., 2012) coping mechanisms that are used by primarily those of low socioeconomic status involved seeking help from traditional healers, herbal medicine, turning to religion for spiritual help as some believe that mental illness is associated with supernatural forces. Tan et al., (2012:4) further goes on to coping strategies that are used by caregivers of mental health patients include physical coping mechanisms like using alcohol, relaxation, overeating, smoking and medication. On the psychological side, there are mechanisms like cognitive (thinking positively), behavioural mechanisms (action focused pursuits and hobbies) and finally social coping mechanisms which include social support, community resources, professional support, spiritual support and self-help groups.

#### Subtheme 7.3: Emotionally cutting off and ignoring

In the face of stressful behaviour from the mental illness patient, some of the participants to cope and remain calm they would just ignore cut off emotional responses and ignore the patient's ranting and mumblings

*Participant 1: "When she starts to shout or becomes psychotic, I just ignore or go into my bedroom and shut the door."*

Another participant said:

*Participant 9: "Sometimes when she goes off I just go outside the house and will return later when she would have calmed down."*

However worth to note is the fact that this is much far detrimental to both the wellbeing of the caregiver and the patient as well as it can create emotional challenges or problems for both parties. This is further supported by (Roe et al., 2004:9) who is of the view that the family and caregivers of those suffering from mental illnesses can to a greater extent affect the outcome of the illness, performance of the patients and more importantly rates of relapses. Thus, it becomes of paramount importance to take into cognisance how the family of the patient and the main caregiver are coping with the situation. In supporting this line of argument further, (Crowe & Lyness, 2014) go on to suggest there is a need for professionals to help the caregiver and the family unit at large with finding good coping strategies and mechanisms as well as larger support systems as doing so will not only improve the family functioning and caregiver wellbeing but ultimately helps the one suffering from the mental condition

#### 3.8.2.8 Theme 8: Caregiver needs

From the data collected, caregivers mentioned that they need support with financial, respite services, counselling support services. This was summed up in the following sentiments.

*Participant 8: "As a caregiver I expect to receive a grant from the government, have professional to talk to and having temporary institutional care support"*

Another caregiver also highlighted that they also need assistance in meeting the daily physical or material demands that become with the role they play.

*Participant 9: "I need assistance in meeting the daily needs of my mother as sometimes I cannot afford on my own since I am unemployed."*

There seems to be no available support for the caregivers of people living with mental illnesses. The available services seem to be concentrating on the patient alone while also overlooking the caregiver's wellbeing or state of mind.

In such situations it is the immediate family members that usually extend support as they are sometimes affected by the situation. Immediate family members like the father, mother, siblings are the that lend their support (Goldenberg & Goldenberg, 2008:15). Thus there is a need for government to streamline mental health services like what has been done with HIV/AIDS services. This will make the mental health services affordable, accessible and convenient.

#### 3.8.2.9 Theme 9: Lack of local services

All the participants in the study highlighted that there was no community based mental health facilities near them as they had to travel to a central point to get assistance.

*Participant 4: "I need assistance in taking care of my father so that the heavy burden I have is reduced. I always have to travel to Harare for medication"*

*and therapy sessions and this becoming costly as the economy is no longer favourable for such frequent travels.”*

*Participant 5: “There are no services available close by as I always have to travel for a long distance to get to the hospital with my patient so that she gets what she needs from the hospital.”*

The caregivers travel long distances to even get the medication for the sick patients which sometimes is in erratic supply and henceforth it becomes costly for them in the long run. This also shows a gap in the provision of community based mental health services in Zimbabwe. The unavailability of community based mental health services are exacerbating ignorance and stigmatisation of mental illness in local communities as the aspect of mental health remains an alien to them. Thus, the provision of community based mental health facilities will lead to even greater awareness on mental health issues as some of the stigma may be attributed to ignorance.

### 3.9 Summary

This chapter captures the analysis of the data collected from interviews with the participants. Data was analysed through thematic schemes and findings of this study was corroborated with findings from other studies. The emerging themes resonated with the set objectives of the present study.

After the relevant themes were identified, they were further supported by verbatim quotations from the interview participants together with supporting literature that was also relevant to the subject under discussion.

The next chapter discusses key findings, conclusions and recommendations of the study.

## CHAPTER FOUR

### KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

#### 4.1 Introduction

This chapter explains how the study goal and objectives were reached through the research. Additionally, key findings and conclusions are drawn, and recommendations are made from the key research findings.

#### 4.2 Goals and Objectives

##### 4.2.1 Goal

The goal of the study was to explore the experiences of caregivers of mental health care users with bipolar disorder in Harare, Zimbabwe. The goal was met through the objectives that were achieved, as is discussed subsequently.

##### 4.2.2 Objectives

The objectives of the study included:

To explore, describe and contextualise bipolar disorder from a biopsychosocial approach.

To explore and describe the biopsychosocial experiences and challenges of family caregivers caring for a person living with bipolar disorder.

To ascertain the challenges and responsibilities of caregivers in caring for a person living with bipolar disorder.

To explore the level of intervention and support provided by professionals to the family caregivers of a person living with bipolar disorder.

The goal was achieved through the attainment of these objectives:

Objective1: To explore, describe and contextualise bipolar disorder from a biopsychosocial approach

This objective was achieved in chapter one and two, where bipolar disorder was contextualised and explained in all its facets that include signs, symptoms and causes, as well as the biopsychosocial approach underpinning this study.

Objective 2: To explore and describe the biopsychosocial experiences and challenges of family caregivers caring for a person living with bipolar disorder

This objective was met in chapter 2: literature study, section 2.5 (paragraphs 2.5.1, 2.5.2 and 2.5.3), where the issues on the biopsychosocial experiences of caregivers were covered, as well as chapter one, focussing on the biopsychosocial approach. The biopsychosocial experiences, of caregivers of bipolar patients were focused on, namely the biological, social and psychological experiences. The researcher was also able to explore the biopsychosocial experiences in section 3.2 where the data collected was categorised into themes that explored the experiences in question.

Importantly, this objective is also intertwined with the following objective below and more information is provided.

Mental illness may be a lifelong condition that adversely affects the patient and the family caregiver. This study gathered that family caregivers are faced with biopsychosocial challenges that worsen their caregiving burden. In respect of this the caregiver's capacity to provide quality care is compromised. This resonates with the objective to explore the biopsychosocial experiences and challenges of family caregivers of mental health care users.

Parents are faced with a myriad of challenges in coping with mental health patients, which takes a progressive toll on their health and psychological wellbeing (Song *et al.*, 2014:122). Therefore, the biopsychosocial approach was applied in the present study because it provided a framework through which parental inadequacies, loss of employment, educational opportunities, stigma and discrimination of mental illness, rejection by family and community, burden of care, broken family relationships and various forms of exploitation and abuse are explored (Smith, 2007:639).

Objective 2: To ascertain the challenges and responsibilities of caregivers in caring for a person living with bipolar disorder

This objective was mainly addressed in chapter 3.2 as the information was derived from the collected interview data. The challenges were categorised into themes and subthemes. See section 3.2

The participants reported that they were facing challenges in the form of strenuous relationships, financial difficulties and disturbances in their sources of income. In addition, the caregivers noted the following roles; bathing, feeding, medication and constant monitoring of the patient. Further, they revealed that these roles and responsibilities are often compromised to engage in other important economic activities.

Objective 5: To suggest the role of social workers in service delivery intervention with caregivers of mental health care users with bipolar disorder

The objective was sufficiently met through the literature study, which aimed to describe the roles of social workers, not only in the delivery of services to caregivers of bipolar patients, but also their comprehensive role in the mental health field. Things like educating the caregiver on the disorder of the patient and how the caregiver may adapt, counselling the caregiver, and also educating the community as a whole were discussed, as the possible roles of the social worker when it comes to service delivery to the affected caregivers. See chapter 2 (paragraphs 2.9.1, 2.9.2, 2.9.3 and 2.9.4).

Furthermore, the recommendations for the role of the social worker in service delivery intervention with caregivers of mental health care users with bipolar disorder are discussed based on the key findings.

#### 4.2.3 Research question

The research question for this study was:

What are the experiences of caregivers of mental health care users with bipolar disorder in Harare, Zimbabwe?

#### 4.2.4 Limitations to the study

This was a qualitative study and therefore the findings could not be generalised because the participants are unique individuals who have different perspectives, experiences, attitudes and behaviours.

The overall research question was answered through the data which was obtained from the interviews conducted during the research. During data analysis, the recorded interviews were transcribed, and themes and subthemes were generated which addressed the research question, to explore and describe the experiences of caregivers of mental health care users with bipolar disorder in Zimbabwe. The following table of themes and subthemes show how the research question was answered.

### 4.3 KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

The key findings and conclusions from this study are discussed below.

#### 4.3.1. Key findings regarding literature study

In the subsequent section, the key findings, conclusions and recommendations regarding the literature study are discussed.

The biopsychosocial approach underpinned this study and is discussed in chapter one. The biopsychosocial approach was relevant to this study and could be linked throughout the study. The literature review unravelled the concept of bipolar disorder, its causes, symptoms and treatment through the biopsychosocial lens. The following categories of bipolar were discussed; bipolar I disorder, bipolar II disorder, cyclothymic disorder and substance/medication-induced bipolar and related disorder, bipolar and related disorder due to another medical condition, other specified bipolar and related disorder, and unspecified bipolar and related disorder. It was also revealed that bipolar disorder has a prevalence rate ranging from 1.3% - 1.6% to 3.8%.

The literature review uncovered that family members are fundamental to the daily care of most mental health patients. Subsequently, the demands of looking after a mental health patient may substantially impact on family caregivers' psychological wellness, financial stability and social relationships. The reviewed literature stressed that caregiving bipolar patients may increase chances of having stress, anxiety, resentment, depression, hopelessness, sense of entrapment, disruption in family life and relationships, financial difficulties restrictions in social and leisure activities and above all a decrease in the quality of life have been reported as aspects of burden

Literature on stigma in mental health was explored, as it affects most of the family caregivers of people living with mental illness. It was gathered that stigma is presented with challenges of knowledge, values, attitudes and behaviours regarding an individual's life circumstances. Stigma related to mental health impacts on several life domains of those afflicted including interpersonal relationships, housing, employment and recovery illness. This is because stigma

often causes social exclusion and isolation for those afflicted. Thus, an important goal of mental health research is to important establish strategies to reduce stigma.

The literature also brought to light that caregivers of bipolar patients' experiences cannot be separated from the social context in which they exist. Cultural standards determine thresholds between health and sickness and thus the common and shared notions determine how support is rendered to a sick person within a community. The knowledge of mental health illness is critical to the establishment of quality support services in communities. When mental sickness is associated with spirituality and sometimes is believed to be a symbol of curse or bad spirit that can be contagious and hence leads to stigma and discrimination of people with mental ailments and their families.

The literature also discussed at length the biopsychosocial approach. It was revealed that the treatment of mental ailments must adopt a multipronged approach for effective treatment. The biopsychosocial treatment approach embraces efforts to address the individual's biological, psychological and social demands bearing in mind that the causes of bipolar can be induced by the systemic environment. The different coping mechanism are also brought to light in the literature review. Caregivers were identified as individuals who have different coping strategies that may range from problem focused coping mechanisms to emotion focused coping mechanisms. The use of denial, resignation and avoidance are identified to be the most common coping strategies adopted by caregivers. In some instances, making use of available social support systems and acceptance of the circumstance are typical coping strategies.

The caregiver roles were also explored in the literature review. It was identified that caregivers of mental health care users are responsible for taking care of the treatment and offering emotional support

Finally, the literature review also provided a discussion of the roles and functions of social workers in mental health. It was identified that the social worker forms part of the multidisciplinary team that include but not limited to psychiatrist, doctors, nurses and psychologist. Their roles could contribute immensely to improving the in curbing mental health stigma through advocacy and information dissemination.

## Conclusions

In conclusion, the literature review gave an overview of bipolar disorder. The literature review also brought an understanding of the different biopsychosocial experiences of mental health care users of bipolar disorder. It also looked at the stigma and discrimination related to mental health. Furthermore, the literature review gave optimism regarding caregivers' experiences by providing some strategies that can be used to mitigate the burden of caregiving.

## Recommendations

The researcher is of the view that further research should be conducted on the experiences of family caregivers of mental health care users in Zimbabwe in different communities. This is key to the formulation of robust mental health policies and strategies that seeks to curb the burden of caregiving for primary family caregivers. Moreover, research also should seek to

find out the knowledge of mental health conditions and individual perception towards mental illness specifically in the context of Zimbabwe.

#### 4.3.2 Key findings, conclusions and recommendations regarding research findings

In the next section the key findings, conclusions and recommendations related to the thematic analysis are discussed according to the themes.

##### 4.3.2.1 Theme 1: Knowledge of mental health

This theme revealed subthemes including the knowledge of bipolar disorder and knowledge on the treatment approaches for bipolar patient.

###### Key findings

The research explored the knowledge of bipolar disorder among caregivers in relation to the aetiology and management of individuals with bipolar disorder. The participants had varied knowledge of the bipolar disorder and its management and they revealed that most of the knowledge was as a result of the experiences of taking care of a bipolar patient. The caregivers interviewed demonstrated an understanding of the causes of mental ailments, as most of them mentioned that mental illness is caused primarily by genetic inheritance, drug and substance abuse and injury to the brain. Nevertheless, participants also expressed that evil spirits are a huge determinant in the cause of mental health in an indigenous African context.

###### Conclusions

It can be concluded that the lack of in-depth knowledge of bipolar disorder or any other mental ailments directly impact on the treatment and management provided to patients. This study gathered that caregivers had varied knowledge on the aetiology of bipolar and its management. While most of the knowledge of bipolar disorder was as a result of the experience of looking after a bipolar patient, the mental health literacy in the community is limited.

###### Recommendations

Caregivers and communities should be educated on mental health conditions to improve on the quality of care for patients. When the community's mental health literacy is improved it reduces the stigma associated with looking after a mental health patient.

Caregivers and families who have a mental health user, should receive knowledge in the form of general training regarding taking care of patients under their care and how they can overcome the challenges they may face daily as they live.



#### 4.3.2.2 Theme 2 Psychological harm

Psychological harm is one of the key themes of this study and a key aspect that resonates well with the biopsychosocial approach. Two subthemes emerged from this theme including emotional stress and misery.

##### Key Findings

The emotional distress theme was formulated as most of the participants in this study revealed that they had experienced emotional distress in taking care of bipolar patients. Most of the caregivers confirmed that most of the time they find themselves thinking about their mental health care user relative and the shame that sometimes comes with a mental health condition. It emerged that most caregivers of bipolar patients undergo emotional disruption, especially during manic episodes when the patient becomes aggressive or abusive to others.

##### Conclusions

Providing care to mental health care users, was reported to cause a lot of psychological stress to the caregiver as a result of the unpredictable behaviour of the patient and societal negative attitudes and stigma towards mental health. This is in tandem with the biopsychosocial approach and contributes to the psychological aspects of the model.

##### Recommendations

It is recommended that caregivers of mental health care psychological support to cope with caregiving related stress.

Establish community support groups for mental health caregivers to debrief and share experiences with others.

#### 4.3.2.3 Theme 3: Physical harm

Physical health harm uncovered two subthemes; sleep depravity and fatigue.

##### Key Findings

This research gathered that caregivers of mental health users, may find it difficult to have normal sleeping patterns, especially when the patient is having a manic episode. The study found that most caregivers are mentally exhausted and fatigued.

##### Conclusions

Providing care to a bipolar patient negatively impacts on the physical wellbeing of the carer. The experiences may compound a caregiver's physical health problems such as diabetes, high blood pressure, sleep apnoea, irregular heartbeat, arthritis, severe hearing loss to mention but a few. In view of the above, these physical aspects are in sync with the biopsychosocial approach used as a theoretical framework for this study.

## Recommendations

Caregivers of mental health care users must be supported with respite support services to relieve them from the burden of caregiving, for instance over weekends.

Establishment of care support network with other caregivers and professional (social workers, psychologists) to debrief on their caregiving experiences.

### 4.3.2.4 Theme 4: Social experiences

This theme revealed subthemes including the issue of stigma and discrimination, social isolation and negative community attitudes.

#### Key Findings

The subtheme of stigma and discrimination emerged from participants experiences with their friends and families, the community in general and other professionals. It was found out that most participants found it difficult to disclose the mental condition, because of the perceived negative reactions from friends, family members and the community.

The study also revealed the subtheme of marriage breakdown and family isolation. It was found that, it is not uncommon for mental health care users with bipolar disorders to experience social isolation. Some participants also indicated that they had interpersonal tension (strained atmosphere, quarrels and irritation) with their mental health patients. In some instances, participants reported to have received verbal and emotional abuse, anger resulting in property breakage, resulting in feelings of dislike from the patients they are looking after. These tensions contribute to isolation by some family members and relatives and can even lead to divorce in some instances.

#### Conclusions

It can be concluded that there is a noticeable thread of negative attitudes from the community that have engulfed families with a mental health care user, which perpetuates the issue of stigma and discrimination. Social attitudes towards mental health care users greatly impact on the social relationships, which exacerbate the burden of care on family caregivers of mental health care users. These social experiences resonate well with the biopsychosocial approach, as it provides the framework for this study.

#### Recommendations

It is vital to develop community awareness programs that educate families and communities on bipolar disorder and other mental conditions to address the stigma and discrimination associated with mental illness.

#### 4.3.2.5 Theme 5: Economic hardships

This theme focused on how most caregivers are financially incapacitated as a result of losing employment opportunities.

##### Key Findings

The majority participants of this study were not employed and survived on informal business such as peasant farming to take care of care of their relatives. The findings revealed that most caregivers quit their jobs or school to provide full care to the mental health care user. Participants of the study drew attention to the financial burden associated with caregiving bipolar and related disorders. The time that caregivers spent on providing care, meant that caregivers are unable to partake in full-time work. As a result, caregivers were impacted negatively financially. Importantly, participants mentioned that there is inadequate financial support from the government of Zimbabwe.

##### Conclusions

Most caregivers were facing financial hardships to meet their patients and the family's needs. Most caregivers of mental health care users with bipolar disorder forgo employment to support their patients. In Zimbabwe, there is inadequate financial support available to mental health caregivers who do not work. Subsequently, this burden is further compounded by the often substantial level of financial support needed for mental health care users. In line with the biopsychosocial approach the economic aspects faced by caregivers can be closely viewed through the social lenses.

##### Recommendations

It is important to develop a national support framework for caregivers of mental health care users to improve their coping capacity to the burden of caregiving mental health users.

Increase national funding on mental health and supporting caregivers of mental health care users.

Inclusion of people with mental health conditions and their caregivers in the flexible labour market.

#### 4.3.2.6 Theme 6: Support system

Social support for caregivers of mental health care users of bipolar patients also emerged as an important theme of this study.

##### Key findings

The first subtheme that was revealed by the participants was the family as a support system. The participants indicated that family and friends were an important support system. The other subtheme that came out of social support was the church and religion who were often mentioned by participants as key to the provision of needed spiritual support to the challenges

they face. The church was empathising with the caregivers and provided the needed support to overcome stigma and isolation.

#### Conclusions

It was identified that the family, friends, community and the church are support systems in place for caregivers of mental health care users. However, these systems in some instances, because of negative attitudes, often do more harm than good to the circumstances of caregivers concerned. To this end the biopsychosocial approach borrows from the systems theory and concerned about how systems function together, this can be closely linked to the findings of this study, on how support systems can be coordinated in mental health.

#### Recommendations

Strengthen social support networks in communities and provide them with the relevant education on mental health.

Engage churches and other religious leaders to champion and raise awareness on mental health care, in order to reduce stigma and discrimination associated with mental health.

#### 4.3.2.7 Theme 7: Coping mechanisms

##### Key Findings

Participants had different ways of coping to the burden and demands of providing care to mental health care users of bipolar disorder. The following subthemes were drawn from this theme that included the following: faith and religion, tradition healers, emotional cutting off.

The subtheme emotionally cutting off emerged as it was found to be the mostly used strategy by participants.

Faith and religion and traditional healers also the other subtheme that emerged as under the major theme coping strategies. The results of this study show that the family members of people with mental illness use the available faith and religion as social support systems to positively care for their ill family member. Participants revealed that most participants often seek spiritual guidance from faith healers and or traditional healers.

##### Conclusions

The strategies identified are perceived to meaningfully contribute to the reduction of stress and the burden of caring for a mental health care user. It is important to realise that in circumstances where the family, religion, professional help is not present, most caregivers struggle to cope with the pressure of caregiving. Thus, during assessments social workers should be able to identify the available support system for each caregiver. As such all the raised support systems identified by this study relate well to the biopsychosocial approach, as it emphasises identifying how physical, psychological and social systems can be utilised by social workers in case plan development.

## Recommendations

Social workers must link caregivers of mental health care users to the social support network that they can thrive on to reduce the burden and stress related to caregiving. It is fundamental for social work to identify resources and be able to refer caregivers and patients to appropriate services.

### 4.3.2.8 Theme 8: Caregiver needs

#### Key Findings

This study also found out that caregivers have central needs in their role. Financial resource and counselling were expressed by most of the participants of this study. It was identified that inadequate support of caregivers in this respect compromise on the quality of care provided to mental health patients. It emerged from this study that caregivers require financial support to travel to the hospital something that would have been avoided in the presence of community mental health services.

#### Conclusions

It was gathered that caregivers need support with financial, respite services, counselling support services. There seems to be inadequate support for the caregivers of people living with mental illnesses. The available services seem to be concentrating on the patient alone while also overlooking the caregiver's wellbeing or state of mind. The biopsychosocial approach was relevant for this study as it was able to provide a framework through which to identify physical, psychological and social needs of caregivers.

#### Recommendations

There is a need for government to prioritise mental health services and work towards services are affordable and accessible in communities. It is central to this study for mental health policies to receive political buy in if implementation of mental health policies is to be realised in Zimbabwe.

### 4.3.2.9 Theme 9: Lack of local services

#### Key Findings.

Lack of local services was also an emerging theme in this study. Almost all the caregivers highlighted that there are no community mental health services available in their communities. They must travel to the central hospital to access medicines and treatment services for their patients. The absence of community mental health services is perceived by this study to exacerbate the burden of caregiving mental health patients in Zimbabwe.

## Conclusions

This study found that there is lack of community based mental health facilities and services remain centralised. Consequently, caregivers must travel long distances to get the medication for patients which is costly for them. The unavailability of community based mental health services are exacerbating ignorance and stigmatisation of mental illness in local communities as the aspect of mental health remains an alien to them. The lack of services in communities directly impact on the biopsychosocial aspects that caregivers are faced with.

## Recommendations

This research suggests that, community based mental health facilities should be decentralised to communities to enable easy access for users. This study suggest that mental health services must offer a package of services ranging from education and training to treatment and management of ailments.

## 4.4 RECOMMENDATIONS

This succeeding section provides the recommendations based on the findings of this study.

### 4.4.1 Recommendations for future research

This study recommends further research to be scaled up to quantitatively measure and evaluate the burden of care for mental health care users in different communities in Zimbabwe as the current study focused only on Harare.

### 4.4.2 Recommendations for practice

- This study suggests that practical assistance, such as financial or respite services should be provided to caregivers of mental health.
- Social workers should help empower caregivers by helping them to make the most of available sources of social support, helping with coping strategies.
- This study also recommends for the promulgation of mental health policies tailor made to suit the needs of caregivers and their patients
- Community involvement should be encouraged and inclusion of people with mental health issues and their caregivers in the open labour market.
- It is key to develop community awareness programs that educate families and communities on bipolar and other mental illness to address the high stigma and discrimination associated with mental illness.
- There is need to involve strong multidisciplinary care teams to provide professional support to caregivers of patients with mental disorders in order to help caregivers deal with biopsychosocial experiences encountered in providing care to bipolar patients.
- There is a need for policy shift to accelerate the decentralization of mental health care services to communities for enhanced access to services by users.

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## 6. APPENDICES

### APPENDIX A: ETHICS APPROVAL



5 July 2019

Dear Mr F Mavingire

Project Title: The experiences of caregivers of mental health care users with bipolar disorder in Harare, Zimbabwe.

Researcher: Mr F Mavingire

Supervisor: Dr CL Carbonatto

Department: Social Work and Criminology

Reference number: 17257655 (HUM020/0319)

Degree: Masters

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 5 July 2019. Data collection may therefore commence.

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.

We wish you success with the project.

Sincerely

Prof Maxi Schoeman

Deputy Dean: Postgraduate and Research Ethics

Faculty of Humanities UNIVERSITY OF PRETORIA, e-mail: PGHumanities@up.ac.za.

Fakulteit Geesteswetenskappe  
Lefapha la Bomotheo

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Mr A Bizos; Dr L Blokland; Dr K Booys; Dr A-M de Beer; Ms A dos Santos; Dr R Fasselt; Ms KT Govinder; Andrew; Dr E Johnson; Dr W Kelleher; Mr A Mohamed; Dr C Puttergill; Dr D Reyburn; Dr M Soer; Prof E Taliard; Prof V Thebe; Ms B Tsebe; Ms D Mokalaaa

## APPENDIX 2: INTERVIEW SCHEDULE (ENG)

### INTERVIEW SCHEDULE

#### Biographic information of Caregiver

Age:

Marital status:

Sex:

Number of children:

Religion:

Home language:

Highest qualification:

Interview Guide

Occupation;

Relationship to patient

Does the patient live with you?

a. if so, does anyone else live in the household?

b. If, yes, please specify.

#### Biographic Information of patients

Age

Sex

Race/ethnicity

Occupation

Educational status

#### Knowledge of Bipolar

1. Tell me your understanding of Bipolar disorder?

#### Diagnosis

2. When was the patient first diagnosed with bipolar disorder?

3. When and how did you learn of the diagnosis?

4. Has the patient been hospitalized for any other mental illness before? If so, how many times?

5. Tell me about How is the present condition of the patient?

#### Treatment

6. Explain the What type of care is the patient receiving now?

7. Tell me about how is the patient is managing and adhering to treatment doing now?

8. How are you involved in their treatment?

a. If so, how?

#### Experience of Caregiving

How long have you been in the caregiving role?

Are you the primary or only caregiver?

What was your reaction when you heard got about the diagnosis?

What are your caregiving responsibilities?

About hHow much time do you spend doing this?

Has caregiving affected your life?

a. If so, motivate how? (E.g. increased stress, employment, social, leisure, health etc.)

14. What has been the biggest change in your life since you've been a caregiver?

15. Do you have any other support in your caregiving role now?
  - a. If you do, please describe
16. Have you accepted the condition of the patient?
17. What do you do to cope with the role of caregiving? ☒
18. How do you experience people's attitude to mental health care users?

#### Available and Needed Services

19. Have you received community and mental health services which you have found helpful?
  - a. If so, please describe.
20. What needs have you identified required by bipolar patients?

#### Conclusion

21. Are there aspects of caregiving that are satisfying to you?
22. Have you discovered any approaches or procedures that you feel are helpful?
23. Is there anything Iwe have left out which you feel is important?
24. How did you find the interview today?

## APPENDIX 3: LETTER OF INFORMED CONSENT



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Department of Social Work and Criminology

### LETTER OF INFORMED CONSENT

#### SECTION A: RESEARCH INFORMATION

Fanuel Mavingire

(4566 Knowe Phase 2 Norton, Harare)

+263771275222

**1. Title**

The experiences of caregivers of mental health care users with bipolar disorder in Harare, Zimbabwe.

**2. Introduction**

The researcher is currently working on the MSW (health care) at the University of Pretoria under the supervision of Dr CL Carbonatto and it is a requirement to conduct research on a relevant topic in the field of study and present the findings in a mini-dissertation.

**3. Purpose of the study.**

The purpose of the study is to explore and describe the experiences of caregivers of mental healthcare users diagnosed with bipolar disorder in Harare, Zimbabwe

**4. Procedures**

The researcher approached the Psychiatric Unit Social Workers to inform them of the study on the caregivers of bipolar patients. An information letter was used to share the study with potential participants who were interested in partaking and met the selection criteria. You gave you contact details to the social worker as being interested in partaking in the study. Purposive sampling was used to select you as a prospective participant from those who gave their contact details to the social worker and met the selection criteria. The researcher will conduct an interview with you that will be approximately 45 to 60 minutes in duration. This interview will be conducted at the Parirenyatwa Hospital Psychiatric Unit or any other convenient place of your choice which will serve as a neutral and non-threatening environment. The researcher will approach the Psychiatric Unit Social Workers to inform them on the caregivers who have participated in the research for long term support services. Purposive sampling will be used to select you as prospective participant if you are willing to take part in the research. If you are still willing to participate in this research, you will be requested to sign this a consent letter that follows before the semi-structured interview will be is conducted with you. The researcher will conduct an interview with you of approximately

45 to 60 minutes duration. This interview will be conducted at the Parirenyatwa Hospital Psychiatric Unit or any other convenient place of your choice which will serve as a neutral and non-threatening environment.

**5. Risks and discomforts,**

If you should experience any emotional harm or discomfort as a result of the interview, you may withdraw from the study at any time. The researcher will debrief you after the interview and if needed, will refer you to the Psychiatric Social Worker in case of if you need any needed counselling.

**6. Benefits:**

You will not personally benefit from participation in the study. However, depending on the outcome of the study, feedback will be given to the Psychiatric Unit on how recommendations from this study could for instance contribute to understanding the experiences of caregivers. effective and efficient caregiving. The findings of this study will be helpful to the service providers to improve their understanding of the experiences of caregivers of mental health care users.

**7. Participants' rights:**

The participation is voluntary and of your own accord and you ; they may withdraw from participation in the study at any time and without negative consequences. RIGHTS OF PARTICIPANTS You have a right to participate voluntarily out of your own accord and may choose to withdraw from the study at any time and without any negative consequences. You will receive debriefing from the researcher after engaging in the interview and will be referred if necessary to the Psychiatry Social Worker for counseling, should any emotional harm difficulties arise resulting from the interview. The researcher will share the findings of the research with you all participants, once the study is completed.

**8. Confidentiality:**

The researcher will ensure confidentiality during the data collection and data analysis. The interview will be audio-recorded with your permission for research purposes only. To ensure anonymity, you will be assigned a number before the interview to ensure confidentiality and to protect your identity.

**9. Access to the researcher:**

You will have access to the researcher for the duration of the study and for three months after completion of the study. You can contact the researcher, Mr Fanuel Mavingire on the following number: 0771275222 at any time during office hours or email: [fanuelmavingire@gmail.com](mailto:fanuelmavingire@gmail.com)

**10. Data storage and usage:**

The data collected is specifically exclusively meant for academic purposes to meet the requirements of a Masters degree in Social Work (Health Care)

The data collected for this study will be stored for 15 years by the University of Pretoria to inform future researches and thereafter destroyed.

PLEASE SIGN THE FOLLOWING SECTION IF YOU AGREE TO PARTICIPATE VOLUNTARILY IN THE STUDY.

Yours sincerely,

Fanuel Mavingire

Researcher.

**SECTION B: INFORMED CONSENT OF PARTICIPANT**

I..... (*Full Name of participant*) declare that I have read and understood the above information. I was given adequate time to consider my participation in the study. I was also given the opportunity to ask questions and all of them were answered to my satisfaction. I hereby give consent to participate voluntarily in this study.

**Signature of participant:** .....

**Date:** .....

**Declaration by researcher**

I..... hereby declare that I have explained the information in Section A: Research Information to the participant and he/she indicated understanding the contents and was satisfied with the answers to questions asked.

**Signature of researcher:** .....

**Date:** .....