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A qualitative investigation of the subjective experience of crises and life changes in the family which precede the onset and diagnosis of schizophrenia

By

Christopher Sampson

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Supervisor: Dr Linda Blokland
Co-Supervisor: Dr Elizabeth du Preez

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Abstract

This study set out to explore the subjective experience of crises and life changes in the family which precede the onset of schizophrenia. The motivation for it arose from the vulnerability-stress model of schizophrenia which proposes that environmental factors such as stressful life events may help to trigger the onset or exacerbation of symptoms in people who have a genetic vulnerability for the condition. Related research suggests that crises and life changes in the family can contribute to the stress experienced by those who go on to become psychologically disturbed. This has led to an increased interest in accessing the subjective experience of schizophrenia as shared by individuals and their families through the use of narratives to provide alternative perspectives on the condition. Indeed, a growing body of evidence from research conducted with people diagnosed with schizophrenia suggests that the content of their actions and statements can be construed as meaningful and logical in the context of their family and life situations.

Four individuals who had been diagnosed with schizophrenia and their families participated in this study. In each case study, two interviews were conducted, one with the individual participant and a second interview with the individual and those members of their family that were willing to attend. The interviews were guided by a semi-structured interview schedule and data from the interviews was analysed using content analyses and the most prominent themes were discussed in relation to the literature.

The themes in the data describe the participants' subjective experience of the many crises and life events and change in psychological functioning that precedes the onset of florid psychotic symptoms. These findings suggest that the schizophrenic symptoms of the participants in this study helped to absorb the impact of family stressors and played a fundamental role in keeping the family systems intact. The associated behaviour appeared to sustain the roles in the family as well as long-standing patterns of interaction between the family members. The numerous interacting influences and sheer variation in the experience of just four families indicates that much still needs to be understood about the experience of schizophrenia. It is recommended that future research investigate how the subjective understanding of schizophrenia affects the lives of those affected.

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Declaration

I declare that this mini-dissertation is my own unaided work. It is submitted in partial fulfillment of the requirements for the Degree of Masters of Arts in Clinical Psychology in the Faculty of Humanities, University of Pretoria, Pretoria. It has not been submitted for any other degree or examination at any other university or institution and all sources used or quoted have been indicated and acknowledged.

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Christopher Sampson

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Chapter 1: Introduction

The vulnerability-stress model of schizophrenia proposes that environmental factors such as “stressful life events may act as triggers of onset or exacerbation of psychotic symptoms” (Horan et al., 2004, p. 363) and research that has explored stressful life events suggests that the quality of relationships within the family, especially long term tension in the home, can increase the chances of becoming psychologically disturbed (Blanchard, Sayers, Collins, & Bellack, 2004; Brown & Birley, 1968; Cullberg, 2003; Horan et al., 2004; Kuipers, 2006; Read, Perry, Moskowitz, & Connolly, 2001).

Findings in a familial context intriguingly suggest that, “often the schizophrenic crisis of one member coincides with the threat that one of the other members, often an adolescent, is about to leave the family” (Selvini, Boscolo, Cecchin, & Prata, 1980, p. 8) which implies that the behaviour of the person diagnosed with schizophrenia is an attempt to keep the family together. In support of this, a diagnosis of schizophrenia is usually made in late adolescence or early twenties at, “a stage of life when people typically attain independence from parents, develop intimate romantic relationships, and/or begin to pursue work or career goals” (DeLisi, 1992 as cited in Walker, Kestler, Bollini, & Hochman, 2004, p. 402). Schizophrenia is a debilitating condition which can affect opportunities for attaining social and occupational success and independence from the family. Thus, the behaviour of the person diagnosed with schizophrenia may be construed as an attempt to maintain stability in the family and it has been noted that “in families with schizophrenics, there is a great effort to maintain a fairly rigid pattern of attitudes against the inevitable changes undergone by family members” (Poster, 1988, p. 20).

Little is known of whether those affected by schizophrenia actually perceive these stressful life events to have contributed to their developing the condition and how they believe the events may have contributed (Cook, Cohler, Pickett, & Beeher, 1997). The subjective experience of the individual and their family may have been overshadowed by the more positivistic explanations contained within the dominant bio-medical model (Jenkins, 1991; Strauss, 2008). Investigating the subjective experience of those affected by schizophrenia and their families may assist in rectifying this by helping to “explore the

patient psychologically, that is, apperceive him as a person with motives, aims, reflections, feelings - feelings also about the illness" (Hoening, 1983, p. 553). Therefore the aim of this research was to explore the subjective experience of crises and life changes in the family which have preceded the onset of schizophrenia using semi-structured interviews with a group of individuals who have sought treatment at a psychiatric hospital and their families. A postmodern epistemology based on social constructionism has been adopted through the use of a narrative approach to elicit the subjective experience of the individuals and their families.

Sullivan (1925, as cited in Sadock & Sadock, 2003) stressed that it was only possible to describe and understand individuals when their behaviour was viewed in interaction with others. Laing and Esterson (1964) describe 11 case studies of people diagnosed with schizophrenia and argue that the content of their actions and statements was meaningful and logical in the context of their family and life situations. Bateson, Jackson, Haley and Weakland (1956) and Laing (1969 as cited in Gelbmann, 2003) provided support for this when they suggested that "the deviant conduct of the individual indicated as 'patient' gains in lucidity not so much as a feature of a single person, but as a feature of the internal organization of this observed person's social system" (p. 1). Using that as a point of departure, this study paid particular attention to relational patterns and alliances within the family firstly, through noting intergenerational patterns and understanding how these may be repeated in the present generations and secondly, through looking at the possible meaning of the symptoms in the family by allowing people to recreate their life narratives and infuse their experiences with their own understanding. The effort to achieve a systemic understanding of schizophrenia acknowledges that this understanding is socially constructed and may be maintained by the interaction of members of the family.

This study recognises the distress and negative effects that have been reported as resulting from the condition, but also takes into account the individuals' own attempts to make sense of their experience and thus refrains from placing a prescribed view of normality on the participants. The term schizophrenia is therefore employed as a necessity rather than a reification of the diagnostic category.

This research report is structured in the following manner:

Chapter one provides a brief introduction to this study outlining the aim and motivation for the study.

Chapter two contains a review of the literature on schizophrenia and is divided into six parts. The first section provides an overview of the history and current understanding of schizophrenia, how it is diagnosed, and outlines the debate around the concept. The second section describes the various theories and factors in some of the different views on the aetiology of schizophrenia. Section three reviews the literature on life crises and changes and the onset of schizophrenia. The fourth section discusses subjectivity and narratives in qualitative research and reviews some findings on the subjective experience of individuals and families of changes that precede the onset of schizophrenia. Section five summarises the themes in the literature and section six outlines a systemic conceptualisation of schizophrenia.

Chapter three describes the epistemology behind the research method, lists the primary and secondary aims, outlines the research design and procedures used, discusses the method of analysis, and highlights the ethical considerations.

Chapter four describes the findings from the interviews with the participants and their families, and analyses and discusses these in relation to the literature reviewed.

Chapter five draws conclusions from the data, highlights the limitations of the study and provides recommendations for future research.

The supporting documentation for this study is located in the appendixes and includes a copy of the consent form, the interview schedule used in the interviews and the genograms which depict the patterns, events and relationships in the families and members that makes up each family. The interview transcripts are saved on a separate compact disk.

Chapter 2: Literature review

This literature review begins with an overview of schizophrenia, followed by an outline of the various theories on how it is believed to arise. The main findings in the research on crises and life changes that have been found to precede the onset of schizophrenia are discussed, and the review continues with an overview of the research on the subjective experience of schizophrenia. A summary of the main themes in the literature is then presented and this is followed by a discussion of the key concepts of systems theory.

2.1 An overview of schizophrenia

2.1.1 An early history of the concept

Early theorists viewed schizophrenia and its subtypes as organic disease syndromes which resulted from damage to brain structures which led to progressive and irreversible deterioration in cognitive functioning (Shean, 1978). Emil Kraepelin defined the deficit symptoms of "abnormalities in cognition and emotion: alogia, avolition, anhedonia, affective blunting, and … attentional impairment" as fundamental to the disorder (Andreasen, 1997, p. 105). However, the drive to discover biological markers of these symptoms led to a focus on more prominently observable symptoms while the importance of the patient's life history, premorbid personality and subjective experience of the condition were downplayed (Hoening, 1983).

Eugen Bleuler expanded on Kraepelin's views by including the subjective experience of psychological changes and introduced the term schizophrenia in 1891 to indicate "the splitting or tearing of the mind and emotional stability of the patient" (Walker et al., 2004, p. 403). The philosopher, Karl Jasper, also stressed the importance of the subjective psychological meaning of the signs and symptoms of schizophrenia. In applying Jasper's ideas, Kurt Schneider, a German psychiatrist, argued that both objective and subjective study of the condition and those affected was necessary to know how the initial course of the condition unfolded in order to identify precise symptoms so as to predict the future course and outcome of schizophrenia (Schneider, 1938 as cited in Hoening, 1983).

Recent thinking around schizophrenia has evolved through various diagnostic systems. One of these, the third edition of the *Diagnostic and Statistical Manual of Mental Disorders*, (American Psychiatric Association [*DSM-III*], 1981) was originally conceptualised as an agreement on what criteria to include for a diagnosis of schizophrenia and never as a full description of the condition. However, through the publication of the *DSM-III* (1981), schizophrenia became a consensus illness where provisional agreement on symptoms of the condition was reified through the publication of 'user friendly' diagnostic criteria (Andreasen, 1997).

2.1.2 The current psychiatric understanding of schizophrenia

Schizophrenia is a chronic and debilitating condition which can have a profound, negative impact on the person's future course of life (Frude, 1998; McGrath, 2004). The impact on the individual and their family begins early in life with several cognitive deficits and social impairments visible from an early age (Walker et al., 2004). It is "characterized by symptoms such as hallucinations, delusions, disorganized communication, poor planning, reduced motivation, and blunted affect" (Saha, Chant, Welham, & McGrath, 2005, p. 414). There is often poor insight which affects compliance with treatment (Sadock & Sadock, 2003). The experience causes great distress to the affected individuals and their families, not least because of the societal stigma attached to both schizophrenia and mental illness in general (McGrath, 2004).

The person's experience during the illness is fragmented and certain commonalities are often described in clinical practice. Their feelings are split from ideas and their acts from thoughts which leads to bizarre behaviour. Confusion between fantasy and reality causes little to make sense to the individual. Safety stems from withdrawal into a private mental world. Poor ego boundaries make it difficult for the person to discern their own actions and thoughts from those of others. A limited sense of self leads to feelings of hopelessness and emptiness that are ascribed to manipulation by others. They may experience overwhelming feelings of terror and isolation which can make it difficult for them to trust others (Kupers, 1976 as cited in Poster, 1988).

It is uncertain whether this experience stems from a single disorder or a group of disorders. There is a "large body of data suggesting that the extent of phenotypic heterogeneity in schizophrenia is too large to support a simple nosological model of the disorder" (Jablensky, 1997, p. 120). "Although it is discussed as if it is a single disease, schizophrenia probably comprises a group of disorders with heterogeneous etiologies, and it includes patients whose clinical presentations, treatment response, and course of illness vary" (Sadock & Sadock, 2003 p. 471). There is also a debate over whether the symptoms of psychotic illness are qualitatively different from normal experience as symptom indicators have been found in the general population (Allardyce, Gaebel, Zielasek, & Van Os, 2007).

2.1.3 The epidemiology of schizophrenia

Schizophrenia is found across social and geographical boundaries with no particular pattern in course and outcome identified as specific to any one region (Jablensky & Sartorius, 2008). Knowing how many people are, or might be, affected by schizophrenia in the future is important for the planning and provision of health care services (Saha et al., 2005), but this is difficult to determine as the diagnosis appears highly variable and unreliable (Shean, 1978). Based on a systematic review of 188 studies from 46 countries Saha et al. (2005), estimated that 4 in every 1 000 people present with signs of schizophrenia. McGrath, Saha, Chant, & Welham (2008) reviewed 383 studies from more than 46 countries on the incidence, prevalence and mortality rate of schizophrenia. They estimate that on average 15 in every 100 000 people develop schizophrenia each year. On average about 7 in every 1 000 individuals are likely to develop schizophrenia during their lifetime. The risk factors for schizophrenia include gender, urbanicity, migration, geographical location or low socioeconomic status, and social or cultural behaviours. The risk of death is two to three times higher for people diagnosed with schizophrenia than for the general population due to suicide and a wide range of comorbid conditions (Allebeck, 1989).

2.1.4 The course of schizophrenia

From a medical model, schizophrenia is believed to be a disease process in which the symptoms appear to unfold in a chronological sequence (Häfner & Maurer, 1991 as cited

in Gross, 1997). Dynamic and cognitive basic symptoms appear as the first signs of the disorder which lead to positive symptoms and later to the development of negative symptoms (Gross, 1997).

Basic symptoms

Manifestations of prepsychotic indications of schizophrenia are said to occur many years before the first psychotic episode. Deficits may be present in some domains as early as infancy with children performing worse than siblings or peers on tasks requiring cognitive functioning (Aylward et al., 1984 & Jones et al., 1994 as cited in Walker et al., 2004). In a typical history, "patients had schizoid or schizotypal personalities characterized as quiet, passive, and introverted: as children they had few friends" (Sadock & Sadock, 2003, p. 490). Home videos of pre-schizophrenic children suggest that signs and indications of the "vulnerability for schizophrenia are subtly manifested in the earliest interpersonal interactions" (Walker, Grimes, Davis, & Smith, as cited in Walker et al., 2004, p. 412). These symptoms cannot be observed by others unless they are pronounced and have to be elicited through exploration with those affected. The most basic symptoms of thought blocking and thought interference are initially only experienced by the patient and fluctuate due to the stress demands of specific situations (Gross, 1997).

Premorbid phase

The deficits in multiple domains of functioning become more pronounced in adolescence with increased difficulty in adjustment. The family may find it difficult to understand this behaviour and is likely to ascribe it to a phase of development. "The most frequently cited possible prodromal symptoms consist of mood changes such as tension, irritability, depression, anxiety, withdrawal, and vegetative changes such as disturbed sleep and loss of appetite" (Norman & Malla, 1994, p. 487). Other observable changes include "loss of interest in school or work, deterioration in hygiene and grooming" (Schultz, North, & Shields, 2007, p. 1823), and obsessive compulsive behaviour in adolescents (Sadock & Sadock, 2003).

There are several issues raised in the literature with regards to prodromal symptoms. Firstly, reliability of the information on the presence of prodromal symptoms may be questionable because the condition affects thinking, feeling and behaving (Jacobs & Myers, 1976). Secondly, patients and families may show bias in what is termed "an effort after meaning" or in trying to make sense of what has happened (Bartlett, 1932 as cited in Brown & Birley, 1968). Thirdly, while the first hospitalisation may be thought of as being near to the first onset of active phase symptoms, the premorbid signs and symptoms in the prodromal phase may be present for months or even years before the first psychotic episode occurs. Although there is agreement on the broad categories of prodromal symptoms, there may be idiosyncratic difference across patients for particular symptoms. Also, not everybody who has experienced a psychotic episode reports prodromal symptoms. This has prompted some researchers to ask whether prodromal symptoms really do precede psychotic episodes or whether they are a reaction to a gradual psychotic process (Norman & Malla, 1994).

The active/acute phase

The first psychotic episode usually occurs in late adolescence or early twenties. Although the symptoms are different in each subcategory of schizophrenia and for each individual, they appear to affect most aspects of cognition, emotion and behaviour (Andreasen, Arndt, Alliger, Del, & Flaum, 1995). The most frequent symptoms in the acute phase include a lack of insight, auditory hallucinations, ideas of reference, flattened affect, suspiciousness, delusions of persecution and thought alienation (World Health Organization *[WHO]*, 1973 as cited in Frude, 1998). However there is little consensus in the literature about the number of symptom dimensions that describe the full clinical picture of schizophrenia (Fanous, Garder, Walsh, & Kendler, 2001).

Remission phase

The course of schizophrenia is said to usually involve periods of symptoms followed by periods of remission in which symptoms are less prominent. Once the first episode of psychosis occurs, patients partially recover and with proper management and compliance with medication may function well for a long period (Sadock & Sadock, 2003).

Prognosis

The pattern established within the first five years following diagnosis may predict the future course of the illness. Each relapse is accompanied by further deterioration in functioning (Sadock & Sadock, 2003). While the severity of positive symptoms decreases with time, the negative symptoms increase in severity. These negative symptoms are much worse for the person's social functioning and family interaction due to the feeling of something being missing and not there (Frude, 1998). There is some variation in the course of schizophrenia. A third of patients manage some form of "integrated social existence, most have lives characterized by aimlessness, inactivity, frequent hospitalizations, and, in urban setting, homelessness and poverty" (Sadock & Sadock, 2003, p. 497). Twenty to thirty percent of people experience relatively normal lives in which they are able to be employed and live independently and the same number continue to experience moderate symptoms (Walker et al., 2004). Most experience chronic impairment with at least 50% of people diagnosed with schizophrenia having a poor outcome (Sadock & Sadock, 2003, p. 497).

2.1.5 Diagnosing schizophrenia

The two main texts that are used to classify and describe symptoms of mental illness for diagnostic purposes are the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association [*DSM-IV-TR*], 2000) and the *International Classification of Diseases and Related Health Problems* (World Health Organization [*ICD-10*], 1993). No disease marker or laboratory test exists for schizophrenia (Thomas, 1993), and diagnosis is guided by clinical convention and based on a psychiatric history and mental status examination following recognition of typical symptoms (Sadock & Sadock, 2003).

DSM-IV-TR criteria for diagnosing schizophrenia

The *DSM-IV-TR* (2000) lists five criteria necessary for a diagnosis of schizophrenia. Firstly, two or more characteristic symptoms of disorganised speech, grossly disorganised or catatonic behaviour, or negative symptoms of affective flattening, alogia, or avolition must be present for the most part of one month or less if successfully treated.

Hallucinations or delusions are not required for a diagnosis and only one symptom is needed if the delusions are bizarre or if the hallucinations “consist of a voice keeping up a running commentary on the person’s behaviour or thoughts, or two or more voices conversing with each other” (Sadock & Sadock, 2003, p. 484). Secondly, signs of disturbance in occupational functioning or social interaction have persisted for at least six months with at least one month of the characteristic symptoms. Thirdly, the six-month period may include periods of prodromal or residual symptoms where the only signs of disturbance are negative symptoms or two or more characteristic symptoms in an attenuated form. Fourth, a schizoaffective or mood disorder with psychotic features must be excluded or if either of these occurs concurrently with active phase symptoms, their occurrence is brief when compared to the duration of the active and residual periods. The fifth requirement excludes symptoms that are due to the physiological effects of a substance or a general medical condition. Finally, if the person suffers from autistic disorder or another pervasive developmental disorder, the diagnosis can only be made if prominent delusions or hallucinations are also present for at least a one-month period, or less if successfully treated (Sadock & Sadock, 2003).

DSM-IV-TR subtypes of schizophrenia

The *DSM IV-TR* (2000) classifies the five subtypes of schizophrenia as paranoid, disorganised, catatonic, undifferentiated and residual. The paranoid subtype is characterised by a preoccupation with delusions or hallucinations, without prominent disorganised speech, disorganised or catatonic behaviour, or flat or inappropriate affect. In the disorganized subtype, the symptoms of disorganised speech, disorganised behaviour and flat or inappropriate affect appear prominently. Patients with the catatonic subtype present with extreme lack of movement, excessive motor activity that is purposeless, extreme negativism or mutism, peculiar movement, mannerisms and expressions as well as echolalia or echopraxia. In the undifferentiated subtype, the symptoms that meet criterion A are present, but none of the criteria for paranoid, disorganised, or catatonic type are met. Patients with the residual subtype have no prominent delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour, but negative symptoms or two or more symptoms listed in criterion

A remain in an attenuated form such as "odd beliefs, unusual perceptual experiences" (Sadock & Sadock, 2003, p. 488).

ICD-10 criteria for diagnosing schizophrenia

The *ICD-10* (1993) describes schizophrenia as, "a syndrome with a variety of causes, and a variety of outcomes, depending on the balance of genetic, physical, social and cultural influences" (WHO, 1993 as cited in Coffey, 1998, p. 490). It also describes the following seven subcategories of schizophrenia: paranoid, hebephrenic catatonic, undifferentiated, residual, simple schizophrenia and post-schizophrenia depression which are largely similar to those in the *DSM-IV-TR* (2000). The most common of these is said to be paranoid schizophrenia. The *ICD-10* (1993) suggests that symptoms have to be present for one month to make a diagnosis of schizophrenia.

As the two diagnostic systems differ somewhat on the less severe and more acute cases, the populations diagnosed with criteria from each system would overlap but not be identical (Jablensky, 1997).

2.1.6 The debate around the concept of schizophrenia

The term, schizophrenia is useful in that it allows professionals to communicate with each other about their experience, management and possible outcome of the condition. However the "diagnostic and other descriptive categories do not fit the world they are meant to represent" (Straus, 1989, p. 180).

Schizophrenia may encompass more than one illnesses

Many believe that schizophrenia is made up of various illnesses with symptoms that cover multiple domains of functioning and using a single term like schizophrenia to refer to a disorder that is "etiologically and pathophysiologically heterogeneous" does not fully communicate what is being described (Andreasen et al., 1995, p. 342).

There may be different levels of predisposition to schizophrenia

The different levels of predisposition in the subtypes of schizophrenia also suggest that schizophrenia is made up of different types of disorders. Evidence reported by Sharma and Murray (1993 as cited in Coffey, 1998) based on genetic findings from a Norwegian twin register suggests a lower concordance rate for twins where a diagnosis of paranoid schizophrenia was involved than for other subtypes of schizophrenia.

Inconsistency in the diagnosis of schizophrenia

There is general inconsistency reported around schizophrenia. The diagnoses of patients with schizophrenia have been known to change over subsequent hospitalisations (Schultz et al., 2007). Different treatment centres and professionals within the same centre may use different criteria. This may all be a result of the "still hypothetical nature of the disease concept of schizophrenia itself and the lack of validated objective disease markers" (Jablensky, 1993 as cited in Coffey, 1998, p. 490). As much is still unknown about the condition, instability in the diagnosis may be a result of the "premature codification of diagnostic concepts and diagnostic terms" (Van Praag, 1992, p. 279).

Schizophrenia appears to be a borderless entity

Schizophrenia is also seen as a "descriptive entity without clear margins" (Gruenberg, 1974 as cited in Dohrenwend & Egri, 1981, p. 12). Not only can non-psychiatric medical conditions such as a brain tumour and the effects of different substances also lead to symptoms of psychosis, but these symptoms can be identical to many other psychiatric conditions, including those of schizophreniform disorder, brief psychotic disorder, schizoaffective disorder, delusional disorder and some personality disorders (Sadock & Sadock, 2003). This has lead "many in the field to conclude that the genetic vulnerability does not conform to the diagnostic boundaries listed in *DSM* and other taxonomies" (Walker et al., 2004, p. 409). One plausible explanation put forward is that "a number of low-incidence syndromes of heterogeneous aetiology but hardly distinguishable phenotypical expression combine together to produce a seemingly uniform rate of schizophrenia across different populations" (Jablensky, 1997, p. 120).

Evidence against the validity of a categorical nosology

More evidence is emerging for a latent continuous distribution of symptom indicators of psychosis in the general population if delusions and hallucinations are accepted as indicators of psychotic-like symptoms. Only a very small proportion of these people meet the *DSM-IV-TR* (2000) criteria for non-affective psychoses (Allardyce et al., 2007). Thus, extremes of behaviour found in the general population are used to diagnosis a condition which will prescribe a course for the rest of the individual's life (Hoening, 1983). This situation raises many questions and hints at many different explanations not least, "the genetic continuity of normal and disease states" (Fanous et al., 2001, p. 669). According to Gelbmann (2003), "the symptoms grouped together under the term schizophrenia *by the act of problematic diagnosis* created a reality that immediately affected not only the current state of medical art, but even more so the treatment of the patients concerned, which could hardly be called adequate" (p. 6).

2.2 How schizophrenia develops

This section will provide an overview of how schizophrenia is believed to arise. No one etiological cause has been proven conclusively, however it is accepted that, "similar syndromes can result from very different causes, and set the stage for the current assumption that the syndrome we call schizophrenia may have multiple etiologies" (Walker et al., 2004, p. 403).

2.2.1 The stress-diathesis model

The stress-diathesis model, first proposed by Zubin and Spring (1977), integrates biological, psychosocial and environmental factors in the conceptualisation of schizophrenia. It is believed that a specific vulnerability (diathesis) may be triggered by a stressful influence which allows the symptoms of schizophrenia to develop. "The diathesis or the stress can be biological, environmental or both. The environmental component can be either biological (e.g. an infection) or psychological (e.g. stressful family situation or death of a close relative)" (Sadock & Sadock, 2003, p. 477).

Two of the sources of biological vulnerability that have been identified are a genetic predisposition and prenatal or postnatal complications (Walker et al., 2004). It is believed that genes contribute about 80% of the risk for developing the illness (Tandon, Keshavan, & Nasrallah, 2008). With regards to complications, people with schizophrenia have been found to have a history of obstetrical complications which affects the development of the foetal brain, often associated with deprivation of oxygen (Cannon, 1997 as cited in Walker et al., 2004). Maternal infections such as influenza and rubella during the first and early second trimesters of pregnancy have also been found to be linked with increased risk for schizophrenia (Penner & Brown, 2007; Meyer et al., 2007 as cited in Tandon et al., 2008). Higher rates of schizophrenia have been in offspring of mothers who were exposed to stressful life events during pregnancy (Welberg & Seckl, 2001 as cited in Walker et al., 2004). Head injury in early childhood before the age of 10 has been found to be more common in schizophrenia (Walker et al., 2004). Other contributing risk factors include childhood trauma, parental separation or death, adverse child-rearing and infection as well as urbanicity in childhood and migration (Tandon et al., 2008).

2.2.2 Brain abnormalities

"It is well established that stress exposure impacts brain function … The chronic stress inherent in suffering from a psychotic illness may also contribute to degenerative brain changes" (Walker et al, 2004, p. 414-415). People with schizophrenia have been found to have enlarged brain ventricles, especially increased volume of the lateral brain, decreased frontal, temporal and whole-brain volume and a reduction in size of brain structures such as the thalamus and hippocampus (Lawrie & Abukmeil, 1998; Dennert & Andreasen, 1983 as cited in Walker et al., 2004). A reduction in activity at the frontal and temporal lobes especially during cognitive tasks has also been noted (Kindermann et al., 1997; Pearlson, 1997 as cited in Walker et al., 2004). Postmortem studies have revealed abnormalities on a cellular level related to neural density, structure and interconnections. Neurotransmitter activity has also been implicated in the development of schizophrenia, the more commonly cited include dopamine, serotonin and norepinephrine (Sadock & Sadock, 2003). However, "no abnormality has been shown to be either specific to schizophrenia or to characterize all patients" (Walker et al., 2004, p. 416).

2.2.3 Psychosocial theories

Historically, most theorists believed that psychological factors in the individual or family were responsible for the development of schizophrenia. While, a biological basis for schizophrenia is now more widely accepted, psychosocial theories have contributed valuable information on aspects of the person's world that may interact with the disease process.

Psychoanalytic theories

According to Freud, schizophrenia is the result of intrapsychic conflict from having to choose between self-gratifying impulses and constraints in the real world due to the person being fixated in an early developmental phase. The individual is said to have a compromised ego structure due to poor early object relations. These disturbances are believed to arise in the early mother-infant relationship in which the child is unable to achieve a sense of identity and remains dependent on the mother. Failure to separate from the mother and achieve individuation affects subsequent relationships. Onset during adolescence corresponds to a period in which the individual requires a strong ego to help achieve independence, a sense of mastery over tasks, internal drives and environmental challenges (Sadock & Sadock, 2005). Although psychodynamic theories were among the first to provide an explanation of schizophrenia and an understanding of the symptoms, they are criticised for their lack of empirical validation, for reducing human experience to scientific casual principles, for their reliance on intrapsychic and childhood factors and for ignoring social and cultural factors which affect the onset and course of the condition (Shean, 1978).

Learning theories

There is no specific theory of schizophrenia within this paradigm; instead it is believed that all behaviours are learnt through modelling and reinforcement (Shean, 1978). Children "learn irrational reactions and ways of thinking by imitating parents who have their own significant emotional problems" (Sadock & Sadock, 2003, p. 483). Therefore it appears that children develop schizophrenia as a result of lack of proper modelling in poor interpersonal relationships that may begin with relationships in the family. Defective

social skills or failure to acquire social skills have been implicated in the development and maintenance of the condition but it is unclear whether social difficulties are a cause or effect of schizophrenia (Shean, 1978). Scheff (1966 as cited Shean, 1978) criticises the behavioural techniques found in learning theories for their limited focus on observable behaviours at the expense of other facets of the individual and their environment.

Social theories

Social theories conceptualise schizophrenia as a social phenomenon. They tend to view schizophrenia as a reaction to social conditions or at least argue that stressors arising from social conditions play a significant role in the onset and the severity of the illness. Among the socioeconomic and cultural factors that are believed to affect people diagnosed with schizophrenia, the focus is on the adverse effects of low socioeconomic status, social selection by migration, stress of social change and cultural susceptibility to schizophrenia as possible factors involved in the aetiology of the condition. Social theorists have widened the context within which schizophrenia is understood to include more of the conditions which have an effect on the individual (Shapiro, 1981).

2.2.4 Family theories of schizophrenia

Early research on schizophrenia in families was strongly influenced by psychoanalytic thinking which stressed the view of schizophrenia as a disturbance in interpersonal relatedness which arises from the build-up of multiple traumas during periods of development (Sadock & Sadock, 2003). Clinical experiences in psychotherapy with individual patients led to the introduction of the term, 'schizophrenogenic mother' (Fromm-Reichmann, 1948 as cited in Koopman, 1997). The work of Theodore Lidz included inadequacies of the father as a focus of treatment. Bateson and Jackson included patterns of communication in the entire family system. Murray Bowen included previous generations in the focus of study (Shapiro, 1981). Haley (1959 as cited in Zuk & Rubenstein, 1965) concisely summarises the historical background of family treatment:

> "A transition would seem to have taken place in the study of schizophrenia; from the early idea that the difficulty in these families was caused by the schizophrenic

> members, to the idea that they contained a pathogenic mother, to the discovery that the father was inadequate, to the current emphasis upon all three family members involved in a pathological system of interaction" (p. 3)

Patterns of family communication - the double-bind hypothesis

Bateson and colleagues viewed schizophrenia as an interpersonal relational phenomenon which resulted from long-term exposure to specific types of communication patterns in families (Becvar & Becvar, 2003). They introduced the concept of the double-bind communication to describe a contradictory communication pattern in which "children receive conflicting parenting messages about their behaviour, attitudes and feelings" (Sadock & Sadock, 2005, p. 484). Due to dependence on the caregiver, the child is unable to comment on the implicit contradiction in the communication and to respond, children have to "deny important aspects of themselves or their experience" (Shean, 1978, p. 190). Constant exposure to such contradictory messages leads to equally incongruent patterns of communication, the extreme form of which is labelled schizophrenia (Shean, 1978). While a useful concept to describe interaction, it is difficult to isolate and study and not unique to parents of individuals with schizophrenia (Sadock & Sadock, 2003).

Patterns of family interaction - schisms and skewed families

Theodore Lidz and colleagues framed schizophrenia as a learnt response or mode of adjustment for individuals that were raised in families who failed to provide the essential requirements necessary to develop an integrated personality. As a result, these individuals are left with a disturbance in ego functioning which manifests in distortions of perception, meaning and logic. The parents in these families often present with disturbance in psychological and emotional functioning and two types of family relating patterns are identified based on the sex of the schizophrenic member. In a skewed family, one parent is either very inadequate or domineering while in a family wrought by schisms one parent is hostile, cold and covertly destructive towards the other (Atkinson, 1986). These difficulties hamper their ability to meet their parental roles and facilitate the child's development. There is pronounced suspiciousness and distrust of the outside world. One

or both parents tends to distort reality in their views and in order to maintain the balance within the family, they insist that other members also distort reality (Shapiro, 1988).

Lidz referred to the transmission of irrationality which stems from difficulties in communication between the parents and causes these families to "routinely deny obvious interpretations of reality. As the child subjugated his or her needs and experiences to the needs of the parents, he or she lost sight of what was real" (Lidz, Cornelison, & Terry, 1958/1965 as cited in Shapiro, 1981, p. 114). It has been argued that there are specific processes like these at work in schizophrenic families which enable the genetic vulnerability to be expressed. "The child … is instructed against the possibility of making his own connections. He is always like a shell of a person. He has many ideas, concepts, and abstractions which he cannot connect with any known experience for he does not have feelings of his own. They are forbidden" (Shainberg, 1973, p. 275-276). This theory is useful because it describes some of the behaviour witnessed in schizophrenic families. However, it lacks objective evidence to support its concepts (Atkinson, 1986).

<u>Style of communication in families of schizophrenics</u>

Wynne, Singer and colleagues viewed "schizophrenia as the result of a failure to develop an adequate ego identity. The failure of ego development is attributed to a family learning environment which does not permit adequate reality testing or provide opportunities for the integration of flexible and appropriate roles in the developing ego" (Shean, 1978, p. 206). They suggest that the entire family relationship is disturbed and in families of schizophrenics a pseudo-mutual style of relating exists where family relationships are maintained at the expense of differentiation of identities. The ill member internalises the characteristics of the family structure which leads to "disturbed modes of thinking, perceiving and communication and renders it impossible for the person to attach clear meanings to his or her own feelings and experiences" (Shean, 1978, p. 195-6).

<u>Existential based family theory</u>

Ronald Laing's view of schizophrenia evolved over his writings. Initially, he viewed schizophrenia as a form of 'survival' by the person to live within the pathogenic

institution of the family. He later referred to schizophrenia as "a communication disorder of the entire family" and labelled it mystification, which he believed served to maintain the status quo and stereotyped roles in the family (Shean, 1978, p. 206). Mystification was described as a process in which family members respond to their own needs but behave as if they are responding to the needs of the others and Laing concluded that there was an inter-generational aspect to this pattern of communication (Shean, 1978, p. 198).

Co-evolution of schizophrenic symptoms and family communication

The Milan systemic therapy school viewed schizophrenia and other psychiatric conditions from a more circular-system standpoint in which the symptoms of schizophrenia and patterns of communication it the family co-evolve. According to Boscolo et al. (1987 as cited in Bertrando, 2006) "the schizophrenic, according to this theory, starts to feel she has no existential sense in the family, and the family, in turn, feels that what the schizophrenic does has no sense" (p. 12).

Intergenerational patterns

Murray Bowen's three-generation hypothesis conceptualised schizophrenia as the result of intergenerational processes within the family that result in a child in each generation being more impaired than the parents. Repetition of this process over several generations leads to offspring with very poor levels of differentiation of self and these offspring go on to marry someone with equally poor differentiation of self. They "will have sufficient impairment in the parental ego mass to produce schizophrenia in a child" (Bowen, 1965, p. 223). The offspring who are later diagnosed with schizophrenia have the lowest levels of differentiation of self and are unable to achieve independence from their family and function as extensions of the family. "Some achieve so little self that they collapse into psychosis during their first effort to function independently … they are extremely vulnerable to loss of the important other, and they can collapse into psychotic nothingness in the face of life events that threaten or disrupt their dependent attachments (Bowen, 1965, p. 221).

The parent problem is transmitted to the child through a family projection process which can begin long before the child is conceived. The child functions as a stabilizing influence for the parents by converting the unstable father-mother ego mass into a more stable triadic system. Any event that threatens to remove the child from its function as a stabilizer evokes anxiety in the family. It was suggested that it is most often the mother who projects the parental problem onto the child because she may be an immature person who lessens her feelings of anxiety by projecting these onto someone who is more inadequate. The child becomes increasingly sensitive to her anxiety and the more anxious the mother becomes, the more psychotic and regressed the child becomes (Bowen, 1965; Shapiro, 1981).

The child's helplessness allows for the anxiety level of the parent to decrease and it does so because it needs a mother to meet its needs and will behave in a way to get these needs met (Shapiro, 1981). However, family anxiety is usually very high if the child collapses into psychosis suddenly as opposed to when the psychosis develops slowly and the child continues to be available for parents to project onto in which case help may not necessarily be sought unless it is urged by someone outside the family (Bowen, 1965).

Expressed emotion

Patients who come from homes where there is a high level of expressed emotion (EE), in which family members are overly critically, hostile, or emotionally over-involved have a higher risk for relapse compared to those from other households (Sadock & Sadock, 2005). An environment with little criticism and straightforward communication is believed to protect against the vulnerability for schizophrenia (Schultz et al., 2007). However, new findings on EE suggest that the role of EE in influencing symptoms of schizophrenia appears to be bidirectional (Woo, Goldstein & Nuechterlein, 2004).

2.2.5 Schizophrenia and abuse in childhood

Hammersly and Read presented highly contentious findings at two conferences in London and Madrid in 2006 by stating that two-thirds of people diagnosed with schizophrenia have suffered physical or sexual abuse. They argue that a proven

connection exists between the symptoms of post-traumatic stress disorder and schizophrenia and the pervasive history of abuse in people with schizophrenia suggests that schizophrenic symptoms might be caused by trauma (Sitford, 2006). Other forms of more subtle abuse were highlighted by Prugh and Harlow (1962 as cited in Adamson & Schmale, 1965) who have focused on the problem of subtle psychological deprivation in childhood. They distinguished two major pathological patterns of child-parent relationship: "distorted relatedness" and "insufficient relatedness" which operate differently to deprive the child of emotional needs (Prugh & Harlow, 1962 as cited in Adamson & Schmale, 1965, p. 573).

2.3 Stressful life events and schizophrenia

2.3.1 Increased life events reported before the onset of schizophrenia

Research with varying populations in diverse locations has found that patients report an increased rate of life events before acute onset of florid psychotic symptoms when compared to non-psychiatrically diagnosed controls (Bebbington et al., 1993; Brown & Birley, 1968; Day et al., 1987). Brown and Birley (1968) found that events such as crises and life changes may influence the onset of schizophrenic attacks and these events tend to cluster in the three weeks before onset. These events were not thought to be sufficient to bring about onset or relapse of schizophrenia on their own, but formed part of a number of factors which contributed to the conditions necessary for an acute schizophrenic attack.

Subsequent studies “have failed to establish, in a clear and convincing manner, the consistency and validity of the original findings reported by Brown and Birley” (Day et al., p. 29). In some studies, only a certain proportion of acute onset psychotic patients report experiencing a higher rate of life events than controls (Al Khani, Bebbington, Watson, & House, 1986; Day et al., 1987). In others, the onset of schizophrenia was not preceded by an increase in life events (Gureje & Adewunmi, 1988). Onset may be gradual, making it difficult to identify a specific precipitating event especially since prodromal symptoms form part of the psychotic process (Bebbington et al., 1993; Cullberg, 2003). In research where people diagnosed with schizophrenia have reported

more life events than controls, the amount of independent events found was not statistically significant (Al Khani et al., 1986; Jacobs & Myers, 1976). Chung, Langeluddecke and Tennant (1986) reported that stressful life events were more likely to precipitate schizophreniform psychosis which suggests that briefer psychoses may be more stress-related.

2.3.2 Type of life events that precede the onset of schizophrenia

Brown and Birley (1968) reported that the events which preceded onset of schizophrenia in their study included a crises or life change and found little evidence for the importance of everyday trivial events. However, the demands of everyday social living can influence a person's ability to function effectively. Indeed, "any event requiring attention and/or some form of behavioural adaptation may be potentially detrimental to one's mental health" (Myers, Lindenthal, Pepper, & Ostrander, 1972, p. 404).

Jacobs and Myers (1976) found that people diagnosed with schizophrenia reported more events of an undesirable nature versus the control group. But the people in their study also reported significantly more "role transitions, events causing moderate upset, and events requiring little adjustment. They also tended to report more developmental events, events of high and low upset, and events of high and moderate adjustment" (Jacobs & Myers, 1976, p. 79). Some events which do not fall into the "crises or life change" category have been found to have particular symbolic importance or significance based on previous experiences (Brown & Birley, 1968). Loss may be one such event that constitutes both a crisis or life change and holds particular importance for an individual. Myers et al. (1972) suggests that the loss of an individual is more strongly associated with impairment than the entrance of someone into one's social life because "societal systems to deal with loss may be inadequate and more meaningful systems of social and interpersonal support may have been developed around gain than loss" (p. 404).

2.3.3 Exposure to events which precede the onset of schizophrenia

It is uncertain whether patients with schizophrenia lead lives that include many acute and major life events (Norman & Malla, 1993a). Horan et al. (2005) report that "recent-onset patients may often withdraw from activities or structure their lives in a manner that limits

exposure to life events" (p. 72). This pattern of limited exposure helps maintain excessive stimulation or avoidance of possibly stressful situations and may be of benefit in the short term but has negative long-term consequences which affect the person's ability to cope.

2.3.4 Relationship between stressful life events and schizophrenia

Events themselves are not believed to be sufficient to cause the onset of schizophrenia (Birley & Brown, 1970a). Rabkin and Struening (1976) suggest that, "illness onset is the outcome of multiple characteristics of the individual interacting with a number of interdependent factors in the individual's social context in the presence of a disease agent" (p. 1 019) because vulnerability to stress is not only based on genetic influences, but also on previous life experiences that interact with any life events that may precede onset. This suggests that something about the way those susceptible to schizophrenia live might lead to their vulnerability (Bebbington et al., 1993).

Significant differences in the rate of events reported by patients and controls may not arise from events leading to onset, but from something that "begins quite far back in time (Bebbington et al., 1993). Those with a predisposition to schizophrenia may experience a large number of early and continuing events that contribute to their vulnerability. Findings do indicate that the early childhoods of those who obtained the lowest level of social adjustment were characterised by very stressful conditions of a serious nature and these early experiences may have contributed to a pattern of behaviour which shows up in later adult relationships (Cullberg, 2003). The behaviour pattern or behaviour traits may interact with other factors to influence these individuals' general approach to life events. They may withdraw and isolate themselves which provides important short-term benefits, but a long-term pattern of withdrawal and isolation might create further vulnerability to stress with fewer buffering experiences. Even more stressful situations may occur because the events to which patients with schizophrenia are prone due to patterns of behaviour and other factors interact with daily stresses and they may become demoralised by events before or during a psychotic episode (Dohrenwend & Egris, 1981).

2.3.5 The influence of cultural changes

The factors involved in onset may differ as the meaning of an event and the accompanying level of stress is intimately connected with the longer term circumstances surrounding its occurrence (Norman & Malla, 1993a). Events which may not be classified as crises can help to precipitate the onset of schizophrenia (Gureje & Adewunmi, 1988). Some people may be affected by a particular source of social stress, which reflects larger social practices such as family atmosphere and rapid cultural change as has been suggested for married female patients in a single study conducted in Saudi Arabia by Al Khani et al. (1986). They argue that life events might operate as precipitants in schizophrenia, "because they are a sample of a larger domain of potentially upsetting social circumstances" that influence the lives of a particular subgroup in society (Al Khani et al., 1986, p. 21). However, the underlying changes involved in onset of schizophrenia are believed to be independent of cultural setting (Day et al., 1987).

2.3.6 Life events, schizophrenia and the family environment

Reported life events are often related to tension or disruption in the family environment (Brown & Birley, 1968). Burnham, Gladstone and Gibson (1969 as cited in Jacobs & Myers, 1976) report that some life events are related to disruption of the family support network or involve relocation or change which leads to loss of external support structure. Beck and Worthen (1972 as cited in Gureje & Adewunmi, 1988) suggest that those who develop schizophrenia may decompensate in situations which may not be overly stressful to others when their social support network is strained or unavailable.

A second hypothesis proposes that the genetic load for pathology influences how a family interacts and this may create unusual events that affect the individual. These unusual events interact with ordinary stressful events and induce events of greater stress. These greater events can affect the mood of those vulnerable either in the time preceding onset of psychotic symptoms or a change in mood may coincide with onset (Dohrenwend & Egri, 1981). Critical attitudes found in high levels of expressed emotion in the family have been reported to predict onset of schizophrenia-spectrum disorders in non-psychotic adolescents (Norton, 1982; Valone et al., 1983 as cited in Norman & Malla, 1993b).

2.3.7 Life events play a triggering role in episodes of the disorder

The evidence for stressful life events playing a substantial role in the onset or relapse of schizophrenia remains relatively weak (Chung, et al., 1986). It is believed that life events trigger the onset of something that would have happened anyway (Birley & Brown, 1970a as cited in Day et al., 1987). The role of stressful life events seems to be limited in schizophrenia, i.e. with stress acting to trigger initial or relapse episodes of the illness. This is compatible with the stress-diathesis theory which emphasizes the interplay between environmental precipitants and a genetically transmitted predisposition for the onset of schizophrenic disorders (Gottesman & Shields, 1976 as cited in Day et al., 1987).

2.3.8 Methodological flaws in the research on life events

Rabkin and Struening (1976) raise several criticisms of the methodology, theoretical aspects and the data findings of the research on life events and illness. Early studies made use of broad diagnostic criteria which lumped together a variety of conditions under the umbrella of schizophrenia e.g. schizophrenia, schizophreniform psychosis, atypical psychoses, brief reactive psychosis. The introduction of the *DSM-III* (1981) led to the definition of these as separate conditions with specific diagnostic criteria which are more useful because life events appear to have a differing role in each disorder (Chung et al., 1986).

Statistically, the size of the correlations found in many reported studies, although significant, is often meaningless given the size of the research samples. Specifically, reported life events count for only a small percentage of the variance in illnesses between sample groups who report more life events before onset and control groups. Evidence also suggests that validity and reliability of life events checklists may be weak and controversy exists on how the items are scored (Norman & Malla, 1993a).

The interplay of life events and other confounding variables has not always been acknowledged. Myers et al. (1972) have pointed out that it is difficult to establish the independence of the life events from the illness itself. Schizophrenia affects a person's

thinking, feeling and behaving which makes dating of onset problematic and affects the ability to discern whether events reported were the cause or effect of the condition (Jacobs & Myers, 1976). Even further difficulties arise with the dating of onset since the prodromal symptoms form part of the psychotic process and can last for a considerable length of time (Bebbington et al., 1993). Previous studies also assessed life events in the period prior to admission rather than prior to onset, so that the role of stressful life events could not be ascertained (Chung et al., 1986).

Norman and Malla (1993b) believe that the influence of stress on the symptoms of schizophrenia may be overestimated due to the difficulty in defining reactions to stress versus symptoms of schizophrenia, the belief that previous studies may have been measuring something other than stressful reactions, misunderstanding in the direction of the relationship between stress and symptoms, recall bias in participants which may have lead to comparisons in recall ability rather than in the level of events experienced, and the tendency of participants and families to remember events as a way to justify the illness.

2.4 Research on the subjective experience of schizophrenia

2.4.1 The importance of subjective experience

Less attention has been paid to the subjective perception of those diagnosed with schizophrenia because the condition is seen to affect a person's thinking, feeling and behaving (Jacobs & Myers, 1976), and as a result they are often believed to have poor insight (Sadock & Sadock, 2003). However, before the value of educating people about their illness was recognised, "it seldom occurred to practitioners to tell people with schizophrenia their diagnosis or to offer them information about the nature of mental illness and its treatment … people experiencing mental illness had little reason to guess that what was afflicting them was a psychiatric disorder" (Roe & Davidson, 2005, p. 90).
The question of insight is a contentious one as insight has often been equated with sharing the clinician's views rather than possible alternative viewpoints (Greenfeld, Strauss, Bowers, & Mandelkern, 1989). Those diagnosed with schizophrenia may opt not to accept or discuss their diagnosis and the condition due to feelings of hopelessness,

helplessness and demoralisation evoked by the idea of having a lifelong diagnosis and from a of stigmatization (Roe & Davidson, 2005).
This research supports both objective and subjective study of schizophrenia because the condition:

> "afflicts a person who has a history, an identity, kin and social roles, gender, age, hopes, ambitions, and these inner and outer selves. But because schizophrenia affects profoundly both how we present *and* experience ourselves, often the person and the disease or diagnosis become joined in scientific and social thinking in the realms of intervention and identity" (Estroff, 1989, p. 193).

Research findings suggest that although "acutely psychotic people have difficulty making sense of their experience, clients in remission give accounts which are stable over time and consistent with external observations" (Cutting & Dunne, 1989 as cited in Barker, Lavender, & Morant, 2001, p. 200). Those who have recovered from psychosis have given accounts of the time preceding onset with remarkable clarity, coherence and thoughtfulness (Adamson & Schmale, 1965; Cutting & Dunne, 1989). Furthermore, "clinical experience … upholds the essential validity of the patient's perception of his life history … (and) … indicate(s) that the patient's portrayal of his family life, although distorted, reflects actual and major disturbances in relationships" (Fleck, Alanen, & Cornelison, 1963 as cited in Adamson & Schmale, 1965, p. 572).

A shift from a single belief based on a dominant medical worldview, "to acknowledging the coexistence of multiple, diverse views may be a necessary precondition for encouraging people with schizophrenia to compose and share their narratives" (Roe & Davidson, 2005, p. 91), and an understanding of the individual's subjective experience of illness and treatment is believed to be of fundamental importance in recovery (Greenfeld et al., 1989). Estroff (1989) elaborates that the illness is but one aspect of the person:

> "There is a configuration of self that exists over time: an enduring entity that precedes, transcends, outlasts, and is more than an illness or diagnosis. While

> clinical accounts often document the course of an illness, they seldom provide a narrative of the person through time, in time both personal and social. The 'psychiatric history' is only a portion of personal history, yet it must be located, situated in the *lifetime* of the person now experiencing schizophrenia" (p. 190).

However, schizophrenia not only erodes the individual's sense of self, but also their ability to relate meaningfully to the outside world through an integrated sense of identity (Fabrega, 1989). These individuals have been found to reconstruct a meaningful sense of themselves, their experiences and the social world in which they live through the use of narratives (Roe & Davidson, 2005), and while expert narratives on schizophrenia are plentiful, they are not always congruent with subjective experience. They often portray the narrative of those with schizophrenia as unreliable due to the illness which negates the person's own experience of themselves and the illness (Barker et al., 2001). Instead, there has been an explosion of diagnostic, structured interview and symptom rating techniques based on observation in the field of life events research. Zubin (1978) argues that to "deepen our clinical understanding we need to return to detailed, firsthand observations of patients" (p. 643).

Because schizophrenia has been described as a denial of selfhood it can also be conceptualised as a process which presents the possibility for self-realisation (Scher, 1960 as cited in Shainberg, 1973). Other paradigms which focus on the phenomenology of schizophrenia have reinterpreted the onset of psychosis as a movement towards "self determining" expression. Roe and Davidson (2005) propose that "the emerging 'recovery' paradigm in community mental health opens an exciting new window onto the rich but relatively unexplored terrain of self and life reconstruction that occurs throughout the recovery process" (p. 89). Estroff (1989) urges us not to forget that before the diagnosis the person still existed, "we know too little about conceptions and recollections of the self and time before voices were heard, and before thinking was derailed; before the 'others' noticed and the interventions began" (p. 191). Attending to subjectivity can be seen as part of "the patients' struggle to define themselves and to maintain and reconstruct some sense of competence" (Lally, 1989, p. 253).

There are countless other reasons for focusing on subjective experience of crises and life changes that precede the onset of schizophrenia. Subjective perception can help in determining the nature of the relationship between changes in life events to changes in mental status, physical health, and role performance (Myers et al., 1972). It may help to differentiate the impact of changes due to predisposition, family or cultural influences from changes brought on by the illness itself on the lifestyle and perception of individuals (Castine, Meador-Woodruff, & Dalack, 1998). Furthermore, subjective experiences may illuminate the importance of the life events within their contextual situation (Dohrenwend & Egri, 1981). Finally, Strauss (2008) states that "it has also been described how more adequate attention to subjective experiences of patients can be important for diagnostic validity and for insuring better treatment alliance, both important for more effective treatment and hopefully for better prognosis" (p. 202).

2.4.2 The subjective experience of events preceding onset of schizophrenia

Barker et al. (2001) investigated family and client narratives of first episode psychosis in those who went on to be diagnosed with schizophrenia. They found that the narratives provided a temporal model of the understanding of schizophrenia and its subjective impact on the self. The narratives of clients and family in their study indicate that the first psychotic episode had been preceded by difficult life events, especially in relation to problematic relationships, in accordance with vulnerability–stress model of schizophrenia. Similar themes are found in the literature on the subjective experience recounted by individuals and their families of crises and life changes that preceded the onset of schizophrenia.

<u>A history of subjective awareness of significant stresses is reported</u>

In early studies on the subjective changes that precede the onset of schizophrenia "most patients reported a succession of significant stresses which had begun in childhood" (Adamson & Schmale, 1965, p. 561). This included a pervasive atmosphere of unhappy interpersonal relationships, poor occupational adjustment and frequent somatic

complaints. In a study by Howard (1997), fathers of individuals with schizophrenia reported that the onset of difficulties began years before an official diagnosis was made and the initial signs of the condition did not provide any indication of its level of seriousness. When diagnosis was made, the fathers seldom understood that it entailed lifelong caring for their offspring. Siblings of people diagnosed with schizophrenia described their relatives in one of two distinct ways: as a person who from early childhood was "always a little off, different, or not right"; or a child who appeared normal but then had a "stormy" adolescence that eventually escalated into a psychotic episode (Gerace, Camilleri, & Ayres, 1993).

Findings by Barker et al. (2001) differ somewhat in that participants and their families reported that a relatively 'normal' life had preceded the first psychotic episode although feelings of low self-esteem, unsatisfactory relationships and specific losses were noted. Before onset, the patient was normally seen as well-behaved by the family, while later behaviour which broke parental and societal boundaries was associated with the development of schizophrenia. Both clients and family members produced narratives in which the first psychotic episode was preceded by recent difficult life events in relation to problematic relationships and adolescence. Marked observable changes in character and functioning of the patients were also noted.

Onset

Tendency in families to normalise early behaviour

Initially, families went to great lengths to normalise the siblings' differentness and incorporate as normal, the abnormal behaviour. In most cases, the siblings' recognised the problem before the parents did. A pivotal event or set of circumstances were identified as responsible for altering the perception of the sibling as 'normal' and this was described as a bewildering and frightening experience. Siblings saw themselves as the ones in the family who paved the way for recognition of the symptoms (Gerace et al., 1993). An average delay of 8.5 years has been reported between the onset of symptoms and the beginning of treatment in one North American study (National Alliance on Mental Illnesses [NAMI], 2008).

Perception of interaction in the family

Siblings not diagnosed with a mental illness report having watched the disturbed relationships between the ill sibling and the family and tried not to get too involved. They later reported feeling a sense of guilt because they felt that the ill sibling had shielded them and they did nothing to rescue them (Newman, 1966 as cited in Nechmad et al., 2000). Siblings of people diagnosed with schizophrenia also reported dysfunctional patterns of interaction in their family centred around the ill sibling (Gerace, et al., 1993). Carpentier, Lesage and White (2007) also found that the primary social networks of the families of patients with serious mental illness to be relatively small with a high proportion of family members.

Timing of onset related to time of growing independence

Carpentier et al. (2007) reported that families perceived the onset of psychiatric illness to occur "at a point in the family life cycle when a young adult is gaining his or her independence (p. 402). Similarly, Howard (1997) reported that "the traumatic illness life event generally occurs during similar family developmental stages when parents normally anticipate that adult children will become independent and care for themselves" (p. 401).

Experience of onset

According to findings by Shainberg (1973), the person is aware of a new event beginning at the onset of psychosis and the initial onset is experienced as a catastrophic disruption of one's world and sense of self. Relatives struggle to make sense of the changes in the individual and the feelings of confusion and fear that they experience. Fathers of children with schizophrenia stated that the periods following diagnosis were experienced as difficult and described feeling "helpless, unbelievable, shock and disbelief and awesome feelings of hopelessness" (Howard, 1997, p. 405). Difficulties for those who had experienced a first episode psychosis revolved around four issues: the disabling effect of schizophrenia and stigmatization, the loss of relationships and the value of support, changes in identity and self-development and ongoing struggles with coping and the health services (Barker, et al., 2001).

The threat of stigma that comes from being diagnosed with a mental illness is a very real fear for many people diagnosed with mental illness and their families. The person with schizophrenia may experience low self-esteem, have difficulty with social relationships, finding and keeping employment and be reluctant to disclose their illness for fear of being discriminated against. The families of these individuals have also reported lowered self-esteem and damage to family relationships caused by the fear related to the diagnosis (Wahl & Harman, 1989). According to Angermeyer and Matschinger (2005), simply educating people about the biological causes of schizophrenia does not automatically lead to improved attitudes towards people diagnosed with the condition and stigma against such people may persist. "The devastating stigma is often further reinforced by the media presenting stereotypical, usually negative, images of people with mental illness" (Roe & Davidson, 2005, p. 91).

Post onset

How individuals and families understand schizophrenia

In a study by Gerace et al. (1993), the siblings of those diagnosed with schizophrenia conceptualised the condition as a complex disease that result from a number of interacting sources and described their relatives as having a brain disease or thinking disorder. Relatives also tended to question childhood events of illness as well as genetics and adolescent factors (Barker et al., 2001). Those diagnosed with the condition may use many different frames of reference to understand their experiences and adopting a frame of reference helps them take a position towards their ailment to reduce anxiety (Romme & Escher, 1989). Lally (1989) reported a tendency in people diagnosed with schizophrenia to link religious themes to their condition which he interpreted as both an effort to destigmatize the condition further and a means of coping with its believed permanence.

A sense of loss

Families of those diagnosed with schizophrenia report having to live with a great sense of loss and frustration at the remembered past, relationships and lost future opportunities

(Smith, 1991). According to Brady et al. (1994 as cited in Howard, 1997, p. 401), "feelings of sadness, anger, frustration, and grief for the loss of the care recipient's previous personality and potential were common".

Effect on families

Caring for the schizophrenic person was considered the most difficult event encountered by fathers of schizophrenic offspring, and rated by them as worse than abuse, critical illness, death, war experience, divorce and job loss due to the infinite nature of the responsibility. One father noted that the experience had had positive benefits in increasing the strength of relationships (Howard 1997). The most common negative consequences reported were the primary caregiver's emotional problems, the disturbance in the caregiver's performance of work, and the disruption in the lives of other adults in the household (Greenberg, Greenley, & Brown, 1997; Friedrich, Lively, & Buckwalter, 1999 as cited in Saunders & Byrne, 2002).

Learning, coping and acceptance

How individuals and their families understand schizophrenia changes over time through interaction with others and themselves (Estroff, 1989). Howard (1997) reported that over time, increased knowledge of the illness helped the fathers to cope and accept the illness by gaining additional information through literature on the illness, self-help groups, discussions and the sharing of experience with professionals and other families. Acceptance was generally facilitated through increased knowledge of the illness, professional care from doctors and psychiatrists, acknowledgement of the seriousness of the illness, religious faith, and hope for a cure and affection for the patient.

2.5 Themes within the literature

2.5.1 Tension exists between the various discourses

Tension exists in the literature between the different discourses on schizophrenia and between the subjective experience of the condition and scientific formulations (Estroff & Strauss, 1989). However, these approaches may in fact complement each other by each

providing information not supplied by the other and thus both are needed (Roberts, 2000).

2.5.2 The negation of existence

The literature emphasises that schizophrenia has a negating effect on a person's existence and this deficit manifests through basic symptoms in the earliest interactions with the environment. The condition of schizophrenia impairs social and cognitive functioning (Walker et al., 2004) which hampers the person's ability to participate freely in the activities of life (Anonymous, 1989). It removes the person's ability to make sense of their world and their experience, forcing them to withdraw into an inner world away from outside stimuli. Aspects of the outside world are taken with them into this inner landscape, however any intrusion into this inner sanctum is experienced as particularly invasive (Kupers, 1976 as cited in Poster, 1988). Most, if not all domains of human functioning are affected (Andreasen et al., 1995; Cutting & Dunne, 1989), cutting the person off from their environment, sometimes completely in case of those diagnosed with catatonia (Sadock & Sadock, 2003). The length of the person's lifetime may be shortened due to adverse effects of the condition on the person, comorbid conditions or long-term use of medication (Allebeck, 1989). The return to the Jasperian views initially promulgated by Bleuler is encouraging as any attempt to treat schizophrenia should try to stem its eroding effect on the individual's existence (Hoening, 1983, Shainberg, 1973).

2.5.3 There is uncertainty over the nature of schizophrenia

Although there is general consensus that schizophrenia is a disorder of the brain with a heavy genetic loading, the search for the exact nature of the genetic basis still continues.
There is though, general caution when it comes to making statements about the nature of schizophrenia as the understanding of schizophrenia is constantly evolving. It is an entity expressed in heterogeneous symptoms leading to variable diagnoses which affect prevalence and incidence. In addition, uncertainty exists over the initial symptoms, onset, course and manifestation of symptoms. There is also little consensus over symptom dimensions. A lack of consensus on what causes schizophrenia has not prevented those diagnosed with it from suffering many undesirable effects based on the underlying belief that they lack insight into their condition (Roe & Davidson, 2005). Many advocate for a

return to focusing on the individual and their unique experience of the condition. One avenue involves further research into the basic symptoms which are more experiential in nature and are only known to the individual (Gross, 1997).

2.5.4 Stressful life events play a triggering or expediting role

Stressful life events may trigger the onset or exacerbation of psychotic symptoms by expediting a psychotic episode that may have occurred much later (Brown & Birley, 1968; Birley & Brown, 1970a). Onset is linked to stressful life events from multiple sources such as family environment, the demands of everyday living, events requiring behavioural adaptation, some form of loss (Myers et al., 1972), and role changes (Brown & Birley, 1968; Jacobs & Myers, 1976). Other onsets may be more insidious, related to long term tension in the home or events that have idiosyncratic significance for the person (Brown & Birley, 1968). The undesirable quality of a stressful life event that is important is stressfulness (Jacobs & Myers, 1976) and people with schizophrenia might appraise events as less controllable and more poorly handled (Horan et al., 2005). Life events are more likely to precede certain conditions than others and only a certain proportion of acute onset patients may report stressful life events preceding onset. Events can also “exert an aetiological effect across a sizeable interval” (Bebbington et al., 1993, p. 77).

2.5.5 Schizophrenia may be a hypothetical disease concept

It is apparent that both genetics and environmental factors are important however, the exact influence of either in the aetiology of schizophrenia is unknown. Many feel that new enlightenments are close by but perhaps it is time to reconsider the fundamental assumptions in schizophrenia and review the strategies of investigation (Tandon et al., 2008). Some researchers see a continuum of symptomology with indicators in the normal population and in other psychiatric conditions. There is a strong assertion that schizophrenia may be a hypothetical disease concept and a more sensible approach acknowledges the complexity of schizophrenia as well as information from various domains that together form a more integrated understanding of what is observed with the condition (Norman & Malla, 1993b).

2.5.6 Schizophrenia can be construed as a systems disorder

The current approach to understanding schizophrenia draws from systemic/cybernetic theory and is one with more permeable boundaries, where information from many disciplines is compiled and shared to understand the entire person and different aspects that make up their being and are affected by schizophrenia (Betrando, 2007). Hoffman (1992) argues "that when a system has moved too far from equilibrium … an element of the random enters in" (p. 11) and thus many unknown factors could be contributing to the onset of schizophrenia in those with a genetic vulnerability to the condition. The interplay between gene pool and environment will be overshadowed by the introduction of a random, unpredictable element that determines future development (Gergen, 1982; Gleick, 1987; Gould, 1980; Prigogine, 1984 as cited in Hoffman, 1992).

2.6 A systemic conceptualization of schizophrenia

There is consensus that "illness onset is the outcome of multiple characteristics of the individual interacting with a number of interdependent factors in the individual's social context in the presence of a disease agent". In accordance with this, casual explanations of conditions such as schizophrenia should move away from a linear relationship towards a conceptualization of the relationship between life events, illness and stress that is "comprehensive, multicausal and interactive" (Rabkin & Struening, 1976, p. 1 019). Systems theory provides such an overarching framework. Based upon cybernetic theory (Haley, 1980), it arose through the efforts of researchers and theorists from a variety of disciplines who were concerned, "with organization, patterns and process rather than with matter, material and content" (Becvar & Becvar, 2003, p. 16). In this approach, schizophrenia does not arise out of any single level, but it is likely that factors at one level may interact with factors at another level to increase the risk of developing schizophrenia long before any signs or symptoms appear (Shean, 2004).

In a systemic framework, family dysfunction is held to follow the principle of homeostasis and the symptoms of schizophrenia are believed to serve a function within the family system and that function is to help regulate the system in order to maintain stability at the expense of change (Zuk & Rubenstein, 1965). The family is "stabilized by

self-corrective governing processes which were activated in response to an attempted change" (Haley, 1980, p. 15). One child who develops schizophrenia may "stabilize the system sufficiently to allow the second child to escape" (Meissner, 1970 as cited in Nechmad et al., 2000, p. 5). Outside of the family the behaviour is labelled schizophrenic because the behaviour is not viewed within the acknowledged and accepted context that has been implicitly agreed upon by all the other family members (Betrando, 2006).

2.6.1 Assumptions of a systemic approach

A systemic approach differs from more empirical theories that are focused on individual psychology. In systems theory, there is an attempt to move away from concentrating on individuals only, and individuals in isolation towards relations and difficulties in relationships between individuals. The focus is on patterns of interaction and on what is happening in the present, rather than on why it is happening. Focus also transfers from those being observed to those doing the observation. Subjectivity is seen as inevitable because in the process of observing, perceiving, and acting, the observers create their own reality which arises out of the interdependence of the observer and the observed as well as from the context of that interaction. It is a noncasual, dialectical process in which parties mutually influence each other in an interactive process of participation (Becvar & Becvar, 2003).

The terms system theory and cybernetics are often used interchangeably, while some view each as a branch of the other. Both are based on the same fundamental principles but a distinction has been made between first-order cybernetics and second-order cybernetics. In first order cybernetics, the observer attempts to describe what is happening inside the family system from outside the system, reality is seen as something distinct and separate, that can be observed and is unaffected by the process of observation. In second-order cybernetics the observer is part of that which is observed and the reality that is described is as much a part of the observer's assumptions and beliefs as they are a description of what has been observed. Reality or lived experience is not an objective external entity but a subjective attempt to derive meaning and impose order on what is experienced (Varela, 1979 as cited in Becvar & Becvar, 2003).

2.6.2 A systemic/cybernetic epistemology

Reciprocal patterns of mutual interaction and mutual influence

In a systemic approach the behaviours and patterns of interaction and relating found in schizophrenia are maintained in the context of mutual interaction and mutual influence between members based on the assumption that each person interacts and influences the other. Meaning derives from the relationship between individuals and how each person's behaviour is defined in relation to that of the other members (Becvar & Becvar, 2003).

Feedback

The behaviour in a system is also maintained through the system's response to feedback which, "refers to the process whereby information about past behaviours is fed back into the systems in a circular manner" (Becvar & Becvar, 2003, p. 68). As a family grows and develops, it requires change or stability in order to maintain its level of functioning. However, in families with schizophrenia there are often rigid boundaries and family rituals that actively resist change in order to maintain stability (Becvar & Becvar, 2003).

Rules and boundaries

Rules consist of the characteristic patterns of relationships within the family, as well as the values and appropriate roles of the system. Rules distinguish systems from each other and therefore form the boundaries of the system. These rules are gatekeepers and regulate the flow of information into and out of the system based on compatibility with the family's values and identity. In schizophrenic families, rigid rules and firm boundaries also contribute to maintaining the stability of the system (Becvar & Becvar, 2003).

Flow of information

The stability and identity of a system is based on the flow of information into and out of the system and is governed by the extent to which the system is open or closed. Too much or too little information moving in and out of the system may lead to disorder and disintegration which threatens not only the identity, but also the survival of the system (Becvar & Becvar, 2003).

Communication

Central to systems theory is communication and how information is processed. Three principles underlie the importance of communication in systemic thinking. Firstly, it is impossible not to behave and secondly, because it is impossible not to behave, all behaviour thus communicates some message (Becvar & Becvar, 1999 as cited in Becvar & Becvar, 2003). Thirdly, meaning is constructed by the observer and is not an external reality that has to be discovered. Communication also occurs at different levels, what is verbally spoken, what is nonverbally transmitted about how the message should be received and the context in which the communication takes place all define how people relate to each other and what is being communicated (Becvar & Becvar, 2003).

The double-bind concept was incorporated into family systems thinking with the belief that communication occurs on different levels and if these levels are in conflict, it would generate a paradox in which no acceptable response is possible (Haley, 1980). Bateson (1972b as cited in Gelbmann, 2003) stressed that the obscuring of signals which help to identify a message may result in a situation where "the authentic intentions of a person can be distorted by communication" and this can create the conditions in which psychopathology arises (p. 2). Although, the double-bind concept is seen an interesting and valuable description of family processes, it has framed the schizophrenic members of the family as victims leading to defensive and angry responses from other family members (Haley, 1980).

Structures

Certain structures have been identified in the literature reviewed on family theories as particular to schizophrenic families. In one such example, problems in the spousal subsystem or dyad have often led to another person, often a child, being drawn into the relationship thereby creating a triangle and allowing the family systems to stabilise. Often in this situation the child is then used to meet the needs of the adult such as in families with skewed or schism patterns ((Becvar & Becvar, 2003; Shean, 1978).

Self-referencing the sense of wholeness

Within this second-order cybernetics, the observer is part of the system that she is talking about, yet cannot get outside of the system to have a truly objective approach. In talking about the system, the observer is defining her own reality with herself in it, in effect referencing herself within the system as if she were outside of it, but acknowledging that because she is part of the system, bias will inevitably creep in (Becvar & Becvar, 2003).

Openness or closedness of the system

At the second-order cybernetic level, the system and observer both exist within a larger closed system. Because we cannot get outside of ourselves to view the system, "each view is both legitimate and flawed, and each is a function of the level at which we choose to punctuate our experience, the systemic reality we wish to create" (Becvar & Becvar, 2003, p. 80). Change or behaviour is a response to other changes in the system.

Reflexivity, punctuation and subjectivity

For each family member there exists a different family within which there is a reality that is as true and valid for them as that of any of the other family members. "Perception now becomes a process of construction; we invent the environment in which we live as we perceive/construct it" (Becvar & Becvar, 2003, p. 85). Instead of a 'true' reality, people hold perceptions constructed about how things are through their lived experience.

2.6.3 Systems theory and subjectivity

As a metatheory, systems theory does not exclude punctuation of subjective experience at appropriate points because the individual and family experiences are not mutually exclusive, but lend meaning to each other. A second order cybernetic perspective acknowledges that reality is a result of how the person constructs their experience.

2.6.4 A critique of systems theory

Many criticisms have been raised against systems theory. These include it being a theory of stability, not of change. Historically, it was criticised because it did not provide simple practical paths to follow in therapy. It made therapists reluctant to intervene due to the

belief that a change in one part of the system may activate resistance in another part. It was also hypothesised that change in one part leads to change in another, and the fear of system substitution made people reluctant to act. Many have argued that it takes away individual responsibility from members of the family system with the claim that one member's behaviour is merely a reaction to someone else's. In contradiction to this, there is an emphasis on individual initiative by family therapists in practice (Haley, 1980).

Chapter 3: Research methodology

3.1 Aim

The aim of this research was to identify and describe themes within the subjective experience of crises of life events in the family that preceded the onset of schizophrenia through an analysis of data collected in interviews with individuals diagnosed with schizophrenia and their families. This qualitative study was undertaken from a social constructionist perspective in order to acknowledge the diversity in the lived experience of schizophrenia.

3.2 Epistemology

The perspective from which data is collected, analysed and interpreted is guided by certain underlying beliefs which define the way we think about problems in research and influence the method and approach used (Henwood, 1992; Nicholson, 1995 as cited in Barker et al., 2001). With this in mind, it is noted that the trend towards greater objectification in the studying and treating of psychiatric illness stems from positivism which declares that all scientific knowledge is based on empirical observation which can be tested and verified. However, social and psychological phenomena do not equate to directly observable empirical facts (Mouton, 1993) and therefore objective methods of inquiry are not believed to be sufficient in and of themselves to describe and understand subjective psychological phenomena (Lieberman, 1989). Psychological states are subjectively experienced. Each person's experience is unique to them and therefore cannot be generalised (Mouton, 1993).

Psychological states are also meaningful to the individual and this meaning is inextricably linked to the meaning of a number of other thoughts, all of which are open to a number of possible interpretations which are themselves based on other thoughts which also have an endless number of interpretations (Dreyfus, 1981; Putnam, 1981, as cited in Lierberman, 1989). Thus, the meaning that an individual attributes to something is radically underdetermined by verbal and non-verbal behaviour and cannot be inferred by

it (Lieberman, 1989). If meaning cannot be inferred by an outsider, it suggests that a more suitable course of action is to ask the individual to narrate their own understanding of their experience. Researchers in the qualitative sphere have embraced the idea that people think and communicate about themselves and their life experiences through narratives (White & Epston, 1990 as cited in Barker et al., 2001).

3.2.1 Postmodernism

Social constructivism and social constructionism

Post-modern theory in literature has given rise to two perspectives on the creation of narrative accounts. The first of these, constructivism, is defined as more of an individual process in which meanings are attributed to events and a storied reality is created to explain personal experience. The second of these perspectives, social constructionism, "focuses on social perspectives and how meanings are negotiated with an individual to create a narrative, co-constructed by the individual interacting with those around him" (McNamee & Gergen, 1992 as cited in Roberts, 2000, p. 433). In the social constructionist perspective there is "a greater emphasis on context, on the social constructions of individuals and problems, and on the creation of narratives, with the understanding that ours is a storied reality" (Becvar & Becvar, 2003, p. 92).

Diagnosis thought to equal a clinical reality

Social constructionists put forward that "individual and social realities are constructed according to cultural and historical norms, and … [are] heavily influenced by the power and status of the decision makers" (Foucault, as cited in Barker et al., 2001, p. 200). They argue that the trend towards greater objectification in the studying and treating of psychiatric illness occurred within a context dominated by positivistic epistemology upon which the bio-medical model is based. Historically, with regards to schizophrenia, "the mere diagnosis of constituted a clinical reality" and "fatal inferences were drawn from the existence of a linguistic expression to the existence of what was thereby signified" (Gelbmann, 2003, p. 6).

Approaches following from postmodern assumptions

Postmodern assumptions lead to different approaches to researching psychological phenomena. Firstly, the focus of the research includes not just the tangible reality of the individual but also their social-psychological constructions of reality. Secondly, research is more an interactive process in which both the researcher and participants actively participate to enrich the data. Thirdly, qualitative methodological strategies are employed to analyse the constructions of participants. Finally, there is also explicit acknowledgment that research is not a value-free endeavour and the end product is as much a product of the researcher's creation as it is the participants' (Lincoln, 2005, p. 161).

Multiple truths assist in reconstruction of the self

From social constructionist perceptive, multiple truths create a foundation upon which the person diagnosed with schizophrenia can construct a narrative of their illness and themselves in relation to the illness. This process of negation and reworking helps not only to separate the person's sense of self from the illness, but also helps to construct a sense of self that is independent of the illness (Roe & Davidson, 2003). "The narrative view holds that it is the process of developing a story about one's life that becomes the basis of all identity and thus challenges any underlying concept of a unified or stable self" (Lax, 1992, p. 71).

Social constructionism and systems theory

Becvar and Becvar (2003) argue that second order cybernetics as a world view is consistent with a postmodern approach, including a social constructionist perspective:

> "Given the assumptions of subjectivity, with reality being understood as perceptually constructed or created, we see the postmodernist, social constructionist stance as logically consistent with the systemic/cybernetic paradigm. Also consistent are both the focus on context and the importance of communication. An understanding of context requires an exploration of individual perceptions and meanings, as well as a consideration of the ecology of ideas and

> the larger social system within which relationships are embedded. The focus is relational; it is understood that all behaviour has communication value and that communication and information processing are basic systemic processes" (p. 98)

3.3 Qualitative research

The tools of qualitative research provide a way to capture the subjective experience and meaning of people through closer collaboration between researcher and participant as they construct a shared understanding within a specific context (Lieberman, 1989). Certain characteristics are commonly found in the different strategies and aims of qualitative research (Geekie, 2007). According to Morse (1992 as cited in Geekie, 2007), these include an effort to portray meaning from the perspective of participants, an acknowledgment of the role of context and using methods of inquiry that are inductive and interactive. Qualitative research is focused more on contextualisation of meaning and experience, rich description, rather than explanation, subjective experience and empowering people in their efforts to enact change (Henwood & Pidgeon, 1992). It is recognised that the social world is complex and dynamic and filled with multiple realities and this research therefore utilises a more inductive approach that attempts to acknowledge that people construct their experience from many different perspectives (Barker et al., 2001). Some of these aspects are discussed further in the following section.

3.3.1 Reflexivity

The underlying assumptions in qualitative research changes how the role of the researcher is viewed. The researcher is seen as an active participant in the construction of meaning with the participants and must therefore acknowledge the notion of reflexivity. The definition of reflexivity differs among researchers. Lax (1992) calls it "the act of making oneself an object of one's own observation" and by turning attention to one's own conversations, "one shifts discourse and thus perspective" (p. 75). It is the awareness that one's own personal experience and stance contributes to the construction of meaning in research and recognition of the difference in meaning brought by the researcher and participant (Parker, 1994 as cited in Nicolson, 1995) to research. This shared space may facilitate the creation of a new narrative with new meanings and insights (Lax, 1992).

3.3.2 Subjectivity

Subjectivity can be said to refer, "to the way an individual experiences themselves, and their identity in a social context" (Nicolson, 1995, p. 341). As qualitative research is a collaborative process in which there is shared understanding, the researcher's own subjective views influence how the results are interpreted.

3.3.3 Self-disclosure and prior knowledge

Because I am the researcher, I will be part of the perceptive process but because I am also trained in a clinical profession, I also have prior knowledge of the condition. Chadwick (2007) argues that the, "blending of both objective and subjective knowledge hopefully will prove illuminating" (p. 166). In addition to my training as a clinical psychologist, I have previous experience with the behaviour that has come to be defined as schizophrenia. Two of my close relatives were diagnosed with the condition early in life and lived in our household throughout my childhood. Their behaviour and actions were both fascinating and alarming in its intensity and its effect on others. I believe that there may be communicable value in the symptoms of schizophrenia and that that communication is not understood when it is removed from the context in which it arose.

3.4 Research design

3.4.1 Procedure

Weskoppies psychiatric hospital was approached and asked for assistance in recruiting possible candidates and their families who would be willing to participate in the study after permission had been obtained from the relevant ethics committees. Information forms (Refer to Appendix A for a copy of the Information sheet for the institution) were disseminated to the relevant staff, including psychiatrists, psychiatric registrars, psychologists and other professionals at the institution. The staff were asked to identify suitable participants, inform them of the study, and contact the researcher if their clients were willing to participate in the study. The researcher then contacted the prospective participants and again explained to them the nature and purpose of the study and outlined what would be required of them. A mutually convenient interview time was arranged with those who agreed to participate in the study.

Semi-structured interviews were used to elicit accounts of the subjective experience of any crises and life changes that had preceded the onset of schizophrenia. An interview schedule (Refer to Appendix C for a copy of the Interview schedule) derived from the main themes in the literature on schizophrenia, subjectivity and life events was used to guide the interview which was held in a consulting room at the hospital at a time convenient to the participants.

Each case unit consisted of two separate interviews. The first interview was held just with the individual diagnosed with schizophrenia while the second interview involved the individual and as many members of the family who were willing and able to attend. The term, "families" here is not limited to blood relatives but includes significant others with whom the individual has had meaningful long-term interaction and can be said to form part of their wider network of social and kinship relations (Speck & Attneave, 1971 as cited in Shean, 1978). The interviews included only those members of the family who were aged 18 and above on the interview date. The first interview was aimed at gathering information on the subjective experience of events that had preceded onset. The second interview sought to obtain similar information from the family but also to observe and perceive the patterns of interaction within the family. All interviews were conducted by the researcher and the interviews lasted on average 60 minutes.

Before the interview, the nature, aims and outline of the study were explained again, including the use of a video recorder for transcription and review of the interview. Issues related to confidentiality were outlined to the participants and time was taken to establish rapport and facilitate an environment conducive to frank disclosure. If they still wished to participate, the participants and their families were asked to sign the attached consent form in which they agree to take part in the study and allow for the interview to be recorded for later transcription and review (see Appendix B for a copy of the Patient information and consent form). All of the interviewees were informed that if they wanted to, they could stop the interview at any time with no consequences and they could refuse to answer any questions without giving a reason. They were also offered the opportunity

to discuss any concerns or distress experienced as a result of the interview with a professional at the institution. This was pre-arranged with the institution.

The interviews were recorded on a digital video recorder. Only the researcher had access to these throughout the study. Each interview was transcribed, identifying details were removed and where necessary the content was discussed with the research supervisor. Some members of the families could not or were unwilling to attend the interviews. To the extent that they were willing and follow-up was possible, these other members of the family were contacted and individual interviews were held telephonically with them.

3.4.2 Context

The research took place at a state owned hospital which specialises in mental healthcare. It provides acute, long-term and forensic psychiatric treatment. Psychiatrists are usually the case managers and the bio-medical view is the dominant approach in treatment.

3.4.3 Sampling

The number of participants was small but this is not unusual for qualitative research which “stresses the importance of detailed studies that describe subjective experiences and preclude the use of large random samples” (Barker et al., 2001, p. 209). Participants were selected from two sources, individuals who have been admitted to Weskoppies Psychiatric hospital located in Pretoria and individuals who had been referred to the study by staff working at the hospital. The participants were screened by referring to case notes to ensure that they met the *DSM-IV-TR* (2000) diagnostic criteria for a diagnosis of schizophrenia. Some changes were made from the sampling procedure outlined in the initial research proposal. This was in response to specific field conditions and reflected an effort to match diagnostic criteria while ensuring that the study could be completed. Onset was dated to within 30 months based on a marked change in the participant’s behaviour accompanied by the public expression of schizophrenic symptoms. All participants were able to communicate coherently in English or Afrikaans.

There was one male participant and three female participants. The participants were all aged between 18 and 30, unmarried and living at home with their families at the time of

the interviews. Only one participant was currently in a long-term relationship and was engaged to her partner of five years. One of the participants was studying part-time at a university, a second participant was working part-time in a store, a third had been a restaurant manageress before falling ill and a fourth, who had never worked, was living at home with his parents. Three of the participants had completed Grade 12 and a fourth had completed Grade 10 at a remedial school. All the participants were interviewed once the acute symptoms had remitted. Participants were assured that the information they gave would be anonymous and their confidentiality would be ensured at all times. The maximum number of participants was limited to four, a number believed to be sufficient to yield the data required for a mini-dissertation of a defined length and limited scope. Further participant information is disguised to protect confidentiality.

3.5.4 Data collection

Data was collected through a semi-structured interview as this method is consistent with a qualitative approach. According to Barker et al. (2001), "the use of semi-structured interviews facilitates the expression of research participants' subjective experiences and beliefs in narrative form" (p. 209). A schedule of questions based on the literature themes around crises and life changes and the onset of schizophrenia was drawn up to guide the interview (see Appendix C for a copy of the Interview schedule). These themes included the nature of events that preceded the onset of schizophrenia, the subjective understanding of schizophrenia, the impact of the condition on the individual and their family, a description of the individual and self in relation to the family, the pattern of response from the family, the individual and family understanding of the process of being treated for schizophrenia and a description of any positive experiences for the individual or the family. At the beginning of each family interview, a genogram which is a graphical representation of the family and family relationships was constructed together with the patient and family to gather relevant background information and to identify patterns of the family (see Appendix D to Appendix G for the family genograms and Appendix H on the compact disk for a copy of the interview transcripts).

3.3.5 Data analysis

Thematic analysis was used to analyse the data. Thematic analysis is based on the assumption that there is a relationship between the actual interviewee responses and the psychological and emotional state of the respondents (Boyatzis, 1998). The objective is to reduce the interview transcripts into logically coherent themes related to the research. Boyatzis (1998) defines a theme as “a pattern in the information that at a minimum describes and organizes the possible observations and at maximum interprets aspects of the phenomenon” (p. 1). The use of thematic analyses involves sifting through the interview data to reduce and categorize the large amounts of information accumulated into more meaningful thematic units for interpretation. It is a way of capturing the qualitative richness of the participants’ experience and assists in exploring the influencing themes (Boyatzis, 1998). A hybrid inductive and data driven approach based on work by Fereday and Muir-Cochrane (2006) was implemented in the analysis due to its congruency with the aims of this study.

Firstly an initial, detailed reading of the each transcript was done and multiple themes were identified within each case unit. This involved identifying subject matter that was important to, and would help to answer the research question. Information that was not relevant to the topic was eliminated. Secondly, the research question was read in relation to the title. Salient keywords which highlighted subject matter and textures of that subject matter were isolated. This consisted of information on significant crises and life changes which had preceded the onset of schizophrenia and included the participants’ and their families’ experience, perceptions, attitudes, opinions and understanding. Each case was again reviewed for the presence or absence of this information. Thirdly, the background information and transcripts for each unit were summarised to determine the presence or absence of patterns among the pieces of information regarded as important. This led to the identification of significant themes and these themes were compared across the units to identify important similarities and differences. The aim was to reduce the information into smaller, more manageable ‘packets’ which contained only the salient information from the raw transcripts. The final step was to highlight patterns of similarities and

differences within each and across each paraphrased transcription, and the accompanying data was used to describe and explain the variation in themes in relation to the literature.

3.5 Ethical considerations

3.5.1 Voluntary participation

Participation in the study was entirely voluntary. The participants and their families were first informed of the study by someone other than the researcher. An information sheet or verbal outline, detailing the nature, aims and outline of the study, and containing information about the researcher was given by the referring professional to those who displayed interest so that they could make an informed decision. If they agreed to participate, they were contacted by the researcher and received further information, and a time convenient to the participants and their families was be set up. Only members of the family that were aged 18 and above at the time of the study were invited to participate in the family interviews to protect any minors from potential distress during the interviews.

3.5.2 Informed consent and rights of participants

At the point of the interview, it was reiterated that participation was entirely voluntary and there would be no repercussions if they decided against participating. They were informed that if they chose to participate, they could end their participation at any time, without any consequences. It was stressed to the prospective participants that they could refuse to answer specific questions. They were also informed that should they have concerns arising from the interview, there was the opportunity available to them, to discuss these with a professional at the clinic. This was prearranged with the institution.

3.5.3 Confidentiality

As the information divulged was of a very private nature, it was important to emphasize to the participants and their families that their confidentiality would be respected. Before the interview they were informed that the only person to have access to the recordings would be the researcher. They were also told that the final research report would contain a copy of the original transcripts, but that any identifying details would be omitted. They were also informed that the study would be written up as an article in a scientific journal,

but that identifying details would be omitted or disguised. The participants were informed that a summarised version of the results of the study would be made available on request.

3.6 Trustworthiness of the research

Qualitative research has been criticized for its lack of validity and reliability. However, many researchers argue that these concepts do not apply in their unchanged form in qualitative research because of their underlying epistemological assumptions which argue the notion of one, indisputable truth. The question of how to judge the quality and integrity of qualitative research is usually framed in terms of trustworthiness of the data. Merrick (1999 as cited in Geekie, 2007) suggests that trustworthiness is increased by both personal disclosure from the researcher with regards to their prior experience and personal orientation towards the area being investigated as well as researchers discussing their findings with others in the field, including participants whose responses are incorporated into the final analysis. According to Banister et al. (1994 as cited in Barker et al., 2001), the process of data triangulation in which data is obtained from two or more sources or perspectives, “makes qualitative research conclusions potentially more valid” (p. 201).

The process of judging the quality and integrity of research is a complex process that is specific to each research project and its aims (Geekie, 2007). However, Lincoln (2005) lists four criteria that have been proposed to judge the trustworthiness of qualitative research which is roughly analogous to the criteria in empirical research. Firstly, the researcher is tasked with ensuring that the findings are not too far removed from the data so that the notion of credibility can replace the quantitative criteria of internal validity. A second aim is to ensure that the findings are transferable to other contexts beyond that in which they were generated analogous to the generalizeability requirement for quantitative findings. Instead of reliability, a third aim is to strive for dependability which provides evidence through an audit trail or good documentation that sound methodological decisions were made and appropriate processes were employed in conducting the research. Finally, confirmability provides ways to trace the data back to their sources and the ability to verify the information that was collected.

The processes followed in this study to ensure trustworthiness were the following:

a. In the analysis of the data, care was taken to keep as close to the data as possible and to ensure that the categories of conceptualisation could be traced back to the data from which they derived. The process of how the data was conceptually classified was made explicit through explaining how the results were grouped into similar themes and why these themes were grouped into similar context categories to show how these categories were arrived at. The suggestion by Turner (1981 as cited in Henwood & Pidegon, 1992) of writing comprehensive definitions to explain why the data has been labelled and classified in a particular way was taken up and the logic behind the establishment of each category was carefully explained.

b. In the analysis and discussion, care was taken to integrate the data with theory at all levels by the researcher documenting the connection between the data and the subsequent levels of categories into which the data are grouped based on the properties of the data as suggested by Glaser and Strauss (1967 as cited in Henwood & Pidegon, 1992). In addition, documentation was kept of all decisions taken and the underlying rational for these decisions during all phases of the research.

c. Reflexivity in the process was acknowledged and the researcher's prior experience and attitude towards the research was discussed.

d. Care was taken to be sensitive to the negotiated and jointly constructed reality created through the research by attributing equal importance to the views of the participants (Henwood & Pidegon, 1992).

e. In this study, attempts were made to meet the confirmability criterion by showing how the results were arrived at using extracts from the interview transcripts to provide evidence of a particular theme.

Chapter 4: Results and discussion of the data

4.1 Description of the participants and their families

All names and identifying details, including those of the family, have been changed. See Appendix D to Appendix G for family genograms.

4.1.1 Participant A and family

Participant A is a 25-year-old, unmarried female given the pseudonym Mandy, who is an inpatient at Weskoppies hospital and was referred by staff at the hospital to the study. Before her admission, she was living with her fiancé, Liam and his family. Mandy and Liam have known each other for five years and have been living together for the last four of those five years. The members of this family who live in the household include Mandy, her fiancé, Liam (26), his mother Lynn (57), his two brothers, Gary (24) and Owen (28). Mandy describes her relationships with Liam and his family as good.

Mandy is the eldest of three siblings, she has a younger sister, Rosy (22) and a brother, PJ (18) with whom she is on good terms. She completed high school up to Grade 12 and was previously employed as a sales manager. Her parents divorced when she was a toddler and both have subsequently gone on to have relationships with other people. She has a tense relationship with her father, James (56) whom she accuses of molesting her as a child. She describes her relationship with her mother, Rachel (44) as close.

Events leading up to admission

In the year prior to her admission to the hospital, Mandy and her fiancé were living in the Eastern Cape where they were both working in the sales industry. During that year, her fiancé, Liam, began to complain of headaches which made it difficult for him to go to work. However, because of the nature of employment in the sales industry, he could not really take time off work. He consulted with his doctor on numerous occasions and the headaches were ascribed to stress and tension. During this time, Mandy would often telephone her mother, Rachel, in Johannesburg for support and guidance. Rachel described Mandy as mostly tearful and distraught during these conversations.

Mandy returned to Johannesburg before the end of 2007 and her fiancé returned a month later. In early 2008, Liam was diagnosed with brain cancer and underwent an operation to remove cancerous tissue. The operation took place at the end of February and coincidently, Mandy's former partner had been involved in a motor cycle accident on the same day of the same month exactly six years earlier. He sustained serious injuries at the time and died in an intensive care unit shortly afterwards.

Family members reported noticing a change in Mandy's behaviour shortly after Liam was discharged from hospital. They said that she would often cry and be inconsolable. At times she was found staring into space or would suddenly laugh inappropriately. Sometimes she would leave the house at night and stand outside, staring up at the stars, telling anyone around her how beautiful the stars were.

A few months later, she attended a lunch with some family members, including her step-cousin and her father. At the end of the meal, she alleges that she experienced recollections of her cousin raping and molesting her as a child between the ages of three and six years of age. She said that her father was allegedly also involved in the abuse at times.

Mandy's mother, Rachel, said that Mandy started sending bizarre text messages to her shortly after this event and she began to notice changes in her behaviour. She would arrive unexpectedly at her mother house, saying that she was scared to be alone. Her fiancé's family states that she started speaking and behaving in a disorganized manner and this behaviour became progressively worse. Shortly afterwards, she was admitted to a local district hospital as an involuntary patient for a 72-hour period of evaluation and later transferred and admitted to Weskoppies hospital.

<u>Participant's background history</u>

No birth history or complications were reported. Developmental milestones were reported as normal with no problems in early adjustment. Mandy recalled struggling at school from Grade 10 onwards with taking in, organizing and recalling information.

Rachel, Mandy's mother, reports a great deal of conflict with her husband over their son while Mandy was growing up. Rachel alleges that her husband was extremely jealous of the close relationship she had with their son. She acknowledges being overprotective of him and supporting him against other family members. Mandy also reports that she and her sister sometimes felt as it they were sidelined by their mother's lack of support because she would favour her son. The parents divorced early in 2000. Mandy has minimal contact with her father.

Substance use

There is no history of substance abuse reported.

Family and psychiatric history (see Appendix D for family genogram)

Rachel reports that her father was treated at Weskoppies hospital but she cannot recall why he was admitted. She, herself is currently being treated with anti-depressants for depression and says that they were prescribed due to the stress that followed Mandy's fiancé's operation and recovery. She also states that she, Rachel, has not yet found a man that can trust her. Contact with members of the maternal family is limited to once a year or less. There is no history of psychiatric illness in the paternal family.

Family interview

The family members that were present at Mandy's family interview included her mother, Rachel; her fiancé, Liam; his mother, Lynn; and his older brother, Owen. Mandy's sister and brother were not present and their mother said that they did not wish to see her in her present state. They did not wish to have the father present at the interview.

A brief history and genogram was taken from her fiancé's family. He is the second of three brothers. Their father was said to be very strict and quick to discipline his sons. There were a number of deaths in the family before he and Mandy started dating. Liam's maternal grandmother died in 1999, his maternal grandfather died six months after his wife. Liam's father died six years later in a motor vehicle accident. There is no history of psychiatric illness in his family.

4.1.2 Participant B and family

Gavin is a 29-year-old unmarried male living with his parents, Ellis (58) and Minnie (50). He needs assistance with daily living due to his low level of functioning brought on by moderate mental retardation. Gavin completed Grade 10 at a remedial school and has never been employed. His father retired early from his job and now cares for Gavin full-time while his mother is the sole source of income for the family. Gavin is the older of two siblings and has a younger sister, Lisa (26), who is married to Ivan (31) and is currently pregnant with their third child. Lisa works as a personal assistant and lives in the same city as the family and although it is not explicitly stated, the relationships in the family are strained for a variety of reasons, including financial difficulties and the stress of both present and past events. Gavin was referred by staff at the hospital to the study.

Events leading up to admission

In 2006, Gavin was diagnosed with type II diabetes following periods during which he would lie in his bed, unable to get up and had to be helped with his basic functions. He was prescribed medication to regulate his insulin levels and referred for speech therapy.

A year later, he almost stopped speaking completely, started exhibiting odd behaviour and there were reported hallucinations. The family took him to a private psychiatrist where an electroencephalogram (EEG) and a number of other tests were carried out before psychiatric medication was added to the medication he was already taking. The information from the family on what he was treated for and what ailments were identified is particularly vague.

The family claims that Gavin lost trust in his doctor and they took him a second doctor. He failed to respond to treatment so they took him to a third doctor where they say “the problem started”. Gavin is reported to have started hearing voices and would tell others that he saw a space ship circling the house. He would put food out for the aliens, constantly talk about aliens and spaceships and was preoccupied with the X-men series on television.

He also became preoccupied with his sister's health shortly after she had a second premature baby who died. His father, Ellis recalls that he behaved in a paranoid way towards his brother-in-law, Ivan. Ellis also alleges that Gavin tried to strangle him on one occasion with the electric cord of his shaver. Gavin would reportedly also grab hold of the house keys and refuse to relinquish them. Ellis recounted that he felt that his son had set a trap for him in the incident that led to hospitalisation. On the morning of the alleged incident, he says that Gavin was holding him hostage and would not allow him to leave the house, convinced that there were snipers in the garden outside. The police arrived and Gavin was admitted to the local district hospital as an involuntary mental health patient for a 72-hour observation period. There was not a bed available at the psychiatric hospital so he was discharged and referred to the local rehabilitation unit.

Participant's background history

Gavin was born by caesarean because of cephalopelvic disproportion where his head or body resulted in him being too large to fit through his mother's pelvis. Prior to being pregnant with Gavin, his mother Minnie, had had nine miscarriages and two still births. The parents report that his developmental milestones were normal, although he did not socialise easily and struggled with his attention and concentration. He also struggled with reading at nursery school so his parents had his IQ tested and it was found to be below average. After one year in a mainstream school, Gavin was placed in an assisted class due to lack of progress. He eventually completed Grade 10 at a school for people with learning difficulties although he reportedly interacted very little with the other pupils.

Substance use

There is no information that the participant abused alcohol. He was said to have "abused" flu tablets for a few weeks, but this cannot be corroborated.

Family and psychiatric history (see Appendix E for family genogram)

Ellis said that his half-brother, Gavin's uncle, who was employed as a game ranger, was admitted to Weskoppies hospital after a battery exploded in his face at the age of 35. He received ECT treatment. One of Ellis' half-sisters reportedly died from eating a poisoned

substance. Ellis describes himself as a deeply spiritual person who sees medication as a last resort. He also claims to be able to speak in tongues and states that the Holy Spirit works through him.

Gavin's mother, Minnie, said that her great aunt suffered from epilepsy and this prevented her from working. One of Minnie's brothers also suffers from depression and is receiving medication for the condition. Minnie is also receiving psychiatric treatment for depression. She has tried to commit suicide twice in the past. When asked about the nine miscarriages and two stillbirths she suffered, she says that although she mourned these events, her husband responded stoically.

Gavin's sister has given birth twice in the last two years and both babies were born prematurely. The first infant died after six weeks and the second infant, after three months. Gavin's mother reports that the first infant died after being born with a hole in its heart while the second infant died from oxygen deprivation while in the womb. She is currently pregnant for the third time. The family did not tell Gavin about the first death because they felt it would upset him. His sister is said to be extremely busy with her job and does not spend much time with the family.

Individual interview

Gavin's father was seen and heard pacing outside of the door during the individual interview with Gavin in a manner that suggested he was attempting to listen in.

Family interview

Gavin and his parents were present in the family interview. Ellis monopolized the conversation but would often seek confirmation about information and events from his wife, Minnie. At one point in the interview, Ellis rolled up the leg of his trousers to show the interviewer his varicose veins. Minnie brought all her medication with her to the interview to show the interviewer. Gavin sat quietly throughout the interview and spoke only when he was addressed. Minnie would often turn to face Gavin expectantly when a

question was put to him. If he was unable to answer or appeared to struggle with formulating an answer, then his father would answer for him.

The family stressed that their daughter was too preoccupied with work to come to the interview but agreed that the interviewer could speak to her over the telephone. A telephone interview was conducted with the daughter who was very cooperative in the interview and downplayed some of the more peculiar descriptions given by the parents.

4.1.3 Participant C and family

Participant C is a 21-year-old unmarried female given the pseudonym Candice, who was living with her mother, Zelda (44). She currently assists her mother, who works in a coffee shop while her father, Ely (49) secretly provides funds for her to be paid a basic salary. She is the older of two siblings and her sister, Ursula (23), is unmarried and lives in the United Kingdom. Candice was referred by staff at the hospital to the study.

Candice completed her Grade 12 in 2005 shortly before embarking on a working holiday in the United Kingdom where she was employed as a care-giver for the elderly. Her parents divorced in 2004 and have a conflictual relationship with each other. She has a better relationship with her father who has remarried, than with her mother, who she often chastises for drinking excessively and socialising with male partners. She has a very poor relationship with her father's new wife, Donna (52).

Events leading up to onset

After completing Grade 12, Candice embarked a on a two year long working holiday in the United Kingdom in March 2006. Shortly before her departure she started withdrawing socially and consciously decided to break off most of her friendships. In June 2007, her mother, Zelda, was contacted by a doctor at a psychiatric hospital in England. He informed Zelda that the police had found her daughter wandering alone in a park and that she appeared disorientated and spoke in a disorganized manner. Candice was said to have no insight into her mental state and refused treatment or hospitalisation. The doctor informed Zelda that they were going to make Candice an involuntary patient in terms of

their mental health act and admit her to a psychiatric institution for an initial period of 28 days for observation and treatment.

Candice's mother contacted her father, Ely, who telephoned Candice and tried to persuade her to cooperate with the authorities. He recalled that Candice denied that there was anything the matter with her. She blamed her behaviour on a lack of sleep and said that she had not slept or eaten for four days while she was at a Hare Krishna festival. Her father says that she claimed to have been meditating in the park as she was now also a Buddhist.

The next day Candice was admitted to a a psychiatric facility and a number of tests were done for substances. These tests returned negative results indicating that she had not been using any substances. Ely recalls speaking to Candice on the telephone soon afterwards and she told him that she could see God who communicated with her, telling her when she was doing something good or bad. The psychiatric facility also sought confirmation that Candice suffered from attention deficit/hyperactivity disorder. During her time in the facility she refused medication. She received visits from her casual boyfriend who brought her her mail. After the 28 days, a diagnosis of acute psychotic disorder was made. Initially the hospital tried to get Candice to follow up on an outpatient basis, but later agreed to discharge her into the care of relatives. Shortly before her release she received a day pass and did not return to the hospital at the alloted time. The police were informed and her boyfriend directed them to a buddhist temple where she was found.

Participant's background history

No birth history or complications are mentioned by the mother. Developmental milestones were reported as normal although Candice's parents noted that there was "something different" about her from a young age. Her father recalls that she would often be in her own world and stare out in front of her. Her mother stated that she would not really seem aware of what was happening around her as she would cross the road without a care for oncoming cars. Around the age of five she collided with someone riding a bicycle and was knocked unconscious for a few minutes. She had a concussion and complained of temporary blindness. At the hospital a few days later, she appeared to have

recovered and as the hospital did not have the necessary equipment to conduct the required tests, her parents did not take her for follow up procedures.

Family and psychiatric history (see Appendix F for family genogram)

At school, Candice was described as often late and disorganized with serious problems in concentration. She was diagnosed as having attention deficit/hyperactivity disorder but did not take any medication for this. She would be given extra time in exams to write. Candice said that she started experiencing symptoms of increased difficulty in attention and concentration at age 16. She passed her Grade 12, although her results were described as below average.

When Candice was in Grade 10, her parents divorced. Her mother admits to being an alcoholic and says that she sought comfort outside of the marriage. It is alleged that both the mother and father had aggressive outbursts. The mother alleges that Ely changed the roles in the house and treated his daughter, Candice, more like his wife and herself, like a child. Candice is also said to have started treating her mother like a child. The family was divided, with Candice and her father on one side and the mother and sister on the other. As a result of this Candice helped Ely to move out while her mother was away from home. Her sister, Ursula, contacted their mother and informed her of the situation.

Candice's maternal cousin has been diagnosed with bipolar disorder and is on medication for the condition. The maternal grandfather, the mother and the maternal sister have also suffered from depression and alcohol dependence.

Substance use

There is long-standing history of substance use. Candice reportedly started using substances over weekends and at parties from age 14. In Grade 10 she started using marijuana and ecstasy. Later she also used Lysergic Acid diethylamide commonly referred to as LSD as described as a hallucinogenic recreational drug as well as Ketamine, which is a general anaesthetic and tranquilizer used by veterinarians. Candice lived with a 'dealer' who sold Ketamine to people for recreational use while she was in

London and she says that at one stage she consumed quite a lot of this on a weekly basis. She says that she stopped using substances six months before experiencing psychotic symptoms.

Family interview

The family interview was conducted with Candice and her father. Her sister lives in England but her mother, Zelda, who lives in a different city, requested to do a separate interview over the telephone. The father was very forthcoming but tended to steer the interview. During the interviews, both the father and mother were difficult to follow as they would often blend timelines and events.

4.1.4 Participant D and family

Participant D is a 22-year-old, unmarried female given the pseudonym Jane, and she is living with her parents, Lisa (61) and Wayne (66) on their farm. She has an older brother, Will (27), who moved out of the family home in the last year. Jane is currently completing a degree in teaching. She was previously an inpatient at Weskoppies hospital and was referred by staff at the hospital to the study. Jane describes her relationships with her family as good. She describes herself and her father as sharing many similarities. However, during her psychosis she would often attack her mother verbally and physically. Her mother, Lisa describes Jane's brother, Will, as clever and short-tempered.

Events leading up to admission

In the year prior to her admission to the hospital, Jane studied art at a local college. Her parents believe that failed to cope with the course because of her results and the comments made by her lecturers. They also said that during that year, she made strange remarks to her family and behaved in a disorganized fashion. She went to see a counsellor at the college she was at and they tried to help her with time management.

She later changed her course and moved to a different institution but over the next two years, her behaviour worsened and she would react aggressively to certain words and accuse her family members, especially her mother, of making derogatory remarks about

her. In 2006, she appeared to lose the ability to move her limbs and her parents took her to the local hospital for treatment. However, they could only get an appointment with the psychiatrist two months from her release date. Instead, Jane was accepted for a year long medical trial where she received treatment at no monetary cost.

In 2007 she had a psychotic episode during which she refused to eat, would not speak or react to others and ran away from home twice. The doctor administering the trial was abroad so her parents took her to a community clinic and they were referred to the local district hospital. She was admitted for a 72-hour observation period and later transferred to Weskoppies hospital.

Participant's background history

No complications in birth history were reported by her mother. Developmental milestones were reported as normal and no problems in early adjustment were noted. Jane reported experiencing problems in concentration when she was in Grade 11. She believes that she would also say things that confused people and describes seeing 'things'. She then went to see a church counselling service where they tried to help her with what they believed was low self-esteem. Jane claims that she struggled at school from Grade 10 onwards with taking in, organizing and recalling material but managed to complete her schooling.

Substance use

There is no history of substance abuse reported.

Family psychiatric history (see Appendix G for family genogram)

Jane comes from quite a close-knit family whose livelihood depends on their farm produce. They report working extremely hard, and admit to finances being a strain on the family and are rarely able to take time off. Jane's experience is kept hidden from other people who the family believes might reject them if they knew. A maternal aunt is the only member of the extended family who was informed of Jane's recent difficulties. Jane's father and brother are said to be very quiet people who avoid contact with others.

Wayne is estranged from most of his family. His parents divorced when he was quite young and he was sent off to boarding school. Both of his parents went on to have subsequent marriages, his mother remarrying four times.

There's no history of psychiatric illness reported in the mother's family. In the father's family, Wayne suspects that one of his cousins may suffer from a psychiatric illness due to what he refers to as her strange behaviour.

Family interview

Jane and her mother were present at the family interview. Her father had to stay behind on the farm and a telephone interview was later conducted with him. Lisa sat with her arms folded protectively over her stomach, legs straight and firmly planted. She faced the interviewer directly and appeared confrontational whilst trying to protect herself. She remained sitting like this for most of the interview, except on two occasions when she threw her arms up into the air to illustrate strong emotions. She often laughed inappropriately.

4.2 Results

The content of each interview transcript was reviewed and a number of themes relevant to the subjective experience of crises and life changes that precede the onset of schizophrenia were identified. These themes were organized into three categories. Each category consists of a number of similar themes, together with further information that helps to describe, explain and elaborate on each theme. The results are limited to the more common themes found across all of the interviews and unusual or significant themes raised only by particular participants and their families. In the following description of the findings, the results are listed first by category with an explanation of what constitutes that category, then by the various themes found within each category. Where two sets of data are available, themes and extracts from the individual interviews are presented first before those from the family interviews. Both are clearly marked as individual or family data.

Category 1: Crises and life changes

Theme 1.1: Various crises and life changes are reported to precede the onset of schizophrenia

The participants and their families reported a number of crises and life changing events in the period before the onset of overt psychotic symptoms. They describe certain of these events as more significant than others. This section lists the events reported.

Crises and life changes reported by Participant A and her family

1999: The maternal grandmother of Mandy's fiancé, Liam, dies.
Six months later, his maternal grandfather dies.

2002: Mandy's ex-boyfriend is involved in a motor-cycle accident. He is placed into the Intensive Care Unit (*ICU*) of a local hospital and dies shortly afterwards.

2002: Mandy and Liam meet.

2003: Mandy moves in with Liam's family.

2005: Liam's father is involved in a fatal car accident.
Liam's brother is diagnosed with low blood pressure and Gilbert's syndrome.
Mandy and her fiancé relocate to the Eastern Cape to seek work.

2007: Mandy's fiancé starts experiencing headaches.
Mandy starts calling her mother who describes her as distraught and tearful.
The couple move back to Johannesburg at the end of the year.

2008: Early in 2008, Liam starts experiencing double vision and he is diagnosed with brain cancer. A month later he is operated on to remove a cancerous growth.
Shortly afterwards, Mandy starts behaving oddly, crying and staring into space, her behaviour begins to deteriorate and she appears disorganized.

A few months later, Mandy has lunch with her step-cousin and her father.

A week later, the disorganized behaviour escalates, she sends strange text messages to her mother, begins speaking in a disorganized manner and is admitted to hospital.

<u>Crises and life changes reported by Participant B and his family</u>

2005: Gavin starts withdrawing from his family.

2006: In May, Gavin's sister gives birth to a premature baby, Jenny. The infant is kept in the *ICU* at the hospital.

In that same month of May, Gavin spends three months lying in bed. He is taken to a doctor and diagnosed as diabetic.

In August, the infant dies. Gavin is considered to be ill and not told about the death.

2007: In February, the mother's brother moves into the family's home. He converts to the Muslim faith.

In the first six months of 2006, the family experiences conflict over financial difficulties and the mother reports strain over being the sole breadwinner.

2007: In April, Gavin's sister gives birth to a second premature baby, Jasmine. Gavin's condition is said to worsen. He starts laughing inappropriately and hears voices.

In June, the infant dies.

2007: In October, the police are called to the family home after his father, Ellis, said Gavin held him hostage, believing that there were snipers outside. Gavin is admitted to the hospital with police assistance. He is later discharged and treated on an outpatient basis with regular appointments at a rehabilitation centre.

In November, Gavin's mother is diagnosed with depression, following two suicide attempts over the years.

In December, the mother's brother marries a woman of Muslim faith.

Crises and life changes reported by Participant C and her family

1992: Candice is knocked down by a cyclist, loses consciousness and is temporarily blinded.

2000: Candice is caught smoking marijuana in her parent's garden.

2002: Candice's parents separate.

2004: Candice's parents divorce. Candice is sent to boarding school. She does not return to the boarding school the following year as she would not follow their rules.

2005: Candice moves in with her father and starts writing on the walls in the apartment.

2006: Candice goes to England. Shortly after her arrival, there is an alleged incident of sexual harassment and she is swindled out of her money, according to her mother. A few months later she decides to become a Buddhist nun. She also starts to worship with Hare Krishna devotees.
She begins a tempestuous relationship which mimics her parents' relationship.

2007: In June, Candice is found wandering in a park and admitted to a psychiatric facility.
In July, her father travels to England to help her move in with relatives.
In December, she misses her flight home and takes a new job.

2008: In January she is escorted onto the plane and arrives back in South Africa.
In February she begins treatment for schizophrenia.

Crises and life changes reported by Participant D and her family

2002: Jane experiences difficulties in concentration while still at school. She finds herself often confused and sometimes sees "things". She seeks help at the school counselling service.

2004: She goes to a local college to study a course. She finds it difficult to cope and experiences a very negative reaction from the other students. She seeks help at a church counselling centre and they provide her with practical tools for time management.
Her brother leaves home and moves into his own house.

2005: She starts developing peculiar tendencies and associates certain words with meanings related to herself.

2006: The strange behaviour escalates, she becomes restless, unable to concentrate and physically attacks her mother. She joins a medical trial for treatment.
Early in 2006 she develops side effects from the medication. She loses the ability to move her limbs and starts shaking involuntarily.

2007: In May 2007, she has what appears to be a psychotic episode. At times she does not want to speak or eat. She runs away from home twice. She is taken to the local district hospital before being transferred to Weskoppies hospital.

Category 2: The subjective experience of crises and life changes

Theme 2.1: A subjective awareness of increasing deficits and isolation

Some of the participants reported a conscious awareness of change, long-term difficulties and feelings of isolation before being diagnosed with schizophrenia.

Participant A remembers being uncomfortable around her abuser without knowing why.

Mandy: *We went to eat at his mother's. And then I just stood on the side of the table and he stood on the other side and then I asked myself, 'Why can't I abide this man in front of my eyes? And he said I must play Makors with him on Facebook …I understand that it was a challenge from his side to me and I wouldn't accept the challenge*

and the fourth time I wanted to accept it and then he started doubting in himself…And then later we went home and I wished I could die. (Long silence). Because he really did rape me.

Participant A also describes a sense of loneliness after withdrawing from others.

Interviewer: *How will they describe you?*

Mandy: *Lonely.*

Interviewer: *Why will they say that?*

Mandy: *Because I never listened when they spoke to me.*

Participant B attempted to express the sense of loneliness and isolation that he has experienced since his sister left home, but his ability to verbalize his thoughts is limited.

Gavin: *Together … together … We didn't play a lot. We didn't actually play a lot since we were young.*

Interviewer: *mm …*

Gavin: *Just watched TV and …*

Interviewer: *What do you mean, didn't play?*

Gavin: *We only watched TV together and chatted with each other.*

Interviewer: *Do you have many friends that you can visit?*

Gavin: *No.*

Interviewer: *Has it always been like that?*

Gavin: *Yes.*

Interviewer: *But when you just finished school, what did you do for that period?*

Gavin: *Nothing.*

Interviewer: *With whom did you play when you were small?*

Gavin: *With no-one.*

Interviewer: *The neighbours or anyone like that?*

Gavin: *No.*

Participant C expressed quite bluntly her own awareness of how she experienced herself and how she felt in relation to others.

Candice: *I worked.*

Interviewer: *As?*

Candice: *A careworker (laughs).*

Interviewer: *Mm?*

Candice: *Which is ironic because I myself needed help.*

Participant C also discussed the behaviour of others towards her. She says that their behaviour amplified her feelings of loneliness and disconnection.

Interviewer:	*How did you perceive their behaviour towards you?*
Candice:	*Uhm … it was very hard for me. Uhm … uhm … because I did not have … in England I was alone for the most part of it. I had a few good friends but it was basically … uhm … So on the one hand I just ignored it and on the other hand it really hurt me.*
Interviewer:	*I'm not sure I understood you well with regards to what hurt you in their behaviour.*
Candice:	*Well, just everybody seeks acceptance. Everybody wants others to like them and then … it just made me feel very lonely. I was already very lonely and then the people that I wanted near me … if they also abandoned me then it was just … uhm … just terrible.*

Participant D recalls changes in her everyday level of functioning.

Jane:	*Oh ok. I was just confused. My brother picked up and my friend also picked up that I confuse things I say … And uhm … then I also hear things sometimes, you know. Then I also see things sometimes.*
Interviewer:	*Ok.*
Jane:	*Not big things, you know, just on occasions and I also couldn't concentrate.*
Interviewer:	*Oh, ok. When did that start?*
Jane:	*When I was in Grade 11.*

Jane:	*And I was quite wrapped up in myself. Yah uhm one of my problems of being schizophrenic is that I'm quite introverted you know. Self-absorbed, sort of thing. When I was last sick, I felt like I was really wrapped up in my self.*

Theme 2.2: The subjective experience of crises and life changes is described as widespread and debilitating

The effect of the crises and life changes is experienced as complex, evolving and believed to exert an etiological effect over a considerable length of time. Some events may have occurred quite far back in time, yet their effect is still described as widespread, forming part of a long-standing pattern of interaction in the family that influences how the person perceives themselves and their world. The individuals define certain trigger events and describe these as devastating, overwhelming, or harsh, accompanied by loss of control and debilitating stress. The family report not initially experiencing the crises or life changes as serious or they tended to believe that these could be managed. Soon the effects became overwhelming and the significance of the event was realized.

The individual participants' experience of the crises and life changes

Participant A describes her reaction after recollecting that she had been raped and molested as a child. This had a rippling effect later in life.

Mandy:	*Uhm … I had a nervous breakdown when my father called me and he told me uhm … "I'm sorry for what I've done to you. I don't know what I was doing to myself."*
Mandy:	*I was raped when I was three years old by a person called Isaac Fenton, and I was raped again later after my father used me as bait.*
Interviewer:	*What sort of bait?*

Mandy: *My mother and father are separated as a result of the thing … Isaac Fenton. And my father did not want to believe it, so he took me to the guy's house where the man raped me and my father molested me.*

Participant B recounts his experience and the events with little emotion, but this is illustrative of the stark emotional reaction of the family to crises and devastating events. He describes the death of his sister's two babies as similar to the helpless experience of being taken to hospital, devoid of affect and personal involvement.

Gavin: *I tussled a bit with my father and then he called the police and then the police came.*

Interviewer: *Uhm … was there anything that happened in your life or the family during this time?*

Gavin: *My sister's baby … she had before this child, two others. They had died.*

Participant C describes a gradual loss of control and descent into chaos. The early conflict in the family relationships appears to have been replicated in her interpersonal relationships.

Candice: *I think the drugs. The drugs that I used in my life. And I don't know if it had any impact but my personal life, my family life before I went to England. It was also sort of chaotic and I couldn't really, didn't really have a place that I could call home.*

Candice: *My parents were divorced and it was really sort of messed up and no … I had a plan that was my house. But I didn't anymore have a family. You know you don't have that oneness anymore. Uhm …*

and I think I just Jesus, I just pushed all my friends away so I think I just had a lot … I don't know. I think I just began searching for something better in my life … Like a family oneness. That … a group of people that supports you.

Participant D blames the stress of trying to get a university degree in a family context which links personal worth to hard work and failure to suffering and shame. This notion of failure is linked to the disappointment and suffering experienced by the father as a results of his own parent's divorces. There is some tension evident between the parents, but divorce is perceived to be a devastating event that destroys the family and bring with it shame and suffering. In the family culture, hard work and 'soldering on' is redeeming.

Jane: *I suppose stress, I don't know.*

Interviewer: *Stress?*

Jane: *Yah, stress about my work and stuff.*

Interviewer: *(To Jane's mother.) You mentioned that you hoped she gets a job or that she wouldn't be able to hold own a job in that state. Is it important in the family?*

Jane's mother: *It's important because we're not well off … uhm … my husband is older than average. So what on earth's gonna happen to her when we die? (Laughs.)*

<u>The family's experience of the crises and life changes</u>

Crises and life changes have happened to the family and it is the family who are affected, not just the individual. The individual may be the person who initially appears to cope best with the events, but they are eventually affected by the stress of repeated trauma.

Family A recounts their experience of a series of highly traumatic events.

Mandy's fiancé: *I had terrible headaches and in February, I started seeing double. I got double vision. Then I went to an optometrist who sent me to a specialist. Then the specialist sent me to the hospital for a scan. It was around the 7th or 8th of February. Then they did a scan and uh it was brain cancer. I then had an operation … Then I went for chemotherapy and I'm finished with it and now it's Mandy who has gotten ill.*

Mandy's mother: *And for me it was terrible, she asked me to go with her to ICU and I said to her, sorry I'm not going because uhm with her ex-boyfriend she also wanted me to go with her to ICU. She expected a lot of things from me. I'm still sitting with that in my head.*

Mandy's mother-in-law: *I was the only child and my mother and father died six months apart and six years after them, my husband died. So I'm sort of through two traumas … two trauma reactions short after each other.*

Mandy's brother-in-law: *I think that it has everything to do with delayed shock. Why I say this is … when I lost my mother's mother and father in 2004, there is my mother sitting, there is my brother sitting. It was a year later, then I will be standing … the next moment I will just fall forwards. Out like a light on the ground …They discovered that I had low blood pressure. They discovered with some of the blood tests that I also have Gilbert's syndrome. Uhm … yes … I was … I was basically the biggest part of neurotic during that time.*

Family B reported how a number of devastating life events impacted severely on them.

Gavin's mother: *Yes. Do you know my youngest brother, Elton. He changed from Christianity to Islam and naturally that made me very unhappy because I mean our parents were all in the Christian, Christianity religion and now he comes and he also married a … an Indian girl. And that made me very unhappy.*

Gavin's father: *… he at a stage gave up his apartment and then he came to live with us inside the house. And with his Muslim religion and the type of prayer that he has, that completely threw our house out of orbit.*

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Gavin's mother: *But if … if I can come in here. Gavin stopped speaking … For almost three months, yes … he didn't speak and Ellis had to … Ellis had to help him to go to the toilet because he just lay in bed.*

Gavin's father: *Sick, this was from the insulin that went too high at times then he'd go into a coma. And then I'd take him from the hall to his bed and then we didn't really know what precisely was going on uh with him.*

Gavin's sister: *You know my daughter was born in May and then he already had things like he would be sitting and suddenly laugh because of something … And when the second girl was born, he knew she had been born and everything and when she was born and that she was still in the hospital but she also died eight weeks later. Because both of the girls were born prematurely so they died in ICU and with the second girl's birth he knew and the voices were already there.*

Gavin's mother: *Let me tell you, oh it's just your financial problems that we all … maybe not you all, but us. I am the sole breadwinner, so basically I pick up all the burdens and carry them. Which is probably not necessary but it's just how I am. It's just every now and then that you get that stress. You know if it gets too much for you and you must find an outlet somewhere you know, then it's a difficulty between the two of us.*

Family C reported events that include life-threatening injuries, substance abuse, divorce and family conflict.

Candice's mother: *(Recounts her daughter being knocked down by a cyclist at the age of five). No, she was seriously concussed. … she was blind for more than half an hour. Then we drove to … hospital and they didn't have x-rays and that kind of stuff that you must do to test her… I made an appointment to take her on the Monday …But they couldn't get her under. The more … medication they … she's at this stage five years old, tried to give her the less she slept. Then the doctor … uhm he said …. Ugh, I don't think it can be that serious. He couldn't get her under anaesthetic. Today I think that was one of the biggest mistakes I made. You know, years later. I don't know. Can it lead to that?*

Candice's mother: *… and then the divorce and the fighting and other things. But you see now I don't know if that also played a role from later years. Could she have been vulnerable to something because of that?*

Candice's mother: *(Recalls first discovering her daughter using substances.) Uh … then … and her father caught her one day with a bunch of kids in our garden. He'd moved out. I stayed in the house. And uhm … she's now 20 … she was probably around 14 …*

Candice's father: *Every morning she was late and I had to rush to drop her off at the next bus stop and things like that. One of the occasions when she wrote an art exam … it was on a Saturday… uhm … it began at 9 … 8 o' clock or whatever. Then that morning she told us she must … pencils, drawing paper and pastels and things like that … So now I must … the shops only open at 08h30. She must start writing exams at 08h00.*

Candice's mother: *I just know that she arrived there with enough money in England and this guy, this chap with who she stayed. His father was bloody Jeeves and things … and they swindled the money out of her. I'm not sure precisely what happened there or what. There was something about a sexual harassment or something,*

Family D reported a gradual unfolding in the subjective experience of stressful events.

Jane's mother: *Well, she just wasn't coping with the subjects she had to … to have. Pottery and all that sort of … she wanted to do the art side. She had to draw all these other things and we had to fight and stuff and she'd get the wrong stuff.*

Interviewer: *What made you think she wasn't coping?*

Jane's mother: *Well, her marks. And the remarks she just didn't seem to … weird she wasn't she wasn't together (gestures by bringing her hands together).*

Interviewer: *The remarks? (looks at Jane.)*

Jane's mother: *Made by the lecturers in her … organized … disorganized ok that's probably the best way of putting it. Very disorganised.*

Jane: *In 2004 I went to the College's counsellors. They just helped me with time management (looks at her mother). They didn't help me with much else. (Starts scratching the top of her hand.) And then … then after that I went to University to become … a communication science … and I decided no I … that's not for me so I started to swap …*

Jane's father: *The University of Technology, or something. And it … it didn't work out there yoh uhh. She was unpopular with the other girls uhm other people in …*

Theme 2.3: The significance of the crises and life changes reported

The significance of the events is not realized initially but only understood once the full impact of the crises and life changes is experienced. The events can exert an aetiological effect over a considerable period of time with current events echoing past happenings and imbuing them with new insights.

Family A: The significance of the events is realized over time.

Mandy's mother- in-law: *In about the month of September he started complaining he gets many headaches. But we ascribed it to the stress and stuff and … and tension and every time he went to the doctor, the doctor said it was stress and tensions that causes it. Until he began seeing double vision and then they saw what the problem was.*

Mandy's mother-in-law: *I think for all of us because no-one really, really expected it to be so serious.*

Mandy's mother-in-law: *(Referring to Mandy.) She was really very, very strong. Uhm … I think what he perhaps is saying with that it had a bigger impact on her … I was the only child and my mother*

and father died six months apart and six years after them, my husband died. So I'm sort of through two trauma … two trauma reactions shortly after each other. So I handled it without fuss. She was really strong but I think inside she struggled to deal with the shock thereof. However, we're very proud of her, she did very, very well. She did come to me in the evenings and then she cried. I said to her, "Cry, it's very good, let it come out of your system", and I said to her, "The only way we are going to get through this is to pray together and hope that Liam gets better". And she was very positive the whole time and she supported us very well, very, very well.

Interviewer: *And then we heard that your ex-boyfriend also … was also in an accident in February around the time when Liam had his operation, did that day mean anything different for you?*

Mandy: *No (shakes her head to indicate no).*

Interviewer: *Did you think about your ex-boyfriend on that day?*

Mandy: *(Nods her head.) That they both lay in ICU.*

Mandy's mother: *The day that Liam was operated on, on that same day in the past her old boyfriend was in a motor cycle accident the same day, 28th February and I couldn't think how she could be so strong, because she was strong.*

Family B: Gavin's sister, Lisa, recounts how the loss of her own two babies reignited memories of her mother's loss of her own babies, stillbirths and miscarriages.

Gavin's sister: *Uhm … and I think the stuff caught my mother a bit off-guard in the sense of emotionally. She was not emotionally ready or it. So … any woman though is emotional about these types of things over your kids. I think it affected my mother emotionally as well as my father, he … he came across very strong and uhm … when things happened and Gavin was admitted, my father, he then only showed emotion and you know … really cried over it which he had not done before. So, I don't know if it is a shock that only came afterwards, but it definitely packed a lot onto the family.*

Gavin's mother: *(Refers to Gavin's uncle.) You know he himself when he was in the army, he drank an overdose of pills. And ok, they could then help him. He probably did not like it one bit.*

Gavin's mother: *Because I saw with my mother's sister, that I didn't tell you … She had a problem with understanding and she, my mother cared for her until she was just about dead. And I don't want to accept that that can happen and when that happened with Gavin, then it almost completely derailed me.*

Family C explained how conflict in the relationships, the use of substances and the possibility of a diagnosis of anorexia overshadowed the early deterioration in behaviour.

Candice's father: *Look, in the beginning before she was diagnosed, everybody thought she suffered from … from … uh … (Scrunches up his face) … (Turns to his daughter.) What do you call that stomach sickness … where the person does not want to eat … If there were times when she behaved oddly or her behaviour was a little weird then I would think it was drugs.*

Candice's mother: *Ursula could naturally … not handle it at all, at all. Not at all. I could not either … uh uh but Ursula even less because then I still did not know that it was schizophrenia. I just knew that something was wrong. And then I just because Ely said it's jet lag and then I said it was nervous breakdown and she and Ursula had a lot of conflict They would scream and fight and she … and Candice would scream back at her and I knew it upset Candice so I said, Ursula don't aggravate this. And she'd say but she can't get away with it. We still didn't know precisely … but she got admitted, she was admitted but Ursula could not …*

Candice's mother: *When she was in England. Before the doctor admitted her. Because she'd say Mummy, I love you so much. I am so awfully awfully … I miss … and then she'd cry. She'd say, I am so sorry and … and … the thing is I didn't … I wasn't there and couldn't see what was going on and when the doctor admitted her, then I told Ely, I want to go to England.*

Family D accepted the participant's early mood changes and difficulties in studying as part of a normal reaction to difficult circumstances, namely pressure from the course she was taking and difficulties in adjusting to life at college with trying to fit with her peers and not indicative of premorbid symptoms. Her difficulty in trying to fit in with her peers mirrored the family's own difficulties in trying to fit into society.

Jane's mother: *Uh no not real change. We just really thought she wasn't really quite coping with the course.*

Interviewer: *What kind of behaviour … can you give me an example, Wayne?*

Jane's father: *Well … well we arrived at this art class … there was that … these girls were there and they were … they were all waiting for the art*

class and they'd just give her these cold stares and they'd been together in class for a while … and you know I thought yis that's bad treatment. You know she probably felt it badly because she's sort of uh socially inclined … you know it means a lot to her to get on with other people you see. And uh … I … think that being ostracised at this place she really felt it badly.

Jane's father: *Well I think it was quite a long time in coming. I … I don't know. She said … she used to act odd and aggressively at times you know like … She'd say uhm you know other girls are going to parties and I'm not and get all aggressive about it.*

Theme 2.4:The participants' attempt to make sense of the experience

The participants reported their personal attempts to understand their experience during the onset of schizophrenia by constructing a sense of meaning that appeared logical and coherent to them at first. Later their ability to make sense of their experience is affected by disturbances in thinking. Once the symptoms are in remission, their understanding is constructed from elements of their social world and their response is intricately connected to the subjective experience of the event.

Participant A linked the symptoms of schizophrenia to the realisation of being molested.

Mandy: *Because it's since I realized that that I started speaking in a disorganized way. I started realizing that he (Isaac Fenton) had raped me and then I had a fast forward button in my head … that I pressed and am now rewinding.*

Interviewer: *When did you press this button?*

Mandy: *One night when I tried to sleep and couldn't get to sleep after I drank a sleeping pill.*

Interviewer: *When was this?*

Mandy: *Uhm … Monday, four weeks ago.*

Interviewer: *Ok. So you pressed the fast forward button? And uhm … how is it going to help you to go on with your life?*

Mandy: *To speak about it. The more and more I speak about it, the more it rewinds.*

Later she explains her behaviour of covering up as a response to the experience.

Mandy: *I developed an identification problem. I couldn't … I used to wear clothes from my feet up to my hands. I wore gloves so that you can just see my face.*

Participant B explained his actions the morning he was forcibly taken from the family home as logical and coherent to him at that time based on the events that had occurred.

Interviewer: *How did you and your dad tussle? What happened? Explain to me again.*

Gavin: *I thought that if he was moved out of the way then I could go where I wanted. Then it didn't work out.*

Interviewer: *Where did you want to go?*

Gavin: *To them, upstairs (points up with his index finger).*

Interviewer: *Ok. Uhm … was there anything that happened in your life or the family during this time?*

Gavin: *My sister's baby … she had before this child, two others. They had died.*

Later he acknowledges the link between the hallucination of the girl who listens to him and his longing for support and peer interaction.

Gavin: *She just listens and …*

Interviewer: *She listens to you?*

Gavin: *Yes.*

Interviewer: *What's it like for you when she listens to you?*

Gavin: *She … she just says yes or no or mmm the whole time.*

Interviewer: *Do you also have other people who listen to you or is she the only person who listens to you?*

Gavin: *She's the only one.*

Participant C drew on the common theme between substance use and hallucinations, her esoteric experiences and her wish to heal others in the explanation of her experience.

Candice: *Yes. Uhm … and I believed … everything is … what is the word? (Laughs), personifies me. Like everything. Movies were like personification of certain aspects of myself. Advertisements were … gave me messages … I drove down a particular street, I believed … there was a … a billboard with washing powder and then I believed that that washing powder was cocaine and now I*

believed I used cocaine because I was now driving down that street.

The nature of her response to these events suggests that it was borne out of the family context in which she was helpless to stop the deterioration in relationships in her family.

Candice: *Well I had a dream before … before … a vision (makes the quote/unquote gestures with her fingers around vision). Uhm … before I went to England. That I was in Mozambique or a third world. Uh … a settlement like a backpackers that I'd open with people that work there and people that stay there and sort of like a commune, a community. And I believed that everything that I did was towards that goal.*

Interviewer: *What was nice for you about that goal?*

Candice: *Well … the thought that I … I thought if you uhm a organ … a state is like an organ in the world, a world organ and you can have a good, a positive flow throughout that place that gives good atmosphere or it can have a negative flow. And I thought if you … a commune that's sort of organic and wholesome then you make a world that's … it's sort of like giving acupuncture to the world.*

Participant D blamed her character traits and her lack of interaction with other people for her susceptibility to schizophrenia.

Interviewer: *Can you help me understand it a bit more?*

Jane: *Just uh you quite very introverted you know you think too much of yourself and that sort of thing yah.*

Jane: *Yeah I don't get up out. Most … most people my age get out a lot. I don't get out much. I go to church and shopping but I don't get out much. Since … kind of boring and lonely.*

Her paranoia that others may be talking about her is based on real life, unpleasant experiences of being slighted.

Jane: *Yah well, the church that I went to … been going there for years, like seven years and you walk past people, no-one greets you, nothing like this. And so you go back down the church and you … been going for like seven years and no-one speaks to you.*

Theme 2.5: Reaction to events followed by a gradual, stepwise deterioration in functioning

Reaction to the crises and life changes appears to follow a stepwise process in which there is a gradual deterioration in functioning and an escalation in symptom behaviour.

Step 1: Individual initially tries to support others

The families' perception of the participants' response to the onset of schizophrenia involved an initial attempt to support other family members who were reeling from the effects of the crises and life changes.

Family A repeatedly describes Mandy as strong and dependable in a crisis.

Mandy's fiancé: *I was in the hospital. I lay in the hospital and she came to visit me in the hospital and every time that she came, she never showed that she was sad. I could see it but she never showed it outwardly. I think she was strong for me. She was always there.*

Family B: Gavin's father never reacted to past traumatic events and his son's loss of mobility during the deaths of the sister's babies not only mirrored the father's lack of

response but also forced his father to take care of others, which he was unable to do with his own infants' deaths.

Gavin's mother: *(Referring to Gavin's father.) He will keep them to himself and will on his own work through it. I … he's not like me who … will cry openly and you … show my feelings. Even with the two children of ours that died, he didn't really show his feelings (her voice breaks at this point), because he is not that type of person. (Father looks down the whole time. Gavin looks straight at the interviewer.)*

Gavin's father: *Yes. Uh … actually I took my wife for treatment. I didn't see it as necessary, I didn't feel it was uh that it affected me that seriously. What I (clears his throat), what I did feel was uh … I didn't want my daughter to go through the pain of drama and trauma that my wife and I went through with those other two children whose death we had to go through. And this … shall we say messed me up or pushed me to a climax.*

Family C described Candice as someone who puts the needs of others before her own.

Candice's father: *Well, I think like I say … sh sh she she she's soft-natured. She cares. I think the experience that she's had now to look after old people and to care for them and so on … uhm …*

Family D: This theme was also found in this family but instead of actively supporting others, this participant submitted herself to the will of the family.

Jane's mother: *So they admitted her to it immediately and sedated her immediately and she was there for five days and she … she was quite willing to … the only time she was not willing to go was when we took her to uhm, the clinic.*

Step 2: The individual eventually succumbs to the stress brought on by event

After initially attempting to support the other members of the family, the person succumbs to the stress brought on by the various crises and life changes.

Family A describes the stress of Liam's operation eventually taking its toll on Mandy.

Mandy's mother-in-law: *It was very difficult for her because she missed him intensely. Uhm … like I said, we tried to keep her going all the time. And then if we cried, if she started crying, I did too. If I cried, she would start to cry too.*

Family B describes Gavin as being sick at the time of the infant baby deaths, yet his sister says that he was aware of something being amiss and showed concern for her.

Gavin's sister: *He was constantly worried about me because, but actually he was the one who was damaged and emotionally unwell. So he contacted me the whole time and wanted to know, how do I feel, am I ok, that sort of thing. Am I ok, you know?*

Family C: Although her father believed she might recover from the initial psychotic episode, Candice's friends later contacted him to say that she was not coping.

Candice's father: *When some of her friends contacted me and told me uhm … Candice was there by them but it's not going well with her. She doesn't look well.*

Family D: Jane's poor treatment by her peers as described by her father may have led to her attacking her mother who appeared to be critical of her at times.

Jane's mother: *Yes, well we noticed that she had … she had … had developed these peculiar tendencies of … like to get a word for example*

probe, I couldn't use the word probe, professional … pro anything. She'd immediately climb down my throat cause I was accusing her (gestures with her head towards her daughter) of being a prostitute. Pro that was … she went through a phase like that and then I dare not use that word. (Brings her hand up to her face and holds it against her cheek.) Because it was immediately I was talking about her, even though I was talking about something completely different.

<u>Step 3: The effect on the self includes erosion, distortion and fragmentation</u>

The participants describe an erosion of their sense of self, they present with distortion in their thinking and fragmentation of their experience.

Participant A's speech is disorganized during the interview and is reflective of her own disorganized experience of herself and events during the onset of psychosis. However, she describes very well how the condition slow eroded her world:

Mandy: *It brought my whole world to a standstill. It brought my whole life to a standstills …I had to stop working because I knew I can't deal with this and work at the same time. I almost lost my fiancé. I almost lost my mother. I almost lost everyone that cares for me in the sense that I never listened to them when they spoke to me.*

Participant B describes the experience of being hospitalized in a dissociated manner that removes any sense of selfhood and agency:

Gavin: *I lay on the bed and … they took blood and everything and things like that.*

His experience of his nieces' deaths is vague and shadowy because he was not fully present at the time and his allusion to these events mirrors his fragmented experience.

Gavin: *It's like … one night we went to eat at a friend's, my mother. And then I saw something in the clouds like a shadow which moves backwards and forwards (illustrated the movement with his finger).*

Interviewer: *Ok. Uhm … was there anything that happened in your life or the family during this time?*

Gavin: *My sister's baby … she had before this child, two others. They had died.*

Participant C describes the distortion in her thinking which threatened to overwhelm her:

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Candice: *Well, it began to make everything too personal. Everything just became too … if people rubbed their noses then I believed you were communicating with your angel (rubs her hand across her nose). That means no. And just say you scratched your face and that meant yes. And it's impossible for everything … and it's food and this is your body language and it's clothes and it's patterns and everything just started to matter too much. It was just too much … to restricting. I couldn't even move or breathe without doing something wrong.*

Participant D describes withdrawing further into herself:

Jane: *When I was last sick, I felt like I was really wrapped up in myself.*

Step 4: Erosion of a coherent sense of self leads to changes in the person's behaviour

The person appears to lose a sense of self and according to the family the individual does not behave like themselves. Instead, they describe the person who goes on to be diagnosed with schizophrenia as behaving strangely or oddly.

Family A:

Mandy's fiancé: *She started speaking in a disorganized manner. She was much disorganized. The one moment she would be happy, the next moment she'd just be terribly sad. And uhm … yes, that was the big … the big …*

Mandy's mother- in-law: *Yes, the two weighed against each other. The one moment she would be so excited and the next moment she'd just cry for an hour long like a baby at shakes and you could not console her. I think that was the biggest two.*

Mandy's mother: *She sent me odd sms' but not, I didn't know what to think. I didn't think that she was busy losing her head.*

Interviewer: *What was odd?*

Mandy's mother: *Uhm … the very first one she sent me was, "I love you all so much, just as if you were my own children." That was her first one and I thought, well that's odd.*

Mandy's mother: *Yes, now that Sunday before she was admitted. I didn't see her the Sunday but I thought something very strange is going on. That Sunday morning, she sent me a sms, "Ready, steady, go". That's all. Now what does that mean? (Dramatically throws her hands up into the air and shakes her head to indicate disbelief. All the other interviewees smile).*

Family B:

Gavin's sister:	*But after that he definitely began to show symptoms of uhm of … something not being psychologically well.*
Gavin's sister:	*What he also started getting it … uh … how can I explain it? Let's say the uh … say the depression that he developed on his own and the fact that he … at a stage he withdrew himself from the … from social world. He, for example, did not at all want to associate with people or socialise with them.*

Family C***:***

Candice's mother:	*I'm sorry. She's here but she's not here.*
Interviewer:	*You say she's here but she's not here.*
Candice's mother:	*Yes … (starts crying). It's not my child.*
Interviewer:	*I can hear that it's very difficult for you to speak about …*
Candice's mother:	*It still upsets me an awful lot, if you knew how she used to be.*

Family D:

Jane's father:	*We sort of just accepted that she's a bit odd …Oh, oh, another … she used to do is when she has this uh… before she got treatment … she used to wander out … out of the plot and wander … and wander all over the place and … like the one day … she'd walk along the road and walk right to (names church) which is right in H which is far away. And the one time, the driver picked her up*

and thought she was on drugs or something (chuckles). And you know she … I … she really behaved oddly before she got … started treatment.

Jane's mother: *In 2006 it got …got worse. These sessions of having a go at me. Mainly me. Apparently they go for the person closest to them. And uhm … that's why Dr A told me, (laughs) and she uhm uh we spoke to the th tho …those same counsellors at W. Wayne phoned them and told her mannerisms. She was TERRIBLY restless. She could not concentrate. She could not sit for five minutes.*

Step 5: There is uncertainty and disbelief within the family about the crises and life changes

The person's response to the crises or life changes creates a sense of uncertainty that the family finds difficult to overcome.

Family A:

Mandy's mother: *She had definitely put aside all her emotions … she was sad, you could see that but she just got over everything too soon and up to now she is still unsure if Liam is ok. That, I know. She believes but it worries her because he doesn't know.*

Family B:

Gavin's mother: *Then he lost trust in Dr Q and uhm we took him to another psychiatrist. It was a doctor in Attertown and when he didn't come right with him we took him to Dr. J in Lionsville. Ok and that is where the problem actually started.*

Gavin's sister: *So he contacted me the whole time and wanted to know, how do I feel, am I ok, that sort of thing. Am I ok, you know?*

Family C:

Candice's father: *Take now the effect of the illness at present … is her ability to see things through … you … uh … you cannot yet see things through. She will … almost half … as if she will lose interest in something (uses hand gestures to help illustrate is point). That, that worries me you cannot … if you're still so sick then you cannot go and study.*

Family D quickly attributed the participant's behaviour to mental illness and incorporated this into their view of their daughter. However, it appeared to influence their view of her ability, competency and the manner in which they treated her.

Jane's mother : *I don't care. I'm passing university (smiles awkwardly).*

Jane's mother: *Yeah, but it's gonna take a few years. It just sort of bothers us that we are bit old (laughs).*

Theme 2.6: Understanding is constructed from personal experience

Each person in the family appears to construct their understanding of the crises and life changes differently based on their own experience which results in different descriptions of the experience.

Family A:

Mandy's mother: *I have spent nights lying awake and wondering … I couldn't … recognize any depression or anything because I … I will know. I couldn't recognize it.*

Mandy's fiancé: *We were closer to each other after my operation. When I got home, we were in love again like we were five years ago when we met each other. It was like that again. I'm not saying our love went missing. It was just, we were … she and I were closer to each other.*

Interviewer: *Tell me, how did things in the family change after Liam's operation?*

Mandy's mother-in-law: *I think they were closer to each other. I think everyone recognizes …*

Mandy's mother: *The one needs the other one.*

Mandy's mother- in-law: *… the one needs the other one (bursts into tears). Then you're grateful and you're … (unable to continue).*

Family B: Gavin's sister provides a view which differs from their parents.

Gavin's Father: *Let me put it this way. He and his sister are reasonably close. (illustrates the point with his fingers). Normally if she, like telepathy. When here is something wrong with his sister, then he tells me or his mother, "Call Lisa and ask her if there is something wrong."*

Gavin's sister: *Uhm … but I wouldn't say we really have a … uh telepathic type of communication or something like that. I think it's more a premonition of him wondering if I'm ok, that type of thing. I will usually just call my mother and ask how is it going with him and is he ok?*

Family C:

Candice's father:	*(Describes his initial frustration at going shopping with Candice.) Uhm … and uhm … in the beginning I used to get cross for such things. You know ... now I buy things and she doesn't want them and I have to return them. You know, that sort of thing.*
Interviewer:	*(Addresses Candice.) This thing about the clothes. Do you remember the thing about the clothes?*
Candice:	*Uhm … It's difficult to explain because it's sort of like I got bonus points if I did certain things. Or certain … I would have rescued people if I did certain things and uhm if I accepted something from those people then … then it would count against me.*

Family D:

Jane:	*Suppose it upset the family*
Jane's mother:	*Little bit, but we just … (shrugs).*
Jane:	*Little bit, how do you mean? In what way?*
Jane's mother:	*We just worry. Well … a feeling of … helplessness. You know how to help her. And you know when she was admitted to Weskoppies. You just (moves her hands and arms close together and then apart in front of her body). You know it's a slow system and we just didn't know what … what on earth we were supposed to do. We were just like grateful that Dr A came on the scene and sorted it out so pretty promptly. But I think it's just the system that's pretty slow.*

Jane's mother: *No, well for us … no really what was positive for us to see the … the change at Weskoppies from when she came in and she left. We just got to remind ourselves often of how ILL she was when she … she was admitted. And how … Dr A told you didn't she what a different person she was when she came out.*

Theme 2.7: Compounding stressors arise from within and outside of the family

A number of compounding stressors are reported to arise from within and outside of the family which introduce further stress for the participants.
Participant A

Interviewer: *What do you find is the most difficult to handle?*

Mandy: *The fact that my mother cries on my shoulder the whole time because I don't know what to say to her anymore.*

Interviewer: *Over what?*

Mandy: *Marriage problems, stress, all sorts of devil things.*

Interviewer: *If you say devil things, what do you mean?*

Mandy: *Negative things.*

Participant B reports feeling isolated and cut off from his peers. In addition the parent's financial difficulties created further stressors for the family.

Participant C:

Candice: *My family has … alcoholism and I was never a big one for it.*

Candice: *And I don't know if it had any impact but my personal life, my family life before I went to England. It was also sort of chaotic and I couldn't really, didn't really have a place that I could call home.*

Interviewer: *Can you explain further for me?*

Candice: *My parents were divorced and it was really … sort of (indicates tension and messed up by moving her hands around), messed up and no … I had a plan that was my house. But I didn't anymore have a family. You know you don't have that oneness anymore. Uhm … and I think I just Jesus, I just pushed all my friends away so I think I just had a lot … I don't know. I think I just began searching for something better in my life.*

Participant D's family report struggling with finances and social interaction. Their life depends on making the farm a working enterprise but it does not appear to be very successful at present. Still, the entire family is expected to help with work on the farm.

Theme 2.8: Resentment against other family members for not sharing their suffering

The experience of the participants appears to be negated by the interaction in the family which leads to a sense of resentment, although there are some positive events reported.

Participant A:

Interviewer: *How … how was your family towards you?*

Mandy: *My father said oh, here comes something. My mother didn't believe me at first, but now she does.*

Interviewer:	*How did you perceive their response? What did you think about how they reacted towards you?*
Mandy:	*It's unfair that they can lead a normal life and I'm not leading one.*
Interviewer:	*Ok. How will say that their lives are normal?*
Mandy:	*They don't have something that's holding them back, like me. They didn't … there's just no something that holds them back. They can just lead their lives the way they want to and nothing's holding them back.*
Interviewer:	*You speak of being held back?*
Mandy:	*The fact that I could never learn further.*

Participant B:

Gavin:	*Everybody was normal … Then I don't know.*
Interviewer:	*What do you mean?*
Gavin:	*Like nothing had happened or something.*

Participant C:

Candice:	*Uhm (laughs). Yes … I think they pity me. I think … I think my sister is angry with me because I was always the stronger one between the two of us. I think she's cross with me because … I wasn't there for her and she's my best friend. And uhm … she*

claims that I sort of dropped her a little bit. She's a bit angry with me and because I got sick and uhm yes.

Interviewer: *Why would she be cross with you because you got sick?*

Candice: *Not cross with me that … sort of uhm because she waited for me to come back and when I came back I was completely out of my mind. And uhm … she's always a little … she … she's obese and she's needs love, human contact like her cats. She's always got cats and her cats are the sweetest animals, they come and give you kisses and she's just got a really loving personality. And she needs someone to love her and I was too psychotic to.*

Participant D defiantly rebuffs her mother's doubt at one point as to whether she will succeed at University.

Jane: *I don't care. I'm passing university (smiles awkwardly).*

Category 3: Family structure and patterns of interaction found in the families of the participants

Theme 3.1: A history of psychiatric illness found in the families

All the families report either a history of psychiatric illness or what they believe to be a linked or undiagnosed condition in previous generations. In addition, three of the four mothers report a history of being treated for clinical depression. One mother reported at least two attempted suicides in the past, another reported a history of alcohol abuse while a third reported ongoing problems in interpersonal relationships with her partners. The husband of the fourth mother, not diagnosed with depression describes her as generally unhappy at their current life situation.

Family A:

Mandy's mother: *I can't … I went to the doctor for myself and said to him, "I don't know how my daughter is handling this because I can't be strong. It's too much stress and things and when the doctor gave me pills, he asked me, "Now how is your daughter?" I said to him she's fine!*

Mandy's mother: *Man uh … when she was in the other hospital then they also asked me and uhm … my father was here. I don't know why. I know he also went off the rails and yes, he was here.*

Family B:

Gavin's mother: *Yes. It was October because I will say why I know so well is that in November I started suffering from depression. And I … the doctor there basically wanted to admit me.*

Family C:

Candice's father: *Ok! At the airport her mother … drinks a lot … drinks terribly. She drank a lot. And I think at the airport when we now went to fetch Candice and when she came, her mother was there as well but you could just smell her mother had drunk alcohol.*

Candice's mother: *There is depression. I was of course totally taken over by depression but not … not that I went easily or anything but I withdrew from everyone and everything. I am actually an awfully social and outgoing person. And it's going … it's going MUCH better with me.*

Family D: When asked to describe the effect, the condition and the events have had on the family, the father responds with the following.

Jane's father: *No it hasn't affected us. We have just … I suppose gets my wife a bit down.*

Theme 3.2: Long term difficulties reported in the family

Evidence suggested that the relationships between some of the parents and their offspring were dysfunctional. It appears that the disruption of the family relationships is overlaid on existing difficulties between the parents. In some of the families there is an enmeshed relationship between one parent and the offspring who has developed schizophrenia while in other families, one of the parents is either over- or underinvolved with one of their children and this has changed the roles in the family.

Family A has an enmeshed relationship between the mother and her son.

Mandy's mother: *(Speaking about the father of her children) He didn't have a problem with the daughters but he had lots of problems with my son and I always stood up for my son. So that did cause conflict but not as in everyday.*

Interviewer: *What sort of problems did he have with your son?*

Mandy's mother: *Uhm … like he would say no, you don't love me because I don't support him, I supported my children. My children must make me happy because he couldn't do it. Things like that.*

Interviewer: *Was it difficult for you, Mandy?*

Mandy: *Very.*

Interviewer: *What was difficult for you?*

Mandy: *The fact that my mother … always had my brother's back (starts crying). And stood up for him. Not that I was jealous.*

Mandy's mother: *No, speak.*

Mandy: *But I also need mom's support.*

Interviewer: *(Question addressed to Mandy) Do you think your father had a reason to say things like that, that he was jealous of your mother's relationship with your brother?*

Mandy: *Yes, he did.*

Interviewer: *What was the reason?*

Mandy: *My mother is very protective over my brother.*

Interviewer: *Ok.*

Mandy: *Too much, I think.*

Later, the mother says something which suggests that she sees her daughter as an extension of herself however, there is not enough evidence to conclusively state this.

Mandy's mother: *I just want to ask something else. What is schizophrenia?*

Mandy: *It is split personalities.*

Mandy's mother: *Split personalities? Oh, thank God because then I'm also schizophrenic.*

Family B's father appears to be overinvolved in the lives of other family members. At one point during the individual interview with Gavin, the father was seen and heard pacing outside the door of the interview room as if he was attempting to listen in to the interview. The tendency to be overinvolved in the lives of others may stem from patterns of interaction in his own family as indicated in the following interview extract.

Father: *Our family is close because I, you can say, grew up with a group of brothers. And I … my parents stayed with me before they passed away and I always reminded my parents, mom it's that one's birthday today, that one's wedding anniversary. And still today, I will do it with my family. I will say to Lisa, you know Lisa, it's dad's birthday tomorrow, Gavin's birthday. You know we … I think she will say we are a really close family.*

Family C: The interaction between the father and daughter during the interview was perceived to border on flirtatiousness. At one point, Candice has been sitting with her eyes downcast, rearranging her scarf. As her father finishes his last sentence she looks up at him and they share a laugh which appears to happen quite often.

Candice's mother: *Ely went overboard with Candice. And Ely … I'm telling you now, I have told him he's guilty and I told him the other day, "You made as if she was the mother and I was the child." And he altered the roles Ely … Ely … not just the roles with Candice but the role with me and him. Ely thought he was the mother. His mother … he is the middle child, he and his mother and a close bond. He … he was her favourite and she didn't have daughters.*

Candice's mother: *But then he went even further and he put Candice in the role of me. She could make the decisions and I think he put more pressure on her than she … actually was entitled to.*

The interaction between Candice and her mother is laden with conflict. Candice's mother does say some things which may have the potential to upset her daughter.

Candice's mother: *She will lately say to me again, "Well, act like a mother." And I'd say uh … "I am not your child, I am your mother. I know what I'm doing." I'm always saying straight that that … who … what role, where does she then get a role model if I was such a bad mother …*

Candice's mother: *Now she eats. She looks now like a round ball. You know, you saw her and she's fat. But I don't fight or shout. There are many who speak to her about that, but I … if she now gets so fat … but if she again stops eating. But then the doctors said it's actually awfully abnormal that she picks up so much weight and they … they worked out a diet for her and uh …*

The relationship between Candice and her father's new wife was also described as poor.

Candice's father: *At present, ok in the meantime I got married. I think that there … good … I think at this moment the relationship between Candice and Donna is very poor. At this point, I just hope the relationship improves in the future …*

Interviewer: *Are there any difficult relationships in the family?*

Candice: *Me and my stepmother … She said to me that I'm like another woman in the house. And she said to my father that if I'm in her life then she'll divorce my father.*

Family D appears to be afraid of interacting with others outside of the home. The tendency to isolate themselves may have provided few opportunities to test their irrational fears about interacting with other people and helped to foster paranoid thinking.

Jane's mother: *(About keeping their daughter's diagnosis a secret from the rest of the family.) I don't think they'd … just … well they might just get her on the phone and gossip to the next one "Have you heard!" (lifts hand to ear and laughs. Daughter appears to be laughing too.) No. He just doesn't want them to know…*

Theme 3.3: The patterns of interaction tend to repeat

A number of different patterns of interaction appear to repeat within the families.

Family A

Illness in the family is followed by closer bonds in relationships

The family describes Mandy as being very strong but she appears very dependent on her mother and fiancé during the interview, often turning to her fiancé for support and validation. Her family provides an explanation for this differing behaviour.

Mandy's brother-in-law: *"… look a person can be strong up to a point. Then your body says to you, "Listen here, enough is enough. Now it's your turn to get attention. Then the other people must look after you." And that's what basically happened with me there. And … I suspect that's what's busy happening with Mandy."*

Mandy: *I think you're 100% right (she laughs).*

Mandy's mother: *She had definitely put aside all her emotions … she was sad, you could see that but she just got over everything too soon and up to*

now she is still unsure if Liam is ok. That, I know. She believes but it worries her because he doesn't know.

The family rules and pattern of interaction links illness to increased contact and intimacy.

Mandy's-brother-in-law: *She's part of the family. We couldn't understand it and if you care about somebody, then you try and help them to get healthy. It doesn't matter what steps you take but if you can help the person, then you help them. Done and dusted.*

Mandy's fiancé: *We were closer to each other after my operation. When I got home, we were in love again like we were five years ago when we met each other. It was like that again. I'm not saying our love went missing. It was just, we were … she and I were closer to each other.*

Triangular relationships

Mandy's mother and brother are said to have a very close relationship which to a degree, excludes the other members of the family. This is similar to the close relationship observed between Mandy's fiancé and his mother, which also excludes other members of the family. Both women appear to clearly favour one specific offspring.

Tendency to negate the other

Both Mandy's mother and mother-in-law place precedence over their own emotions and tended to interact with others on the basis of their own needs. Mandy is rebuffed when she tries to share her thoughts with her mother. The mother also does nothing to allay her daughter's fears about her fiancé's cancer returning. Instead she is more concerned with her own feelings and adds to Mandy's anxiety, especially when she emphasizes that she shares her daughter's doubt over whether Liam will overcome the cancer.

Mandy's mother: *It's not that she says she doesn't believe you. Look, I … (puts her hand over her heart), I believe if you say to me now that you're ok, I'll believe it. But, here in my heart I'm wondering … I hope you're alright.*

During the interview when interacting with Mandy, her mother-in-law tended to respond based on her own needs, not Mandy's. At one point she is being complementary toward Mandy's of how she handling Liam's illness, but then compares it unfavourably to her own handling of previous traumatic events.

Mandy's mother-in-law: *I must say Mandy was very strong. She was really very, very strong. Uhm … I think what he perhaps is saying with that it had a bigger impact on her … I was the only child and my mother and father died six months apart and six years after them, my husband died. So I'm sort of through two trauma … two trauma reactions short after each other. So I handled it without fuss. She was really strong but I think inside she struggled to deal with the shock thereof.*

A similar pattern was also noted in the interaction between Mandy's fiancé, his mother and his brother. Mandy's brother-in-law persists in putting across his point of view but is often interrupted by his brother and mother during the interview. His mother negated whatever Liam's brother said and seldom responded to his statements. It could be that he tends to play the role of the spokesman for the family's difficulties. This explains why he is often interrupted, not acknowledged and seldom addressed because he speaks about difficulties that make the other members of this family uncomfortable as in this extract where he refers to the sexual molestation that nobody had so far directly mentioned.

Mandy's brother-in-law: *I think it's something traumatic that happened in a person's life or few things that you haven't really worked*

through that then at a later stage … it's like a boomerang, you throw it and it comes back.

Mandy: *Yes, we were using the fast-forward button, now we using the rewind button.*

Family B

Tendency to negate the other

During the interview, Gavin's mother constantly referred to him by looking at him when questions were addressed about him. However, more often than not, his father tended to interject and answer for him.

Gavin's parents also appeared to be more willing to focus on their own health problems. They described their own illnesses during the interview. The father rolled up his trousers and pointed out his veins while the mother recounted her battle with depression and multiple suicide attempts.

Interviewer: *Can I ask this … this incident when Gavin was in hospital. When in 2007 was it? Was it definitely in October?*

Gavin's mother: *Yes. It was October because I will say why I know so well is that in November I starting suffering from depression. And I… the doctor there basically wanted to admit me for uh …*

Interviewer: *You said that you presently take epilim … and the other two medications?*

Gavin's mother: *Yes, the other two that I showed you (When the family arrived, the mother took our all the medication she was on and showed it to*

me.) I find that I forget very quickly about the medication, things that I should've done and so on (hands the medication to me).

Gavin's father: *All that I have, I only use a dispirin. What happens to my veins in my legs, they burst through the skin and make these blue spots (rolls up the leg of his pants to show the spots). I only drink that… like one or half a dispirin in the evening and that's basically everything.*

Interviewer: *What is the dispirin for?*

Gavin's father: *It's for … for my blood vessels that burst under the skin. Then it makes these blue spots.*

Gavin's symptoms coincided with family struggles

The appearance of or escalation in Gavin's symptoms coincided with the occurrence of events in the family or an escalation of existing difficulties. In the first extract, the initial prodromal symptoms coincided with the death of his sister's first daughter.

Gavin's mother: *No, uhm … you know it was in the time period before my … my grandchild was born. My grandchild was born on the 18th May (2007). So it's in the months before. It's probably there by February, March, April, around there.*

Gavin's father: *It was also the period when Gavin started becoming …*

Gavin's mother: *Sick.*

His symptoms worsened when finances in the family created tension between the parents.

Gavin's mother:	*Let me tell you, oh it's just your financial problems that we all … maybe not you all, but us. I am the sole breadwinner, so basically I pick up all the burdens and carry them. Which is probably not necessary but it's just how I am. It's just every now and then that you get that stress. You know if it gets too much for you and you must find an outlet somewhere you know, then it's a difficulty between the two of us (indicates she and her husband). But ugh … furthermore it is (shrugs) so so …*
Interviewer:	*It sounds as if there was some uncomfortableness in this period?*
Gavin's mother:	*Mmm, yes. There was, yes.*
Interviewer:	*Was this in the first six months of 2006 or …*
Gavin's mother:	*Oh, you know what? It was probably in 2007, that's when it was.*

His tendency to isolate himself mirrors the parent's own sense of social isolation.

Gavin's sister:	*I just ascribe it up he … he … isolated himself too much from the rest of the world I think I can say and was too much on his own and formulated his own ideas. And many of those ideas were … were very … were not, what's the word that I'm looking for uhm … uh … now I don't have the word. It won't come. It was very … I can't think well what I want to say, not in the real sense or actual situation.*

<u>Repeated patterns allowed for cathartic reaction in family members</u>

Both the mother and daughter in this family had the traumatic experience of having their infant babies die. It is said by the family to have added further sadness and trauma to the experience of the event. Yet, the impact of the experience repeating led to a catharsis for

the father as seen in the extract below.

Gavin's mother: *(Speaking about Gavin's father) Look, what happened to Jenny was actually a big dramatic thing for him because he never held her. He couldn't … we … he only held her the morning that she died. And that was traumatic for him. And he also didn't go for treatment to talk about the whole story. And even with Jasmine ... with Jasmine's uh he's not actually a guy who shows his emotions (touches him on the shoulder). He will keep them to himself and will on his own work through it. I … he's not like me who … will cry openly and you … show my feelings. Even with the two children of ours that died, he didn't really show his feelings (her voice breaks at this point), because he is not that type of person. (Father looks down the whole time. Gavin looks straight at the interviewer.)*

Gavin's father: *Yes. Uh … actually I took my wife for treatment. I didn't see it necessary, I didn't feel it was uh that it affected me that seriously. What I (clears his throat), what I did feel was uh … I didn't want my daughter to go through the pain of drama and trauma that my wife and I went through with those other two children whose death we had to go through. And this … shall we say messed me up or pushed me to a climax. In this regard with the counselling that I took her to uh … she uh … how can I say? (Turns to the mother.) How many times did we go for counselling? A few times?*

Gavin's mother: *I'd say three or four times.*

Gavin's father: *Three or four times we were there and the last time I think that we were there then … of the times she… as she says just cried and … opened up and you know that tension broke. And I in the last*

counselling session that she had, we also just spoke and when I just opened up and started crying that the water streamed out of my eyes and I felt that it was just a weight that dropped from my shoulders.

Gavin's sister: *I think it affected my mother emotionally as well as my father, he … he came across very strong and uhm … when things happened and Gavin was admitted, my father, he then only showed emotion and you know … really cried over it which he had not done before.*

Family C

Among the patterns of interaction that appeared to be repeated in the family noted, three stood out. Firstly, the relationship between Candice and her father is similar to that between her father and his mother.

Triangular relationships

Candice's mother: *And he altered the roles. Ely … not just the roles with Candice but the role with me and him. Ely thought he was the mother. His mother … he is the middle child, he and his mother and a close bond. He … he was her favourite and she didn't have daughters.*

During the interview there was a lot of mock anger and bantering in the interaction between Candice and her father.

Interviewer: *You say that if there was something wrong you thought it was because of drugs?*

Candice's father: *Ja … Just one day she … she half … the … the … redesigned the apartment if I can put it that way. And she had uh …*

Candice:	*That wasn't drugs! (Turns to her father with a mock shocked expression.) It was just the place looked bloody awful (father and daughter laugh).*

Later, there is a similar interaction:

Candice's father:	*And uh … there was one lady who I think was good for Candice. I don't know who helped who there? If Candice helped the woman who she worked for or if the woman helped Candice (laughs).*
Candice:	*Dad is just talking nonsense. I helped her.*

Secondly, it appears that there were attempts to recreate the triangular relationship that existed between Candice and her parents in the relationship between Candice, her father and her stepmother which led to further conflict in the family.

Interviewer:	*Are there any difficult relationships in the family?*
Candice:	*Me and my stepmother.*
Interviewer:	*You and your stepmother? What do you mean?*
Candice:	*She said to me that I'm like another woman in the house. And she said to my father that if I'm in her life then she'll divorce my father.*

<u>The parents tended to draw their offspring into their disputes.</u>

Candice's mother:	*… he said the divorce was my fault. I played around and I will say to you, yes, but ask me why did I? And then he involved the children in it … that I didn't feel was right, even now because*

Candice and I still talk about it now and she will still now say to me, it's your fault. I said, Candice you have never been married. You've never had kids. The day will come … no, the day will come when you have kids.

Family D

Tendency to negate the other

The mother in this family tends to be quite critical in her responses. At one point the following exchange occurs between mother and daughter.

Jane: *(Shakes her head to indicate yes). Yah …I … am sort uhm … (looks at her mother).*

Jane's mother: *She's still a bit disorganized (laughs).*

Jane: *In 2004 I went to P College's counsellors. They just helped me with time management (looks at her mother). They didn't help me with much else (starts scratching the top of her hand). And then … then after that I went to University to become … a communication science … and I decided no I … that's not for me so I started to swap to education and I'm doing full I'm doing ok at this moment (stops scratching and looks at her mother).*

Jane's mother: *We persuaded her brother to take her to a movie and she could not sit through that movie. She had to walk out of that movie… and he … he refused to ever take her again (laughs and gestures by crossing and uncrossing her hands).*

Paranoia and irrational behaviour

Both parents tend to have paranoid tendencies and feared interacting with others which impacted on how the daughter expected other people to behave.

Jane's father:	*I dunno, sometimes the … the … the … like they can just decide to … the other kids can decide to like … like Sharon's not with it or something and they all get together and they gossip and you know that sort of thing.*
Interviewer:	*What kind of behaviour … can you give me an example, Wayne?*
Jane's father:	*Well … well we arrived at this art class … there was that … these girls there and they were … they were all waiting for the art class and they'd just give her these cold stares and they'd been together in class for a while.*
Jane's mother:	*I don't think they'd … just … well they might just get her on the phone and gossip to the next one "Have you heard!" (Lifts hand to ear and laughs. Daughter appears to be laughing too.) No. He just doesn't want them to know …*

Theme 3.4: There is extensive use of non-verbal communication

Common to all families is an emphasis on using non-verbal communication to supplement their speech content and to add to the context of their communication.

Family A:

There was a marked contrast between how the participant and her mother communicated in comparison to the members of her fiancé's family. Both mother and daughter blended events, times and emotions into their speech affecting the clarity of their communication.

Family B:

The parents in this family tended to use their hands a great deal to support the content of their speech. They also relied on concrete forms of communication which perhaps does suggest that they struggle with abstract entities e.g. the mother showing the interviewer all the medication she is required to take and the father displaying the veins on his leg to illustrate his physical ailment.

Family C:

The father and daughter make repeated eye contact and laugh repeatedly at each other's jovial statements. In contrast, large parts of the mother's interview were barely intelligible as she combined timeline, people, events, emotions, thoughts and actions into a continuous outpouring.

Family D:

Both mother and daughter presented an uncomfortableness during the interview, constantly shifting position in their chairs, the daughter fumbling in her handbag and repeatedly hinting that they should be leaving, thus the interview was of an extremely short length at their request. The father's speech also lacked clarity, enunciation was poor and he blended events, dates, actions and other experiences into his stilted speech.

Double-bind communication

Jane's mother tended to put her daughter into a double-bind by saying something that appears to be sympathetic and then laughing inappropriately or showing some other non-verbal action that modifies the content of the message.

Jane's mother: *… but she was convinced that she was going to hell. That was one thing. Absolutely convinced that she was going to hell no matter what I tried to tell her, she was going to hell (gives a stifled laugh).*

Jane's mother: *At school when was she was in Std 9 and as she said when she went to see the counsellors and the … she just seemed to develop*

this thing that she had uh felt the people were laughing at her (laughs). That was the only…

Jane's mother: *College. Probably the stress and the unhappiness. She was very unhappy and instead of saying I CANT COPE (the mother raises her hands to her temples and throws them down into her lap), she battled her way through that year (chuckles).*

This type of contradiction appears again the in the way she describes her son:

Jane's mother: *Her brother gets impatient with her, I suppose. But he's impatient with all of us because he's … he thinks we're all dumb (scrunches up her face and laughs). He's clever.*

Jane's mother: *I don't think he's a great social success. He's … he enjoys his work. He's got a couple of friends that he's known mainly tied up with his job. He's a programmer so … you know what they are like. When they on a job, they don't talk till it's finished.*

Theme 3.5: Intense fear of stigmatization

Three of the four families reveal a fear of stigmatization; however, this fear does not arise in the individual interviews with the participants. Within the families, this fear leads to secrecy about schizophrenia and fears of being be discriminated against by others.

Family A: This theme was absent from both the individual and family interview.

Family B feared the consequences of people finding out about Gavin's condition.

Gavin's father: *You go for example to a rehab centre or you go to Weskoppies, then a stigma sticks to you. And if you for example … later go back or get into contact with those people, I wouldn't say they cut you*

off … those that understand will know what it is about. But the large majority of, especially the young people, don't have what an Englishman would say, a clue as to what really happens or what is the cause and a person doesn't now … say for example recount seven years of history and say listen here, he's now the topic of interest and at the end of the day, it gets misused. So in other words we just kept it to you know, our own family. Those that … let me say at some stage got an inkling … uh didn't really know what, what happened.

Gavin's mother: *You know he was in a special school, ok. Uhm … I myself realize that it was a mistake. I kept it away from my friends. I was scared that if I tell them that I was in a special school then I was going to lose their friendship. Until I spoke to a friend of mine one day and I … she said to me that her husband was also in a special school. So I said to her, I cannot believe it. She said to me, yes. I never had the courage to speak to her about Gavin because she knows that her husband was in a special school and today there he is, a qualified electrician at the town council. The … I realized but listen here, it's not necessary to hide him away. He also has a right to live with others and from then I opened up and my friends did not push me away. We became closer rather than distant.*

Family C feared telling their own family members about their daughter's condition.

Candice's mother: *His mother didn't know. He did not want to tell his mother. His family did not know. My family knew at the end of the day because my one brother's daughter is also a medical … a medical doctor. And uhm I called her and she did in a way … Ely was … uh … uh … he said if I married him then I didn't have to call him. I did scream and swear at him … I'm the first one to admit it but then I*

was very angry. I'm like any person. It's … it's as if it's now for me … now but then he went to tell his mother schizophrenia. My mother knew. I just said if it's like that then it's something we need to … because my brother's daughter had said to me, deal with it. Sort it out, deal with it … but I must uh … for any person, I don't want to go and sit on the corner of the street now and tell someone she has it but it is … it is if something is not part of your life as I said to you yesterday, then you're too ignorant and I uh you don't really know.

Family D were the most wary of others findings out about schizophrenia, but they also voiced much fear and anger about the reaction of others to family events.

Jane's mother: *People don't talk about these things. Eish, they don't talk about these things. Schizophrenia phwoo! (Laughs.) (Daughter smiles, looks down into her bag. Looks up again and smiles while glancing from her mother to the interviewer.)*

Interviewer: *How is it in your family? Is it discussed in your family?*

Jane's mother: *No. The only … I haven't spoken … I have not told any of my husband's family … he does not want them to know. He just doesn't want them to know. He feels it's … he doesn't want Jane to be embarrassed. And my immediate family, they know.*

Interviewer: *(Turns to Jane.) Do you feel the same?*

Jane: *I don't know … I'm not very good at picking up things like that, I don't know. (She laughs, spread her hands out and looks at her mother.)*

Jane's mother: *She doesn't seem to worry her so much. We just feel that that … ostracise her or not that they have much to do with her. Well it's not their business (spreads her hands out and laughs). So why should we tell them. (Her tone suddenly changes and becomes steely.) We just feel it's not their business.*

Jane's mother: *Well, you know what we also worried about Jane's … she's gotta get a job one of these days. (Daughter looks down at her bag, unclasps her hands, scratches on the outside of her bag, reclasps her hands and looks at the mother.) And if people think she's … there is a stigma attached to any form of mental illness. And we just don't want people to know that she's … has a problem.*

4.3 Discussion

The first part of the discussion will focus on the general themes found in the data and these will be related back to the content discussed in the literature and review. The second part of this discussion will organize and analyze the data according to the fundamental questions in a systemic approach outlined by Becvar and Becvar (2003).

4.3.1 Crises and life changes are reported to precede the onset of schizophrenia

Crises and life changes involve the entire family system

The initial motivation for this study was the suggestion that the schizophrenic crisis of one member coincides with the threat of another member leaving home (Selvini et al., 1980). This was only found to have occurred in the case of Family D and the older brother did actually leave home. In their subjective reports, neither the participant nor her family established a connection between the two events. While Selvini et al. (1980) relates onset to the threat of an adolescent sibling leaving home, Howard (1997) relates the timing of onset to growing independence of the individual herself who goes on to be diagnosed with schizophrenia. This is consistent with family theories that suggest the failure to develop an adequate ego identity is responsible for a psychotic disturbance in

the face of increasing environmental demands (Shean, 1978). However, the findings of this study suggest that the threat of anyone in the family embarking on greater independence may threaten the structure, rules, roles and myths of the family. Therefore the threat is against the identity and survival of the family system in its current form.

The threat of crises and life changes is located in the possibility of loss

The types of events described by the participants and their families differ but a common theme was loss or the possibility of change that was either life threatening and/or would alter the structure of the family forever. This finding was consistent with the theme of loss reported in the findings of Smith (1991). According to Myers et al. (1972), loss is be more strongly associated with impairment because "societal systems to deal with loss may be inadequate and more meaningful systems of social and interpersonal support may have been developed around gain than loss" (p.404).

Some examples of these events include that of Participant A, who was going to marry her fiancé creating the possibility of disruption in his family. The threat of disruption also arose from her fiancé's being diagnosed with a life-threatening illness. In Family B, the maternal uncle had decided to remarry someone of a different race which upset the family and was experienced as a threat to its identity. The daughter also began to establish her own family. Both of these faded in comparison to the loss of the infant granddaughters. In the case of Participant C, the situation is unclear because there are so many interacting events. Firstly, both her mother and father began new relationships, her sister prepared to leave home and live abroad, there was significant substance use on her part and she spent more than a year away from the family. The exit from the family home of Participant D's brother may have triggered a long-standing fear of family upheaval and break up of the family system which threatened to continue if Participant D completed her studies. The case of Participant D also suggests that the person with schizophrenia may struggle to attain what is valued in these families. Participant D was compared to her brother whose graduation was "the best thing that had happened to the family" and it was implied that now she was "ill", she would probably not meet the goals and outcomes valued by the family.

Underscoring the theme of loss, onset occurred at a time of transition for the family which related to the threat of change in the family structure. This is consistent with findings by Carpentier et al. (2007) who drew attention to the, “transitions experienced by families when a young adult member of home-leaving age begins to develop a severe mental illness” (p. 397). However, the findings of this research suggest that transitions are experienced in the family, not just with losses but also with gains which alter the family system and raise the possibility of change in the status quo which requires some form of adjustment from the family.

The type of life crises and life changes reported by the participants

Consistent with the findings of Myers et al. (1972) and Jacobs and Myers (1976), most of the events reported by participants were of an undesirable nature including life threatening illness in the family, deaths, recollection of sexual abuse, divorce, family conflict and feeling socially ostracized. Many of these events required some form of adaptation or role transition and failure to adapt or acquire a new role left the individual diagnosed with schizophrenia behaving in a way that could be labelled dysfunctional.

Recent events appear to trigger the memory of earlier events

Some of the events can be construed to have had an aetiological influence over a considerable amount of time as they had occurred many years previously but were still experienced by the participants and their families as significant. This is consistent with earlier findings by Bebbington (1993) who found that events can “exert an aetiological effect across a sizeable interval” (p. 77) and with those of Brown and Birley (1968) who noted that some events were of particular symbolic significance based on previous experience. In most instances, recent events triggered the memory of earlier events. Participant A was reminded of being raped after seeing the perpetrator and her fiancé underwent an operation on the same day her previous partner had been involved in a serious crash. In Family B, the deaths of mother’s own children were relived because of current events. Family C’s triadic relationship repeated with her father and his new wife and in Family D, the feared threat of a family break-up was evoked by a son leaving home.

The relationship between life events and social circumstances

The narratives of the participants lends support to the arguments put forward by Al Khani et al. (1986) that some life events might operate as precipitants in schizophrenia, "because they are a sample of a larger domain of potentially upsetting social circumstances" that influence the lives of a particular subgroup in society (p. 21). Three particular themes are noted with regards to this aspect. Firstly, the difficulties brought on by low social economic status and financial struggle created particular stressors in Family B and Family D between the parents, but also contributed to their fear of being stigmatized and ostracized by others. The second theme related to this, is the defining of traditional sex roles for men and women and the families' reaction to them. There was particular tension between the parents in Family B as the mother who is the sole breadwinner said that during times of stress it becomes an issue in the relationship. A similar dynamic appeared in Family D where the mother describes farming as being very hard work with little reward and despite this, her husband's still insisted on continuing.

4.3.2 The subjective experience of the participants and their families

There is a history of subjective awareness

Consistent with the literature findings by Aylward et al. (1984) and Jones et al. (1994 as cited in Walker et al., 2004), all the participants, except for Participant B, said that they first experienced subjective changes during the pre-psychotic phase when only they were aware of subtle differences in their own experience. The most often reported symptoms were difficulties in concentration and a sense of general confusion. In two cases, this picture was contaminated due to other medical conditions or substance use.

The results reflected variation in the history of subjective awareness of significant stresses reported. There were certainly overt stressors and losses reported as in the findings of Barker et al. (2001) in all of the families but there was variation in the extent of unhappiness reported in the interpersonal relationships (Adamson & Schmale, 1965). The level of dysfunction ranged from incestuous rape, to inappropriate parent-child relationships, to covert resentment and unhappiness at the family or marriage situation. Unlike the experiences reported in the literature, there was no mention of frequent

somatic complaints from the participants themselves but more from three of the four families. Only one participant's history matched one of the two descriptions noted by Gerace et al. (1993). Participant C was said by both parents to "always be in a daze" from early childhood and a little "off".

The family's description of Participant D was consistent with results by Barker et al. (2001) of someone normally well-behaved but who began to break parental and societal boundaries during late adolescence with the development of schizophrenia. Difficult life events such as being ostracized at college and her brother leaving the home were said to have preceded onset and lead to marked observable changes in character and functioning.

Onset of schizophrenia

In all instances, basic symptoms were present long before the onset of prodromal symptoms. However, at these times, the families were reacting to other crises or life changes and the gradual changes in the individuals were viewed within this stressful context. Thus, the prodromal or even pre-psychotic symptoms did not lead to immediate action, something that is significant for the debate regarding the existence and importance of prodromal symptoms as outlined by Norman and Malla (1994). Some of the strange symptoms which the individuals presented with were construed as exacerbations of long-standing behaviour accepted by the family. Carpentier et al. (2007) stated that assessing the physical and mental states of a person is a complex process influenced by cultural values and attitudes and that the amount of time that passes before help is sought depends on what level of tolerance the family has as a result of their own beliefs and experiences.

The participants described their experience of the onset of schizophrenia consistent with that put forward by Cutting and Dunne (1989) who stated that, "on the basis of subjects' recollections … there is an undoubted and dramatic change in the way they perceive the world and experience the working of their own mind at the onset of the disorder" (p. 230). The experience of fragmentation outlined by Kupers (1976 as cited in Poster, 1988) was predominantly recounted by the individual participants when they described the initial onset of psychosis and said that their world appeared to "fall apart". Onset was

gradual in all cases with a temporal unfolding of symptoms consistent with earlier findings described by Barker et al. (2001). The families were able to recognize changes in behaviour at the time but in retrospect noted earlier indications of a serious condition. Onset of psychosis was defined by a combination of the appearance and escalation of psychotic symptoms and a marked change in the individual's everyday social functioning consistent with the description of onset described by Chung et al. (1986). The time of onset was in late adolescence or early adulthood for three of the four participants which is consistent with literature findings reported by Sadock and Sadock (2003).

In the majority of the cases in this study, the behaviour changes were dramatic, perhaps partly due to comorbid illness (Participant B), the nature of the stressful event (rape in the case of Participant A), long-standing conflict and tension in the home (Participant C), and specific family dynamics (Participant D). During the active phase, the most often noted symptoms by participants and their families were hallucinations, delusions of reference, strange or odd behaviour, ideas of reference and thought alienation, matching those listed by the *WHO* (1973 as cited by Frude, 1998).

Significance of the experience

The subjective experience of schizophrenia reflected some of the difficulties the participants struggled with in their families. The condition impacted severely on the participants' ability to care for themselves, incapacitating the individuals and hampering their attempts to move forward in life.

Participant A said that the condition overwhelmed her and brought her world to a standstill. The withdrawal from others impacted on the fundamental ability to relate to others. She suffered repeated denials of her own experience and personal boundary violations within her family which subsequently led to further withdrawal.

Participant B had a lack of peer interaction and his hallucinations provided him with someone to interact with. There was significant deterioration in his ability to care for himself. More importantly from the perspective of the family as a whole, the impact of

the loss of the sister's two daughters can be explained using the concept of symbolic loss referenced in Adamson and Schmale (1965). A symbolic loss is defined as a type of loss "which, although of little current significance, reawakened conflict over actual or fantasized past losses" (p. 564). In this case, the father had never grieved for his own children lost and he reports a cathartic unburdening which arose from mourning the loss of his current grandchildren.

Participant C's experience of leaving home and living in a foreign country, together with the crises and life changes that occurred before and while she was abroad suggests that she may have decompensated in a situation where her social support network was strained or unavailable, something that has been described by (Beck & Worthen, 1972 as cited in Gureje & Adewunmi, 1988).

Her symptoms and appearance hampered her ability to function in a social and occupational context because everything acquired special significance. She viewed her psychosis as a "spiritual journey" to help her bring a "sense of oneness to the world", a sense of cohesion that was clearly missing from the relationships in her family. This is not unusual as Bowers and Freedman (1966, cited in Buckle, 1981) have previously noted that there are similarities between some aspects of mystical experience and the onset of psychosis, notably the experience of heightened consciousness or awareness.

The participant also reported experiencing a sense of "specialness" in which she could interpret hidden messages and possessed special powers. "This sense of noesis is often accompanied by a state of exultation and a feeling of being in direct communion with God" (Buckley, 1981, p. 516)**.** Within an analytical perspective, the participant's dream of rectifying world errors can be constructed as a wish to reconstruct her "broken" family. Buckley (1981) argues that there are important differences between psychosis and mystical experiences, namely the disruption of thought seen in the acute psychoses is not something that is usually found in accounts of acute mystical experience and mystical experiences are usually self-limited and generally brief.

Participant D struggled with the prospect of failure in a family that valued success and equated failure with shame. Of all the families, the tendency for isolation from social interaction was most pronounced in this family. Isolation with diminished opportunities for reality testing of delusional fantasies may have served to reinforce the psychosis in this participant. Certainly, some aspects of her psychosis such as the belief that people were hostile and would be inclined to speak ill of her was shared by both of her parents. This again suggests that it is not clear for how long the premorbid symptoms may have been present before her family decided on treatment. This is illustrative of Geller's (1995 as cited in Carpentier et al., 1999) observation that, "delays in professional consultation, compounded by the isolation that characterizes certain families, can exacerbate the person's paranoid symptoms and reinforce the erratic behaviour that will trigger situations that lead to the use of coercive measures" (p. 397).

In two of the case studies, there was significant other factors noted. Participant B was diagnosed with high blood pressure and pancreatic difficulties. Participant C had significant substance abuse. Both of these may have influenced both the clinical picture they presented with and their subjective experience of events that preceded schizophrenia. This is consistent with the debate around the issues of diagnosis which state that medical conditions and the effects of different substances also lead to symptoms of psychosis, but these symptoms can be identical to many other psychiatric conditions (Sadock & Sadock, 2003).

4.3.3 The participants' understanding of schizophrenia

Participants' reveal little formal knowledge of schizophrenia

Consistent with findings by Roe and Davison (1995), the participants had little formal knowledge of schizophrenia and even when they were admitted for treatment, there appeared to be little transferring of the formal medical knowledge of what was afflicting them. Thus, if insight is equated with knowledge of schizophrenia, then these patients would be classified as having little insight. However, they do have rich and in-depth explanations drawn from their own experiences.

The families were also reluctant to accept the diagnosis of schizophrenia because it is believed to be a lifelong illness and they also feared the accompanying stigma. Apart from Participant B who had been diagnosed with moderate mental retardation and spoke very little, all the patients gave a history that was coherent and reflected the major crises and life changes in their family lives and relationships consistent with findings by Fleck, Alanen and Cornelison (1963 as cited in Adamson & Schmale, 1965).

There is a tendency to focus on the more prominently observable symptoms

Consistent with the literature there is a greater focus on the more prominently observable symptoms, usually an aspect of schizophrenia or mental illness that has been publicly seen or discussed, such as hearing voices or the person speaking to themselves when the families conceptualise schizophrenia (Hoening, 1983), yet families recount their experience of the person very much in line with Bleuler's motivation for introducing the term schizophrenia, that there is a "splitting or tearing of the mind and emotional stability of the patient" (Walker et al., 2004, p. 403). This justifies Schneider's call for both objective and subjective study of the person with schizophrenia. It is clearly evident that the symptoms described in the *DSM-IV-TR (2000)* do not fully describe any of the cases and substantiates the belief that the diagnostic framework is more geared towards providing general criteria for a possible diagnosis and not a complete description of the condition.

All of the participants were aware of being treated for a condition called schizophrenia even though their understanding of schizophrenia as a mental illness was minimal. The ability to understand the condition is complicated by the variation in presentation but also by the participants' and their family's reluctance to accept that they have a debilitating condition. More often the participants and their families related the person's state to events that had occurred within and outside of the family such as trauma.

The poor understanding of schizophrenia reflects some of the more pertinent aspects raised in the debate on the concept of schizophrenia. Firstly, milder forms of the behaviour identified as symptoms of schizophrenia have been present, not just in the

participants but in attributes of the family members for years. Secondly, this behaviour fluctuates over time. Thirdly, there are many differences in how and with which symptoms the participants present. All these points make it difficult for the families to initially identify that the person is suffering from schizophrenia before the overt symptoms set in (Gerace et al. 1993; Norman & Malla, 1993b).

Beliefs on the origin of schizophrenia

There was consensus across the interviews that traumatic events led to stress which could result in a condition called schizophrenia. However, the nature of the traumatic events was particular to each family. Most of the participants believe that stress from life changes and crises contributed to the development of schizophrenia. Poor insight was not as much of a problem as lack of knowledge on schizophrenia, especially lack of familiarity with the bio-medical model of mental illness.

Sexual abuse was only overtly mentioned in one instance but its presence in the history of someone with a diagnosis of schizophrenia is not surprising based on findings which suggest that up to two-thirds of people diagnosed with schizophrenia have suffered physical or sexual (Sitford, 2006). It is argued that there may be similarities in the symptoms of post-traumatic stress disorder and schizophrenia. Participant A recalls an active dislike of and an aversion to her abuser. It also appears that she suffered from memory loss and only recalled the incident in the period before being admitted to a hospital. This suggests some link between the trauma of the recollected abuse and her symptoms. However, further investigation would be required into these tentative links.

In the period after onset, the descriptions of experience were consistent with the findings reported by Gerace et al. (1993). The patients tended to find their own understanding of why they had developed schizophrenia but also noted the medical explanation of a brain disease or genetic disorder. There was a tendency to question early childhood events and recall similar behaviour observed in a relative of a previous generation. There was a great deal of variation in the personalized explanations for the onset of schizophrenia and taking a position appears to be less anxiety-provoking for the family.

4.3.4 The interviewer's experience of the families

Consistent with the literature on factors in the family that may contribute to schizophrenia, the condition involves interaction between the entire family.

There is a tendency in the families to be reticent and guarded

The information provided by the families was not always complete. For example, one participant's mother was almost admitted to an institution for depression and she failed to mention this when asked if anyone in her family had been treated for mental illness. Similarly, when asked about difficulties in the family, the family of Participant B suddenly went into an unusual silence. Instead, Participant B who has been quiet for most of the interview answered without being prompted. The father of Participant C continually checked himself where he spoke about his divorce. These omissions suggest that the respondents were less than candid in providing information. The overall trustworthiness of the information has to be accepted with this in mind.

Families evidence a disorganized communication style

The disorganized communication style of the participants and their families led to some difficulty in understanding them. They blended events, dates and places so often that clarification constantly had to be sought. The degree of disturbance differed from family to family, but an element of this was present in all the families. The central role that communication and the processing of communication has in systems theory suggests that this style of communication may be contributing to the patterns of interaction in the family. As noted in the literature review, it is hypothesized that the genetic load for pathology influences how a family interacts and this may create unusual events that affect the individual, inducing events of greater stress that can affect the mood of those vulnerable to schizophrenia either in the time preceding the onset of psychotic symptoms or by a change in mood that coincides with onset (Dohrenwend & Egri, 1981).

Laughter was present in all the family interviews, except Family B. This appears to reflect the intense sadness and mourning that that family is recovering from. In the other families, laughter served a different function in each case. In Family A, it served to

provide an entry point for Liam to take off his hat and speak candidly about his brain surgery and show everyone the staple and scar from the operation. In Family C, it served to lighten communication that may have caused conflict between father and daughter. In Family D, it was initially the researcher's subjective perception that laughter served to modify the message communicated by the mother. This recalls a similar situation of the mother of a patient described by Bateson (1972b as cited in Gelbmann, 2003) who continually contradicted her own message identifier by laughing at things that were least funny to her. This was said to make the interpretation of messages in communication extremely difficult. However, Zuk (1964 as cited in Zuk & Rubenstein, 1965) has presented "evidence to show how laughter may be used to disguise or qualify information; how it may be used to maintain an alliance among family members against an outsider; and how it may be used to discourage psychotherapists from pursuing certain lines of inquiry" (p. 20).

The relationships in the families

In all the families, there appeared to be some form of conflict between the parents. In two of the families this conflict had become overt and led to divorce. In the other two families, underlying tension was acknowledged and accepted as part of being in relationship with others. The relationships between the people in the family were destructive or potentially destructive to the family system because of immature or pathological responses. However, these responses appeared to maintain some of the behaviour of the person diagnosed with schizophrenia.

The participants' mothers report suffering from depression

In three of the four families interviewed, the mothers all suffered from depression either at the time of the interview or they had previously been treated for depression. The mothers also appear very emotional and dramatic in how they communicated. The depression indicates that some underlying pathology or vulnerability was present in the mothers from the child's early years. Children raised in such an environment with all the boundary violations and rigid roles are speculated to suffer from several developmental

shortcomings or deficiencies in psychosocial functioning which may contribute to the conditions necessary for the development of schizophrenia (Walker et al., 1994).

The characteristic patterns of interaction in the family

Families B and D voiced pronounced suspiciousness and distrust of the outside world and in both families there is a tendency to distort reality. What might be termed irrational ways of thinking and behaving also appeared prominently in both families. In Family B, the father believed he could "channel the holy spirit" and that his offspring had a telepathic connection in which they could communicate psychically. In Family D, there is a great distrust of other people and seemingly innocent interactions may be construed as hostile. Obvious interpretations of reality are continually denied in favour of those that fit the family culture and reality testing is seemingly poor.

Family D also expressed a deep paranoid-like fear of social shame which might result from outsiders gaining knowledge of the family, from their socioeconomic status and the possibility of divorce, even though there was clearly tension between the parents. This type of behavioural pattern is significant in learning theory which suggests that children learn and imitate the irrational behaviour of their parents and go on to develop schizophrenia as a result of lack of proper modelling in poor interpersonal relationships that begin with relationships in the family (Sadock & Sadock, 2003).

The experiences and needs of the person with schizophrenia appear to be continually negated in their interaction with their family. Participant A's mother responded to her daughter on the basis of her own needs in a way that is consistent with the explanation for schizophrenia put forward by early psychodynamic theorists (Shean, 1978). The mother makes all her daughter's difficulties her own and behaves as if she has been affected by schizophrenia. She often did not validate her daughter's experience but negated it in service of her own needs. The importance of the daughter's own experience was repeatedly ignored. This picture was also found in Participant C's family where the parents were caught up in their own emotional tussle and the constant struggle for each to recognize the other's position drew their children into it and made it seem that the

parents' needs were more important that the offsprings'. As a result, the offspring with schizophrenic may have become extremely sensitive to the needs of others and their continual attendance to the needs of others helped to further diminish the validity of their own experiences. Participant B focused solely on the affect on his sister of her loss. In Family B, the family tradition that does not acknowledge grief and suffering perpetuated by the father makes it difficult for him to interact genuinely with other members. This negation of the person with schizophrenia's needs and experience features prominently in the literature on schizophrenia and subjective experience (Shean, 1978). However, these findings suggest that in addition to the effects brought on by deficit symptoms, the manner in which the person is treated also negates their existence.

Certain patterns of interaction are continually replayed during the interview. The interaction of Participant A, her fiancé and her stepmother replayed the triangular relationship between herself, her mother and her brother. There seemed to a covert rivalry in both families between the mothers and daughter (and daughter-in law) to be closer to a son. A similar pattern of triangular relationships is also repeated between Participant C, her father and his new wife which replayed the earlier interaction between her mother, herself and her father. Her stepmother refers to this when she says that Candice is like, "another woman in the house. And she said to my father that if I'm in her life then she'll divorce my father."

There was also a great deal of criticism in this family towards its members and consistent with research findings, this type of highly expressed emotion may have contributed to at least one relapse through mutual influence between the family and the person with schizophrenia (Woo et al., 2004).

<u>The rules and roles in the family systems</u>

The family systems tended to have rigid rules and subsequently rigid boundaries. These were maintained by the behaviour of the members in the system. The family of Participant A's fiancé had strictly enforced rules maintained by behaviour that seemed jovial and light-hearted but repeatedly communicated the same message that members of

the system were expected to buy into the family myth that they were a happy family where change and differing opinions were seen as threatening to the system's survival.

The roles in the system were often enmeshed and alliances often crossed hierarchical boundaries. Participant A's mother formed an alliance with her son which excluded her husband. Participant B's mother did the same with her son to a lesser extent at the exclusion of her husband. Participant C's father was said to have clearly "changed the roles" by putting his daughter into the role of the mother and treating the mother as the child in the system. The mother formed her own alliance with her other daughter and together they would verbally attack the father. Divorce in this family clearly led to the crises of divided loyalties for participant and her sibling where each sided with one parent (Cullberg, 2003).

Family roles appear to be inflexible and help the prevailing pattern of interaction continue. The descriptions of the individual provided by the family change little when they move from speaking about the person as a child or more recently as an adult. Wynne and colleagues attributed schizophrenia to a failure of ego development that results from similar family environments as that of the participants "which do not permit adequate reality testing or provide opportunities for the integration of flexible and appropriate roles in the developing ego" (Shean, 1978, p. 206). By the schizophrenic person becoming ill, it allows those around them to continue in their previous roles and maintain the previous family structure with all its pathological and dysfunctional aspects.

In accordance with Murray Bowen's (1965) views, it certainly appears that in some of the families, the person with schizophrenia helps to bring stability to the family system by acting as a stabilizing influence. Certainly some of the parents' own inadequacies are overlooked when presented with a person diagnosed with schizophrenia for whom they now have to care. Indeed, during moments in the family interviews that appeared to the interviewer to evoke anxiety in the parent or parents, the focus returned quickly to the schizophrenic member's inadequacies and helped to lessen tension and anxiety.

Openness and closedness of the family systems

In two of the families, there appeared to be people acting as gatekeepers helping to filter out information that was incompatible with the beliefs that had become entrenched in the family. The father of Participant B spoke of the family "being introverts and keeping to themselves". He did not readily allow in information and experiences that were contrary to his worldview. New experiences were generally just excluded and not meaningfully integrated into the family systems. He describes the intensity of he and his wife's last counselling session but goes on negate the powerful effect. "And I in the last counselling session that she had, we also just spoke and when I just opened up and started crying that the water streamed out of my eyes and I felt that it was just a weight that dropped from my shoulders. And it was uh … something that happened and it's over."

The father of Participant D also tended to behave in ways that were consistent with his own early experience of divorce, that allowing change was potentially harmful to the system. In this, he was adequately supported by the mother's paranoid-tinged thoughts that people "gossip and look down on the family".

Indicators of symptoms of schizophrenia in the family

Interestingly, certain commonalities could be detected between the behaviour of some of the family members and the symptoms that the individual had presented with. These included difficulties in communication, disorganized thinking, odd behaviour, paranoid thinking in certain instances and changes in affect. This may lend support to the arguments that the symptoms of psychotic illness can be found along a continuum in the general population (Allardyce et al., 2007). Paranoid-like beliefs were found in the parents of Participants B and D. A tendency to withdraw and isolate themselves from society was also found in the behaviour of the parents of these families. A lack of behaviour that indicated firm boundaries was evident in three of the families. Participant A was allegedly molested by her father. Participant B's father appeared to violate his son's right to privacy by trying to listen in to the individual interview. He and his wife presented their own medical complaints in a bizarre manner during the family interview. These parents also hold peculiar beliefs that their children have a telepathic connection.

The function of the symptoms in the families

Gregory Bateson argued for a "contextual understanding of psychopathology" in which he suggested that the way people live and the language games that accompany this manner of living provides a "*meaningful context* that has to be identified in order to let a disturbance become explainable" (Gelbmann, 2003, p.1) This is consistent with the idea that the symptoms of schizophrenia are believed to serve a function within the family system and that function may be to help regulate the system in order to maintain stability at the expense of change. With this in mind, the following conceptualizations are presented regarding the possible function of the symptoms in the families interviewed (Zuk & Rubenstein, 1965).

Family A appears to need someone to be ill because it is only when that person is ill that they are paid attention and their existence is validated and affirmed. Therefore, although Mandy was initially said to be "strong" because of the support for Liam, she was required to fall "ill" to demonstrate how difficult the process was for her and receive the support of other members. Liam's brother says as much in his description of the family. The idea is also rooted in Mandy's family where Mandy's mother refers her to a doctor for medication when she reveals her anxiety and fears. The mother herself says she does not know how her daughter is able to cope without medication.

In Family B, Gavin's illness may be construed as a symptom of the family's dysfunction or failure to acknowledge emotional pain. His silence reflects his parent's silence on the death of his niece and also his father's silence at the pregnancies his wife lost; to quote a cliché, his silence speak "louder than words". Although it is pure conjecture, one can argue that systemically, all behaviour has purpose and Gavin had to stop speaking and become ill to allow his father and mother to turn to each other and start communicating about family pain and suffering.

Also in Family B, physical pain and tangible elements are more attended to than emotional pain and in the interview they present their physical complaints and medication as proof of their humanity. They may be unable to heal themselves and therefore show

their pain to others hoping they will acknowledge it. Gavin's illness draws attention away from their own individual physical afflictions and forces them to care for another.

In Family C, Candice tends to behave in ways that force her father to pay attention to her, using substance at the age of 14, writing on the walls when they lived together, going to write exams not having the proper equipment. One can surmise that when she is in difficulty, he appears to rescue her. He acts out this role even to the extent of secretly providing a salary for her. However, behaviour like this repeats the previous patterns of interaction in which the father's relationship with his actual spouse is threatened.

The mother in Family D puts the daughter in a classic double-bind with repeated conflicting communication in which the message and expected response is unclear, leaving her daughter unable to respond. In one example, the mother says her daughter was convinced she was going to hell, but then laughs at the thought which obviously caused her so much distress that she physically attacked her mother when she believed the mother called her derogatory names. Later, she speaks of her daughter's belief that people were laughing at her, but then she also laughs at this. Perhaps the laughter is a way to hide her own discomfort or anxiety.

The threat of the family breaking up is also a much feared one in Family D. During the genogram discussion, Jane's mother spoke at length about how devastating his parent's divorce was for Jane's father. It would appear that any event that threatens the break up of their nuclear family (as Jane refers to it) is resisted against and there is also a general isolation of the family from others, even their own extended relatives. Jane's illness might be thought of as a way of keeping her from achieving independence and therefore preventing further change to the family structure, however this is only conjecture. The meaning given by the family to schizophrenia is that it is an inexplicable event which increases their daughter's dependence on them and makes it less likely that she will become independent because the condition affects her ability to continue her studies.

Chapter 5: Conclusions, limitations and recommendations

5.1 Conclusions

The subjective experience of sufferers was highlighted by early thinkers in the field of schizophrenia as an important aspect of understanding the condition and its affect on people. Documenting the subjective experience of schizophrenia in the family from a systemic perspective was an attempt to understand the behaviour in a context within which it is seen to have meaning and be functional. This research tried to incorporate aspects of this approach by looking at the patterns of interaction within the family, by noting intergenerational patterns in the family and understanding how these may be played out in current generations, by looking at the possible meaning in the family of the symptoms displayed by the person diagnosed with schizophrenia and by allowing the participants to recreate their life narratives in order to infuse their experiences with their own sense of meaning.

The results of this study are consistent with findings in the literature that those with a predisposition to schizophrenia may experience a large number of early and continuing events that contribute to their vulnerability and that vulnerability to stress is not only based on genetic influences, but also on previous life experiences that interact with any life events that may precede onset (Cullberg, 2003; Bebbington et al., 1993). The subjective experience of those affected and their families suggests that events such as crises and life changes may influence the onset of schizophrenic attacks. However, further carefully thought out investigation is required to find further proof of the impact of these events on the onset of schizophrenia. The biggest hurdle in gathering such proof arises from the view that schizophrenia is still a much debated concept and the diagnosis is not without its shortcomings. Furthermore, the findings of this research suggest that the events do not appear to be sufficient to bring about the onset of schizophrenia on their own, especially in the light of long-standing difficulties reported by both the individuals and their families.

Crises and life changes which precede the onset of schizophrenia appear to involve the family which suggests that the family should be the primary unit of investigation in future research. The most significant aspect of these life events is the possibility of loss and threat to the family system. Past events which hold particular significance have the potential to have an etiological effect over a considerable amount of time and recent events may trigger the memory of these earlier events indicating that early psychological and emotional difficulties may resurface at any time. The results suggest that the schizophrenic behaviour of the participants in this study served to absorb the impact of stresses that resulted from family crises and life changes and played a fundamental role not just keeping the family systems intact, but also in helping to make sense of the interaction within the family. The behaviour served to maintain some form of relationship between the family members by drawing the family members into the 'crises of being diagnosed with schizophrenia' and allowing earlier patterns of interaction to be replayed.

The participants' accounts indicate that people who are diagnosed with schizophrenia may be aware of deficits or difficulties in functioning long before the onset of overt symptoms. Greater psychoeducation may improve attempts at early intervention as the lack of formal knowledge left the participants in this study with little information on what they might be suffering from. Finally, it is suggested that in addition to psychiatric care, efforts should be made to understand more of the patient and family's subjective experience as many aspects of this experience are drawn into their psychosis and occupy their concerns. The amount of interacting influences at different levels and the sheer variation in experience of just four families indicates that there is still much that needs to be understood about the condition of schizophrenia.

5.2 Limitations and recommendations

There were a number of limitations to this study. The most important shortcoming from a systemic view was that all the members of the families were not present in the family interviews. This makes it difficult to understand the interaction of the family as all members of the system were not present and family patterns of interaction involve all of

the family members. However, steps were taken to obtain information from these absent members and negate the effects of this shortcoming as much as possible.

The timeframe between the onset of schizophrenia and the interviews could be improved upon. The diagnostic criteria make it difficult to diagnose schizophrenia upon first admission as the time of onset cannot always be established. However, research with a larger population and more extensive resources could aid in eliminating these difficulties.

The reliability of the information cannot be validated. As a qualitative piece of research this limitation is not of too much importance because the experience of the person is not always rational and logical, especially with this specific population. However, it should be noted that the dates, events and occurrences are as much a function of the perception of the participants and the interviewer as they are part of an 'objective reality'.

The nature of this volunteer sample differentiates it from the general population. As the participants were receiving treatment it means they had more understanding of schizophrenia and its possible causes than the general population.

It is important to note that "observations of any kind can never be expressed without some error" (Bless & Higson-Smith, 2000, p. 138). One type of bias that this research was most susceptible to was respondent bias. Due to the nature of the research, it was possible that unresponsive participants, uncooperative participants, and participants who answered cautiously due to sensitivities around schizophrenia and family life may have introduced biases by withholding information, introducing inaccurate information or framing events in a manner which may have been potentially misleading.

Of particular importance was the issue of language difficulties. Three of the participants spoke Afrikaans and it was possible for misunderstandings to occur over certain words or questions in the manner that they expressed themselves. The interviews were translated into English from Afrikaans by the interviewer who is a first language Afrikaans speaker.

Other limitations include the brevity of the time provided by the interview. This means that the priority in the interview was to explore the participants' answers to the questions listed on the interview schedule, and allowed little time for follow up of important responses. One way to address this in future would be to design the research as a long-term treatment outcome study.

The interview space may also have introduced some limitations. The interview was held in a consulting room at the hospital and may have contextualised the interview for the participants in terms of the condition. This means that broader information may have been omitted and it is possible that the participants confined their responses to information that they believed was relevant to the clinical environment.

Recommendations for further study are centred on two areas. Firstly, family interaction has received inconsistent support as a factor in the aetiology of schizophrenia. However, as highlighted in the literature review, it may play a more indirect role by socialising the individual into a particular way of interacting with others that reinforces earlier dysfunctional patterns of interaction. This aspect requires further research to uncover whether this may indeed be so. Secondly, the difficulty in identifying onset, particularly in a context where lesser extremes of schizophrenic behaviour are viewed as acceptable provides another area for future research. Thirdly, future research should undertake more in-depth investigation of the significance of events related to possible loss or events which threaten the family system in families with members diagnosed with schizophrenia.

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