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Exploring perceptions of sibling relationships affected by schizophrenia in South Africa.

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CHAPTER 1: INTRODUCTION

Mental illnesses are among the most common conditions affecting health today, both in developed and developing countries. WHO (2001) figures indicate that mental and behavioural disorders are likely to affect at least 10% of the general adult population at any one time, and at least 25% of all people at some time in their lives. From a variety of different viewpoints, it is held that the family plays an important role in the development and maintenance of psychopathology (Hetherington & Martin, 1986). This is due to the fact that, amongst other things, a family member's perceptions are crucial for understanding and intervening in family systems (Deal, Wampler & Halverson, 1992).

The sibling relationship has been regarded as the most enduring of all family relationships (Smith & Greenberg, 2008). With a diagnosis of schizophrenia, the devastation is experienced not only by the person who is mentally ill, but also by the entire family. Among the most vulnerable and most affected, are siblings (Friedrich, Lively & Rubenstein, 2008; Gerace, Camilleri & Ayres, 1993), and consequently, sibling relationships are significantly affected by such a diagnosis.

With the aging of the population, and increasing difficulties of social circumstance, research has begun to shift its attention away from parents towards siblings as future caregivers of their brothers and sisters with schizophrenia (Hatfield & Lefley, 2005; Smith & Greenberg, 2007; Smith, Greenberg & Seltzer, 2007). The sibling relationship may be coloured by a variety of factors such as stigma, type of sibling relationship, gender and living situation. Previous studies have indicated that these aforementioned factors may play an important role in the relationship between an individual with his or her brother or sister with schizophrenia (Gubman, Tessler & Willis, 1987; Phelan, Bromet & Link, 1998; Smith & Greenberg, 2007; Smith & Greenberg, 2008). This research aimed to explore the perceptions of the sibling relationship and the factors that influence this relationship, post-diagnosis, from the perspective of the siblings who have a brother or sister with schizophrenia in a South African context.

RATIONALE

Families are often considered to exercise a great influence on one's development. Consequently when a child's development deviates from the norm, one of the key issues to be considered is the familial environment (Cutting, Aakre & Docherty, 2006; Gerlsma, Snijders, van Duijn & Emmelkamp, 1997). Most research on the inter-relationship between a family member and patient has focused on the spousal and parental-patient relationship, specifically the maternal-patient relationship. That is, studies have neglected the role of the paternal-patient relationship, as well as the sibling-patient relationship (Cowan & Cowan, 2002; Gerace et al., 1993; Mathijssen, Koot, Verhulst, De Bruyn & Oud, 1998; Phares & Compass, 1992).

A family member's insights can be invaluable for both understanding and intervening within the family system (Deal et al., 1992). This can be understood to be primarily due to the notion that, from different perspectives within sociological and psychological theory, the family holds significant roles in the determination and continuation of psychopathology (Hetherington & Martin, 1986).

Previous research has indicated the importance of working with siblings to explore their perceptions of their brother or sister's illness (Smith & Greenberg, 2008). Goetting (1986) was of the opinion that the most important tasks of sibling-ship, throughout life, are companionship, friendship, comfort, and affection. Significantly, given Goetting's (1986) views, there has been a growing recognition of the importance of social relationships in the quality of life of people with schizophrenia (Baker, Jodrey & Intagliata, 1992). Sibling relationships may be particularly important because few adults with schizophrenia marry and have children. Their parents grow older and ultimately pass away which leaves many individuals suffering from schizophrenia quite alone. In such times of need, many adults with mental illness may turn to their siblings for help and companionship (Hatfield & Lefley, 2005; Samuels & Chase, 1979).

However, the role of the sibling is undergoing a change due to increasingly scarce community services (Friedrich et al., 2008). The Health Systems Trust (2000) identified that one of the gaps in South African mental-health research, surrounded areas of de-institutionalisation, and the development of community-based mental health care. Furthermore, a number of projects have delineated the difficulties that have arisen due to rapid de-institutionalisation and inadequate community facilities to

care for the chronically mentally ill (Dartnall & Porteus, 1998; Mzimela & Uys, 2000). More specifically, there is an important need for the assessment of the impact of schizophrenia on society, as well as to identify ways in which to reduce the burden of schizophrenia. In particular, the role of social support for people with mental illnesses has been identified as a breach in current South African research (Health Systems Trust, 2000). Consequently, it may be argued that the sibling relationship, for individuals affected by schizophrenia, has the potential to play a significantly protective function.

The emerging social problem, for which few siblings are prepared, is the future care-giving for individuals with mental illness (Lefley, 1987). Although siblings are considered to be the logical caregiver replacements for aging parents, it is unclear what their roles will be or how this will impact their lives (Friedrich et al., 2008). Given the significance and enduring nature of sibling relationships over time, it is notable that studies on families and mental illness have largely excluded siblings (Lobato, Faust & Spirito, 1988). This exclusion holds specifically in the area of schizophrenia as well.

Previous research has indicated that as a consequence of the unrelenting stress due to a schizophrenia diagnosis, multiple aspects of siblings' lives are affected. Despite the fact that siblings experience extensive burden, little attention has been paid to specific mental health services and programs that could be implemented to reduce their stress (Friedrich et al., 2008). Over the years, siblings have been left out of the treatment process, which contributes to a lack of knowledge and skills that are typically needed to manage and cope with the circumstances surrounding the illness (Friedrich et al., 2008). Furthermore, research findings have provided evidence of the saliency of the sibling relationship to the quality of life of people with schizophrenia (Smith & Greenberg, 2007; Smith & Greenberg, 2008). Accordingly, it is an important area of study.

It has been indicated by Rutter (1992) that an affected individual's diagnosis, symptoms and overall quality of life can be shaped, in part, by the way with which he/she is dealt in his/her greater environment. Consequently, the perceptions of siblings with relation to the sibling-relationship, as affected by psychopathology may be very illuminating (Mathijssen, Koot, Verhulst, De Bruyn & Oud, 1997). Hence, it seems that one's perception of one's relationship with another may be coloured by a psychopathological diagnosis such as schizophrenia. More specifically, an

individual's perception of the sibling relationship may possibly be influenced by their developmental and psychosocial experiences due to having a brother or sister diagnosed with schizophrenia (Friedrich et al., 2008; Teschinsky, 2000).

This research tentatively hypothesised that attitudes and perceptions associated with a diagnosis such as schizophrenia had the potential to play a large role in the relationship between an individual and their brother or sister with schizophrenia. Furthermore, and as noted by previous research, the behaviour of family members of an individual with schizophrenia, may be viewed as an important factor when investigating the schizophrenia diagnosis (Cutting et al., 2006; Dixon et al., 2001).

Previous studies have called for more in-depth qualitative research into the perceptions of familial relationships with regard to psychopathology (Cutting et al., 2006; Mathijssen et al., 1997). The difficulties facing a sibling who has a brother or sister with schizophrenia are many. However, by exploring what variety of aspects of living with schizophrenia impact upon the sibling relationship, we may be able to focus on how to use the sibling relationship as a resource for individuals with schizophrenia.

More specifically, the investigation of the types of sibling relationships, the influence of gender and living situation, as well as the effects of stigma can aid in the exploration of the legitimacy of these findings in a South African context. Through the interrogation of these factors, the researcher hoped to acquire an enhanced understanding of the perception of sibling relationships affected by schizophrenia in South Africa.

Furthermore, research has indicated that the more stressful the environment in which the affected individual lives, the greater the chance of relapse (Bebbington & Kuipers, 1994; Cornwall & Scott, 1996; Ostman & Kjellin, 2002). Thus, in order to contribute to knowledge that can prevent this occurrence, this study aspired to explore the perceptions of sibling relationships affected by schizophrenia.

This research aims to yield an in-depth description of siblings' perceptions of the ways in which the schizophrenia diagnosis had affected the sibling relationship. To contextualise, explore and expand on such a relationship, this research explored the perceptions of siblings, surrounding the psychopathological diagnosis schizophrenia, within the framework of the South African family. It is hoped that the study will help guide mental health care professionals so as to develop programs, and interventions that support and sustain the involvement of siblings in the lives of their

brothers and sisters with schizophrenia in South Africa, and stimulate further research in this area.

It is an important area of investigation as it will potentially illuminate ways in which mental health professionals understand those affected by schizophrenia, and as such may contribute to the development of future psychoeducational programs. The hope for such programs is that the quality of life for individuals can be increased, so as to help the sibling relationship deal more efficiently with the demands of schizophrenia. This in turn, has the potential to increase the quality of life of both siblings (Friedrich et al., 2008; Smith & Greenberg, 2007).

RESEARCH AIMS

This research aimed to explore the perceptions of sibling relationships, affected by schizophrenia, within the context of South Africa.

How individuals perceive their relationships with others, is likely to be affected in some way by a diagnosis like schizophrenia. This study endeavoured to investigate an individual's perceptions of his or her relationship with a sibling with schizophrenia, post-diagnosis. The study also explored the factors that are perceived to have influenced this relationship. In particular, this study examined the role that factors such as; living situation, stigma, and gender, and how these have played a role in the quality of the sibling relationship.

This aspect of the study was crucial for a greater understanding of those affected by schizophrenia, in order to contribute to future psycho-educational intervention programs.

STRUCTURE OF THE REPORT

This research report consists of eight chapters including the literature review, research method, results, discussion and conclusion. The structure of this report is discussed in more detail below.

The current chapter provides an introduction to the report, and establishes the rationale behind the research, the aims of the study, as well as outlining the structure of the report. This chapter acts as a brief synopsis for the reasons for the study and its objectives so as to provide an understanding of the focus of the study for the reader.

Chapter 2 discusses relevant literature related to the perceptions of sibling relationships affected by schizophrenia. The function of this review is to provide the reader with an overview of existing ideas, knowledge and research related to the sibling relationship as it is affected by schizophrenia. The literature reviewed is examined, and existing themes in current research are noted.

The literature review begins with a brief overview of schizophrenia, comprising of definitions, diagnostic criteria, epidemiological information, as well as information regarding course and comorbidity. Following this, the literature places schizophrenia within the context of the family, and then specified its focus on the factors that impacted upon the type of sibling relationship, when one sibling has schizophrenia. The chapter proceeds to examine family systems and developmental theory in an attempt to ground the literature within a theoretical framework, in that way adding to the depth of understanding of how schizophrenia impacts the family system and sub-systems.

Following this the aforesaid chapter, the research questions are presented in the beginning of *Chapter 3* so as to provide the reader with the questions that guided this study. The research approach and method are then presented so as to afford the reader an understanding of the interpretive methodology, and the qualitative nature of the study that was undertaken so as to answer the research questions. Subsequently, the procedures regarding the manner in which the research was conducted are outlined and explicated. The process of the selection of the participants is discussed, and relevant details about the participants are provided. Thematic content analysis is then elucidated so as to gain a greater understanding of the results, after which ethical concerns regarding the study, as well as methods undertaken to manage these concerns are discussed.

Chapter 4 encompasses the presentation of the research findings. This chapter presents the data by using quotes from the interview transcripts. This structure was taken in order to provide an understanding of the participants' subjective experiences of the sibling relationship as it is affected by schizophrenia. These experiences are interpreted and discussed in order to gain a deeper awareness and understanding of the participants' experiences. Simultaneously, the results are related to existing literature so as to note areas of similarity and difference.

The findings have been divided into five sections, each representing central thematic categories. These thematic categories include factors impacting on the

relationship, the redefinition of the family, adjustment, the impact of schizophrenia and interaction with service providers.

An overview of the results and the broader picture they present is discussed in *Chapter 5*. Within this discussion of the results, a theoretical examination of the participants' experiences is attempted with the goal of providing an enhanced understanding of the sibling relationship, and how it is affected by schizophrenia. It is hoped that by providing a theoretical discussion of family systemic and developmental assumptions, an in-depth understanding of this study's findings will be achieved.

Following this elucidation of results, the report is concluded by way of final comments, and various limitations of the study are discussed. In addition to this, possible directions for future research are also addressed.

OPERATIONAL DEFINITIONS

The underlying terms are the central concepts within this study, and consequently they are defined accordingly, for the desired purposes of this study.

Participant

For the purposes of this study, the 'participant' refers to the sibling who is not diagnosed with schizophrenia.

Perception

'Perception' has been operationalised according to a constructivist viewpoint for the intentions of this research. Constructivists view knowledge as grounded in both the real external world, and within individuals, as well as their socio-cultural context (Mahoney, 1988). This construction is strongly mediated by social context in which there are individual differences, and therefore there may be some uniqueness of meaning (Held, 1995).

Relationship

For the purposes of this study, the 'relationship' has been operationalised as the notion of what it means to be a sibling, which can denote a relationship in which emotional attachment has occurred.

Schizophrenia

Schizophrenia is a disorder that lasts for at least 6 months and includes at least 1 month of active-phase symptoms (that is, two [or more] of the following: delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour, negative symptoms) (APA, 2000).

Sibling

For the purposes of this study 'sibling' has been operationalised as any biological brother or sister that has a brother or sister with schizophrenia.

Siblingship

The notion of what it means to be a sibling can denote a relationship in which emotional attachment has occurred, where the members interact regularly, and share concerns for the growth and development of individual family members, as well as the family as a whole. That is, siblingship can refer to the type of bond, and relationship that siblings share.

Social Support

Social support can be communicated through beliefs that one is loved, respected, held in esteem by, and involved with family, friends, and others (Cobb, 1976).

CHAPTER 2: LITERATURE REVIEW

The surveyed literature brings attention to the perceptions and experiences of families in relation to schizophrenia, as well as to the familial relationships. The occurrence of schizophrenia in a family can be transformative, both for the diagnosed individual, the family as a unit, and the individual members themselves. Furthermore, research has indicated that the more stressful the environment in which the affected individual lives, the greater the chance there is of relapse (Bebbington & Kuipers, 1994; Cornwall & Scott, 1996; Ostman & Kjellin, 2002). Therefore, in order to contribute to knowledge that can prevent this occurrence, this study aspired to explore the perceptions of sibling relationships affected by schizophrenia. Specifically, this literature review focuses on areas that have a substantial impact on the perception of siblings whose brothers or sisters have schizophrenia. These factors include the types of sibling relationships, the influence of gender and living situation as well as the effects of stigma. Prior to the investigation of these aspects under consideration, the literature review will explore the notion of mental illness and the family in order to contextualise the study.

SCHIZOPHRENIA

Schizophrenia is a life-altering mental disorder in which the affected individual can experience a "complete loss of self" (Martens, 1998, p. 1). It is a severely immobilising disorder that has a substantial effect both on the diagnosed individual, as well as on the affected family members and friends. For the significant others of individuals affected by schizophrenia, their symptoms can be confusing, frightening and disturbing. The affected individual's reality, at times, becomes so distorted that he or she cannot trust his or her own perceptions and thoughts. More specifically, it is a term that recalls a persistent, often chronic, and usually severe psychopathology that influences many aspects of behaviour, emotion, perception and cognition. Consequently, the experience of schizophrenia has been found to be profoundly disruptive (Sadock & Sadock, 2007).

Clinical Features, Course and Prognosis

Individuals who go on to be diagnosed with schizophrenia usually experience months of a prodromal period prior to the active expression of psychotic symptoms (Kapur, Mizrahi & Li, 2005). During this phase, patients experience an intense amount of novelty in their worlds (Kapur et al., 2005). Thus, patients may become hyperaware of his or her surroundings, without having an explanation for why this is so.

The symptoms of schizophrenia are generally categorised as positive and negative. Positive symptoms reflect a distortion of normal functions, and Psychiatrists often explain these symptoms in terms of a surplus or an alteration of normal functions (APA, 2000). More specifically, these positive symptoms refer to delusions, hallucinations, disorganised speech, and grossly disorganised or catatonic behaviour. Negative symptoms reflect a loss of normal functions and largely account for its morbidity. These symptoms include affective flattening, alogia or avolition (APA, 1994), and tend to have devastating and distressing effects on the lives of the affected individuals. However, their subjective experience of what is happening to them is often not as profound as it is for their family members, who witness their behaviours and personality transformations so significantly (Martens, 1998). Often such behaviours are the first signs to significant others that there may be a problem, and they often report that they experienced the individual 'gradually slipping away' (APA, 2000). The effect that the disease has on the family members of people with schizophrenia is especially shocking.

Various subtypes of schizophrenia have been identified, and these subtypes contribute to the overall clinical picture of the individual with schizophrenia, however these may change over time. The most common form of schizophrenia is the paranoid type, which is characterised by delusions and or hallucinations as well as by the absence of such symptoms as disorganised speech and behaviour or flat affect (Sue, Sue & Sue, 2003). The disorganised subtype of schizophrenia is typically characterised by extremely disorganised behaviours that are manifested in disorganised speech and behaviour, and flat or grossly inappropriate affect (Sue et al., 2003). Whereas the primary characteristic of catatonic schizophrenia is a marked disturbance in an individual's motor activity – either extreme excitement or immobility; alternating periods of excited motor activity and withdrawal may occur in this disorder (Sue et al., 2003). Undifferentiated schizophrenia may be diagnosed

when an individual's behaviour shows prominent psychotic symptoms that do not meet the diagnostic criteria for the paranoid, disorganised or catatonic categories (Sue et al., 2003). Finally, the diagnosis of the residual schizophrenia subtype is reserved for people who have experienced at least one previous episode of schizophrenia, but who then show an absence of prominent psychotic features (Sims & Owens, 1993).

Statistics report that annual incidents of schizophrenia are most often in the range of 0.5 to 5.0 per 10.000 people, which makes it quite a common disorder (APA, 2000). This occurrence is relevant to all societies and in all geographic areas. Furthermore, the incidence and prevalence rates seem to be approximately equal worldwide (Sadock & Sadock, 2007). It has been found that the prevalence of schizophrenia is equal between men and women; however the two genders differ in age of onset (APA, 2000). Typically the age of onset for men is younger than for women. More men will be diagnosed between the ages of 16 and 20, whereas more women will be diagnosed between the ages of 25 and 30 (Torrey, 1983).

The course of schizophrenia is variable, and there is variation between and within individuals (Werry & Taylor, 1995). Usually there is a delay of approximately 1 to 2 years between the onset of the psychosis and the beginning on treatment; and this period is an important forecaster for future clinical outcomes. That is, clinical deterioration has been argued to be related with the period of the psychosis as well as the number of episodes of psychosis. This deterioration usually arises during the first 5 years after onset, and then stabilises where the individual has relentless symptoms and has marred functioning (First & Tasman, 2006). Furthermore, following onset, individuals experience deterioration in cognitive performance, and they tend to experience more hallucinations and delusions at this phase. However symptoms of disorganisation and inappropriate affect occur more commonly at later stages of the illness (First & Tasman, 2006).

Prognosis may be further complicated by extraneous variables such as the use and abuse of substances by individuals with schizophrenia (Sadock & Sadock, 2007). Substance abuse is common in schizophrenia, so much so that it has been estimated that there is a prevalence of 50% (Sadock & Sadock, 2007). This is of importance as drug abuse has been associated with poorer functioning and an increase in positive symptoms (APA, 2000). Of the variety of drugs available both legal and illegal, there has been particular significance in the relationship between schizophrenia and cannabis (Murray, Grech, Phillips & Johnson, 2003). Research has indicated that

individuals, who had reported using cannabis on more than 50 occasions, were six times more likely to have an increased risk of schizophrenia when compared with non-users (Sadock & Sadock, 2007). This may be due to the fact that excessive cannabis use has been found to intensify the instability of the mind (Murray et al., 2003). Additionally, the use of cocaine, amphetamines and similar drugs are of great concern as they have a great ability to increase psychotic symptoms (APA, 2000). Therefore the use of these drugs by individuals with schizophrenia can have potentially devastating consequences.

Additionally, and as noted in previous research, there has been much debate about the relationship between substance abuse and schizophrenia, more specifically these debates centre around whether substance abuse can cause schizophrenia, or whether an individual who is predisposed to schizophrenia is likely to abuse substances. From an epidemiological viewpoint, there may be a number of explanations for this association. Substance abuse may cause schizophrenia, or in contrast it may simply reveal a psychosis that had been previously dormant (Murray et al., 2003). Alternatively, schizophrenia may lead to increased drug use, either by self-medicating due to unpleasant symptoms or social stressors related to schizophrenia (Murray et al., 2003).

Nevertheless, the association between schizophrenia and substance abuse remains a substantial road-block to overcome, as an individual with schizophrenia who is in remission, but then returns to abusing substances, can precipitate a relapse into psychosis. A further problematic factor associated with substance abuse is that it often results in noncompliance with antipsychotic medication, which leads to decreases in self-care and occupational functioning, in turn resulting in poverty and social crisis (Murray et al., 2003).

Thus, it may be evident that substance abuse is a major source of concern in the area of schizophrenia, as it has the ability to interfere with an individual's progression, as well as setting in motion the grounds for relapse. While the individual with schizophrenia is affected by his or her own actions, the family members are inadvertently affected due to the repercussions of those actions. Seen in this light, the management of individuals with schizophrenia is an area that opens itself as an area of importance.

Management

Effective treatment and long-term compliance of medical regimes produce relatively positive outcomes. However, those who begin antipsychotic treatment earlier usually have a better response than those who do not, and have 1 year remission rates greater than 80% (First & Tasman, 2006). Prognosis is highly determined in terms of decline and deterioration. While some deterioration is common, the extent and pace of the deterioration will negatively affect the prognosis. Mortality rates increase as do suicide rates as individuals do not initiate or comply with treatment. Young men with schizophrenia are more likely to successfully complete suicide attempts especially earlier on in their illness (First & Tasman, 2006). As schizophrenia is a chronic condition, re-hospitalisations do occur on occasion due to remissions; however women tend to have less re-hospitalisation than men (Maxmen & Ward, 1995). Schizophrenia is a disorder that requires continuous psychiatric supervision and consequently, when the disorder becomes inactive there may be slow but limited improvement over many years (Werry & Taylor, 1995).

Another manner in which schizophrenia can be managed is via the employment of support. Due to the life-long effects of schizophrenia, support can be important to both the individual with schizophrenia, and to those affected by schizophrenia. Social support has the potential to influence health and psychological outcomes in a variety of situations (Cobb, 1976). Furthermore, there has also been significant interest in the notion that social support may be able to protect people, as it has a buffering effect which may attenuate the disruptive effect of stressors (Friedland, Renwick & McColl, 1996; Swindells, Mohr, Justic & Berman, 1999). In addition, apart from its nurturing function, social support has been shown to act as a defence against stressors related to mental illness (Swindells et al., 1999).

Studies have indicated that sources of social support, as well as the level of satisfaction with social support can significantly influence an individual's coping style (Swindells et al., 1999). Coping, in turn, can be said to have direct effects on psychological outcomes (Fleishman et al., 2000). However, acquiring social support is not straight-forward. Despite wide-spread discussion and education about the stigma of mental illness, and the fear of rejection experienced by people affected by mental illness, little has changed in people's behaviours toward this population. That is, the

stigma attached to the illness makes it difficult to gather social support (Friedland et al., 1996).

Apart from its nurturing and emotional functions, social support has been shown to act as a defence against the impact of a wide variety of stressful life experiences (Swindells et al., 1999) including those related to a schizophrenia diagnosis. Social support is a multifaceted concept, encompassing tangible assistance, provision of information, and expression of caring and emotional connectedness (Fleishman et al., 2000). Different types of support have been identified, explicitly, 'informational' and 'emotional' (Friedland et al., 1996). Typically, the source of informational support is health-care professionals, while the source of emotional support is usually from family members, friends or partners. Friedrich et al. (2008) inferred from their study that social support was a major contributing factor as to how the sibling coped. This was discussed both in terms of emotional support from the family, friends, and support services as well as informational support from mental-health care professionals. The supposition is that whether a sibling receives some form of social support or not, will have an impact of the perception he or she holds regarding the schizophrenia diagnosis, as well as the diagnosed individual.

The management of schizophrenia begins with the precision of the initial diagnosis of schizophrenia, which typically requires a high level of clinical knowledge. Due to the high rate of misdiagnosis of psychotic disorders, which often results in inappropriate treatment, it is essential that the mental health practitioner makes a suitable diagnosis (First & Tasman, 2006). It has been identified that one of the most difficult diagnostic dilemmas occurs when an individual has both psychotic symptoms and affective symptoms which results in a difficulty of differentiating between schizophrenia and schizoaffective disorder (First & Tasman, 2006). Other difficulties regarding differential diagnoses occur with schizophrenia, brief psychotic disorder and schizophreniform disorder. The distinction between these disorders is made based upon the duration of active symptoms. Additional complexities arise when there are psychotic symptoms and a mood disturbance that involve both manic and depressive episodes, which would result in a diagnosis of bipolar disorder not otherwise specified (APA, 2000; First & Tasman, 2006).

The mental health practitioner would also need to assess a situation where psychotic symptoms and disorders may be due to substance use. Notably, short-lived episodes of a few hours are highly suggestive of drug-induced states (Werry &

Taylor, 1995). For example phencyclidine, chronic amphetamine use or chronic alcohol intoxication may result in schizophrenia-like symptoms (First & Tasman, 2006); in such an instance the differential diagnosis would be substance-induced psychotic disorder (APA, 2000).

It has been noted that after the initial diagnosis or hospitalisation, the family members are forced to become aware of the negative stereotypes, and stigma attached to such a severe mental disorder; (a group to which they now belong). If a family is not educated about the disorder, and are not given effective support, they may find it difficult to deal with their relative's condition effectively (Martens, 1998). Previous literature has indicated that the more stressful the environment of the individual with schizophrenia is, the more chance there is of relapse (Bebbington & Kuipers, 1994; Cornwall & Scott, 1996; Ostman & Kjellin, 2002). Thus, it is imperative for mental health professionals to aid family members in contributing to the well-being of their diagnosed relative in a positive way. In order to accomplish this task, it is necessary to understand how the perceptions of each family member, including the sibling, contribute to their relationship with the affected individual. Due to the lack of focus surrounding siblings in previous research, it is important to place emphasis on sibling relationships affected by schizophrenia, and to first understand the family's experiences and perceptions of mental illness.

FAMILIES AND MENTAL ILLNESS

Characteristically those people that are closest to a mentally ill individual are his or her family members, and it is this group of individuals that are most influential on the life of the patient (Cutting et al., 2006). 'Family' can be conceptualised as consisting of different relationships and different sub-systems (Mathijssen et al., 1997). "A single family member may exhibit symptoms, receive a diagnosis, and undergo treatment, but because of the interdependence that exists within a family system, each and every family member is affected in some special way" (Kinsella, Anderson & Anderson, 1996, p. 24). Both parents and siblings of a relative suffering from a mental disorder need education and support in trying to understand and deal with its repercussions. As mentioned above, family members react to the diagnosis with a range of emotions and must be able to develop a variety of coping behaviours in order

to deal with multiple feelings that accompany having a relative with mental illness (Teschinsky, 2000).

Family members involved in the lives and the care of adults who have serious mental illnesses often provide emotional support, general advocacy, and housing to their mentally ill loved ones. While some may interpret such behaviour as being rewarding, it also inflicts significant burdens, both on the family as a whole, as well as on the individual family members (Cutting et al., 2006; Dixon et al., 2001; Ostman & Hansson, 2000b). Previous research has shown that the outcomes of patients improve when the needs of family members for information, clinical guidance, and support are met (Dixon et al., 2001; Ostman & Kjellin, 2002). Such psycho-educational practices may affect how individuals perceive, and understand a certain psychopathological diagnosis, which can, in turn, play a role in their behaviour toward an affected individual. Furthermore, it has been indicated by Rutter (1992) that an affected individual's diagnosis, symptoms and overall quality of life can be altered, in part, by the way in which he is dealt in his greater environment. More specifically, Rutter (1992) mentioned that a positive parent-child relationship is likely to elicit a decrease in the general level of family conflict. Additionally, a good parent-child relationship can increase the child's self-esteem, which could function as a protective factor thus helping to improve quality of life.

Families and Schizophrenia

There has been substantial research on the psychopathology of schizophrenia and the family (Asarnow, Tompson, Hamilton, Goldstein & Guthrie, 1994; Cutting et al., 2006; Lee, Lee, Chiu & Kleinman, 2005; Martens, 1998; Phelan et al., 1998). Findings of these studies are similar to those as discussed above. They indicate that family members seem to experience substantial distress due to the impact of having a family member with schizophrenia (Asarnow et al., 1994; Cutting et al., 2006; Lee et al., 2005; Martens, 1998; Phelan et al., 1998). This is predominantly due to the disruption of family life, and consequently the life trajectory of the family may have to be changed (Teschinsky, 2000).

More specifically, since schizophrenia is typically diagnosed in late adolescence, parents' expectation for their young adult to start an independent life and

begin detaching from the family is suspended. The parents may have to continue their roles as caregivers and deal with caring for their regressing child. This interruption in the family life-cycle often causes parents to neglect their expected future-life-task of beginning to focus on their own lives and needs. Additionally, some of those older parents may begin to worry about what will happen to their child when they die (Teschinsky, 2000).

Notably, little attention has been paid to family adjustment to a mentally ill family member, principally from the perspective of a sibling. This is significant as the sibling relationship has been argued to be the most resilient family relationship (Hatfield & Lefley, 2005; Gerace et al., 1993; Samuels & Chase, 1979). As mentioned above, prior research has specified the importance of studies regarding siblings so as to investigate their perceptions of their brother or sister's mental disorder, as well as how this affects the sibling relationship (Smith & Greenberg, 2008). The sibling relationship has several characteristics that place emphasis on its distinctiveness from other social relationships. Generally, sibling relationships extend over a long period of time, as they continue throughout the life cycle. However, this continuance does involve variations of degrees of intimacy and investment. Siblings also share, more fully than other family members, in a common genetic structure (if they are biologically related), social heritage, early environmental experiences, and a common cultural background (Lamb & Sutton-Smith, 1982).

Research has indicated that one of the greatest sources of stress for siblings was the anxiety surrounding who will care for their sibling suffering from schizophrenia when their parents become too incapacitated to do so, or pass away (Friedrich et al., 2008). This can partially be attributed to de-institutionalization, and the lack of sufficient community-based services and organisations (Health Systems Trust, 2000). Thus, many individuals with mental illness turn to their families for support (Smith & Greenberg, 2008). Even with the presence of some community services, family members, specifically parents, often step in to fill in the gaps in the community system. However, many of these parents are heading toward old age and their retirement years. Hence, increasing amounts of adults with schizophrenia look to their siblings for support as their aging parents' capacity to provide care, weakens (Hatfield & Lefley, 2005; Samuels & Chase, 1979; Smith & Greenberg, 2008). Research has indicated that individuals would like service providers to assist with

long-term planning for their sibling with schizophrenia, and to help clarify the sibling-role in future care (Friedrich et al., 2008).

Lefley and Johnson (1990), indicated that the families of individuals with schizophrenia have, on occasion, been seen as a part of the patient's problem, and at other times, as part of the treatment plan. Other studies also show that the outcome of patients seems to improve when the family members are more emotionally stable, thus providing a more secure, and peaceful home environment. Conversely, the person with schizophrenia is more likely to experience a relapse when placed in situations of intense stress (Asarnow et al., 1994; Cutting et al., 2006; Lee et al., 2005; Martens, 1998; Phelan et al., 1998). Therefore, due to the fact that stress acts as an environmental trigger, family relationships are exceptionally important as they can have a negative or positive effect on the well-being of the individual with schizophrenia (Martens, 1998).

Families, Schizophrenia and Expressed Emotion

Families can greatly affect the stability of an individual with schizophrenia (Teschinsky, 2000). This notion has primarily been investigated through the concept of *expressed emotion* (EE) which was introduced by Brown, Birley and Wing (1972). EE has been described as an "index of the emotional climate in the home" (Asarnow et al., 1994, pp. 129-130). Research on EE has shown the implications of familial relationships on the well-being of people with schizophrenia (Martens, 1998). EE has been said to be made up of certain emotional components, specifically criticism, and emotional-over-involvement (Cutting et al., 2006; Martens, 1998; Sadock & Sadock, 2007), and it can be assessed by analysing both what is said and the manner in which it is said (Sadock & Sadock, 2007). Importantly, individuals with schizophrenia have reported feeling increased stress-levels when interacting with high-EE family members (Cutting et al., 2006). Furthermore, research has found that people with schizophrenia are negatively affected by critical and emotionally over-involved attitudes of family members, that is, when encountering high-EE family members, the rate of relapse is higher (Asarnow et al., 1994; Brewin, MacCarthy, Duda & Vaughn, 1991; Cutting et al., 2006; Sadock & Sadock, 2007). Given these findings, it can be argued that improved familial interactions can benefit the family member with schizophrenia by creating a less stressful environment (Martens, 1998).

Thus, it is imperative that mental health professionals, involved in the area of developing treatment interventions for those suffering from schizophrenia, should expand upon their understanding of the experiences, and subsequent perceptions of family members of individuals with schizophrenia. Previous research has noted the benefit that siblings may receive from psycho-education and support groups (Kinsella et al., 1996). The idea here is to provide the sibling with normalisation, so as to reduce their feelings of isolation in having a relative with a mental disorder. Furthermore it has been suggested that in such groups, they should receive individual attention, including attention to emotions and involvement in the treatment process (Teschinsky, 2000).

In order to contextualise, explore and expand on the occurrence of schizophrenia and the family, this research explores the perceptions of sibling relationships affected by schizophrenia, within the framework of the South African family. It is in this vein that the researcher attempted to explore siblings' perceptions of their relationship with their brother or sister with schizophrenia. However, prior to doing this, it is relevant to explore the current notions of siblings and siblingship.

SIBLINGS AND SIBLINGSHIP

Type of Sibling Relationship

Research has indicated the importance of the quality of sibling relationships, as they have a significant impact on the lives of individuals with schizophrenia (Smith & Greenberg, 2007; Smith & Greenberg 2008). Furthermore, this quality of relationship between siblings has also been said to be influential in terms of future sibling involvement, and consequently the quality of life of the individual with schizophrenia (Smith & Greenberg 2008). That is, the quality of the sibling relationship may affect an individual's willingness to take on a future care-giving role.

Families are often thought to exert a powerful influence on psychosocial development, for better or for worse. Studies have indicated a tendency by the mentally ill individual, to present the family in an extremely undesirable light (Gerlsma et al., 1997). The effect that stigma can have on perception is further experienced, depending on the social background and situation of the mentally ill

individual and his or her family. This, together with the type of relationship between the patient and a specific family member, in this case the sibling, has the capacity to determine the extent to which the patient is stigmatised as well as the degree to which stigma is perceived by the sibling (Phelan et al., 1998).

Among the many scopes around which family life revolves, parental rearing behaviour is conventionally considered as one of the main issues to be considered when a child's development deviates from the norm (Gerlsma et al., 1997). It has been noted that psychiatric patients frequently recollect their parents' behaviour as having been less affectionate, more rejecting and overprotecting (Blatt & Homann, 1992; Burbach & Borduin, 1986; Gerlsma, Emmelkamp & Arrindell, 1990; Parker, 1988). It must be noted however that the individual with schizophrenia and their behaviour plays an important part in the family group, and it potentially affects all interactions (Martens, 1998). Additionally, when a family discovers that their son, daughter or sibling has developed schizophrenia, each family member is suddenly faced with traumatic role-changes (Martens, 1998).

As discussed above, the family life cycle and life trajectory is interrupted by the schizophrenia diagnosis (Teschinsky, 2000). This impacts all family members, and in particular, the sibling. The altered family experience will have different effects on the sibling depending on his or her age. But irrespective of this, the sibling experiences a loss of an idealised brother or sister, who transforms into a 'bizarre' person who needs to be taken care of. Siblings are severely affected by this as well as by other familial factors, such as overall familial conflict, marital discord, social isolation and lack of support, to name but a few (Teschinsky, 2000). More specifically, if the sibling is a young child, they will rely more heavily on the parents; however due to their brother or sister with schizophrenia, they may not receive enough attention. Whereas an older child, who developmentally should be focusing on making strong social connections to the world outside of the family and gaining independence, may stay home to provide help and support, both to their affected sibling, as well as to their parents (Jones, 1997). Subsequently, research has indicated that there is an important interplay between earlier stressful life events and the later adult relationship (Smith & Greenberg, 2008). This sibling position of having a brother or sister with a mental disorder may result in ambivalent emotions about their earlier years. That is, there may be some current resentment, but at the same time there may be fond memories of earlier times. The often intrinsic loyalty that comes

with siblingship may result in conflict for the sibling in other parts of his or her life (Jones, 1997).

There are certain factors that play a role in determining the quality of relationship between siblings. The lives of siblings exist across time, with early experiences playing a role in shaping the quality of current relationships (Smith & Greenberg, 2008).

Research conducted on normative sibling relationships advocates that the quality of adult sibling relationships is robustly influenced by the family environment during childhood (Smith & Greenberg, 2008). More specifically, children who were raised in families that were cohesive, tended to have closer sibling relationships (Brody, Stoneman & McCoy, 1994; Smith & Greenberg, 2008). Additionally, studies have found that the strength of sibling bonds were sustained when siblings initiated contact that provided opportunities to enjoy one another's companionship in activities typically shared by adult siblings in the general population (Smith & Greenberg, 2007). However, there seems to be a double-bind here, as unless a sibling perceives his brother or sister in a positive light, he will not initiate such activities. On the other hand, without being involved in such activities, one's perception will be negative, and therefore perpetuate a not-good-enough siblingship. This would not allow for the possibility for perception alteration and growth. Despite this, research does indicate that the siblings that spent social-activity-time with their brother or sister with schizophrenia, had significantly higher quality of relationships than siblings who did not share or rarely did social activities together (Smith & Greenberg, 2007).

It must be noted that while a schizophrenia diagnosis can have harmful effects on the sibling of an individual with schizophrenia, it may also emphasise the resiliency of individuals, and their capacity of the relationship to grow from the distress experienced due to having a brother or sister with schizophrenia. There are a variety of things to be gained from managing with the stress of a mental illness, including an increased awareness of one's inner strengths. In cases where the sibling is aware of and experiences some of these positive transformations, the result may be a more positive, mutually supportive relationship with his or her sibling with schizophrenia (Smith & Greenberg, 2008).

Gender

Another factor that may hold a position in determining how an individual perceives the quality of relationship between him or herself and his or her sibling, is gender. Gender plays an important role in shaping childhood socialisation experiences, and by extension, the quality of the adult sibling relationship (Smith & Greenberg, 2008). Campbell, Connidis and Davies (1999) found that sisters are more likely than brothers to provide support and have good relationships with their siblings. Furthermore, it has also been discovered that sister-sister dyads were closer when compared with brother-brother or brother-sister dyads (Cicirelli, 1993; Gold, 1989). Different suggestions have been provided for this occurrence, among which is the socialisation of women in many cultures. That is, women are socialised from an early age to care for others (Chodorow, 1978). This explains other research findings that sisters are more likely than brothers to provide support and have close relationships with their siblings (Campbell et al., 1999; Cicirelli, 1989).

Studies have noted that there seems to be a difference in the psychological factors of stigma according to the mentally ill relative's gender (Ostman & Kjellin, 2002). Specifically, it has been discovered that families are more likely to attempt to conceal the disorder if the affected individual is female, and are more likely to perceive a mentally ill male to be aggressive and dangerous (Phelan et al., 1998). Furthermore, it has been found that family members tend to be more distressed when a female family member has schizophrenia, compared to a male relative with schizophrenia (Martens, 1998). Possible reasons behind this are not clear, but it has been suggested that it may be related to different behavioural expectations due to the social roles of men and women (Martens, 1998). However, it has also been indicated that families of men with schizophrenia experience higher levels of distress than those of women with schizophrenia (Martens, 1998). Therefore, there seems to be a discrepancy in previous findings.

In an earlier study that examined siblings of individuals with schizophrenia it was found that the majority of sibling respondents were female, and the majority of individuals suffering from schizophrenia were male (Friedrich et al., 2008). This study hoped to gain some insight into the sibling relationship, when there is a diagnosis of schizophrenia involved, especially in terms of what kind of sibling dyads

seem to be the most involved when it comes to care-giving in the South African context.

Living Situation

When a family member is diagnosed with a mental disorder, large alterations tend to have to be made in order to account for this new variable. Consequently, there are bound to be changes experienced in the home, such as restriction of social and recreational activities, social and familial consequences, and feelings of burden and strain (Martens, 1998), which may have an effect on the sibling relationship. Studies have indicated that many household complaints occur due to the behavioural problems, such as temper tantrums and bizarre behaviour, of individuals with schizophrenia living with their families (Gubman et al., 1987).

Interestingly, it has also been noted that the level of distress experienced by family members did not differ when the family member with schizophrenia lived with their family or elsewhere (Winefield & Harvey, 1993). Yet, Noh and Turner (1987) found that the longer the relative was maintained in an institution or a community home, the more chance there was for elevated distress levels. It may be understood that if a relative with schizophrenia lives with the family, the family members will be more likely to be exposed to stigma due to greater interaction between the patient, family members, and acquaintances of the family. Such situations could account for an increase in the sense of distress among family members (Phelan et al., 1998).

Conversely, it was discovered that more concealment of the ill family member occurred when the patient did not live with the family. Thus, the extent of disclosure was determined by whether the individual suffering from schizophrenia lived with his family or not (Phelan et al., 1998). Previous research has noted that distancing strategies, such as living apart from the sibling, were initially perceived as reducing distress, however, this was found to be an unhelpful coping mechanism (Friedrich et al., 2008; Spaniol, 1987).

There appears to be a significant inter-relationship between the experience and manifestation of mental disorder, and the complex factors which make up the socio-cultural environment (Thakker, Ward & Strongman, 1999). The aforementioned information has clear implications regarding the need to address ignorance and negative community attitudes toward mental illness in South Africa. Ultimately, how

the diagnosis is perceived by the larger community, and therefore dealt with *within* a family, and the relationships he or she experiences within this family context, can have vast implications for how the diagnosed individual readjusts his self-concept post-diagnosis. As mentioned above, individuals with schizophrenia benefit from social activity, and consequently, with the socialising that would come with spending time with one's sibling, the individual with schizophrenia would potentially be more adept to finding ways to deal with his greater environment, society and community (Hatfield & Lefley, 2005; Samuels & Chase, 1979).

Stigma

Negative attitudes exist in abundance in society, and one group of people that are consistently discriminated against are people with mental illnesses (Ostman & Kjellin, 2002). Substantial research has documented that the stigmatisation of mentally ill people can have very negative consequences (Lee et al., 2005; Ostman & Kjellin, 2002; Phelan et al., 1998). Those individuals suffering from schizophrenia, experience their diagnosis as a mark of shame, and therefore the social stigma that is due to society's fear and lack of understanding cause these individuals to isolate themselves (Teschinsky, 2000). Recently, it has been noted that this stigma may extend to the family of the psychiatrically affected individuals (Lee et al., 2005; Ostman & Kjellin, 2002; Phelan et al., 1998).

Stigma may be defined as that which detracts from the character of an individual or a group. It is used as an implication indicating that something is not considered average or standard according to societal norms (Phelan et al., 1998). Goffman (1963) defined stigma in terms of that which disgraces or discredits an individual, as well as that which encourages the prohibition of full social acceptance. Such experiences would, according to Goffman (1963) motivate the efforts by the stigmatised individual, to conceal the stigmatising mark.

Notably however, it has been commented that the difference between those who are deemed 'normal', and those who are stigmatised, is simply a difference of perspective rather than actuality (Ostman & Kjellin, 2002). Thus, it may be deduced that stigma exists through the elements of labelling, stereotyping and discrimination, which in turn exist in situations that are directed by a greater command of power dynamics (Ostman & Kjellin, 2002).

Recently, there has been an increase in the awareness that the effects of stigma extend beyond the psychiatrically diagnosed individual to affect their families as well (Lee et al., 2005; Ostman & Kjellin, 2002; Phelan et al., 1998). This is principally due to the support of organisations such as the National Alliance for the Mentally Ill (NAMI) (Sommer, 1990). Furthermore, this type of stigma, in which a person is stigmatised simply due to their connection with another stigmatised individual, has come to be known as *associative stigma* (Mehta & Farina, 1988). According to Mehta and Farina (1988), being a close relative, especially a sibling of a mentally ill person creates a difficult and delicate position for that individual, as the entire family is likely to take up the shame and burden of the diagnosis, and in order to avoid such negative emotions, family members are likely to conceal the mental illness (Lee et al., 2005). The stigma experienced by family members may cause them to avoid talking about how they are feeling, or to deem themselves to be social outcasts for having the illness in their family. This would be especially counter-productive as it would create a potential barrier to receiving the social support that is so important to their psychological health (Teschinsky, 2000). It has been acknowledged that associative stigma has been perceived to be a grave problem by many family members, including siblings (Lee et al., 2005; Ostman & Kjellin, 2002; Phelan et al., 1998).

The pervasiveness of associative stigma can be identified by the paradoxical dualism it creates. That is, research also indicates that family members of a mentally ill individual may hold the dual role of being both stigmatisers, and victims of the stigmatisation themselves (Lee et al., 2005; Ostman & Kjellin, 2002). Family members might project their anger, suffering and frustration onto the mentally ill person (Lee et al., 2005), thus alienating him or her even more. This is specifically detrimental to the person with schizophrenia, as it worsens the outcome of schizophrenia (Lee et al., 2005). In particular, intra-familial stigma experienced by a mentally ill individual, specifically an individual diagnosed with schizophrenia, has been noted to lead to dysphoria (Lee et al., 2005).

Both the characteristics of the mental illness, as well as the social characteristics of the family were found to be significantly related to levels of familial stigma (Phelan et al., 1998). Thus, societal stigma may be hypothesised to have a strong influence over a family member's behaviour toward their relative suffering from schizophrenia. There is evidence that symptomatic behaviour, and psychiatric labels themselves affect the levels of stigma directed toward the mentally ill

individual (Phelan et al., 1998). Specifically, it has been hypothesised that the more symptomatic the behaviour, the more noticeable the illness, and the more the family members fear stigma. Thus, in psychopathologies that involve psychosis, such as schizophrenia, where there are positive symptoms such as hallucinations and delusions, there is a greater chance of stigmatisation. This can be attributed to the fact that psychosis is seen as a particularly perplexing and disturbing mental illness, and strongly corresponds to the public's notion of mental illness (Phelan et al., 1998). There is also substantial evidence that psychiatric labels themselves cause stigmatising responses (Phelan et al., 1998). Schizophrenia is one such label that is recognised as a descriptor of severe psychotic conditions, and thus is associated with greater reports of stigma (Phelan et al., 1998). Thus, it seems to be understandable that family members often choose to conceal their relative's psychopathological diagnosis (Lee et al., 2005; Ostman & Kjellin, 2002; Phelan et al., 1998).

This is especially true for siblings who may be adolescents or young adults, and typical of this developmental stage, are still trying to settle with their identity, and resolve concerns about who they intrinsically are (Erikson, 1968). Social expectations at this point in one's life may have profound effects on how one chooses to cope with difficult or distressing situations.

While research data is lacking, intra-familial stigma has also been connected with high-EE, which worsens the outcome of schizophrenia (Lee et al., 2005). This can be interpreted to be as a result of the pervasive nature of intra-familial stigma. Studies on psychiatric stigma have focused primarily on public attitudes, but the subjective experiences of stigma by a mentally ill person, focus specifically on how the stigma affects their subjective realities. That is, how stigma affects their everyday interpersonal connections, which involves family members, and specifically their siblings (Lee et al., 2005). Research has indicated that the experience of intra-familial stigma by individuals with schizophrenia, was high (Lee et al., 2005). Research has also indicated that those relatives that obtained support were able to alleviate the pressures of stigma, thus decreasing their own psychological distress, and were better equipped to provide a well-functioning and supportive network around the person with mental illness (Ostman & Hansson, 2000). This is significant as this type of positive environment has been shown to reduce the event of relapse (Bebbington & Kuipers, 1994; Cornwall & Scott, 1996; Ostman & Kjellin, 2002).

"Intra-familial and social connections of moral favour and relationship can break down in the face of the powerful forces of stigma" (Lee et al., 2005, p 156). That is, the connections within a family, both those based on relationships and the belief systems of the family, can be disrupted by stigma. Notwithstanding the fact that psychiatric disorders have recently become more prevalent worldwide, few programmes have been developed to deal with stigma arising from a mentally ill person's significant others, consequently affecting familial relationships (Lee et al., 2005). Appropriately, understanding the source of the stigma attached to a psychopathology can bring about increased knowledge regarding how the stigma colours the way individuals perceive the diagnosis. This perception can then be extrapolated to the diagnosed individual, and his/her family members.

It has become common knowledge that community attitudes and perceptions influence the help-seeking behaviour of mental health sufferers (Hugo, Boshoff, Traut, Zungu-Dirwayi & Stein, 2003). It has been suggested that the greatest stigma is attached to those conditions in which the person's behaviour is perceived as unpredictable or potentially dangerous (Hugo et al., 2003), such as some of the more bizarre behaviours of the person afflicted with schizophrenia. As discussed above, widespread social rejection, isolation and abuse of people with psychiatric disorders have been documented (Hugo et al., 2003).

It can be gleaned from the above literature that the importance of the sibling relationship in the event of schizophrenia is substantial. Humans are relational and emotional beings and, as expressed by previous literature, their EE can potentially play a role in the prognosis of the schizophrenia of one of the family members. The majority of previous research has focused on the role of the mother. This research neglected the importance of the sibling relationship, which has been argued to be the most resilient of familial relationships. This is especially relevant today, as due to de-institutionalisation and the lack of sufficient social services, the responsibility of future care-giving for those affected by schizophrenia, tends to fall to their siblings.

Siblings' perceptions of their relationships with their brothers or sisters with schizophrenia are coloured by certain factors as discussed, and elaborated upon in the above literature. Specifically, these aspects are the type of sibling relationship, gender, living situation, and stigma. Each of these factors has been understood to play a part in the way in which an individual perceives his/her relationship to his/her brother or sister with schizophrenia, post-diagnosis.

THEORETICAL FRAMEWORK: FAMILY SYSTEMS AND DEVELOPMENTAL THEORY

The aforementioned literature outlines how families are affected by mental illness, and specifically by schizophrenia. Of note in the above is the interaction that occurs within families affected by schizophrenia. Consequently this study employed the theoretical framework of family systems and developmental theory so as to fully explore and engage with the changes that occur in families affected by a mental illness such as schizophrenia.

A family systems orientation is well-known for its view of the family as a transactional system and each organism in this system is viewed to interact reciprocally (Andolfi, 1979). In this system, stressful events and difficulties of an individual family member have impacts upon the whole family, with ripple effects for all members and their relationships with each other. In turn, how the family handles and communicates problems contributes significantly to their ability to adapt to the situation in a positive way, or to individual and relational dysfunction. Therefore, individual problems need to be considered and viewed within the context of the larger family system (Manocchio & Petitt, 1975).

When viewing a difficulty within a family, such as a difficulty experienced by an individual member within that family, one needs to recognise the complex interplay of individual, family and social processes that exist. Furthermore, the family needs to be viewed as an open system that functions in relation to its broader sociocultural context and evolves over the life cycle (Minuchin, 1974).

Family systems theory advanced the conceptualisation of human functioning and dysfunction from a linear, and deterministic view of causality, to the recognition of multiple influences within and beyond the family that shape both individual and family functioning over the life course (Rolland & Walsh, 2009). Thus this approach takes into consideration the family's interface with larger systems, such as the mental health care system. Despite the origin of difficulties, the family is regarded as a vital partner in treatment, with the potential for promoting the best possible adaptation to the identified difficulty as often it is the family system that is ill (Manocchio & Petitt, 1975).

In a systemic model of human development, both individual and family developments are understood to co-evolve over the life-span (Carter & McGoldrick,

1999). In this view, the family moves in predictable stages over its lifespan with multiple transitions occurring concurrently within the family system. Each generation undergoes its own developmental processes, which in turn affect the rest of the familial system. For example, a young adult child may be preparing to leave home, while his or her parents are coping with the declaration of their child's independence (Goldenberg & Goldenberg, 2000). The developmental processes that one member is experiencing will therefore impact the rest of the family system. Thus, relationships grow and change, boundaries are altered and roles are redefined, which leads to necessary adaptation (Rolland & Walsh, 2009).

Haley determined that there are six stages within the family life cycle which included: courtship, early marriage, childbirth and dealing with the young, middle marriage, weaning parents from children, retirement and old age (Mandanes, 1984). Courtship includes the commencement of a relationship between two individuals, which then leads to marriage. The stage of early marriage especially, involves the creation of the family, and the establishment of the family home. The couple is then expected to bear and raise their children. Middle marriage is the phase during which the children are settled and are placed within educational settings. Relatively few changes occur at this stage, however the children become increasingly independent within the household (Goldenberg & Goldenberg, 2000). Weaning parents from children is the following period, during which children begin to assert their independence. More specifically, they leave the home, become involved in their own intimate relationships and get married themselves. The couple are then believed to enter retirement and eventually old age. This stage may involve the loss of the spouse, and increased dependence on their own children (Goldenberg & Goldenberg, 2000).

Andolfi (1979) stipulates that a healthy family is able to accomplish these stages effectively. This is understood to be due to these families' resilience to undergo the necessary transitions between the aforementioned stages. More specifically, since they use their resources, relationships, and strengths adequately in order to move smoothly into the next stage, they are better able to make the transitions between stages as opposed to families who do not use their resources, relationships and strengths effectively.

According to Brown and Hanna (2004), difficulties arise in the family because the family is unable to make the transition between family life-cycle stages, and their

development as a family has arrested at the developmental stage they were in. For example, a young man who is developmentally supposed to be preparing to leave home is diagnosed with schizophrenia and now is no longer able to live alone. His parents, who are developmentally supposed to be coping with the declaration of their child's independence, are now caring for their adult son. This family system's development has arrested at an earlier stage of development as perhaps the child with schizophrenia not only lives at home, but has become increasingly dependent on his parents. Consequently the family becomes fixated in a particular stage. Additionally, during periods of increased stress, the family may regress to earlier stages in the family life-cycle (Goldenberg & Goldenberg, 2000), as can be noted in the above example.

Family difficulties or dysfuctions that occur are understood to be as a result of the family's reaction and interactions surrounding the problem, as well as their coping mechanisms elicited in order to manage the problem. This view is in opposition with the view of the problem simply lying with the individual presenting with the symptoms that are causing the problem (Stanton, 1981). In this way, the family is understood to be an interactive system, rather than a unit made up of individual parts. More specifically, family members are interrelated in such a way that each individual affects all others, and the group as a whole in turn affects the first member in a circular chain of influence (Rolland & Walsh, 2009).

In light of the notion that family function and dysfunction is based upon the family's reaction and interactions to a problem (Stanton, 1981), certain key processes have been identified for effective family functioning. Therefore it may be hypothesised if these processes were unstable, or unbalanced, dysfunction may result. Rolland and Walsh (2009) identified these processes as family belief systems, organisational patterns and communication patterns.

Shared belief systems are at the core of all family functioning (Reiss, 1981). Such beliefs incorporate relationship explicit and implicit rules about roles, expectations, actions and ultimately guide family members' behaviours. Therefore a family's beliefs pertaining to their problem situation, as well as the meaning it has for them, that is - how it came about, and how it might be improved is especially important when attempting to understand a family's script surrounding a problem within a family (Reiss, 1981).

Family organisational patterns refer to the manner in which a family is

organised and maintained so as to foster healthy development of family members. This may also be understood as a family's transactional pattern (Andolfi, 1979). Various organisational patterns include how adaptable the family is, that is, the family's ability to be flexible and stable so as to manage family interactions, and changes within the family. The family needs to adapt in order to afford family members with stability and a chance for psychosocial growth (Minuchin, 1974). Families at dysfunctional extremes tend to be either chaotically disorganised or overly rigid (Andolfi, 1979). The latter case, is a tendency to repeat transactions in automatic, rigid ways, so as to maintain the system's homeostasis in families where one family member expresses pathological behaviour (Andolfi, 1979). In times of familial crisis, such as the diagnosis of a serious illness, flexibility for change must be balanced by the ability of the family to destabilise. This is important so as to allow the family to re-establish patterns by which to live their life (Rolland & Walsh, 2009).

Connectedness is another dimension of family organisation. This connectedness or cohesion represents the family's balance of closeness and mutual support, together with the respect for individuality and autonomy. Extremes of disengagement or enmeshment tend to be viewed to be dysfunctional, as both extremes are understood as having inappropriately rigid boundaries (Andolfi, 1979). The manner in which a family is connected and organised is also determined by the boundaries that form its structure. According to Minuchin (1974) family boundaries are essential structural requirements that need to be clear and firm, yet simultaneously permeable. This promotes differentiation and autonomous functioning as well as maintaining the hierarchical organisation within the family.

The final process involved in family functioning is that of communication. Communication, both verbal and nonverbal, facilitates all family functioning. The ability of a family to communicate openly and in a constructive manner assists in the reduction of pain in the family system. Therefore, it is important how family members handle dialogue and tackle issues (Monnachio & Petitt, 1975). Having clarity and actions that are congruent to the communication is essential for healthy family functioning (Rolland & Walsh, 2009). This being said, the opposite can be hypothesised to be true of dysfunctional families. Thus, communication is about interaction and rules for interaction which implicates both sender and receiver (Poster, 1978).

From the above, it can be understood that the framework of systemic family

theory together with a developmental understanding of the family, can further enlighten the narratives surrounding families and mental illness, and specifically surrounding the mental illness of schizophrenia. More specifically, this framework has the ability to extend a deeper exploration into the sibling relationship as a result of its' view of relationships being based on transactional dynamics. Consequently, it provided a sufficiently extensive theoretical model through which to interrogate the narratives provided by the participants, as well as to understand the hidden dynamics within the family.

The following section will discuss the central research questions arising from the literature reviewed and will examine the research method chosen to explore these questions in this study.

CHAPTER 3: METHOD

This chapter outlines research questions that have emerged from the literature, and which provide a focus to the study. The research approach and methods that were employed to answer these questions are then described. The choice of the interpretive social science paradigm and the qualitative research method utilised in this study is investigated. Following this, the approach to sampling is explained and an overview of the sample is given. The procedures undertaken in conducting the research interviews and the thematic content analysis of the data are then investigated, following which reflexivity is discussed. Finally, ethical concerns, and the manner in which these were managed and addressed are discussed.

RESEARCH QUESTIONS

The following research questions were drawn from the literature reviewed and served to guide the current study:

1. How would the individual describe their relationship with their brother or sister with schizophrenia?

2. What factors and experiences affect the individuals' relationship with their diagnosed sibling?

    2.1 How did the living situation affect the sibling relationship?
    2.2 How did the level of stigma attached to the schizophrenia diagnosis affect the sibling relationship?
    2.3 In what way did the gender of the diagnosed sibling affect the sibling relationship?

3. How did the individual’s relationship toward his or her diagnosed sibling change post-diagnosis?

RESEARCH APPROACH

Burrell and Morgan (1979) have presented four paradigms for analysing social theory, one of which is the interpretive paradigm. This paradigm emphasises that the social world is nothing more than the subjective construction of individual human beings who, through the interactions of everyday life, create and sustain a social world of inter-subjectivity. More specifically, interpretive researchers have attempted to show how the concrete, tangible aspects of life are dependent upon the subjective constructions of individual human beings (Burrell & Morgan, 1979).

The paradigmatic standpoint of this research is the interpretive paradigm. The interpretive paradigm is relevant to this study as it is orientated toward obtaining an understanding of the subjectively created social world. It sees the social world as an emergent social process, which is created by the individuals concerned (Mattila & Aaltio, 2006). In this vein, the proposed research is interested in the subjective reality of siblings of individuals with schizophrenia (Oksman, 2007). It is primarily interested in the exploration of how a sibling perceived his or her relationship with his or her brother or sister with schizophrenia, from his or her personal viewpoint.

Interpretive research typically tries to understand the social world as it is perceived from the perspective of individual experience; hence it has an interest in subjective worldviews. The goal of this paradigm is to generate a 'thick description' of the participants' worldviews. This paradigm is of the opinion that humans are creators of their worlds and that therefore, the agency in shaping their everyday world is of fundamental importance to the paradigm (Rossman & Rallis, 2003).

This type of research is guided by a set of beliefs and feelings about the world and how it should be understood and studied. Furthermore, the interpretive paradigm makes particular demands on the researcher, including the questions he or she asks, and the interpretations the researcher attributes to them (Denzin & Lincoln, 2003).

This study adopted a qualitative research method. Auerbach and Silverstein (2003) described qualitative research as "research that involves analysing and interpreting texts and interviews in order to discover meaningful patterns descriptive of a particular phenomenon" (p.3). Thus, qualitative research focuses on listening to the subjective experiences and stories of the people being studied (Auerbach & Silverstein, 2003). Ultimately, this is due to the fact that qualitative researchers seek

to systemically understand the peoples' lived experience without extricating them from their natural environment (Rossman & Rallis, 2003). Auerbach and Silverstein (2003) purport that there are variations in experience, rather than a universal norm, and that the researcher may not know enough about the phenomenon under study to generate a valid hypothesis, which concretises the notion that participants should be seen as experts in their own lives. Qualitative research has some unique features; specifically, the researcher is the means through which the study is conducted and, that the purpose of this type of research is to learn about some facet of the social world (Rossman & Rallis, 2003).

Following the aforementioned notion of learning, this type of research is conducted in order to improve some social circumstance; in the scope of this study it aimed to acquire knowledge on a sibling's perceptions of his or her relationship with their brother or sister with schizophrenia. The qualitative researcher gathers what he or she hears, sees and reads from people, places, events and activities. This research is conducted in natural settings so as to learn about some aspect of the social world of the participants and to generate new understandings that can then be used. Qualitative researchers, become a part of the inquiry process, continually making choices, testing assumptions and reshaping their questions. As the inquiry process grows, both the researcher and the participants are often transformed (Rossman & Rallis, 2003). Traditional research assumes that subjectivity and values as sources of bias that have to be eradicated or controlled. Thus, qualitative research may be viewed as being biased and unscientific, but qualitative research assumes that subjectivity and values are a necessary part of human interaction and therefore cannot be eliminated or managed (Auerbach & Silverstein, 2003).

Regarding the interpretive nature of this type of research, once the researcher has developed a description of the available data, he or she will interpret these, and draw meaning, both personal and theoretical (Creswell, 2003). To elaborate on this concept, it is necessary to note that the qualitative paradigm includes a reflexive stance that provides the opportunity for the researcher to examine his or her biases. This allows the opportunity to accept the responsibility for examining oneself, which in turn increases the probability that the research process will not be exploitive or oppressive for the participants (Auerbach & Silverstein, 2003).

PARTICIPANT SELECTION

Participants were obtained via non-probability, purposive convenience sampling. The sample consisted of eight siblings of individuals diagnosed with schizophrenia. They met the inclusion criterion of being over the age of eighteen years, and the participants' siblings needed to have been diagnosed with schizophrenia for at least five years. The participants were chosen according to the inclusion criterion, from a group of volunteers acquired from the Schizophrenia and Bipolar South African Association (SABDA). This research was only carried out once permission, through the medium of a letter (Appendix C), had been obtained from SABDA in order to access their client base. Once permission and access were given by SABDA, the researcher advertised for participation in the research, with the aid of significant members of the above organisation. The researcher then approached those individuals who responded to the advertisement, and they were informed of the research and were invited to participate.

Attainment of possible participants for interviewing proved to be difficult, hence the researcher was put in touch with other possible participants by SABDA, through a process of snowballing. Snowballing is a widely used non-probability sampling technique in qualitative research. More specifically, it is especially helpful when access to appropriate participants proves to be difficult (Grey, Williamson & Karp, 2007). In order to initiate the process of snowballing, the researcher typically locates one individual, or in this case an organisation, who is able to connect the researcher to other individuals, or organisations which may be willing to participate (Grey et al., 2007). Snowball sampling is therefore an invaluable tool for gaining access to well informed and experienced individuals who have the ability to provide in-depth information on a particular topic (Grey et al., 2007).

These individuals were then approached by the researcher and they were informed of the study, and invited to participate. Of the 8 participants, 7 were female and 1 was male, while the majority of the participants' siblings were male. Thus, the majority of caregiving relationships appeared to be composed of sister-brother dyads, in which the sister was the caregiver and the brother had schizophrenia. Additionally, participants' ages ranged from 25 to 60, while their siblings' ages ranged from 23 to

50. It is of further interest to note that all the participants were older than their sibling with schizophrenia.

Table 1: Participant Description

	±Sibling Age at diagnosis	*±Participant Age at Diagnosis*	*Siblings current living situation*
Participant 1	16	17	Lives with parents
Participant 2	19	21	Lives alone
Participant 3	18	22	Lives with participant
Participant 4	12	14	Residential home for the mentally ill
Participant 5	20	28	Residential home for the mentally ill
Participant 6	18	18	Residential home for the mentally ill
Participant 7	17	19	Lives with parents
Participant 8	37	51	Residential home for the mentally ill

The above table describes the participants selected for this study. Participants were between the ages of 14 and 51 when their siblings where diagnosed with schizophrenia. Their siblings were between the ages of 12 and 37 when they were diagnosed. From the aforementioned ages, it is interesting to note that all the participants were older than their sibling which suggests that the older sibling tends to adopt the caregiving role. Caregiving in this sense is regarded as being involved with their sibling in such a way that it led them to being a part of this study. With regard to the living situation, currently 2 siblings live with their parents, 1 lives alone, 1 lives with the participant (their sibling), and 4 siblings live in residential homes for the mentally ill. From these findings, it is pertinent to witness that only one sibling lives with his or her brother or sister – the participant. This may be suggestive of the

difficulty involves in caring for someone with schizophrenia. This may be further noted by the majority of siblings living in residential homes for the mentally ill.

DATA COLLECTION TOOL

This study made use of a semi-structured interview schedule (Appendix A) as the data collection tool. Each interview was approximately one hour in length. In addition to the interview, the researcher requested the participant to fill out a demographic questionnaire covering information about age, gender and living arrangements of the participant, as well as of the sibling with schizophrenia. This questionnaire also enquired as to what age the individual with schizophrenia was diagnosed.

Semi-structured interviews allow for the exploration of how individuals experience an event, and how they think and feel about this event. Typically, semi-structured interviews are conversations in which the researcher has a set of questions to be asked, and a good idea of what topics will be covered (Miles & Gilbert, 2005), however, the conversation is free to vary and is likely to change substantially between participants. Semi-structured interviews provide a framework to establish a rapport, as well as to gain knowledge of characteristic patterns of living and coping behaviours (Gamble & Brennan, 2006).

The amount of structure a researcher uses in the questioning technique will vary depending on the research questions to be addressed. This lack of structure may appear to be a disadvantage of semi-structured interviews, but it is actually an advantage. By having flexibility surrounding questioning, the researcher can address aspects that are important to individual participants, and by doing so, the researcher can gain a better understanding of the research question. Due to the flexible nature of the semi-structured interview, it can potentially yield data that is incredibly rich in detail (Denzin & Lincoln, 2005; Miles & Gilbert, 2005). More specifically, the wording of the questions can be altered, as well as added to, so as to ensure clear and accurate responses that are relevant to the research questions. Furthermore, the open-ended nature of the questions allows for unanticipated answers that reveal participant's true values, beliefs and knowledge (Miles & Gilbert, 2005).

Semi-structured interviews are a versatile means of collecting data, as they can also be used to develop a much deeper understanding of the research questions by

exploring contradictions within the participants' accounts. If this be the case, the researcher would be able to explore the contradictions in more detail by careful questioning (Miles & Gilbert, 2005). While it may be argued that semi-structured interviews do not allow for generalisability, as social scientists, we are interested in individual experiences of, and responses to events. The primary role of the researcher is to allow participant to 'tell their story' by asking a series of questions. By applying this approach the researcher can get a clear and accurate definition of the main problems or areas of interest (Gamble & Brennan, 2006).

These types of interviews provide a more appropriate format for discussing sensitive topics as opposed to other interviewing styles. While the interview may still be somewhat uncomfortable for the participant, the fact that the researcher can talk aspects through with the participants is reassuring. If need be, the researcher can also debrief them afterwards, and answer their questions about why this research is being conducted. Furthermore, this format of interviewing gives the participant the option to choose to end the interview at any point, thus ensuring the integrity of the participant (Miles & Gilbert, 2005).

While the use of semi-structured interviews is mostly advantageous, some disadvantages include the time-consuming nature of this data collection method. Conducting each interview takes a significant amount of time, as well as the organisation of the raw data, which can involve hundreds of pages of interview transcripts (Lofland & Lofland, 1984). In addition to the amount of work post-interviews, the researcher will also have to conduct pilot interviews prior to the commencement of the official interviews, so as to confirm that the interview schedule is appropriate. This is essential as ultimately the quality of the study relies of the quality of the interview questions being asked (Morse & Field, 1995).

Another aspect of semi-structured interviews is that the researcher needs to be constantly cognisant of the notions of participant bias and researcher bias. Members of the social sciences are likely to recognise that interviews are interactional encounters and that the nature of the social dynamic of the interview can shape the nature of the knowledge generated from the interview (Denzin & Lincoln, 2005). The researcher has a remarkable effect on the way which the interview unfolds, and the quantity and quality of what the participants talk about. It is worth examining how the researcher conducts the interview and the way in which he or she affects the interview (Miles & Gilbert, 2005).

For example, the participant may not give an accurate response, and as a result, the researcher's questions may lead the respondent (either consciously or unconsciously) in a certain desired direction (Bennet, Glatter & Levacic, 1994). This brings into focus the importance of the researcher's self-awareness. This is exceptionally important as the study can benefit from the researcher's self-reflexivity as highlighted previously, therefore this aspect of the interviewing process needs to be acknowledged by the researcher.

PROCEDURE

Prior to the commencement of the research, ethical approval was sought and received from the University of the Witwatersrand for the continuation of the research. As detailed above, permission from SABDA, from which the participants were sought, was obtained. This was achieved through a letter, (Appendix C), that outlined the rationale and aims of the research. Furthermore, permission was required from the individual participants, which was achieved through a participant letter, (Appendix E) that described and explained the intentions of the research. The letters guaranteed confidentiality and requested consent to continue the research.

Once permission was granted, individuals were then approached to participate in the study. For the individuals accessed through SABDA, this initially occurred through a liaison at the organisation. For the individuals approached independently of the organisation, the researcher contacted them directly and informed them of the nature of the study and invited them to participate. These individuals were asked to complete informed consent forms to ensure that they were made aware of, and understood the nature and intention of the study. If participants confirmed their willingness to participate, consent was also obtained (Appendix G) for their interview to be audio-recorded, and transcribed. Once a participant agreed to the aforementioned, the interview commenced at a location of convenience to the participant.

It must be noted however, that the interviews were not piloted as a result of the difficulty in finding participants. Furthermore it was found that the initial interviews facilitated appropriate discussion which suggested that the interviews would be sufficient in order to attain the necessary information for the purposes of the study.

DATA ANALYSIS

Interviews were transcribed by the researcher so as to maintain confidentiality, as well as to ensure thorough connection with the data. Self-reflexive notes were also kept for each interview, and will be discussed in the section on reflexivity.

The method selected to analyse the interviews was a thematic content analysis. Thematic content analysis is a technique of analysis that will provide an objective and systematic presentation of interview content by identifying themes within the interviews (Titscher, Meyer, Wodak & Vetter, 2000). Accordingly, content analysis has been selected as it provides an overall view of the available information. It assesses the frequency of occurrence of emergent themes which is used as an indicator of their prominence or ascribed importance (Titscher et al., 2000). While this technique may be considered limited in its ability to deconstruct complex issues, it does however suffice for the purposes of the suggested, chiefly exploratory research, which will investigate themes around the perceptions of siblings of individuals diagnosed with schizophrenia.

In order to analyse the data, explicit rules known as criteria of selection were established prior to the actual analysis of the data (Berg, 1995). Criteria were derived from theoretical background, and research questions (Mayring, 2000). These criteria attempted to be exhaustive, and thus account for each variation of interview content (Berg, 1995). An objective coding scheme was applied to the transcriptions of the recorded communications, and categories were developed from patterns that emerged from the data (Berg, 1995). The data was analysed minutely so as to ensure extensive theoretical coverage. Categories were then revised and reduced to main categories as the initial categories were tentative (Mayring, 2000).

The categories that emerged captured various processes, tensions and contradictions that emerged form the data, with a focus on those that were related to the theoretical underpinnings of the study, and that were associated with the research questions (Braun & Clarke, 2006). Ongoing analysis was conducted in which themes were refined, defined and named, and the relationships between the themes were explored (Braun & Clarke, 2006). Once coding of the data was completed, a complete analysis of the data had been achieved, and these results are presented in the results chapter below.

REFLEXIVITY

Qualitative methodologists often refer to the researcher as the instrument, or tool of the study. More specifically, researchers construct understandings of their topics through the questions they ask, the contexts they study and their personal life histories (Rossman & Rallis, 2003). Examining the way one's own subjectivity influences one's research is called *reflexivity* and is a goal of qualitative research (Auerbach & Silverstein, 2003). It requires that researchers acknowledge their own subjectivity and values, and reflect on them in systematic and disciplined ways because these personal factors can act as a source of knowledge about the phenomenon being studied (Auerbach & Silverstein, 2003). Thus, in order to monitor this reflexivity and complexity, the researcher kept a journal, recording her observations, feelings and thoughts of each interview.

Creswell notes that "the researcher filters the data through a personal lens that is situated in a specific socio-political and historical moment. One cannot escape the personal interpretation brought to qualitative data analysis" (2003, p.182). It is helpful to consider that the researcher's personal experiences are relevant to his or her interest in studying a specific phenomenon, although it is essential that the researcher acknowledges that his or her subjectivity influences the way in which the research is conducted (Auerbach & Silverstein, 2003).

In this case, the researcher's personal interest in the sibling relationship and how it is affected by the schizophrenia diagnosis was influenced by a combination of factors. Her training as a psychologist and interest in types of psychopathology, such as schizophrenia, as well as her interest in the nature of the interpersonal played a role in the specificity of the research topic. More specifically, the nature of the sibling relationship, and how this relationship may be affected by various pressures, as well as the resilience that this relationship may have, provided a key area of interest for the researcher. Furthermore, the researcher has had extensive contact with individuals who have experienced familial relational difficulties due to mental illness, and thus her interest was specifically piqued in this area.

Consequently, the researcher's personal experiences can be understood to be especially relevant when considering concerns of subjectivity (Auerbach &

Silverstein, 2003). It is for this reason however, that the researcher kept a self-reflexive journal so as to ensure that the researcher acknowledged her subjectivity.

Qualitative research has been described as being "quintessentially interactive" (Rossman & Rallis, 2003, p. 35). The researcher is in direct contact with the participants of the study, and their interactions may be complex and varied. It is also necessary that the qualitative researcher takes note of their reactions to what research participants say, as it gives important information about their feelings and experiences (Auerbach & Silverstein, 2003).

The researcher made note of specific experiences that could be related to her being a young female within a specific socio-cultural environment. A participant made inferences about the researcher's gender and youth, while discussing the role of women in that participant's culture. Reflecting on this aided the researcher in gaining a deeper understanding of how the socio-cultural environment impacts upon the sibling relationship due to the roles that men and women are believed to fulfil in this culture.

The self-reflexive journal was also used to capture the researcher's own responses in relation to the participants during the interview process. As discussed above, the knowledge assembled during a qualitative study was interpretive (Rossman & Rallis, 2003). For example, the researcher noted that some of the participants had little or no knowledge of what schizophrenia was, or made no effort to discover what this illness encompassed. On reflection, the researcher's interpretation was that it was quite informative that the participants' did not have this knowledge or actively seek it. The researcher hypothesised that it suggested the manner in which the participants dealt with the diagnosis and how their possible unprocessed response to the diagnosis has led to avoidance thereof. This may be associated to the difficulty that the researcher encountered in acquiring participants for the study. A substantial number of individuals whom the researcher contacted did not wish to participate, which may suggest that they too avoid their sibling's diagnosis of schizophrenia as a result of their own unprocessed emotions toward the occurrence.

The self-reflexive journal served an important purpose for the researcher in that it acted as a tool of catharsis. More specifically, due to the sensitive nature of schizophrenia, interviews with the participants tended to be quite emotionally charged. Each of the participants appeared to have experienced a substantial loss within their lives, and consequently the emotional content of the interviews was

heightened due to participants' grieving processes. The journal allowed the researcher to reflect on the interview and on the emotions expressed by the participant, as well as on what these emotions elicited within her. This process aided her in the interpretation of the data (Rossman & Rallis, 2003).

The analysis of data is never entirely neutral as the researcher's perspective will undoubtedly affect the interpretation of the results (Alvesson & Skoldberg, 2005). In addition to the issues of self-reflexivity, ethical considerations were also an important part of the research, and will be discussed further below.

ETHICAL CONCERNS

The research was conducted once the university issued an ethical clearance certificate, and the following ethics clearance protocol number was issued: MACC/09/009IH. Approval was provided with regard to the ethical considerations, as outlined below.

Permission had been granted from SABDA (Appendix C), as well as from the participating individuals. Participants were informed of the exact nature of the study, and it was be emphasised that their decision to participate was entirely voluntary. Furthermore, it was made clear that it is the right of the participant to withdraw his or her participation at any time during the study.

Participants were also made aware, both verbally and by means of a consent form (Appendix F), that all responses are confidential, and due to the sensitivity of schizophrenia, the participant is free to answer only those questions that he or she is comfortable with, and for any reason may terminate the interview. Additionally, the interview was recorded and transcribed only once permission was obtained from the participant (Appendix G). The participant was also assured that interview audio-recordings, and transcripts would be stored in a secure facility until the examination of the research is complete, or for two years after publication. Furthermore, should there have been any questions about the research, the researcher's contact details were provided on the consent form. Additionally, should research participants wish to see the research results, they will be able to contact the researcher, or get feedback from the organisation from which they volunteered, where a summary of the research findings will be made available to them.

Individuals who have siblings with schizophrenia may not be considered to be a necessarily vulnerable population to study, as they may not be perceived to be psychologically at risk. Yet the interview content was thought to possibly evoke an emotional response from the participants. Consequently, ethical issues were of great importance in this study.

As the researcher was an intern psychologist at the time of the study, and was being trained in psychotherapeutic skills, this offered a further means of managing risk to participants. Furthermore, the psychotherapeutic training and experience of the research supervisor aided the researcher in guaranteeing that the process of the interviews, and the management of the participants, was carried out appropriately. Additionally, the researcher made provisions for the contact details for free counselling if needed through the South African Depression and Anxiety Group, Lifeline and the Schizophrenia and Bipolar Disorder Association.

As discussed above, the content of the interviews was of a sensitive nature, and consequently it was of essential importance that the participants gave informed consent to participate within the study. In order for participants to give informed consent, the researcher gave the participants sufficient information about the nature and possible effects of the research (HPCSA, 2008). Despite this, some of the participants experienced difficulty when answering interview questions. It therefore became necessary for the researcher to spend time emotionally containing the participants with the use of her psychotherapeutic training. This action was undertaken in order to keep with the ethical principle of non-maleficence. Thus, the researcher attempted to minimise any risks or harm to the research participants (HPCSA, 2008).

In line with the principle of non-maleficence, the researcher made referrals when she saw fit to do so. In such situations when referrals were seen to be necessary, the researcher either suggested one of the free referral sources given to the participants on their information forms, (as discussed above), alternatively, the researcher discussed the possibility of attending psychotherapy with the participant, and aided the participant in finding a psychotherapist to fit his or her needs.

This study has identified the siblings of individual's with schizophrenia to be an infrequently accessed population, which may have contributed to the difficulty that the participants experienced when discussing their experiences. It is hypothesised that their heightened emotional states may be the result of their discussing the loss they

felt, and the grieving process they appeared to be experiencing. Yet, it is considerable to note that despite the difficulty experienced in discussing certain topics, the participants did not choose to withdraw from the study, notwithstanding being made aware of their autonomy within the study (HPCSA, 2008).

As the research required the researcher to make use of direct quotes from the interviews conducted with the participants, it was essential to ensure the principle of confidentiality (HPCSA, 2008). Thus, in making reference to participants, the researcher allocated the term 'participant' and a number, in place of that participant's name. When participants used first names in their interviews, the researcher changed these to proper nouns in order to maintain the meaning conveyed in the interview, yet uphold the principles of confidentiality. In addition, as participants often made reference to health care facilities, hospitals and residential homes for the mentally ill, the researcher replaced the original names of these places with descriptive phrases so as to maintain confidentiality.

CONCLUSION

This chapter outlined the central research questions that guided, and provided a focus for this study. The interpretive research approach with its focus on the subjective experiences and meaning making of the participants was discussed. A description was provided of the study's qualitative research method that was employed to assist in the understanding of the participants' lived experiences of having a sibling with schizophrenia.

Following this, the approach to participant selection was explained and the sample of eight individuals who met the criteria was discussed. The data collection tool of a semi-structured interview, and the reasons for the choice thereof were then outlined. Procedures for accessing and interviewing participants were described, as was the thematic content analysis by which the data was analysed. Reflexivity was then discussed, and factors such as personal interests, gender and cultural dynamics, as well as potential biases on behalf of the researcher were discussed. Lastly, potential ethical concerns, and the methods taken to manage these were addressed. Data collected in the manner detailed above, will be presented in Chapter 4.

CHAPTER 4: PRESENTATION OF FINDINGS

This chapter presents the findings of the research as obtained via interview data and information from the researcher's self-reflexive journal. This data has been interpreted and related to relevant existing literature. Extracts from the interview material will be presented in order to substantiate the themes that arose. More specifically similar themes that arose were factors that impact the relationship, the redefinition of the family, adjustment, the impact of schizophrenia and interaction with service providers. These themes will be discussed in the subsequent sections.

FACTORS THAT IMPACT THE RELATIONSHIP

The focus of this research was the exploration of factors and experiences that affected an individual's relationship with his or her sibling with schizophrenia. Among the factors that impacted upon the sibling relationship was a level of understanding of schizophrenia. This perspective can be understood to be mediated by the behaviour changes in the sibling with schizophrenia, as well as the diagnostic processes. Factors that were also identified to impact the relationship were contextual factors such as gender, living situation and the stigma attached to a schizophrenia diagnosis and symptoms.

Understandings of Schizophrenia

Families' definitions, understandings and experiences of schizophrenia are important as they have the potential to affect how individuals care for their brothers or sisters with schizophrenia (Gerace et al., 1993). "Families' understanding of schizophrenia is based on subjective experience" (Gerace et al., 1993, p. 638). Therefore how siblings define and experience their brother or sister's illness can be understood to play an important role in the sibling relationship as it is affected by schizophrenia.

The participants' narratives suggested that a better understanding of the schizophrenia diagnosis and symptoms impacted positively upon their relationship with their siblings. Martens (1998) identified that if an individual is not educated about schizophrenia, his or her ability to cope effectively with a sibling's condition may be compromised. The ability to understand that their sibling's behaviour was not

necessarily in their control, and that their ability to function had been altered, seemed to affect how successfully participants were able to manage with their siblings, as well as how they experienced their siblings. Therefore, education about mental disorders is essential for individuals trying to support, understand and deal with the repercussions of the mental illness for their siblings (Teschinsky, 2000).

For the participants in this study, some made an effort to learn about schizophrenia, while others did not. Those that did not comprehend the schizophrenia diagnosis, seemed to experience more difficulty in understanding the symptoms and behaviours of their siblings. Additionally, this seemed to affect their relationships with their siblings as these participants seemed to experience more intolerance and resentment toward their siblings than those participants that had a better understanding of the schizophrenia diagnosis and symptoms.

An insufficient understanding of schizophrenia can be evidenced in the following excerpts.

> I don't understand schizophrenia and I never really read anything about it so I don't know at what stage it develops. (Participant 2)

> I knew there was a problem..., but I mean I'm as young as he is, I don't know anything … remotely … anything about mental illnesses, disabilities, incapabilities … I don't know … to me it was just abnormal behaviour. (Participant 4)

> I'm not really sure … uh … what schizophrenia is. It's not his fault that he is ill. But when he is ill, then I can see he is ill. (Participant 8)

Participant 2 identified that she had never made a point to learn about schizophrenia, while Participant 4 acknowledged that she knew that her sibling's behaviour was "abnormal" but did not know anything about mental illnesses. Participant 8 was aware that the schizophrenia was not his sibling's fault, but he was not well informed as to what exactly schizophrenia is. Therefore he acknowledged that his brother's behaviour was not within his control, yet he did not seem to gain a deeper understanding into what schizophrenia is. These participants had not developed the knowledge and skills that are typically needed to manage and cope with the circumstances surrounding the illness (Friedrich et al., 2008). This may be due to being left out of the treatment process, which contributes to their lack of knowledge (Friedrich et al., 2008). However, it also seems to be partially due to their own lack of

undertaking to research and discover the meaning of schizophrenia and the repercussions thereof.

If one were to hypothesise possible reasons for these participants insufficient understanding about schizophrenia, one may connect Participant 2's disinterest as being a part of her avoidance of the reality in which she has been forced to live. In contrast, Participant 4 seems to acknowledge that her brother had a problem, but the reason she gave for not having greater knowledge of schizophrenia was that she was young at the time when he was diagnosed. Her allusion to her age, and connection to her lack of knowledge may be interpreted to link to her possible feelings of being disempowered by her youth, as a result of the restrictions that may have gone with her age. More specifically, she may have been left out of the treatment and management of her brother, which would have contributed to her lack of knowledge. Participant 8 on the other hand expressed uncertainty about his knowledge, yet he emphasised his ability to know when his brother was ill.

More specifically, participants who undertook the responsibility of being informed about the illness seemed to be more accepting of their siblings.

> My mother...googled everything that she could. And then obviously she also shared that information with me. (Participant 1)
>
> I didn't understand the full extent, I mean I got a lot of reading material and all of that… (Participant 3)
>
> With knowledge you can actually help the person who is suffering from schizophrenia. (Participant 7)

Participant 1's quote speaks to the important role that parents play in including their other children in their information gathering, exploration and discussion. Participants 3 and 7 attempted to discover what schizophrenia is, and what the diagnosis and symptoms mean. Participant 3 appears to have made the effort to have researched schizophrenia, and yet despite her efforts she still does not understand the disorder entirely. Participant 7's excerpt suggests that by understanding schizophrenia, one is better armed to assist their sibling. This speaks to Cutting et al., (2006) who identified that the family members of the individual with a mental illness are characteristically the closest to that individual, and thus the most influential on the life of that individual.

This research shows that understanding schizophrenia would impact the sibling relationship as it would be a strong determining factor that impacts the sibling relationship.

Difficulties surrounding diagnosis

Making an accurate diagnosis of schizophrenia requires extensive knowledge of schizophrenia, as well as sophisticated application of the diagnostic principles (First & Tasman, 2006). Often, individuals with psychotic symptoms are misdiagnosed, or their diagnoses are placed on hold while mental health practitioners search for more evidence (First & Tasman, 2006). Both Participant 1 and Participant 6 seemed to encounter these types of diagnostic difficulties with their siblings.

> I think it took about 2 or 3 years before he was actually really diagnosed with schizophrenia. And I don't know why it took so long for him to get diagnosed. But I mean he was in and out of hospitals …uhm they did all sorts of tests on him uhm … At first they thought he had OCD … then they discovered it was schizophrenia. (Participant 1)

> He was in and out [of hospitals] and they didn't really know what he was. It was just one thing to the next. One day it was bipolar the next it was this and the next it was this. (Participant 6)

The above excerpts identify the types of diagnostic difficulties that individuals with schizophrenia encounter, specifically the time that it takes to make a diagnosis. It may be hypothesised that the delay in making a diagnosis may have impacted the participants' responses to the diagnosis. Furthermore, it may have had a role to play in individuals not seeking out information related to the diagnosis, especially if it is not a concrete diagnosis. That is, brothers and sisters of individuals with schizophrenia may have not made an effort to learn about the diagnosis if the diagnosis was not concrete. As a result, it may be hypothesised that the response to the diagnosis, as well as the response and affect upon the sibling relationship may have been delayed.

Participant 6 noted that mental health practitioners considered a bipolar diagnosis, which suggests a possible differential diagnosis with mood features. Research has indicated that a substantial number of individuals with schizophrenia suffer with symptoms of depression. This tends to be associated with impaired

functioning, higher rates of relapse, hospitalisation and relapse (First & Tasman, 2006), which may be as a result of a bipolar diagnosis.

> And then the other thing, his biggest problem also is uh depression. (Participant 8)

The large overlap between schizophrenic and affective symptomatology has a role to play in the difficulty of diagnosing schizophrenia. Yet, in some cases, especially where there is a familial history of mental illness, the possibility of bipolar disorder is alerted to (Werry & Taylor, 1995). For example, Participant 4 suggested that her brother's diagnosis of schizophrenia had a genetic link to her mother's bipolar disorder diagnosis.

> My mother suffered similar … she didn't have the schizophrenia she had the bipolar … it was so … we knew more or less it was my mother's side. (Participant 4)

Family studies provide evidence that there is a substantial genetic component and that there is little doubt that schizophrenia manifests as a family disorder (Maxmen & Ward, 1995). The risk of an individual developing schizophrenia is higher if an individual's parent, as opposed to an individual's sibling has schizophrenia. Additionally, results have suggested that the possibility for developing schizophrenia rises with the number of affected relatives (Werry & Taylor, 1995). Thus the greater the family history of mental illness, the greater the vulnerability an individual may have for developing a mental illness.

Participant 4's sibling schizophrenia diagnosis seems to be complicated by bipolar disorder symptoms.

> It wasn't just schizo – it was like bipolar mood disorder he's a lot more depressed now. (Participant 4)

Thus, a significant difficulty arises when diagnosing individuals with schizophrenia when they experience affective disturbance. More specifically, it is important to distinguish between depression as a syndrome, and depression as a symptom when it does occur. This is especially difficult in individuals with schizophrenia as they may "lack the interpersonal communication skills to articulate their subjective states well" (First & Tasman, 2006, p. 234). Furthermore, Participant 5 indicated that the diagnosis of her sister was difficult due to mental health professionals believing her

symptoms were precipitated by stress due to separation as a result of her mother passing away.

> We had taken her to uhm psychologists and ... but nobody could see anything at that time except for what they though was just grief and you know the effects of losing our mother. (Participant 5)

A possible reaction to grief by children is acting out behaviours (Worden, 1996), which is the type of behaviour that Participant 5's sister engaged in when her mother passed away. Yet, she was only diagnosed with schizophrenia approximately 10 years after her mother had passed away. It may be hypothesised that the stress that was resultant of the separation from her mother acted as a precipitating factor for the onset of her schizophrenia.

A number of studies explore psychiatric comorbidity and schizophrenia, however medical comorbidity in schizophrenia has been studied to a lesser extent. Some medical conditions have shown to be causative for psychiatric symptoms, while others have shown to exacerbate a pre-existing psychiatric disorder (Jeste, Gladsjo, Lindamer & Lacro, 1996). Nevertheless, individuals with schizophrenia have been reported to have elevated rates of cardiovascular and respiratory diseases, among others (Dixon, Postrado, Delahanty, Fischer & Lehman, 1999). Medical comorbidity can have an adverse impact on mental health (Dixon et al., 1999), and consequently it is an important factor that contributes to quality of life for individuals with schizophrenia, and well as their caregivers. Such problems regarding medical comorbidity and schizophrenia were discussed by Participant 3:

> She is also mentally retarded...She didn't have a memory, she had a serious learning problem, mental retardation and schizophrenia...Sleep apnoea...Emphysema...Enlarged heart... In this sense since schizophrenia was just another thing to have to manage about her, schizophrenia just compounded all of that and made it all more worse. (Participant 3)

Participant 3's sister suffers from multiple comorbid complications, and consequently her schizophrenia diagnosis was experienced as yet another element added to an already complex combination of diagnoses. The array of comorbid diagnoses that Participant 3's sibling experiences seem to have resulted in Participant 3 experiencing a significant sense of despair.

Harris (1988) has indicated that individuals with schizophrenia have an increased risk for cardiovascular disorders (cited in Jeste et al., 1996). There is also a large body of existing research that illustrates that schizophrenia is associated with moderate cognitive impairments. Such deficits are thought to be a feature of brain dysfunction in schizophrenia, and are thought to have progressive deterioration during the initial stages of the illness (Jeste et al., 1996). However, in the case of Participant 3's sister, she was diagnosed with a severe mental delay from a very young age, prior to the schizophrenia diagnosis. Consequently her cognitive impairments may be understood as not being as the result of the schizophrenia, but may be a possible causative factor (Jeste et al., 1996).

The diagnostic procedure as well as complexities related to the diagnosis can be understood to contribute to factors that influence the sibling relationship as they play a role in how one understands the diagnosis, and is therefore able to manage the repercussions thereof.

Behaviour Changes of Sibling with Schizophrenia

The behaviour of the individual with schizophrenia plays an important role in the family system, as it potentially affects all interactions, including sibling interactions (Martens, 1998). Consequently, the changes in behaviour that occur within an individual with schizophrenia can be viewed to be a factor that influences that sibling relationship.

With the onset of symptoms of schizophrenia, an individual's life is forever changed. Symptomatic expressions of schizophrenia may be frightening experiences such as hearing voices, feeling threatened by unknown forces, seeing scenes that seem real but are not, losing the ability to concentrate as well as many other manifestations of the illness (Brady & McCain, 2004). Trying to cope with these experiences, as well as in the resultant behaviour often results in interferences with both individual developments as well as in family life (Brady & McCain, 2004).

Previous studies have found that the basis of family reactions to their relatives' schizophrenia-related symptoms was often rooted in how the family interpreted these symptoms (Brady & McCain, 2004). Therefore in attempting to understand the changes in behaviour of their siblings with schizophrenia, participants' understanding of the diagnosis plays an important role in the manner in which their interactions were affected.

> It was difficult not to sort of … sort of for us not to sort of laugh because it was like … we weren't allowed to turn the television on because Margaret Thatcher was a drug dealer and she was spying on [her] particularly because she knew that she bust Margaret Thatcher's drug dealing… I don't think she's evil or …I just think she doesn't get it (Participant 2).

Participant 2's reaction to her sister's bizarre behaviours, as indicated above, seems to suggest a defensive reaction to the absurd behaviour. Her defense of laughing may speak to her denial and avoidance of the reality of her sister's schizophrenia diagnosis, and the repercussions thereof.

According to Participant 2, her sister displayed paranoid delusions, as outlined in the extract below. Such false beliefs and the subsequent behaviour can be seen to have impacted directly on the sibling relationship as it instructed a certain way of living and being, that was contrary to how the family had lived prior to the diagnosis. When Participant 2 discussed this memory, she placed emphasis on how absurd this behaviour was. Furthermore, this Participant did not particularly understand the symptoms involved in a schizophrenia diagnosis and was consequently quite incredulous when making reference to such incidents, as can be reiterated below.

> She was like clutching onto her handbag...like we were going to steal her handbag and then came back clutching it and sort of sat there anxiously and looked darting looks at my face to see if I was going to actually kill her. (Participant 2)

When speaking of this incident Participant 2 remarked on how irrational her sibling's behaviour was, and she struggled to understand it. The behaviour, and the absurdity it seemed to represent for her seemed to cause her much pain, which then appeared to be converted into anger and irritation.

> That skittish behaviour is not normal. It's odd, it's not normal behaviour. Its not rational behaviour which made me think something was wrong with her. (Participant 2)

Consequently, it may be hypothesised that if Participant 2 had a better understanding of the symptoms related to schizophrenia, she may have been more understanding of her sister's unusual behaviour. That is, individuals diagnosed with schizophrenia often live in a world of uncertainty and threat due to symptoms such as false beliefs and altered sensory perceptions. These are especially difficult for the individual to

explain, but it often involves a distortion of some aspects of their environment (Cutting & Dunne, 1989).

Research has evidenced that often family members have thought that the family member with schizophrenia used the symptomatic behaviour purposely to aggravate or provoke other family members (Hooley & Campbell, 2002). While it may be argued that in situations such as the one mentioned above, Participant 2 may have experienced the schizophrenia-related symptoms as deliberate and annoying. In contrast, Participant 5 seemed better able to contextualise her experiences of the symptoms, even when they seemed to provoke her directly.

> The radio was on and she would say … just listen, they are talking about me, can you hear they are talking bad things about me. She would get up in the middle of the night in total hysteria. They are coming to get us, they are coming to get us, can you hear them, look and they are bombing the place. We'd just be sitting like you and I are sitting here now and she would say you are thinking bad about me. I know what you are thinking and you are thinking really bad things about me. (Participant 5)

Participant 5's sister seemed to experience perceptual distortions of her environment. In the above extract Participant 5's sister displays both paranoid and referential delusions which may have affected the relationship as the sibling had the false belief that her sister was thinking bad things about her. However, Participant 5 seemed to have an understanding of schizophrenia-related symptoms and consequently she seemed able to contextualise such events within the illness.

Understanding symptoms and consequent behaviour can often be linked to how one reacts to an individual with schizophrenia. If one experiences difficulty grasping the full extent of schizophrenia symptoms, or has not been educated about what such experiences may entail, one's reactions to them may result in fractures or breaks in relationships.

Embarrassment about the illnesses signs and symptoms is common amongst those affected by schizophrenia, especially when behaviour is unpredictable and involves psychotic symptoms (Friedrich, Lively & Buckwalter, 1999). Participant 8's brother seems to illustrate grandiose delusions, which Participant 8 experienced as embarrassing, especially when in a social context.

> Well you feel uncomfortable when you sometimes like… where he was in this funny situation, you don't want him to sit there and say to you …

> you know, that red ring on your scarf there … that's actually the ring of God that's protecting you …Then you have to explain to them don't worry about him he's … you don't want to explain to everybody what's the situation. (Participant 8)

Participant 8 preferred to try and avoid such instances wherever possible:

> Then I prefer not that he goes there you know. (Participant 8)

Participant 8's lack of understanding around the symptoms of schizophrenia may have contributed to his reaction to his brother, thus affecting their relationship. However, this reluctance may be due to the stigma attached to the schizophrenia diagnosis (Phelan et al., 1998). The stigma related to schizophrenia, and its impact on the sibling relationship will be discussed further on in the report.

One of the most difficult behaviours family members are forced to deal with is that of aggression, and violence. Many aggressive acts among individuals with schizophrenia occur within the family (Steinert, Wiebe & Gebhardt, 1999), and what makes them particularly difficult to understand is that there is no single explanation for them. These types of violent behaviours occur within a larger system that involves the whole person and his or her environment (Swanson et al., 2006). Studies have evidenced that this violent behaviour that is often observed in individuals with schizophrenia, is motivated by psychotic symptomatology. Therefore, "the understanding of violence in schizophrenia patients requires consideration of psychiatric symptomatology" (Fresan et al., 2005, p. 511).

Family members are frightened and confused by their family members' strange new beliefs and behaviours. All familial relationships are severely tested in response to the symptoms of schizophrenia, and most often families do not know how best to respond to these changes in their family member (Brady & McCain, 2004).

Often the memories surrounding aggressive behaviours of their siblings leave individuals helpless, fearful and resentful. Participant 1 related the following incident:

> He actually threatened my mother and my father with their life, he chased my mother … he actually pushed my mother right across the kitchen…but now he's extremely strong so he pushed her right across the kitchen, she fell on a breakfast nook uhm …which smashed underneath her so he grabbed the leg and he tried to swing it at her...He smashed my mother's car up with the leg …he actually chased

> my mother to her car and started smashing up the car while she was in there. (Participant 1)

This incident was experienced as quite traumatising for Participant 1 as she related the following:

> I had to come home and then we had the cops there, we had the CMS, we had the negotiators we had 10 hostage negotiation guys, we had the ambulance … we had the CMS and I think it took 10 or 12 big guys to actually subdue him. (Participant 1)

Violent and aggressive acts can occur through physical acts, violence against self and others, as noted above, as well as verbal aggression as illustrated below (Steinert et al., 1999). Participant 2 related an incident in which her sister was arrested as she was trying to burn the house down. When the police came to take her away Participant 2 recalled that:

> She just sort of held onto the grills [of the police van] and said 'I fucking hate you, I hate you all'. (Participant 2)

This is significant as data gathered from Participant 2 suggests that the familial communication style was high in expressed emotion. Furthermore high EE has specifically been connected with greater symptoms of aggression and hostility (Brady & McCain, 2004), which may partially account for Participant 2's sisters aggressive behaviours. Nevertheless, Participant 2's lack of understanding of the schizophrenia diagnosis and symptomatology seemed to contribute to the sibling relational difficulties.

Similarly, Participant 4 and Participant 7's lack of a greater understanding of schizophrenia seemed to contribute to their experiences of their brothers' behaviours.

> He would do that. He … when he lose his temp … lost his temper, then he would go all out of control…and there was no ways of restraining him. (Participant 4)

> He had basically thrown a chair through the window or something its things like that…or like something that I sort of remember quite strongly … is uhm … him sort of throwing things out of the room and banging and whatever and …and us…my mom, dad and I just standing in the dining room not knowing what to do. (Participant 7)

The sense that these participants had, that there was no way to restrain their siblings speaks to Participant 1's experience of her brother, as discussed above. This suggests

a sense of helplessness and fear amongst the participants when it came to their siblings' aggressive and violent behaviours.

Research has indicated that there are specific risk factors that were associated with such violent behaviour. Specifically positive psychotic symptoms increased the risk of minor and serious violent behaviours, while negative psychotic symptoms lowered the risk (Swanson et al., 2006). Aggressive behaviours have been noted to include breaking furniture or household items, as well as tearing clothes and paper, or throwing things out. These types of behaviours have been identified to cause some public concern as can be noted by the aforementioned excerpts (Tsoi, 1993).

It may be hypothesised that had these siblings had a better understanding of their brothers' experiences, they may have felt less helpless and afraid, and in turn such schizophrenia-related behaviours may have impacted less upon the sibling relationship.

In addition to aggressive and violent types of behaviour, individuals with schizophrenia also exhibit odd and bizarre behaviours. Positive symptoms such as severe thought disorders, hallucinations and delusions have been evidenced to be overtly noticeable and bizarre, especially to family members of individuals with schizophrenia (Brady & McCain, 2004). Such odd behaviours may be the individual exhibiting expressionless gazes, suspicion and social withdrawal among others which tends to lead to confusion in the home (Teschinsky, 2000). Such expressionless gazes can be specifically noted by Participant 1's experience of her sibling's behaviour:

> He would just stare at you as if … you know he was going to kill you with those stares...travelling in a car with him was actually quite nerve wracking … cos you are driving and all of a sudden he would like stare at you…it actually used to 'gril' me… He used to laugh…there was some voice telling him jokes (Participant 1)

Participant 1's experiences of her sibling's behaviour suggest that she becomes afraid of him when he stares at her, and when he laughs randomly. This behaviour seems to impact the sibling relationship as Participant 1 becomes uneasy when her brother stares incessantly, and laughs randomly as these can be seen as experiences in which she cannot share. She does not know what he is staring at, and his humour cannot be shared.

Studies have indicated that many familial complaints occur due to the behavioural problems, such as temper tantrums and bizarre behaviour, of individuals

with schizophrenia living with their families (Gubman et al., 1987). One such 'bizarre behaviour' was noted by Participant 5:

> She'll phone me and she's very impatient though, with a 'please call me' when she phones, she gives me that please call me and most of the times I am at work. Uhm if I haven't like picked up the phone and phoned her straight away, 2 seconds later there is another one (Participant 5).

Participant 5's sister's phone calls and insistence seem to affect their relationship as Participant 5 appeared to feel forced to accommodate her sibling's needs, while often forsaking her own. Nevertheless, Participant 5's greater understanding of schizophrenia-related symptoms seem to assist her in managing such behaviours, in that way impacting less upon the sibling relationship.

In contrast however, while Participant 7 seems to have an understanding of schizophrenia, her ability to manage her sibling's behaviours did not appear to be as developed as Participant 5. Participant 7 noted her fear of managing her brother's seemingly unusual and unpredictable behaviour:

> I'm afraid that he's going to … go running out the shopping centre like the most extreme things and then go well he's just going to run out of here because its really too loud. (Participant 7)

Friedrich et al. (1999) found that unpredictable embarrassing behaviour in public was found to be amongst the most disturbing behaviours for families to cope with. Consequently, while Participant 7 may have an adequate understanding of schizophrenia, her ability to manage unusual behaviours associated with the illness is limited and consequently seems to affect her relationship with her brother. Despite an understanding in the bizarre behaviours by her sibling, their relationship is impacted upon as it informs the type of activities in which they can engage together. This removes the positive enjoyment from the sibling relationship and the relationship may experience difficulties shifting from pre-diagnosis to post-diagnosis.

Contextual Factors

Gender, living situation and stigma were specific factors that have been evidenced to impact upon the sibling relationship in previous literature, as discussed in Chapter 2.

This study corroborated these findings as it determined that these factors played a role in the sibling relationship within the South African context.

Gender

Previous studies that examined siblings of individuals with schizophrenia found that the majority of sibling respondents were female, and the majority of individuals suffering from schizophrenia were male (Friedrich et al., 2008). This study had similar findings in that the majority of respondents were female. This may be attributed to the evidence that sisters are more likely than brothers to provide support for their siblings (Cicirelli, 1993; Gold, 1989). This may also be accounted for by the manner in which women are socialised into a caregiving role in many cultures (Chodorow, 1978). However, while sisters were identified to be more likely to provide support for their siblings, this did not immediately translate to having closer relationships with their siblings as suggested in previous research (Campbell et al., 1999; Cicirelli, 1989). This will be discussed in more detail in later sections of the report.

This study noted the importance of the gender role in the sibling relationship. LaTorre and Piper (1979) defined gender role as the social expression of one's personhood as male or female (cited in Nasser, Walders & Jenkins, 2002). However this expression of gender is a socially constructed concept that refers to expectations, attitudes and behaviours that are believed to be appropriate for each gender in a particular culture (Notman & Nadelson, 1995 cited in Nasser et al., 2002).

Participant 8 identified just how such roles are constructed, and how such constructions may influence relationships affected by schizophrenia:

> I think it could have much more easier if he was a woman because then he would have done sewing and he would have with other woman he would have done … he's doing nothing … he would be doing some needlework and some little bit of artwork and things. (Participant 8)

Participant 8 believed that if his sibling was female rather than male, that life would have been easier due to the ability to socialise with more feminine tasks. Furthermore he believed that the relationship would be altered if the gender of his sibling was different. Additionally Participant 8 would have had his sibling live with him instead of the residential home in which his sibling currently lives.

> I have a lot of respect for women, I think that would have been uh … maybe then she wouldn't have stayed in [the residential home] – she may most probably then would have stayed with us if she could behave herself and …you know act like a woman (Participant 8)

This may be understood to be indicative of the manner in which the female gender role has been socialised in Participant 8's family and culture. It may be hypothesised that this family has adopted more conservative and traditional expectations of gender roles. That is, traditional notions of masculinity suggest that a male gender role tends to be that of achiever and the breadwinner (McClelland & Watt, 1968). Such social and occupational role demands may be greater for males in such environments, which may lead to less realistic expectations for male schizophrenic patients' readjustments into their families and into society (Haas, Glick, Clarkin, Spencer & Lewis, 1990). However, it seems that in this specific context if a woman is unable to work, it is generally accepted. Therefore "current culturally based sex-associated expectations, may lead families to maintain educational and achievement expectations for males, despite having accepted a more reasonable future for females" (Seeman, 1983, p. 356).

Thus norms and expectations in families with more rigid and traditional gender roles may experience more difficulty adjusting to mental illness and the subsequent role changes, especially for men.

In such families, there also seems to be a particular role that a female is socialised to play. This notion was held by Participant 7:

> Maybe a sister would be different because of the way you say like women are different … are more sort of aware of the emotional side of things … (Participant7)

Participant 7 believed that a sister would have been more in touch with the emotional aspects of events due to being a woman. This belief seems to be held as women are generally considered to be more sensitive and emotional than their male counterparts. Participant 7 believed that having a sister with schizophrenia would have changed their relationship:

> I think if he was, if I had a sister… if he was a girl I think it would be easier...I could say 'well let me hold you its gonna be fine or but now there's sort of uhm …but a girl I think I could actually hold her and we could like actually sob, or maybe not (Participant 7)

From the above extracts, Participant 7 suggests that she believes that if her sibling were female, they would have been able to commiserate, and find solace with each other. It appears that Participant 7 was alluding to the notion that females are typically more emotionally inclined than males, and consequently a sister-sister dyad would be able to relate to each other on a more emotional level than a brother-sister dyad. This socially constructed definition of how women are viewed, needs to be understood in context with an individual's family and specific environment. That is, the manner in which men and women are socialised into society seems to play a substantial role in terms of how the participants viewed their siblings, and the manner in which they related to them. Previous studies have evidenced that in contrast to this popular notion, some parts of males' unconscious self-image is sensitive, and in fact more feminine, while some parts of the female's unconscious self-image is insensitive and more masculine (McClelland & Watt, 1968). Furthermore, a study on sex-roles and schizophrenia found that males and females with schizophrenia often experience sex-role reversal (Ecker, Levine & Zigler, 1973). Thus, the manner in which one perceives the impact of gender on the sibling relationship, needs to be viewed cautiously as gender nuances and subtleties exist in all cultures, families and relationships.

In contrast to the more rigid and traditional families discussed above, more liberal types of families seem to react differently to gender role construction and consequently to mental illness. That is, those families that seem to take a more liberal stance to gender role construction appear to be more accepting of their relative with schizophrenia, male or female. This was illustrated by Participant 4, whose family may be understood as being quite liberal as opposed to traditional.

> I don't … see why if it's a girl we should handle it differently to what if it's a boy, I mean … it just doesn't … there is no boy / girl with that kind of thing …(Participant 4)

While Participant 4 did not view gender to be a relevant factor that played a role in influencing her relationship with her brother, it may also be argued that she did not consider gender to be a contributory factor with regards to the schizophrenia diagnosis. That is, "people with schizophrenia are often considered 'genderless'" (Nasser et al., 2002, p. 355). That is, the individual with schizophrenia is often viewed as 'the schizophrenic' rather than the male or female who has schizophrenia.

In such cases the diagnosis may be understood to take over the individual's identity. This has been identified to be one of the greatest sources of pain for the individual with schizophrenia, their loss of personal identity, and the acquisition of the role of the 'schizophrenic' (Brady & McCain, 2004).

The role of gender and how it influences the sibling relationship may also be due to the ability of the sexes to relate to each other, as discussed by Participant 5:

> It probably would be different because there's probably things that I won't speak to my brother about I mean … you know … like about female things. I just think men aren't as sensitive uhm … as women. I really don't … so they don't – there's certain things that I probably speak to [my sister] about that I probably couldn't speak with a brother about. (Participant 5)

Participant 5 makes reference to her ability to relate to her sister as being easier as a result of being of the same sex, and consequently being able to discuss 'female things'. This seems to suggest that had her sister been male, there would have been more difficulty to relate due to more limitations placed upon perceived appropriate discussion topics.

Nasser et al. (2002) have documented that much of the schizophrenia symptomatology may be manifested as an exacerbation or inversion of 'normal' male or female gender roles. Therefore how one interprets certain behaviours is informed and affected by the degree of congruity with prevailing gender stereotypes (Page, 1987).

In this vein, previous findings have suggested that families are more likely to perceive a mentally ill male to be more aggressive and dangerous than a mentally ill female (Phelan et al., 1998). This study's findings uncovered similar results as indicated by Participant 1:

> I think if he was a girl, I don't think he would have had so much strength. Uhm … and I don't think he would have pushed my mother right across the kitchen … I mean he did that often … he actually physically abused my mother (Participant 1)

Participant 1's perception of how gender may influence her sibling relationship, seems to be related to physical differences between the genders. The assumption that a female sibling would not have been able to have been as aggressive or abusive may have some basis in the physiological gender differences, yet the question that this

uncovers is whether Participant 1 believed that a sister would be unable to be aggressive. This would speak to the social roles of men and women and how violence and aggression are socially constructed as masculine behaviours.

As discussed above, this study found that more sisters act as caregivers or provide support for their siblings with schizophrenia, as noted by previous literature (Campbell et al., 1999). However, in contrast to this literature, gender in this study did not seem to determine the type of relationship the siblings had. Furthermore, this study acknowledged some exceptions to the belief that there would be a different reaction to a sibling with schizophrenia depending on his or her gender, as suggested by previous studies (Martens, 1998; Ostman & Kjellin, 2002). That is, some participants in this study did not believe the gender of their sibling impacted on the sibling relationship.

Living Situation

Whether one lives with or apart from their sibling with schizophrenia has been noted to impact the sibling relationship. This may be due to the substantial alterations that have to take place in a family due to such a diagnosis, as well as the consequent changes experienced in the home. Such alterations may be restrictions in recreational activities, and the feelings of burden and strain (Martens, 1998).

The participants' siblings lived in various places; some lived with their parents, others with their siblings, some on their own, and others lived in residential-care facilities. The focus of this exploration however, is on whether these various forms of living situations affected the sibling relationship, and affected whether siblings would care for their siblings in the future.

> [He] can't live on his own...He now lives at home (with his parents). (Participant 1)
>
> She lives in her own flat. (Participant 2)
> She lives with me so she affects my life directly...I'm kind of stuck with her. (Participant 3)

When considering the aforementioned different living situations of Participant 1, 2 and 3's siblings, it is of particular interest to note that the level of distress experienced by family members has been evidenced not to differ when the family member with schizophrenia lived with their family or elsewhere (Winefield & Harvey, 1993).

However, Participant 2 indicated that she and her sister would be incompatible living partners:

> I think that even if we were living together I would have killed her…I would imagine that even if I had lived with her, I would have killed her...I mean she would have just driven me insane. (Participant 2)

This excerpt appears to indicate how Participant 2's life has been affected by her sister's schizophrenia-related behaviours. The emotive language she uses to emphasise how she and her sister would be unable to live with each other seem to suggest that she uses living apart from her sister as a coping mechanism to survive her sister's symptoms (Spaniol, 1987). Participant 2's opinions differ from the other participants as she seems to have especially strong feelings about not living with her sister.

According to Gamble and Midence (1994), some individuals with schizophrenia who returned to live with their families after hospitalisation did worse than those living in other types of living environments. Studies have suggested that alternative housing should be considered if the individual with schizophrenia is unable to lead a normal life, if all family events revolve around the ill individual or if the caregiver is single (Teschinsky, 2000). Participant 1's description of her family life suggests that family events revolve around her brother, who lives with her parents, which impacts on the individual family members:

> "When [my brother] doesn't get his way then he also puts up sort of like a tantrum then eventually actually my parents give in. And also to spend a day with [him] is actually … its mentally taxing. You get very tired at the end of the day… I understand that he gets lonely during the day … so obviously he wants to get out. But now say you've got a list of things you wanna do. You end up doing … not doing half those things because you know you get so rattled that you just come home because he wants anything that he sees, he wants" (Participant 1).

On the other hand, Participant 3 is single and in such situations at-home care may become too burdensome, which may necessitate alternative living arrangements (Teschinsky, 2000).

> I get driven to such ends sometimes that … you know you scream and shout and she wont listen … and then if I don't you know be forceful and firm, then nothing gets done (Participant 3).

Furthermore previous studies have indicated that one of the greatest sources of stress for siblings was the anxiety surrounding who would care for their sibling suffering from schizophrenia when their parents become too incapacitated to do so, or passed away (Friedrich et al., 2008).

> I suppose when that day comes, I will probably take over the reins of him being with us. (Participant 1)

> Had she been in some institution where she had proper support and rehabilitation ... [The relationship] would probably be a lot different, ja, definitely, I've just you know been living with her all my life. (Participant 3)

Participant 1 and Participant 3 accepted the future care-giving role. However Participant 1 seemed to accept the role as she did not feel she had another option, and Participant 3 seemed to accept the future care-giving role as she had been entrenched in this role most of her life. In contrast, Participants 6 and 7 did not accept the possibility of the future care-giving role:

> No, no … I wouldn't even consider it. Oh no, no, no. I can't take care of him. No…Well I wouldn't even consider it. (Participant 6)

> I think uhm I don't even have that … uhm … that relationship with my brother to be able to look after him. I feel I'm that im so far uhm … uhm removed from him, or in knowing him like my parents I think that they know that it wont be an easy task for me to look after him. (Participant 7)

Participant 6 advised that she would not accept the caregiving role, and Participant 7 did not believe she had the correct type of relationship in order to care for her brother. These participants seem to be using distancing strategies – such as living apart from their sibling - in order to try and attempt to reduce their levels of distress; however it has been found that this was an unhelpful coping mechanism (Friedrich et al., 2008; Spaniol, 1987).

The living situation of the participants' siblings seemed to impact, rather than determine the type of sibling relationship. That is, Participants 6 and 7 were adamant that they would not have their sibling live with them in the future, while Participant 2 was resolute about not living with her sister at all. Participant 1 accepted the possibility of her brother coming to live with her, in contrast however, Participant 3,

whose sibling currently lives with her, suggested that if her sibling had been living elsewhere, their relationship would have been different. Consequently this study identifies the living situation of individuals with schizophrenia as a potential factor that may affect their relationships with their sibling.

Stigma

Stigma has been shown to be a powerful force that has the ability to break down relationships (Lee et al., 2005). This is especially relevant for familial relationships where it has been found that the relatives of a mentally ill person are likely to take up the shame and burden of the diagnosis (Mehta & Farina, 1988). However, in order to avoid negative emotions, family members may attempt to conceal the illness (Lee et al., 2005). This concealment may result in family members avoiding talking about how they are feeling, or they may view themselves to be social outcasts for having mental illness in their family.

This study, however, contradicts these findings in that some of the participants indicated that they were not concerned with any stigma attached to the schizophrenia diagnosis.

> When I met my husband I said …I said this is what's wrong with my brother … you either take me or you leave it. I've told everybody upfront… and they've all accepted it as well. So I mean I don't try and hide him and make him stay in his room and you know … ja, I've told people straight. (Participant 1)

> It doesn't bother me because I know its an illness and I'm doing the best I can so I don't give a damn what people say or think and I would not think anything about telling anybody that she has schizophrenia. (Participant 3)

> I didn't care much about what people had to say…(Participant 4)

Therefore the participants seemed to communicate that they had accepted their siblings' diagnosis of schizophrenia and that they did not care about what other people thought about the matter. However, it may be argued that even these participants who suggested that they were not affected by stigma may have been affected by it more than they had anticipated. For example, Participant 2 initially stated:

> We are quite a down to earth family in that we don't really give a toss what people think...you've got to not care I mean this is my sister. (Participant 2)

However she later went on to say that:

> There've been embarrassing instances...inappropriate but I don't think she knew what she was talking about. (Participant 2)

Thus, while siblings may argue that they are not affected by stigma, it seems to play a large role impacting upon the sibling relationship. However what needs to be acknowledged, as can be identified from the above extracts, is that not all family members, or siblings are equally affected by a construct such as stigma – as previous studies have suggested. As Participant 2 noted above "you've got not to care" suggests awareness that people have negative perceptions toward people with schizophrenia, and consequently the pervasiveness of how stigma affects the sibling relationship can be understood to be variable.

Societal stigma seems to have a strong influence over relatives' behaviour toward their family member suffering from schizophrenia. There is further evidence that symptomatic behaviour, and psychiatric labels themselves affect the levels of stigma directed toward the mentally ill individual (Phelan et al., 1998). Thus, the more symptomatic the behaviour, the more noticeable the illness, and the more the family member's fear stigma. Participant 6 discussed why such fear was necessary:

> My mom even had a best friend who … stopped talking to my mother because of it. (Participant 6)

Such widespread social rejection, isolation and abuse of people with psychiatric disorders have been well documented (Hugo et al., 2003). Therefore it may be considered that in psychopathologies that involve psychosis, such as schizophrenia, where there are positive symptoms such as hallucinations and delusions, there is a greater chance of stigmatisation, and consequently a greater impact on the sibling relationship. The lack of public awareness about schizophrenia, and schizophrenia-related symptoms has been identified to be a substantial source of stigma. Participant 7 identified the lack of greater awareness and understanding to have contributed to difficulties for her.

> The stigma is in that a lot … uhm I feel that from people … uhm because of their lack of wanting to understand is almost a stigma…So that makes me angry … the fact that people just brush it off or they give it a kind of like its Satanism or … whatever... or he must have done something wrong or he must be – he must have taken drugs or something. (Participant 7)

As can be noted from the above excerpt, Participant 7 identified the conflation of mental illness and social deviance. That is, the diagnosis of schizophrenia and the related behaviours were confused with drug abuse and engagement in Satanic acts. In this view, society can be said to have been victim blaming as Participant 7's brother was experiencing symptoms of schizophrenia, and he was held responsible for having these symptoms by the society around him. Participant 8 found the lack of public awareness and understanding to be frustrating, and this frustration seems to have impacted upon his relationship with his brother.

> Ag I think over all the years...its time wasting… you have to explain to everybody right through your lifetime now what happened...you know you just say don't worry about him he's just … and then somebody else will tell them no he's had a … but everybody that we know our closest friends, everybody knows about it. (Participant 8)

Thus, it appears that while close family and friends are privy to the sibling's diagnosis and mental state, excuses are made to other individuals so as to try and avoid difficult conversations about the sibling's symptomatic behaviour. The lack of public awareness and understanding of schizophrenia may be linked to associative stigma. That is, when an individual is stigmatised due to his or her connection with another stigmatised individual. Associative stigma was identified by Participant 4 as being a concern:

> People asking …'you must be both crazy – is your family ok upstairs?' Everybody judges you and they have a lot to say about your parents and family. (Participant 4)

Typically, individuals in such a position attempt to avoid the negative emotions associated with the stigma, and consequently avoid contact with the stigmatised individual by concealing the mental illness (Lee et al., 2005). This has shown itself to be especially counter-productive as it would create a potential barrier to receiving the social support that would be so important for their mental health (Teschinsky, 2000).

This study therefore confirms that associative stigma is a grave problem for family members, including siblings (Lee et al., 2005; Ostman & Kjellin, 2002; Phelan et al., 1998).

This study identified specific factors that impacted the relationship. Among these factors was how the participant understood schizophrenia which indicated that an understanding of schizophrenia would be a important factor that affects the sibling relationship. This related to the participants' ability to understand that the siblings' behaviours were not necessarily in their control, and that their ability to function had been altered. For the participants in this study, some made an effort to learn about schizophrenia, while others did not. This study noted that participants that comprehended the symptoms and behaviours of their siblings seemed to have better relationships than those participants that did not comprehend the schizophrenia diagnosis.

A further contribution to the factors that affect the sibling relationship were the complexities related to the diagnosis; these appeared to play a function in how participants understood the diagnosis, and was thus able to manage the repercussions thereof. Linked to the complexities surrounding diagnostic procedures, and the participants understanding thereof, were the potential effects of the sibling's behaviour on the relationship. The study illustrated how the sibling interaction was affected by the sibling's behaviours, and the participants' understandings thereof. The better understanding the participant had of the symptomatology, the more understanding the participant was when regarding their siblings' unusual, aggressive or embarrassing behaviours; and thus, the better the relationship.

As identified by previous research, contextual factors such as gender, living situation and stigma played a role in affecting the sibling relationship. The study found that the sibling gender dyad and how this affected the sibling relationship varied from individual to individual. Yet, this study found that majority of caregivers were female and siblings with schizophrenia were male. This study identified that the living situation of siblings acted as a potential factor that impacted upon the sibling relationship. Furthermore, the majority of the siblings argued that they were not affected by the stigma attached to the schizophrenia diagnosis, yet not all siblings argued this point equally. Thus the pervasiveness of how stigma affected the sibling relationship was variable.

These various factors impacting upon the sibling relationship can all be linked to the participants' understandings of schizophrenia, as one's ability to understand a phenomenon influences one's interpretation of that phenomenon and the repercussions thereof. The aforementioned factors can be understood to be connected to various redefinitions that take place within the participants' lives; specifically, the redefinition of the family.

REDEFINITION OF THE FAMILY

Impact on the Family

Studies have found that with the onset of symptoms come profound effects on families and individuals within those families, as they struggle to come to terms with the significant changes in their loved ones' lives within the family (Sin, Moone & Harris, 2008). There has been substantial research on the psychopathology of schizophrenia and the family (Asarnow et al., 1994; Cutting et al., 2006; Lee et al., 2005; Martens, 1998; Phelan et al., 1998). Findings of the aforementioned studies are similar to those as discussed above. They indicate that family members seem to experience substantial distress due to the impact of having a family member with schizophrenia (Asarnow et al., 1994; Cutting et al., 2006; Lee et al., 2005; Martens, 1998; Phelan et al., 1998). This is predominantly due to the disruption of family life, and consequently the life trajectory may have been changed (Teschinsky, 2000). It has also been identified that gathering personal meaning and preserving one's own identity were recurring themes among family members of individuals with schizophrenia (Teschinsky, 2000).

The impact of schizophrenia on the sibling has been shown to be profound. In fact, previous studies have identified that the sibling struggles to define the experiences associated with the schizophrenia, as well as fulfilling his or her needs without feeling like the ill brother or sister is getting all the attention from their parents (Teschinsky, 2000). It may be hypothesised that a sibling that feels that the schizophrenia has dominated the family, and that sibling may have been unable to preserve his or her own identity, or find meaning in their life. Participant 2 identifies her anger surrounding how her sibling dominated the family and continues to do so:

> The anger that I feel is much more about how she sort of dominated the entire family because she dominates the family. (Participant 2)

Furthermore, Participant 2's perception of how the schizophrenia and the schizophrenia-related behaviour of her sister has impacted upon the family, suggests that the schizophrenia has a fragmenting affect on family life.

> I don't think that she's aware of the trauma that she created in the family… I don't think that she's aware of the destruction she caused. (Participant 2)

The fragmentation that is alluded to by Participant 2 seems to be in line with the notion that "a single family member may exhibit symptoms, receive a diagnosis, and undergo treatment, but because of the interdependence that exists within a family system, each and every family member is affected in some special way" (Kinsella et al., 1996, p. 24). Similar sentiments were held by Participants 1 and 7:

> We've always been a close family but that also just tore us apart. (Participant 1)

> I remember going and shouting at him and saying well you know you are destroying the family … and it wasn't his fault … [Schizophrenia has] stolen a lot of quality … or stolen our history almost it's as though the schizophrenia has stolen … it has stolen memories. (Participant 7)

Therefore, siblings are severely affected by the schizophrenia-related behaviours as well as by other familial factors, such as overall familial conflict, marital discord, social isolation and lack of support to name but a few (Teschinsky, 2000). In addition to these, and as can be identified in the excerpts above, siblings appear to be affected by the disruption in the course of the family's life, as suggested by Participant 1. Participant 7 identified how the schizophrenia diagnosis and the repercussions thereof disrupted not only the life of the family in the present, the trajectory of the family's life for the future, but that is seemed to rob the family of its past.

The loss associated with the illness can be related to the sibling's sorrow, and perhaps a sense of having 'lost' the brother the way that he was before (Stalberg, Ekerwald & Hultman, 2004). It may be argued that the family's life, from the time of diagnosis, becomes split into 'before' and 'after', and that the earlier relationship has

gone forever, but the sibling needs to discover a new kind of relationship (Stalberg et al., 2004).

For some individuals however, finding new kinds of relationships is viewed to be insurmountably difficult as a result of the sorrow and loss that they feel. This was illustrated by Participant 7:

> We can't carry on like this and things are just deteriorating as a family in my own home there isn't that like banter around the … that's another thing like around the kitchen or round the dining room table in a normal family – but there isn't that any more, there isn't that sort of banter, there's no nothing like that … The atmosphere in the home if he's not there its sort of a light, you feel like you can ... Because he's not sleeping you can talk louder or you can laugh if something's really funny you know … life's not that great, you shouldn't be laughing at stuff and things and there's this burdened feeling there which is awful, its terrible. (Participant 7)

Participant 7 alludes to having been robbed of her family's 'before', and consequently her family can be understood to have been redefined, and perhaps consumed by the schizophrenia. This speaks to the struggle that siblings encounter in knowing how to respond to some of the illness behaviours that are exhibited by their brother or sister (Sin et al., 2008). The impact that schizophrenia can have on the family as a whole is especially important in exploring how the sibling of an individual with schizophrenia experiences the sibling relationship.

Another area in which schizophrenia impacts the family is via the parental relationship. Since schizophrenia is usually diagnosed in late adolescence, the independent adult life of the child and subsequent separation from the parents is interrupted. Often, parents continue to be caregivers of their son or daughter with schizophrenia, instead of continuing on with their own lives and future tasks of reflecting on their lives and needs (Teschinsky, 2000). Parents experience feelings of prolonged grief and loss as a result of the loss of their idealised child who has been transformed into a bizarre child that needs to be taken care of (Teschinsky, 2000). Participant 7 noted how her parents' relationship had been affected due to the schizophrenia:

> I can see my parents' relationship is really deteriorated … I can my parents its like taken years off their lives and they sort of get irritated with each other but 99% of it is because of the financial stress and the emotional thing of having somebody there that's not actually … not

> interacting with much that you … uhm having to think about all the time even though they are sleeping or awake at different times to you or … you know its such a … you can't escape the situation … whatever you do. (Participant 7)

The undertone of the above excerpt seemed to be the impact that schizophrenia had on the parental relationship, which in turn had an impact on familial life, and thus on Participant 7. As discussed above, siblings are severely affected by familial factors, such as marital discord (Teschinsky, 2000). Such findings were uncovered by Participants 1 and 7:

> My parents were fighting I think there was going to be a divorce because you know my dad would say something and then my mother would say something and then she would always stick up for [my brother]. And then they would end up fighting. There was a lot of tension. (Participant 1)

> Over the years I can see that their relationship is actually just like a survival thing. I never, never ever heard my parents raise their voices at each other, but now like my dad is always totally irritated with my mother. My mother is always saying 'you know your father drives me scatty'. (Participant 7)

Participant 1 recalled concerns about her parents possibly getting divorced as a result of tension in the home. This tension seemed to arise due to Participant 1's mother defending her son with schizophrenia, which lead to marital discord. Participant 7 discussed how her parents' relationship has become altered, and how they often argue. Both Participants 1 and 7's parents' marital difficulties seemed to impact upon their lives.

Therefore the impact that schizophrenia has on the family as a whole and on the parental relationship is vast. The alteration of the life trajectory of the family as well as of the individuals within the family seems to play a substantial role in how the family is affected by the schizophrenia diagnosis.

This study suggests that the family is redefined by the schizophrenia diagnosis as in all of the participants' experiences the family was dominated by the schizophrenia. However, due to the interdependence that exists within a family system, each family member is affected which led to a sense of fragmentation within the family. This fragmentation seemed to be manifested primarily by a sense of loss experienced by each family member. This loss contributed to the difficulty family members experienced in attempting to redefine their roles, and relationships, which

seemed to contribute to overall family conflict, and specifically marital discord. Therefore, the alteration of life trajectories, and the roles one traditionally adopts within a family, plays a substantial role in how the family is affected by the schizophrenia diagnosis.

Perception of the Sibling Relationship

How a sibling perceives his or her relationship with his or her brother or sister will play an important role in determining the outcome of Goetting's (1986) proposed tasks of siblingship; namely companionship, friendship, comfort and affection. In line with Goetting's (1986) views, other studies have identified that the strength of sibling bonds were persistent when siblings initiated contact that allowed for companionship in activities that were traditionally shared by adult siblings (Smith & Greenberg, 2007).

According to Jones (1997), the position of having a sibling with a mental illness can be seen to involve ambivalent feelings about earlier times where there is some current resentment, yet a distant fondness of earlier times. Participant 2 noted that her experience of her relationship with her sibling was contrary to this belief:

> We actually had quite a good relationship the last few years since she's been stable. We talk to each other and we go out every now and then …we weren't close sisters …when we were little... we're not really great friends as … I imagine some sisters are. (Participant 2)

Participant 2 seems to vacillate between her ambivalence surrounding her relationship with her sister in saying that they had a good relationship, but this was only while her sister was stable. However now that her sister has had a relapse, they are no longer close. She does speak about their lack of closeness as sisters in general and in their youth, yet there were times during the interview when she seemed to recall some fond memories from their childhood. However, Participant 2's recollection of her relationship with her sister seems to be consumed by her negative experiences due to the schizophrenia- and the repercussions thereof. Consequently there seems to be some ambivalence surrounding the sibling relationship.

Unlike Participant 2, Participant 6 spoke of her relationship with her brother with much clearer signs of ambivalence. She recalled their youth and the fact that

they were very close, and juxtaposed this by noting that at present, she and her brother do not have a relationship due to his schizophrenia-related behaviour, and current condition.

> We don't really have a relationship … It did affect my relationship because of the way he is now … he was like my soul mate. (Participant 6)

Participant 6 also mentioned that:

> I didn't even have children, get married because of that … which I suppose in retrospect is stupid. But at the time it was a choice I made. (Participant 6)

Therefore, Participant 6 seemed to feel some resentment due to the decisions she made as a result of her brother's schizophrenia diagnosis. Her loyalty to her brother may be understood to have conflicted with other parts of her life, including her own life choices (Jones, 1997). More specifically, the schizophrenia of Participant 6's sibling resulted in her own arrested development in that she did not move beyond the life stage of being single in order to care for her brother.

It has been noted in previous studies that siblings who report being physically hurt or threatened by their brother or sister with schizophrenia, who express greater fear of him or her, as well as those who believe that he or she has control over symptoms, would report a poorer relationship (Smith & Greenberg, 2008). In the following excerpt Participant 7 indicated how her fear impacted upon her sibling relationship:

> Not like a normal brother and sister at all … So the relationship is…almost non-existent…because I don't know him anymore … Whatever it's like totally the relationship is nothing like it used to be. Nothing at all … Like I must always be careful that I don't say the wrong thing or that maybe he is sad or feeling down today and whatever … so its always like walking on ice. (Participant 7)

Participant 7 seems to fear upsetting or hurting her brother, and consequently she appears to sensor her communication in such a way so as to protect herself from his unpredictable responses. This fear indicates how fragile the sibling relationship has become due to Participant 7's brother's schizophrenia. Yet this behaviour appears to

have taken a severe toll on the sibling relationship, resulting in her current perception of the relationship being 'non-existent'. Sibling confusion and fear surrounding not knowing how to respond to some of the illness behaviours, as well as the concerns about doing or saying the 'wrong' thing has been referred to as a difficulty in other studies (Sin et al., 2008). The impact that such concerns can have on the sibling relationship is evidenced by Participant 7, in that her fear of communicating with her brother has resulted in her not knowing him anymore, which seems to have translated into them not having a relationship at all.

Participant 5 notes that she and her sister have good communication, which seems to play a significant role in their relationship.

> I can basically tell her everything and she tells me everything. (Participant 5)

Previous studies have identified that siblings who felt that their mentally ill siblings provided them with support, reported a greater amount of current caregiving (Horwitz, Tessler, Fischer & Gamache, 1992). That is, relationship reciprocity between siblings may have a powerful symbolic value in strengthening sibling bonds (Jewell & Stein, 2002). Participant 5 went on to say that:

> It's a good relationship but maybe it's not what I … would want, I would want to have her by me more often … I see her about twice a month. (Participant 5)

Thus, while Participant 5 believed that she and her sister have a good relationship, she still noted that it is not the relationship that she would have wished for; she desired for a greater level of closeness within the sibling relationship. Participant 5 attributed this to the fact that they do not live near to each other, as her sister lives in a residential home, and as a result she does not see her very often. It may be hypothesised that they are unable to partake in as many conventional sibling activities as Participant 5 would have liked. Thus, there seems to be a sense of a loss of an idealised sister (Teschinsky, 2000).

Therefore, this study shows how the manner in which the participant perceived their relationship with their sibling impacted upon the type of relationship he or she had with that sibling. More specifically, if the participant regarded their sibling with feelings of ambivalence, fear and resentment or made an effort, or conversely no effort to communicate with their sibling, the sibling relationship was

affected. In this light, the process of mutual influence can be understood to have occurred in that the perception the Participants had of the sibling relationship affected the type of relationship they had with their siblings.

Role Changes

When a family discovers that their son, daughter or sibling has developed schizophrenia, each family member is suddenly faced with distressing role-changes (Martens, 1998). As discussed above, the family life cycle and life trajectory is interrupted by the schizophrenia diagnosis (Teschinsky, 2000). This impacts all family members, and in particular, the sibling.

The altered family experience will have different effects on the sibling depending on his or her age; for example an older child, who developmentally should be focusing on making strong social connections to the world outside of the family and gaining independence, may stay home to provide help and support, both to their affected sibling, as well as to their parents (Jones, 1997). It is of significance that all of the participants in this study were an older brother or sister to their sibling with schizophrenia.

Parentified Role

Previous studies have identified that siblings often viewed their most important contribution to be supporting their parents as primary caregivers. That is, some siblings have reported sharing the monitoring and caregiving role with their parents with regard to symptoms, medication and other forms of practical support (Sin et al., 2008).

Participants from previous studies have identified that they were forced to mature at an increased pace, yet they believed that the activities in which they involved themselves post-relapse were part of a conventional sibling relationship (Sin et al., 2008). As indicated by the following excerpt, this study suggests that while participants matured quickly, certain recovery activities were not considered to be a part of the traditional sibling role:

> Being the eldest, I grew up very quickly because I needed to help [my mother] … So I became the caregiver for my sister...You know and took full care of her and all of that. When she relapsed I would

> actually even bath her and all of that you know I take care of her you know. (Participant 3)

Participant 3 seemed to suggest that the caregiver activities that she adopted after her sister had experienced a relapse, were that of a caregiver as opposed to a sibling. Furthermore, Participant 3 appeared to be incredulous that she adopted the extent of caregiving role as she did; that is by bathing her sister.

Furthermore, previous research indicates that individuals that spent social time with their sibling with schizophrenia had a better quality relationship than siblings who did not share or rarely did social activities with their brother or sister (Smith & Greenberg, 2007). However the role that was adopted by Participant 3, together with the context that dictated the need for the adoption of this role, did not allow her to spend social time with her sister:

> There was never that sibling relationship. Never. It was always parental. So I had to be uhm … a … the discipline person...It was so hard to get her to say you know you need to get off your lazy ass and start doing a couple of things you know so it was instilling that discipline and all of that she's not like my sister, she's like my child. (Participant 3)

Participant 3 seemed to adopt a disciplinarian, parental-type role with her sister, and as such stated clearly that she considers her sister to be like her child. In contrast, Sin et al. (2008) identified in their study that siblings perceived their role as their brother or sister's social companion, and as such included them in their social circles of friends. However the following participant, like Participant 3, noted how she has always felt like more of a mother toward her sister:

> It was a different relationship that I had with [my sister], it was more … and I think because uh …my mom died when she was small … you know when she was small, it was … I always felt more of a mother towards her than… I know she is my sister, but you had, I had a different maybe rel …thing… relationship or feeling with her … She looks up to me I think she looks at me a bit of like her mother. (Participant 5)

Participant 5 seems to discuss the complexities of the sibling relationship, especially when there is a substantial age difference between siblings, and when contextual factors affect the roles within the family. The loss of Participant 5's mother at a young age may have propelled Participant 5 into a parent-type role for her younger

sibling. Consequently the requirement for a caregiver, together with the age difference between the siblings may have contributed the alteration of roles (Jones, 1997).

Participants 2, 5 and 7 noted that not only did they take on a parentified role at times, but that they became a part of the parental dyad in many cases. Literature evidences that "siblings' contributions as secondary caregivers in supporting their parents … [is] widely recognised" (Birchwood, 2003, p. 34). That is, they seemed to take part in the decision making processes surrounding their sibling with schizophrenia, as well as other important family matters.

This study confirms the aforementioned findings as may be evidenced by Participants 2, 5 and 7:

> So what they did was they talked to me a lot and it was like oh what should we do with [her] ... shall we commit her, shall we adopt the child … all of those decisions. From then it was always … what do I think if they put her in [mental health care institution] … or what do I think if… (Participant 2)

> My dad also looks to me when there is anything with [her], he looks to me; I mean I am the oldest one. (Participant 5)

> My mom tends to uhm … to offload onto me and then I feel like you know what I can't actually solve any of this … I can't … I feel like she is saying you know how do we solve this? And sometimes I think you know what I am so exasperated I don't know … I can't solve it. So, I'll listen but it actually irritates me to listen even. (Participant 7)

Participants 2, 5 and 7 discussed how their parents often called on them to aid in the decision-making process regarding their siblings. However, Participant 7 noted how drained and irate she becomes when she is asked for advice on issues regarding her brother. It may be hypothesised that the inclusion of the other children into the decision-making process may be related to the support of the parental dyad due to potential marital discord around decisions about the family member with schizophrenia.

From the above excerpts, it seems that strain that is placed upon the family due to having a child and a sibling diagnosed with schizophrenia. This not only alters the life trajectory of the family, but the life trajectory of each member within the family (Teschinsky, 2000).

This study identifies that the alteration of roles amongst siblings of individuals with schizophrenia often takes a parental course which results in the sibling's life trajectory being altered in such a way that they are completing tasks and are situated in a position too soon for their chronological age.

Previous studies have suggested that siblings adopt certain roles – such as a caregiving role as a result of interactions with their parents. This can be understood to be as a possible result of feelings of obligation toward one's parents, or due to the sibling's expectations of their parents' needs and expectations about the assistance to be given (Jewell & Stein, 2002).

> I went to see my parents … it would be like … we've just got to discuss… what do we do with this child. Shall we adopt the child …what am I going to make a decision when I could only have been about 23 at the time, I mean for God's sake … So I think she identifies me with my parents. (Participant 2)

Participant 2's parents seem to expect her assistance in matters regarding her sister, and consequently she seems to have been forced into a parental role. In contrast, Horwitz (1993) suggested that siblings may adopt such roles when they have been explicitly asked to do so by their parents, as can be indicated by Participant 8:

> Before my mother passed away on the way to hospital when I took her to hospital she said to me and [my wife], 'don't push him aside you know, please look after him'. (Participant 8)

The excerpt above illustrates that Participant 8 may have been forced into a caregiving role which may have been due to feelings of guilt, or alternatively to a sense of obligation. It has been suggested that a sibling's willingness to assist in the caregiving of their mentally ill brother or sister, by assisting their parents, has been related to how emotionally supportive their parents have been to the sibling in the past (Jewell & Stein, 2002). Therefore it may be hypothesised that siblings that take on the role of caregiver, felt supported by their parents.

Siblings of individuals with schizophrenia seem to adopt parentified roles in relation to their siblings. This appears to occur primarily through sharing the caregiving role with their parents, either currently, or in the past. Participants also

noted that they were forced to mature at an increased pace when their brother or sister was diagnosed with schizophrenia.

Due to the stressors related to a schizophrenia diagnosis, it seems that they had to adapt in order to cope. In addition, certain contextual factors seemed to play a role in the adoption of the parentified role by participants. Specifically, a death, or incapacitation of a parent may have propelled the participant to attempt to fill a parental role. Furthermore, it was noted that participants assumed the role of support to their parents in that they shared responsibility for their sibling with their parents. Such acceptance of responsibility and in turn, a parentified role, may or may not have been due to parental expectation, or to a sense of obligation that the individual may have felt toward his or her parents.

Family Duty

The siblings of individuals with schizophrenia vary in terms of the timing in their own lives when their brother or sister's illness first occurred. Some siblings were children or adolescents at that time while others were adults and living independently when their brother or sister experienced the onset of symptoms. Those individuals who were still living with their sibling during the time of first diagnosis may have been socialised to adopt greater familial responsibilities than those individuals who were living independently (Marsh & Dickens, 1997).

It has been purported that the level of sibling involvement may be sustained by family values that emphasised responsibility or family duty (Horwitz, 1994). Therefore it may be hypothesised that Participant 1's family placed stress on responsibility and duty:

> I suppose when push comes to shove, I'll take the responsibility like a dutiful daughter. (Participant 1)

The literature discusses a sense of responsibility with regard to the 'voluntariness of the sibling tie' (Connidis, 1992). That is, it is believed that the siblings' responsibility seems to change when parents are no longer available (Horwitz, 1993). Participant 1 appeared to be suggesting that when her parents are no longer able to care for her brother, she would take on the responsibility of caring for him. Similarly, this notion was also illustrated by Participant 3:

> My mom is 67 now and uhm … she can't possibly do more than she does, somebody had to do that because uh my mom couldn't. My mom is too old to do all of that kind of thing you know, she's tired you know … and I stepped in as caregiver. (Participant 3)

Participant 3 discussed how she took on the responsibility for caring for her sister when her mother became too elderly to do so. It has also been suggested that the adoption of the caregiver role, as well as the sense of responsibility that a sibling may feel toward their brother or sister, may be as a result of a sibling bond, and a desire to want to help their sibling (Stalberg et al., 2004).

> We had to grow up very quickly and be responsible from a young age...we were forced into doing that … I took on a lot of the responsibility … She's family and I want to take care of her and do the best for her you know but, ja, there are limitations. I've just...taken on the responsibility I can't uh … ignore her and disregard her, she's family. It's my responsibility to do it. (Participant 3)

However, what appears to contrast with the notion of the desire to help one's sibling, is the sense of forced roles of responsibility and caregiving. Participant 3 seemed to communicate more resentment toward her sister, than a desire to help her. It seemed that this resentment may be linked to the amount of responsibility she felt she had been forced into taking. Similarly, Participant 6 seems to have similar sentiments as Participant 3:

> I have to. I haven't got a choice. It's not easy I do get angry because I am the one whose left with all the trouble … that I have to deal with everything. (Participant 6)

Participant 6 noted that she felt that she did not have a choice as to whether she would adopt the caregiver role or not. She commented that there was no one else who could take the responsibility and consequently, she was forced to do so. Jewell and Stein (2002) have noted that some siblings who have parents who have been the primary caregivers for many years, and who request caregiving assistance result in the sibling feeling compelled to 'step up' and provide the care. This can be seen with Participant 7:

> I just felt like a … I must look after him. Its more like a sort of I've got to look after you …and I do try...So there's this like I have been brought up with that you know 'he's your younger brother so you are responsible

> for him' and then now its just blown out of all proportion because he's now like a real … almost like a baby brother some what's because uhm … it's not like having someone whose almost your equal. My folks always … they always just said take care of him whatever and I've got that sense of responsibility is there and I can't get rid of it. (Participant 7)

Participant 7's parents did not necessarily explicitly request assistance from her, yet her perception of her role and her obligation to fulfil it may propel her to accepting the caregiving role, despite not wanting it (Jewell & Stein, 2002).

Another salient feature that seems to contribute to a sense of family duty among individuals, is whether they feel they 'ought to' or 'should' provide assistance to their parents for their sibling, or their siblings directly (Jewell & Stein, 2002). This suggests that the mental illness, in this study the schizophrenia, can result in complex family pressures and perceptions about responsibility towards one's parents and one's sibling that have the potential to affect not only familial relationships, but other relationships as well. This can be illustrated by the following excerpt:

> Before we even got married I said to [my husband] … when he asked me to marry him I said like … why should I even marry you … mustn't I stay at home … and look after my brother? (Participant 7)

Participant 7's concerns about her responsibility to her brother and to her parents clearly affected her life as she considered not getting married so as to care for her brother. What this participant illustrated was the guilt that an individual may feel about moving to a new life stage, especially a life stage that his or her brother or sister is unlikely to accomplish. In this sense, Participant 7 appeared to have difficulty separating from her family and in turn being able to individuate with starting her own family.

Thus, the responsibility and duty that an individual feels toward his or her parents and sibling may affect the possibility of the sibling adopting a parentified role. However, the responsibility that one feels toward his or her sibling is also influenced by family values and beliefs, as well as by contextual factors, such as parent unavailability. Such duties to one's family can result in substantial pressures both on the individual, as well as on the family as a unit.

When a family experiences a crisis such as that related to the diagnosis of a severe mental illness, each member as well as the family as a whole is affected. The

alteration of life trajectories and the consequent role changes plays a substantial role in how the schizophrenia diagnosis impacts the family. This study identified that the manner in which the participant perceived the sibling relationship and how this affected the type of relationship the siblings had. If the participant regarded their relationship in a specific way and made an effort, or conversely no effort to communicate with their sibling, the sibling relationship was affected.

In addition, and as discussed above, this study noted the role changes that often occur when a sibling is diagnosed with schizophrenia. Specifically the participant more often than not took on a parentified role, and assisted in the caregiving of their sibling. Additionally, participants assumed the role of support to their parents in that they shared responsibility for their sibling with their parents. This study identified that often these roles were adopted due to a sense of responsibility, or duty, that the participant had to his or her sibling or parents. Furthermore, it was indicated that duties to one's family can result in substantial pressures both on the individual, as well as on the family as a unit. The pressures placed on the individual, and how he or she manages them may be understood by the way in which the individual has adjusted to living with their sibling with schizophrenia.

ADJUSTMENT

When a family member is diagnosed with schizophrenia the family members may react to the diagnosis with a variety of emotions. Over time, the family members' ability to adjust to the diagnosis and the repercussions thereof by way of their coping behaviours, and their making use of services to aid their adjustment processes may aid them in dealing with their multiple feelings they have about their relative with schizophrenia (Teschinsky, 2000).

Coping Mechanisms

Coping seeks to reduce or eliminate the brunt of demands and is defined as all the cognitive and behavioural efforts used to gain control over, minimise, or endure demands with which one is confronted (Rice, 1999). The efforts to gain power over stressors may be positive and negative, healthy or unhealthy. While individuals employ coping mechanisms in order to affect a positive outcome, the strategies they

use may not always be constructive. The literature outlines categories of problem-focused coping and emotion-focused coping (Rice, 1999).

Problem-focused is a cognitive strategy of facing one's problems and trying to solve them (Santrock, 2003), and includes techniques which are viewed to be proactive, and appear to be the most rational option when it comes to stress reduction. Specific strategies utilised in this form of coping are optimism, problem solving, diverting of one's attention to constructive activities, self-disclosure and catharsis, information seeking, stress monitoring (Rice, 1999).

Emotion-focused coping is responding to stress in an emotional manner (Santrock, 2003). While the need for relief from emotional distress is understandable, the typical coping methods employed in such situations have been found to be self-defeating, and often not reality orientated (Rice, 1999). Furthermore, research has discovered that emotion-orientated coping is generally maladaptive (Friedland et al., 1996). These negative coping techniques are avoidance, withdrawal, suppression and religion (Rice, 1999).

Many family members experience a range of emotions when a relative is diagnosed with schizophrenia. Among these emotions are anger, shame, resentment and sadness. In the long term however, family members develop mechanisms by which to cope with this range of emotions (Teschinsky, 2000). Spaniol (1987) discovered that these individuals coped by using such strategies as involving themselves in strategies and rewarding work away from the mentally ill individual.

Siblings of individuals with mental illness have been found to make use of specific coping mechanisms (Kinsella et al., 1996). One such coping skill was that of constructive escape, which allowed siblings not only to occupy their time, and attention, but also brought them pleasure (Teschinsky, 2000). The coping mechanism of constructive escape has been viewed to be similar to avoidance (Kinsella et al., 1996), and may consequently be understood to be an emotion-focused style of coping, as discussed above. It has also been suggested that the use of such coping mechanisms results in a 'detached' style of sibling relationship (Stalberg et al., 2004).

> When I'm away from it then I try and just keep myself busy with work and whatever and that's with the whole situation I don't even like to think of the future with my folks and ja, I don't like to. If I have to think about it then I end up becoming so stressed because its like … ja … ja … I rather fill my life with work … I like become overcommitted

> at work and over … I take on far too much because then there's no space for … for worrying about him, I'd rather worry about work – at least I can solve that. But I can't solve their problems, that's how I sometimes feel. (Participant 7)

Participant 7 engages in avoidance techniques in order to distract herself from her concerns and worries about her brother's schizophrenia. She distracts herself by working excessively as she believes she can solve problems at work, but cannot solve her brother's schizophrenia. The use of such coping mechanisms suggests that Participant 7 feels helpless and may not have adjusted well to her brother's schizophrenia, and the repercussions thereof. The above excerpt also suggests that Participant 7 finds little refuge at home, and consequently work becomes an escape and an excuse to avoid home and the difficulties she experiences there.

Participants 2, 4 and 7 appeared to use emotional withdrawal and repression, as coping mechanisms in order to manage their siblings' schizophrenia diagnosis. These forms of coping can be understood to be forms of avoidance. This emotion-focused coping mechanism has been evidenced to be utilised in cases when mental illness disturbs the traditional life trajectory of the family (Spaniol, 1987).

The blocking off of feelings has been noted to be an unhealthy form of coping, yet it is also able to emphasise the impact that the illness has on the sibling (Teschinsky, 2000). Participants 2, 4 and 7 utilise this form of emotion-focused coping.

> When she started going off the rails I was writing Matric at the time… I was just … block it out … (Participant 2)

> I do what I do with everything else … if there's a death I put it one side...I don't think about it … now and then it will blow over and then I'll just put it right back up … I don't have time to deal with it. I didn't and I don't, I adapt quickly. (Participant 4)

Participant 2 noted that when her sister has a relapse she attempts to block it out of her thoughts. Participant 4 on the other hand seems to make use of isolation as her coping mechanism. According to Kinsella et al. (1996) this coping mechanism can be understood, together with descriptions of the internalisation of emotions, as an unhealthy escape from an identified situation. This is illustrated by Participant 7:

> I don't really talk about it … I just carry on and a lot of it from my side is almost like putting my head under the sand and thinking well … I can't actually face this … uhm … let me just carry on…(Participant 7)

Participant 7 discussed how she prefers to hide away from the truth so as to protect herself temporarily by not having to concern herself with it. Therefore avoidance of one's emotions and cognitions may be actively applied in order to cope with one's feelings of confusion and sadness. However previous studies have suggested that this coping mechanism is usually implemented in order to protect one's own health (Stalberg et al., 2004). Nevertheless, while such coping mechanisms are often implemented in order to protect oneself, they may not always result in a positive outcome as the strategies utilised may not always be constructive, as discussed above (Rice, 1999).

Alternative methods utilised for coping that have been identified in previous studies, and which were found in this study was the setting of behavioural limits for the individual with mental illness – in this study, for the individual with schizophrenia (Spaniol, 1987).

> Its really difficult coping with her … So it got to be more work for me because I had to find out how to manage this so a lot of work on my part, a lot of work and stress on my part…managing her you know … Its constant reinforcement … to … to maintain some semblance of normality … I had to learn to find coping mechanisms and how to deal with her and manage her … it becomes very hard to manage, you've got to manage her you know like in the minutest way possible. (Participant 3)

Participant 3 attempted to micro-manage her sister in order to help her cope. Maintaining order and structure in their lives by monitoring her sibling's behaviour seems to be one way in which Participant 3 manages her daily life of living with schizophrenia.

Despite the extreme levels of rigidity and structure that the above excerpt seems to communicate, it also seems necessary to identify that many siblings identify some strengths that they have developed due to the difficulty of having schizophrenia in their family (Teschinsky, 2000). It may be hypothesised that Participant 3 was able to create self-reliance, be assertive as well as improve on her levels of resiliency. Such factors have been identified as strengths that can be developed by an individual when facing a life altering event such as a schizophrenia diagnosis within the family

(Kinsella et al., 1996), and consequently may be considered to be a problem- focused coping mechanism.

It is important to note that according to Kinsella et al. (1996), it is healthier to engage in more active forms of coping such as avoidance, rather than isolation, which is a passive form of coping. Nevertheless, it is necessary to recall that the use of avoidance is simply healthier, not necessarily the healthiest, coping option.

This study illustrated how the majority of siblings made use of emotion-focused coping techniques, such as avoidance and isolation. However, these techniques have been found to be self-defeating and not reality oriented (Rice, 1999). The problem with such coping techniques may have been identified with one of the participants who engaged in the use of avoidance. This participant became intensely emotional as soon as she began discussing the impact her sibling has had on her life. Thus, while avoiding difficult content may aid an individual in the short term, it is not reality oriented in that the emotions are not dealt with.

Social Support

Problem-focused coping influences the behavioural measure of quality of life, and these active coping strategies include the seeking of social support (Moneyham et al., 1998). Social support can be defined as the belief that one is loved, respected, esteemed by, and involved with family, friends, and others (Cobb, 1976). There has been significant interest in the notion that social support may be able to protect people, as it has a buffering effect which may attenuate the disruptive effect of stressors (Friedland et al., 1996). Therefore, one may reconceptualise social support as a method of 'coping assistance' (Friedland et al., 1996), or adjustment assistance.

Families need to be able to vent their disappointments and frustrations regarding the illness, and seek support from others. Identifying such sources of support includes the professional system, family, friends, and spiritual resources (Rose, 1997 cited in Teshinsky, 2000). Family therapy and support groups are also available for individuals affected by schizophrenia. Such devices may aid individuals on normalising their experiences and reducing their feelings of isolation about having a relative with schizophrenia (Teschinsky, 2000).

While support groups exist, siblings are often not included, which may be as a result of the little research conducted on the psycho-social needs of siblings affected

by schizophrenia (Teschinsky, 2000). Nevertheless, Participant 1 noted how she was not included in the family therapy or group sessions, and consequently did not receive support from this arena.

> I never went to therapy or group sessions. It was always my parents and [my brother] … My parents went to some or other group where the schizophrenic parents get together and they discuss all their problems. (Participant 1)

Support groups have been found to be an important resource for family members' adaptive coping as well as a prominent predictor of decreases in burden and depressive symptoms (Greenberg, Kim, & Greenley, 1997). Furthermore, participation in support groups can provide opportunities for the individual to gain knowledge and become more confident in their capacity for caregiving (Lefley, 1996). However, and as noted by Participant 1, such meetings tend to centre on parents, and even if siblings were to attend family support groups, they may be concerned to express their true emotions for fear of placing more pressure on their parents (Sin et al., 2008).

It was inferred from a study that social support was a major contributory factor to how siblings coped (Friedrich et al., 2008). More specifically social support was referred to in terms of being either emotional or informational (Friedland et al., 1996). In the following excerpt, Participant 7 seems to yearn for specifically emotional support:

> I can't go to my mom – I don't fell like I can go to her and sit there and just cry my heart out … my dad either… there isn't anybody – none of my friends have any kind of understanding. (Participant 7)

Participant 7 makes reference to the complete lack of tangible social support. Previous studies have found that often siblings do not approach their parents for support as they perceive their parents to already be under considerable pressure (Sin et al., 2008). Therefore, in such situations, it has been predicted that an individual in such a position will experience increased symptoms of burden (Dyck, Short & Vitaliano, 1999). In turn, this is hypothesised to impact the perception that the sibling holds of his or her brother or sister with schizophrenia.

> My husband...He's never been very … uhm supportive of … we've had a bit of family problems because of family because my husband

> thinks that family is just me and the kids and its not. He's changing, he's getting better with time, so it causes problems…But I am restricted because if I try and do certain things its gong to affect my life at home … so ja, that has been a bit of a problem as well for a while. (Participant 5)

> I mean I have a lot of friends who and my old friends well they all know [my brother]. But people, just, when you've got problems, they vanish … And I don't have any family here, my friends have become my family. (Participant 6)

Participant 5, like Participant 7 appears to long for emotional support from her partner, while Participant 6 suggests that while she has been neglected in the past as a result of stigma, she receives support from friends. Therefore, the source of emotional support that one receives may be a family member, partner, a friend or a support group, plays an important role in how one perceives their sibling, as well as how one is able to adjust to the schizophrenia. What Participant 5 identifies is that her sibling's schizophrenia affects her marriage. There seems to be a transfer of stress from the schizophrenia onto the Participant's marriage resulting in marital discord. This in turn affects Participant 5's ability to receive social support.

Another area where an individual may be able to receive social support could be religion and the religious community to which one belongs. For the individual, religion provides a world-view that helps him create reasonable explanations for events happening to him or his family member (Rice, 1999).

> [We were] trying to work out what was wrong … he had gone to like quite a few people at church and uhm … because there was no knowledge there he was perhaps given the wrong …they didn't know what was going on because of misunderstanding of mental illness – they didn't give any help so things deteriorated … (Participant 7)

Participant 7 discussed how her brother approached their religious community for aid, yet they were unable to assist him as they did not have knowledge of mental illness. Therefore it is important to acknowledge that religion and spirituality may signify a source of pain for some. Religion allows individuals to develop their own subjective justifications for occurrences. These explanations however, do not always have a logical or coherent backing in an objective sense, but rather in a subjective and personal sense (Rice, 1999).

> So that makes me angry … the fact that people just brush it off or they give it a kind of like its Satanism or whatever … they just they just don't try and understand it. And they try and put their own belief of the cause of it, try and solve it for you like … you better go and see some … I don't know … like spiritualist or something and he will be fine. (Participant 7)

As can be noted from Participant 7's excerpt about possible origins for her brother's behaviour, often these explanations include the notion of control. That is, about the degree of control an individual perceives he has over an incident – in this study, the diagnosis of schizophrenia; specifically he or she may feel they must hand control over to 'a higher power' and thereby make this power responsible for all the events (Rice, 1999). This is what Participant 7 seemed to allude to by relating what the religious community members suggested to her family. The suggestion that her brother's behaviour was due to Satanism seemed to make her incredibly upset and may have contributed to the following comment:

> We were quite a religious family … a Christian family … It's also spiritually it does … it affects you as well because I think well God why did you do this. (Participant 7)

Participant 7 no longer seems to regard herself or her family as religious. It may be hypothesised that her experiences with religion during the earlier stages of her brother's schizophrenia may have contributed to this, and may have consequently contributed to her current level of adjustment, which seemed to be quite poor. Thus while a religious community may act as a supportive mechanism for family members in times of need, they too can act as sources of additional pain.

Families need people or places to whom to vent their disappointments and distress regarding the illness, and to whom they can turn to for support. Such places and people include support groups, religion professionals, friends and family. However the ability and success of these places and individuals to provide the support required is viewed to be minimal as evidenced within this study.

This study identified that the ability of participants to adjust to the schizophrenia diagnosis and the repercussions thereof, was primarily mediated by the use of emotion-focused coping techniques such as avoidance and isolation. These techniques have been found to be self-defeating and not reality oriented in previous

studies (Rice, 1999), and this finding was reiterated in this study. Another manner in which siblings and families are understood to adjust to life with schizophrenia was through people or places that offered support. However this study identifies that the ability and success of these places and individuals to provide the support required was insufficient in order to aid families' adjustment processes. The manner in which one is able to adjust to having a sibling with schizophrenia is of importance as it can be seen to act as a mediating factor for how the individual is impacted upon by the schizophrenia. That is, how the individual is able to cope and manage having a sibling with schizophrenia.

IMPACT OF SCHIZOPHRENIA

The findings of previous studies have highlighted that a brother or sister's schizophrenia profoundly affects his or her siblings, emotionally and psychologically (Stalberg et al., 2004). The impact of schizophrenia on the sibling relationship as a result of the difficulty of living with the repercussions of the illness, can lead to significant barriers in the sibling relationship.

Emotional Impact

In previous studies measuring the emotional impact of having a brother or sister with schizophrenia, sibling participants described feelings of being "overwhelmed by the psychological impact of the brother's or sister's onset of psychosis and the subsequent impact on their own lives and emotional well-being" (Sin et al., 2008, p. 35). Identified emotions included anger and envy (Stalberg et al., 2004), as well as resentment and blame (Sin et al., 2008).

Siblings in this study expressed feelings of anger, envy and resentment both directly and indirectly. Such emotions are typically not always allowed to be felt by societal convention, yet they are important for the understanding of the sibling's emotional experiences (Stalberg et al., 2004).

Participant 2's anger emerged when she spoke about a letter she had received from her sister, requesting distance from each other:

> I've just been so angry with her because how dare she write me a letter saying … "just because you're my sister doesn't mean I have to make an effort" … I mean I'm like … I've been making this fucking effort for years. Why do you think I make the effort … because you are my sister… If they can't help themselves you have to support them. But you … doesn't stop you from internally being extremely angry. And … and irritated and pissed off and all of the rest of things. (Participant 2)

Feelings of anger can also be interpreted as being connected to feelings of sorrow as there may be a certain level of dejection, when efforts have been made to be inclusive of the sibling (Stalberg et al., 2004). Such anger may become further complicated by envy - a common theme in sibling relationships (Stalberg et al., 2004).

> I mean as much as I try … and it makes me so furious, but unfortunately she is my sister and I feel the anger that I feel is the destruction she's caused … because of her behaviour … you know and she just has dominated everything … I think you get such … you get so angry that you … that she's putting you through this, … you know you get such anger in you … because of … because of all this … (Participant 2)

Participant 2's anger seems to be punctuated and exacerbated by the envy and resentment she feels toward her sister for dominating the familial context, and in so doing, dominating her life indirectly.

Participant 7's life seems to be dominated not only by her brother, but in contexts that are entirely separate to her brother. Her emotions related to his schizophrenia, and the repercussions this has had on her life and on her family's life seems to dominate her life with negativity and anger:

> What I'm really angry at the situation, really angry with you and get that anger out… That anger can't go …where can it go to? … I often feel that it comes out in other ways... the person probably wouldn't deserve it but a lot of that anger some days I think you know what … just because I've got so much unspent anger. Its there and its got nowhere to go so it gets …even my daughter thinks sometimes that I shout at her because its … the angers there and like the littlest sort of uhm irritation makes me angry. (Participant 7)

The above excerpt describes how anger seems to be so pervasive within Participant 7's life. Sin et al. (2008) noted in their study that siblings often experience a paradox of resentment toward their brother or sister for dominating their parent's time, yet

they also often experience a sense of guilt for not being able to be more empathic and supportive toward their sibling.

> I remember going and shouting at him and saying well you know you are destroying the family … and it wasn't his fault. (Participant 7)

This study concurs with the former proposition indicating that individuals seem to experience resentment toward their siblings, but does not seem to agree definitively with the latter. That is, individuals often experienced guilt for not being able to do more for their siblings. More specifically, while Participant 7 felt guilty for being angry with her brother (as can be noted in the previous excerpt), Participant 2 did not experience such guilt. This is expressed more specifically by the following excerpt:

> The problem is I feel like … all my life I can't have an interaction with [my parents] without her dominating the agenda and I feel … I am tired of it all … I am just so Goddamn sick of it … My relationship with my parents … has always been that's what dominates … I don't think my parents ever … I think they were so bewildered by this that they never stood back and said well, what are my other children thinking about this? (Participant 2)

Participant 2 appears to feel the resentment toward her sister for dominating her parents' time, resulting in them having little space and energy for Participant 2. In this way she seems to express anger toward her parents, yet simultaneously holds her anger's origin within her sister.

> I do think that there should have been acknowledgement that the other people in the family are also suffering and that they … you know you can't dominate … your parents can't dominate the conversation with your sister. It's not right – they need to be told … you know you need to go out and do other things with your other children so that it doesn't dominate everything in the whole family. (Participant 2)

However, Participant 2 did not seem to indicate feelings of guilt throughout the interview process, thus challenging Sin et al. (2008) findings. The resentment that seems to be felt toward siblings with schizophrenia seems to be especially prominent as it affects how individuals perceive family life.

This study found that a brother or sister's schizophrenia profoundly affected his or her siblings, emotionally and psychologically. The predominant emotions that

participants appeared to display were anger, envy, resentment and sorrow. Participants' anger and resentment of their siblings' diagnosis often resulted in them blaming their siblings for dominating the familial context, which in turn resulted in little space for them.

The Difficulty of Living with Schizophrenia

As discussed above, adult siblings often assume increasing responsibilities for their mentally ill sibling (Samuels & Chase, 1979). Previous studies have described how mental illness affected subjects' lives, and placed this range on a continuum from pervasive to discrete. Three general patterns of impact have been noted to be apparent: pervasive impact, moderately pervasive impact, and discrete impact (Gerace et al., 1993).

The pattern of pervasive impact suggests that all areas of an individual's life are affected by the situation, and this is experienced as negative. A moderately pervasive impact is considered as coming mainly from the ill sibling and the family, with the sibling was seen as the central problem. The impact on the family was perceived as deriving from stress inherent in having a family member with schizophrenia (Gerace et al., 1993). In contrast however, individuals who described a pattern of discrete impact perceived the impact as originating specifically from a mentally ill sibling (Gerace et al., 1993).

Previous research has indicated that despite the growing awareness surrounding mental illness, it has the potential to impose extensive burden on families (Fadden, Bebbington & Kuipers, 1987). The intensive level of burden that a family may experience due to schizophrenia is presented in the following excerpt:

> There isn't a sort of click your fingers answer. There isn't an answer its something that's there… I thought well how can we get out of this and I thought uhm …no wonder people commit family murders …there is no way to get out of the pain except for like… sort of go ahead and it would help [him] if uhm …but go in and kill him and my folks…and then kill myself … its actually fine … it solves the problem because uhm … because there isn't a solution … (Participant 7)

Participant 7 seems to express desperation and helplessness surrounding the impact that schizophrenia has had on her life. Her description of the impact that the schizophrenia diagnosis has had on her family suggests that she feels like she has no

way out, and that the whole family is in it together as they have all been affected by it. Consequently the phantasy of a family murder appears to be an option to her as it is an act in which the whole family is involved. Due to the intensity of this phantasy, it may be considered odd that the impact of mental illness on siblings has not generally been considered (Gerace et al., 1993) when such powerful and pervasive emotions exist within their experience.

Estroff (1989) defined schizophrenia as an 'I am' illness. That is, an illness that is recognised ostensibly by others, yet it also irrevocably alters the self inwardly. With this understanding, schizophrenia may be defined and experienced not only by the individual with schizophrenia but also by each family member of that individual. This was experienced by Participant 8 through his experiences of his brother:

> Every month they come and visit us … and then he arrives here … we don't know what we are gonna expect when he arrives here… he can be very nice and sometimes he just goes into one of these moods you know … (Participant 8)

Therefore, the way in which Participant 8 experiences his brother can be viewed to be in a state of confusion or ambivalence as he is only able to understand his brother's overt behaviour; he is unable to fully acknowledge the impact of his brother's internal state.

The level of burden that a family may experience due to schizophrenia has the potential to be intensive. Siblings often experience emotions such as desperation and helplessness surrounding the impact of schizophrenia both on their lives as individuals, as well as the life of the family. Therefore schizophrenia is experienced not only by the individual with schizophrenia, but by each family member of that individual as well.

Previous studies have indicated that individuals who have siblings with schizophrenia are profoundly emotionally and psychologically affected by their siblings' diagnosis (Stalberg et al., 2004). This study corroborated this finding in that participants appeared to display predominant feelings of anger, resentment and sorrow. Their anger and resentment contributed to them feeling left out of the family as they perceived the family to be dominated by schizophrenia and their sibling with schizophrenia, which resulted in little emotional space for them within the family unit. Such emotions and psychological effects were indicated by participants' helplessness and desperation surrounding their perceptions of living with

schizophrenia. Contributing to this burden is the family's ongoing interaction with service providers such as managing the sibling's diagnosis and treatment, as well as the repercussions thereof.

INTERACTION WITH SERVICE PROVIDERS

When a family member is diagnosed with schizophrenia, the interaction that the family has with service providers is automatically increased. That is, the increased need for mental health services, medication, hospitalisation, or institutionalisation as well as general case management. However, in addition to such services, this study also showed an increased interaction with social and community services, such as the police, and residential homes for the mentally ill.

Treatment and Ongoing Management

The factors that lead to a vulnerability to schizophrenia abound, however explicit causal connections continue to elude disproof. Consequently a variety of treatment approaches have been utilised over the years, including pharmacological treatments, and institutionalisation and community care.

Antipsychotic medications are not in themselves a 'miracle cure', they do not erase an individual's delusional content, yet they are able to satisfactorily relax individuals with schizophrenic (Sue et al., 2003). Such positive effects of medication are evidenced by Participants 4, and 8 who acknowledge improvements in their siblings' behaviour:

> But I mean it's the medication I'm positive that's calming him and keeping him …in control. (Participant 4)

> I mean he is 10 times better now that he is on medication and that type of thing you know. (Participant 8)

However, these medications have many unwelcome side-effects (Sue et al., 2003). Participant 6 expresses the negative side to her brother's medications:

> If he'd had better medication...they used to give him this medicine that made him shake and for 2 weeks of the month he was ill and … so I can't blame him in a way, those medicines don't make you feel good. And he won't, he fights with them every month for the injection but otherwise he won't take anything. (Participant 6)

Participant 6 mentioned that her brother would not take any medication unless it was closely monitored, which brings to light the issue of medication compliance. An important consideration with pharmacological therapies, and especially with antipsychotic medications, is that they require regulation and monitoring, especially as noncompliance is a difficulty experienced with individuals with schizophrenia (Sue et al., 2003). This can also be noted by Participant 1's experience of her brother's difficulty adhering to his medication regime:

> [He] wont take his medication by himself I mean … I think I suppose we'll also got to learn to trust him that he will take it by himself … uhm … sometimes he does ask for his medication so he can go to bed early … but then on the other hand sometimes he says to my mother why I am I still taking these tablets … I'm not sick. (Participant 1)

A common occurrence of not adhering to one's medical regime is relapse. Participants 1 and 2 recall incidences of relapse:

> I'm not quite sure what happened next but she went off the rails again. She started to go off the rails and become crazy and so my parents committed her. (Participant 2)

> But every time there's a relapse also, I mean it also puts a hell of a lot of strain on everybody. (Participant 1)

When relapse occurs, it is common, post-relapse, for the need to be re-hospitalised or re-institutionalised (Maxmen & Ward, 1995). Therefore institutionalisation is common in the aftermath of a relapse. Participants 1, 2 and 8 were forced to institutionalise their siblings after a relapse:

> Ja when he went to [a mental health care facility], I mean its also hard to go see him in there … [The mental health care facility] is … its almost like a prison sentence… But I mean that really sorted [him] out. I don't know what they did. I don't want to know what they did, but that sorted [him] out. (Participant 1)

> She went into to [a mental health care facility] at that stage and they treated her there and she seemed to get better … Then she went back into to [the mental health care facility] as she was pregnant and then … after the baby she sort of went a bit crazy again and threatened to chuck … kill the child …so they took the child away then put her back into [another mental health care facility]. (Participant 2)

> So we went to court and got a court order and we booked him in at to [a mental health care facility]. (Participant 8)

Participant 1's repulsion and fear of the mental health care facility indicate her feelings surrounding her brother's stay at the facility. However, she also acknowledged that whatever means were employed at the facility, they aided in helping her brother. Participant 2's sister seemed to frequent various mental health care facilities and Participant 8 was forced to get a court order to get his brother committed.

Consequently the treatment and management of individuals with schizophrenia is an ongoing process that includes constant management of medication, problems with adherence to medication, relapses and rehospitalisation or commitment to mental health care facilities.

Social and Community Services

Social functioning is deeply affected in individuals with schizophrenia, and is one of the strong predictors of the increase in, and intensity of symptoms, as well as of rehospitalisation (McGlashan in Ikebuchi, 2007). This may be understood to be due to the notion that social dysfunction is a primary source of stress and thus prevents individuals from developing or maintaining supportive relationships (Ikebuchi, 2007).

A possible contribution to the difficulty to maintain supportive relationships may be the socially dysfunctional behaviour that leads to police involvement. Due to deinstitutionalisation, and the influx of mentally ill individuals into the community, the police have become those professionals who deal with these individuals when they experience a crisis. Police are called upon to take this responsibility as it is within their power and authority to protect the well-being of the community, as well as to protect those individuals with disabilities (Lamb, Weinberger & DeCuir, 2002). Participant 2 recalled her sister's involvement with the police:

> She was arrested in [a foreign city] by the police. She stole one of my parent's cars and sold it for like R4000 and went to [a foreign country]. She was arrested in [a foreign country] for stealing bread … and then they deported her to South Africa. (Participant 2)

However, as Participant 2 related, her sister was arrested and deported back to South Africa by the foreign police. This brings to attention the role of police as potential

gatekeepers in deciding whether an individual may have a mental illness. If care is not taken in such a decision, criminalisation can occur. Therefore, there appears to be a need for police officers to be trained in recognising mental illness and knowing how to access the appropriate care facilities (Lamb et al., 2002).

Police officers have a legal obligation to respond to calls and provide transport services for individuals with mental illness if there is probable cause to believe the individual is a danger to those around them or to themselves. However some police officers accept this role reluctantly and with resentment (Lamb et al., 2002). Previous studies have identified that police officers are a significant source of stigmatisation and discrimination against individuals with mental illness (Watson, Corrigan & Ottati, 2004).

In this vein, the following concerns of Participant 7 regarding whether or not to call the police for assistance are informative about the current state of police aid for the mentally ill in South Africa:

> Because we didn't know who to phone or you don't know … you don't want to phone the police because you know I don't think the police know how to handle anybody … (Participant 7)

Thus it appears that Participant 7 did not feel comfortable calling upon the South African Police Services for assistance with her brother when she required it as she did not trust the police to aid her or her brother in the manner in which they required.

Furthermore the inadequacy of service delivery by the police may be translated to other areas of service. Due to poor services provided in public-care and rising costs in private mental health care facilities, as well as the inadequacy of delivery of treatment to certain sections of the population changes have been made in order to try and address these shortfalls. Literature suggests that such changes have attempted to make services more accessible, available and more affordable (Sue et al., 2003).

These poor services in public care and the inadequacy of treatment was discussed by Participant 6:

> [He] stayed in a place in [a suburb] … that place should be shut down, they even had a fire there and someone was burnt to death. Anyway, [my brother] lay there … he lay there for 5 months. He didn't get out the bed. (Participant 6)

Participant 6's description of one of the places in which her brother lived illustrates the dire conditions of some places of public-care. She subsequently moved her brother to a privately subsidised residential home:

> The [private organisation] support most of them… They go and take them to theatre, they take them here they do … you know its home. And they give them jobs. (Participant 6)

The contrast of the above description in comparison to the one mentioned previously is clear in that the private residential home seems to provide better care and a better environment for their attendees.

South Africa has recently seen the development of Non-governmental organisations (NGOs), as well as non-profit organisations (NPOs) in order to provide more services and reduce costs as much as possible for the public. However, at the same time, governmental funding for such services are diminishing which results in such organisations turning to companies, private benefactors or depending on donations in order to continue service delivery.

However, there are many disadvantages to this type of mental health care as with the reduction in cost, there has been a reported reduction in the quality of services, which would ultimately determine the treatment of clients (Sue et al., 2003). This can be noted in the following excerpt:

> I put her in [a residential home] again like last year some time because she was just going crazy and the behaviour… I would know that she would be okay there, you know and then I'd visit her now and then … I sent her to [the residential home] for a year last year thinking she'll get better you know, but she didn't, she actually got worse. And then I … she got very ill so I took her out now this year and she's back at home … (Participant 3)

Thus Participant 3 experienced difficulties with the residential home where her sister has been living. In contrast to Participant 3's experience however, research on community-run homes (or residential homes) has produced positive results. It has been suggested that these community facilities provide environments in which individuals with chronic schizophrenia are able to find friendship and ultimately experience fewer symptoms when compared to individuals who had been formally institutionalised (Sue et al., 2003). This view is corroborated by Participants 4 and 6:

> [At the residential home] he's in good hands and I don't have to stress myself, he's in a very big hurry to get out of there. (Participant 4)

> They are a family and they do care about each other … they look after each other. (Participant 6)

Participant 4 noted that her brother is being cared for by professionals, and her statement indicated that she trusted his wellbeing with the professionals running the residential home. Participant 6 discussed how her brother, and the other individuals that live at the residential home have become 'like a family', thus finding social connection in this environment.

In such environments, the goal is to integrate individuals back into the community, thus these environments provide local transitory facilities (Sue et al., 2003). Participants 5 and 8 elaborate on how such an environment can act as more than just a transitory facility:

> Though its not to me ideally situated now, it was in a few years back when she first started … when she was first put there … and its not a bad place, [the residential home] has where its got workshops and you are living on your own basically I mean. It wasn't and it's not still an easy thing to know that she's there, but I think it's the best place for her (Participant 5)

> Now at the moment he is in [the residential home] … there are some activities they have to work in the kitchen, they have to do this, they have to do that … at least that keeps him busy. (Participant 8)

Being involved in workshops, activities, and having the opportunity to live on ones own is believed to help to facilitate the reintegration into society. However Participants 5 and 8 allude to the fact that their siblings have been living at the residential home for quite some time, and that they will continue living there. That is, the residential home seems to be more than a transitory facility; it is their home.

It is important to acknowledge that while some residential homes exist for the purpose of being transitory places of accommodation for individuals with schizophrenia, some individuals with schizophrenia may not be able to live alone, and may not be able to fully reintegrate into society.

When a family member is diagnosed with schizophrenia, there is automatically an increase in the dealings that the family has with all treatment and management services, as well as with social and community services. This study identified that the treatment and management of individuals with schizophrenia is an ongoing process that requires constant supervision and organisation. As social functioning is severely affected in many individuals with schizophrenia, the interaction with community services such as police, and residential homes for the mentally ill have been identified to increase. This study noted that a sibling's social dysfunction, and the family's interaction with service providers were a substantial source of stress that prevented individuals from developing or maintaining supportive and close sibling relationships.

CONCLUSION

This chapter presented the findings of the research as it was obtained via interview data and information from the researcher's self-reflexive journal. Overall, various factors were found to impact upon the sibling relationship, yet of these, the participant's understanding of the schizophrenia diagnosis stood out as an especially important factor as it affected the other factors. The themes of how the family was redefined noted the changes that the family underwent, as well as the role-changes that occurred within the participants' families. The participants noted specific parentified roles that were often linked to a sense of family duty. The ability of the participants to fulfil these new roles and manage with the redefinition of the family was then identified to be mediated by how the participant had adjusted and coped with their sibling's diagnosis. Their ability to cope, in turn, mediated the impact the schizophrenia seemed to have on the participant, and the participant's interaction with service providers due to their sibling's schizophrenia diagnosis, and how this impacted upon their lives and played a role in their perception of their sibling relationship. The existence and importance of these interrelationships, and the possible deeper meanings behind them will be discussed in the following chapter.

CHAPTER 5: DISCUSSION AND CONCLUSION

This chapter focuses on enhancing the understanding of the findings of this study. It centres on the perceptions of the sibling relationship as it is affected by schizophrenia. Family systems and developmental theories are applied to the findings in order to provide a greater in-depth understanding of the sibling relationship when it is affected by schizophrenia.

Following this, a synopsis of the study and concluding comments will be provided. In addition to this, some of the limitations of the study are discussed, and areas for potential future research are identified.

DISCUSSION

The discussion focuses on enhancing the understanding of the existence and importance of the interrelationships, and the possible deeper meanings behind the themes presented in the above chapter.

Family difficulties that occur can be understood to be as a result of a family's reaction and interactions surrounding the problem, as well as their coping mechanisms utilised so as to cope with the difficulty. This view is in opposition with the view of the problem simply lying with the individual presenting with the symptoms that are causing the problem (Stanton, 1981). In this way, the family is understood to be an interactive system, rather than a unit made up of individual parts. That is, family members are interrelated in such a way that each individual affects all others, and the group as a whole in turn affects each member in the group (Rolland & Walsh, 2009).

This study acknowledged various factors that impacted the sibling relationship. Of these factors, the participant's understanding of the schizophrenia diagnosis was noted to be a strong determining factor in the participant's ability to understand that the behaviours of their siblings were not necessarily in their control (Teschinsky, 2000), and played an important role in determining how the participant perceived their sibling, and thus their sibling relationship. This is in line with previous studies which acknowledged that if an individual is not educated about schizophrenia, his or her ability to cope effectively with a sibling's condition may be compromised (Martens, 1998).

Furthermore, this study noted that participants that understood the symptoms and consequent behaviours of their siblings appeared to have better relationships than

those participants that did not understand the schizophrenia diagnosis. The study also illustrated how the sibling interaction was impacted by the sibling's behaviours, and the participants' comprehension thereof. If the participant had a good understanding of the schizophrenia symptomatology, the participant would be more likely to have a better understanding of their sibling, and thus have a better relationship.

The individual's understanding of his or her sibling's schizophrenia diagnosis can be linked to the family's method of handling problems. That is, when considering a difficulty within a family, such as the difficulties related to a diagnosis of schizophrenia of an individual member within that family, it is important to be cognisant of the complex interplay of individual and familial system processes that exist (Rolland & Walsh, 2009). For example, an individual's understanding of his or her sibling's schizophrenia diagnosis can be viewed to be related to the manner in which the family system communicates.

Communication processes facilitate all family functioning (Rolland & Walsh, 2009), including the understanding of a sibling's schizophrenia diagnosis. All verbal and nonverbal messages, including silence, conveys interpersonal messages. Thus, in families where conversations about the schizophrenia diagnosis was avoided, the silence was interpreted by each family member in a specific manner; for example denial and minimisation of the diagnosis. Ryan et al. (2005) noted the importance of communicating openly and with clarity about pragmatic and emotional issues (in Rolland & Walsh, 2009). Understanding seems to be increased when clear and congruent messages are conveyed, however in ambiguous situations, when communication is avoided, the risk for depression and anxiety have been identified to be increased (Rolland & Walsh, 2009). In addition to this however, it can be argued to be especially difficult for the sibling with schizophrenia to communicate as they often lack the interpersonal communictaion skills necessary to express their experiences (First & Tasman, 2006).

Furthermore, this study corroborated and emphasised previous studies' findings which noted the basis of family reactions to their relatives' schizophrenia-related symptoms was often rooted in how the family interpreted these symptoms (Brady & McCain, 2004). In an effort to understand the changes in behaviour of their siblings with schizophrenia, individuals' understandings of the diagnosis played an important role in the manner in which their interactions were affected.

It must be noted however, that many particiants had poor understandings of schizophrenia which may also be as a result of being left out of the treatment process, which contributes to their lack of knowledge (Friedrich et al., 2008). However, and as discussed above, together with the family context, it also seems to be partially due to their own lack of undertaking to research and discover the meaning of schizophrenia and the repercussions thereof that contributes to their lack of understanding.

Previous research findings have identified contextual factors such as gender, living situation and stigma as being factors that impact the sibling relationship when it is affected by schizophrenia. This study corroborated earlier findings with regard to gender and living situation, in that it identified that the majority of caregivers were female and the majority of siblings with schizophrenia were male (Friedrich et al., 2008). In addition, this study identified that the living situation of siblings acted as a potential factor that impacted upon the sibling relationship, whether the siblings lived together with their brother or sister with schizophrenia, or separately from them (Winefield & Harvey, 1993).

Despite the similarities to previous research, this study noted the importance of considering each individual's background, culture and beliefs surrounding issues of gender. More specifically, different cultures construct gender-roles in different ways (Chodorow, 1978), which can, in turn, affect the sibling relationship. While thus, while this study identified similarities with previous research, it also illuminated areas of specificity that may improve the understanding for certain results.

Family belief systems can be understood to be central in all family functioning in that they provide a set of unspoken rules and expectations that guide the family's behaviours (Reiss, 1981). These beliefs are in turn influenced by broader systems such as the family's cultural, ethnic and religious beliefs. Thus, family belief systems influence the gender conceptualisations of men and women. For example social and occupational role demands may be greater for males in such environments, which may lead to less realistic expectations for male schizophrenic patients' readjustment into their families and into society (Haas et al., 1990). Consequently norms and expectations in families that tend to have more fixed, and rigid gender roles may experience more difficulty to adjusting to mental illness and the subsequent role changes.

The results of this study highlighted that not all individuals with siblings who have schizophrenia are affected by stigma, or associative stigma at the level of

intensity as suggested by previous literature. That is, the majority of the participants did not feel troubled about the stigma attached to the schizophrenia diagnosis, as they had chosen not to be affected by it. However, this is not to assume that the participants were never affected by stigma, but rather that the stigma that they occasionally experienced, did not have as severe repercussions as previous literature had identified. Alternatively, one may debate that participants learnt to adapt to stigma, perhaps because it is practically more difficult to deal with their siblings with schizophrenia than it is to manage the stigma associated with the diagnosis. Thus, the participants may have more trying pressures to cope with than stigma.

The aforementioned factors that have been identified to impact upon the sibling relationship can all be related to the participants' understandings of schizophrenia. The ability to understand a phenomenon influences the interpretation of that phenomenon and the repercussions thereof. Accordingly, it is argued that the participants' understandings of schizophrenia influenced how they interpreted schizophrenia and the schizophrenia-related symptoms, behaviours and other repercussions.

In a systemic model of human development, both individual and family developments are conceptualised to co-evolve over the life-span (Carter & McGoldrick, 1999). The alteration of life trajectories and the resultant role changes, evident in this study, played a significant role in how the schizophrenia diagnosis impacts individual family members, and the family system as a whole. Brown and Hanna (2004) note that difficulties arise in the family because the family is unable to make the transition between family life-cycle stages, and their development as a family has arrested at the developmental stage they were in. A family system's development may be arrested at an earlier stage of development when the child with schizophrenia not only lives at home, but has become increasingly dependent on his parents. Consequently the family becomes fixated in a particular stage due to the altered life-trajectory and role changes.

This study identified that the manner in which the participant understood and perceived their sibling affected the type of relationship the siblings had. Yet, the study found significant emphasis on the role changes that occur within the family when one individual is diagnosed with schizophrenia. Previous studies have tended to focus on the effects of schizophrenia on parents, while this study focuses on siblings. Thus it is of interest to note that this study found that more often than not, participants

tended to take on parental roles so as to assist in the caregiving of their siblings, as well as to share the responsibility for caregiving with their parents. This study identified how some sibling's role definition accelerates their jump to a parentified role, which in some cases involves them skipping their own phase of marriage and having a family. Thus, participants' development became arrested as many of them became extensions of their own parents in the caregiving of their siblings with schizophrenia. Consequently, one may notice that the family did not only experience arrested development as a unified whole, but individual family members experienced their own development being arrested as a result of the schizophrenia diagnosis.

Systemic theory identifies specific boundaries that are essential for the healthy functioning of the family. Specifically, family boundaries need to be firm and stable, yet permeable (Minuchin, 1974). Interpersonal boundaries denote those boundaries that define each family member as different and autonomous from another, while generational boundaries maintain hierarchical organisation within families (Rolland & Walsh, 2009).

This study identified that generational boundaries are often blurred within a family that has a child or sibling with schizophrenia. Specifically, these boundaries become blurred when a parent uses a child as a parental surrogate, as can be noted by the participants having adopted parentified roles. In some cases it may be functional and necessary for older children to assist parents with certain responsibilities (Rolland, 1999). However, when individuals perceive there to be rigid role expectations, as identified in this study by the participants heightened sense of family duty, this can lead to that individual's own developmental needs being sacrificed (Rolland & Walsh, 2009). This was noted by a few of the participants who felt that their siblings with schizophrenia dominated their lives, especially as they felt they were forced to mature at an increased pace, and aid their parents in decision-making processes that they felt they were not developmentally ready to partake in. In this way, the sibling with schizophrenia may dominate the life of the participant as the participant has become enmeshed in his or her family, and within a particular role.

The strains placed upon the individual, and how he or she manages them may be appreciated by the way in which participants adjusted to living with their sibling with schizophrenia. Some participants' lives became enmeshed with the lives of their sibling with schizophrenia, while others spoke of their other siblings who had 'escaped', either to other cities or countries. These individuals may be argued to have

sacrificed their family lives for their own independence. These two extremes of either becoming enmeshed or escaping from a life affected by schizophrenia can be argued to speak to the depth of impact that the schizophrenia diagnosis can have not only on the diagnosed individual, but on the affected family as a whole. In this case more specifically, how it may affect siblings and the sibling relationship. A sibling that chooses to escape suggests a sense of desperation and hopelessness, as well as a sense of fear that one needs to protect oneself. These intense emotions indicate the need for early intervention in the sibling population of individuals with schizophrenia.

In light of the above, in order to function well, a family needs predictable, consistent rules, roles, and patterns of interaction. But with a family member diagnosed with schizophrenia, these are difficult to achieve, thus the family must be able to adapt to changing circumstances or developmental priorities (Rolland & Walsh, 2009).

In times when disruptive transitions occur within the family, such as the diagnosis of a serious mental illness, flexibility for change must be counterbalanced by efforts to re-stabilise and reorganise patterns by which to live daily life (Rolland & Walsh, 2009). This study identified that the ability of participants to adjust to having a sibling with schizophrenia, was mediated by the use of emotion-focused coping techniques such as avoidance and isolation. Previous studies have noted that these techniques have been found to be self-defeating and not reality oriented (Rice, 1999), which was reiterated in this study.

It was however gathered from the results of this study that how the individual is able to cope and manage having a sibling with schizophrenia will be affected by his or her understanding of schizophrenia. That is, if an individual had a better understanding of schizophrenia, he or she may be better able to manage and cope with the repercussions of the diagnosis, and in that way adjust better to life changes that occur as a result of the diagnosis.

Previous studies have indicated that individuals who have siblings with schizophrenia are greatly affected by their siblings' diagnosis, both emotionally and psychologically (Stalberg et al., 2004). This study identified that siblings' experiences of feeling left out of the family, as they perceived the family to be dominated by schizophrenia and their sibling with schizophrenia, which resulted in little emotional space for them within the family unit. Consequently the family unit, in these cases had been dominated by the schizophrenia which resulted in a disturbance within the

family system. For some participants this manifested as anger toward the sibling, but for others this seemed to manifest as anger towards the parent.

Thus, this research highlights the notion that in order for there to be improvements within the sibling relationship as it is affected by schizophrenia, focus may need to be placed on the psychoeducation of family members about the schizophrenia diagnosis and the relevant symptomatology. More specifically, support needs to be provided for siblings of individuals with schizophrenia, not only for parents. Furthermore, support for siblings should be separate to support for parents as if siblings are grouped together with their parents in this arena, they may inadvertently be further parentified, thus creating a dilemma for those in the mental health profession.

It is suggested that most factors that play a role in impacting the sibling relationship, will be influenced by the level of understanding that the individual has about schizophrenia. An improved understanding of the diagnosis is hypothesised to result in better interactions between siblings as a result of greater awareness of the sibling's ability to control certain behaviours. This may in turn decrease the severity of the emotional impact in terms of the individual's feelings of anger and resentment, which may lead for less cause for avoidance and isolation.

Strengths and Limitations

It is important to acknowledge some of the strengths and limitations inherent in this investigation. One such limitation of this research report is that a higher proportion of female siblings have been interviewed, consequently this study may not be representative of the general population. Furthermore, this study utilised a small sample of participants so as to gain greater depth in the understanding of their experiences. This study also offers a retrospective description by the participants as a result of the selection criteria of the siblings with schizophrenia having been diagnosed as such for at least five years. Given the aforementioned limitations, the results cannot be generalised beyond the sample studied and is thus limited in terms of its representativeness. However due to the qualitative and exploratory nature of the study, the in-depth nature of the data obtained is in line with the research approach.

The researcher was also cognisant of the limitations of small sample size and the non-random recruitment of participants. However, difficulty to recruit participants with variable contact with the patient was encountered. This was supposed to be as a

result of the sampling technique selected as it positioned participants in relation to their sibling with schizophrenia. Thus, it excluded potential participants who were totally out of contact with their siblings with schizophrenia. Furthermore, individuals who have siblings with schizophrenia are typically not individuals who are brought into treatment management, and are therefore difficult to source. Nevertheless, the current sample covered a diverse group, including participants who did not have regular contact with their sibling with schizophrenia.

As the majority of siblings were from Westernised backgrounds, their experiences may differ when compared with other cultural groups. However the study also noted that the participants were from varied socio-economic backgrounds, which highlights the prevalence of schizophrenia. It is also necessary to note that due to the wide variation in age of siblings at first diagnosis, 12 to 37 years old. The homogeneity of the sample is questionable as this would inform what developmental life-stage both siblings and participants were at during this time, and in turn this would impact the manner in which the sibling relationship was affected by schizophrenia. As detailed above, a further limitation was that the majority of the participants were female, which may affect the variability of the results in terms of effects on the sibling relationship. The different dyad combinations of participant-sibling, could not yield homogenous results.

The qualitative approach has both limitations and strengths. The researcher selected a qualitative methodology in order to facilitate the emergence of the siblings' whole experiences. The semi-structured interview schedule formed a basis for the reasoning and identification of major themes. This method proved to be useful as it assisted in discovering the richness of the interview material.

In terms of the interviews, the participants gave information that was based on personal experience and was consequently self-reported in nature. Therefore the data collected was subjective in nature. While this is within the understandings of the qualitative research approach, it affects the objectivity of the study.

Similarly, researcher bias is inherent in such studies, and thus the researcher cannot fully exclude bias and possible selective coding and analysis of the data. In order to attempt to control for this, the researcher kept a reflexive journal and the coding was checked by her research supervisor. However due to the interpretive nature of the study, there will always be bias as a result of the interaction between the

researcher and the participant. Consequently bias was used as a tool within this study, through the process of interpretation.

A further limitation may be that the researcher did not conduct interviews with the sibling with schizophrenia in addition to the participant as this was not within the scope of the study. However this may have aided the researcher in drawing comparisons of the perceptions of the sibling relationship by each sibling.

Directions for Future Research

This study explored an area of research that seems to be frequently overlooked, however it is an area that has the potential for value. From the data and the theoretical understandings of the study, it can be gleaned that greater understandings of the sibling relationship as it is affected by schizophrenia, is of substantial value when exploring the nature of impacts of schizophrenia.

Specifically, this study noted the need for further service development in terms of psychoeducation, information for siblings, support groups, and other specific interventions that should reflect the siblings' needs as identified in this study. Supporting and educating siblings about mental illness may help them develop a deeper understanding of their brother's or sister's experiences, which may foster a closer relationship.

Future research should also be directed at replicating this study but making the sample size bigger so as to increase the number of experiences explored. However in taking such an approach, it would be necessary to focus on specific aspects such as gender, age of diagnosis or culture so as to create more homogeneity in sample. That is, as this study did not have a wide representation of male participants. A study to assess the sibling relationship affected by schizophrenia and the role of gender would provide further insight into this trend. In addition studies that have specific areas of focus that were considered areas of contention within this study, such as age and culture, can create more homogeneity in the sample, and thus enhance our understanding of sibling relationships when they are affected by schizophrenia.

Furthermore, due to this study's varied sample, it is suggested that other areas of research, with a particular focus on specific dyads of sibling relationships may benefit the current field of knowledge. Specifically a focus on participants who are the

younger sibling within the sibling dyad may give some indication about any age discrepancies in sibling caregivers for individuals with schizophrenia.

This study also identified that it would be beneficial for future studies to conduct interviews with the sibling with schizophrenia in addition to the participant. It is hypothesised that this may aid the drawing of comparisons of the perceptions of the sibling relationship by each sibling.

CONCLUSION

This section provides a synopsis of this study and some of the strengths and limitations of this study are discussed, in addition to areas for potential future research which are identified.

This research explored the perceptions of the sibling relationship affected by schizophrenia in a South African context using a qualitative approach. Interviews were conducted with individuals who had a brother or sister with schizophrenia. Central themes that emerged from the data were factors that impact the relationship, the redefinition of the family, adjustment, impact of schizophrenia and interaction with service providers. These themes appeared to be interwoven with a common thread of the individual's understanding of schizophrenia, which in turn impacted upon their perceptions of the sibling relationship.

Furthermore, this study highlighted the importance of the acknowledgement and exploration of the sibling relationship within the greater system of the family. The family system and developmental stages at which the family is at provides an in-depth understanding of the sibling relationship when it is affected by schizophrenia.

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CHAPTER 8: APPENDICES

APPENDIX A: Semi-structured Interview Schedule

1. How did you find out that your brother/sister had schizophrenia?

2. How would you describe your relationship with your brother/sister?

3. In what ways, if any, do you feel that your brother/sister's diagnosis of schizophrenia impacted on your relationship with them?

4. What factors affect how you perceive your relationship with your brother/sister?

a) How does the living situation affect your relationship with your brother/sister?

b) In what ways, if any, did the social stigma around schizophrenia affect your relationship with your brother/sister?

c) Do you believe that the gender of your brother/sister influenced the quality of your relationship? And if so, How?

APPENDIX B: Demographic Questionnaire

Please tick

Gender	
M	**F**

Gender of your sibling	
M	**F**

1. How old are you?

_____

2. How old was your brother/ sister when he/she was diagnosed with schizophrenia?

_____

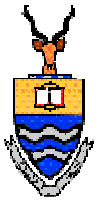
3. How old were you at this time?

_____

4. Where or with whom does your brother/sister currently live?

_____

APPENDIX C: Consent Form for Schizophrenia Organisations



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The University of the Witwatersrand
Department Of Psychology
Ms. L Kallmeyer
Supervisor: Ms Tanya Swart

Good Day,

My name is Lisa Kallmeyer. I am currently a Psychology Masters student at the University of the Witwatersrand. To fulfil the requirements for my degree, I am researching the perceptions of sibling relationships affected by schizophrenia in South Africa.
To achieve this, I wish to conduct interviews with siblings of individuals with schizophrenia. In your facility I would like to interview approximately 10 individuals from your support group, and would be grateful if you could help me with this. These individuals will be approached via a working member of the organization, who has already established rapport with the individuals. Each interview will take approximately one hour. To allow for transcription and analysis, these interviews will be audio-recorded with the permission of the participant. The results of this research will be presented in the form of a research report.

Should your organisation wish to participate in this study, please note that due to the use of face-to-face interviews, anonymity cannot be assured. However confidentiality will be guaranteed as no identifying details of the participants will be used. It is acknowledged that schizophrenia is a sensitive topic and the participant will be at liberty to answer only those questions that he or she feels comfortable with, and may stop the interview, or withdraw from the study at any time. The interview will be recorded only if the interviewee grants permission to do so. Only my supervisor and I will have access to the interview tapes and transcriptions. The transcripts and audio-recordings will be stored in a secure facility until examination of the research is completed, or for two years after publication. Once the study has been completed, the researcher will provide a summary of the research findings to your facility.

Please remember that participation is entirely voluntary and that there will be no negative consequences should you choose to not participate. If you have any further enquiries, do not hesitate to contact me, or my supervisor.

Please complete the attached consent form if your organisation wishes to participate in this study.

Kind Regards,

_____

Ms. Lisa Kallmeyer

Masters student in community-based counselling psychology
Department of Psychology, University of Witwatersrand

Ms. Lisa Kallmeyer
Tel: 083-947-7289
zesty.lisa@gmail.com

Ms. Tanya Swart
Tel: (011) 717-4586
tanya.swart@wits.ac.za

APPENDIX D: Consent form for the organisation

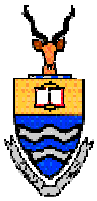
I have read the above letter and acknowledge both the nature and purpose of the research.

I _____hereby grant permission to Lisa Kallmeyer to conduct approximately ten interviews at this facility.

Signature: _____

Date:_____

APPENDIX E: Participant information sheet



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The University of the Witwatersrand
Department Of Psychology

Good Day,

My name is Lisa Kallmeyer. I am a Psychology Masters student at the University of the Witwatersrand. As part of my studies, I am trying to explore the perceptions of individuals about their relationship with their brother or sister with schizophrenia. That is, this study I hope to investigate individual's perceptions of their relationship with a sibling with schizophrenia post-diagnosis, and explore factors that may have influenced this relationship. I hope that this information will help to guide the development of programs for individuals with brothers or sisters with schizophrenia to help manage the difficulties related to mental illness. To find this out, I would like to interview individuals with siblings who have been diagnosed with schizophrenia. I would like to invite you to participate in this study.

Participation in this research will require that you are above the age of 18 years, and that your sibling has been diagnosed with schizophrenia for at least five years. Participation will in the study entail being interviewed by myself, at a time and place that is convenient for you. The interview will be approximately one hour long. With your permission this interview will be audio-recorded and transcribed so that I can explore what is said carefully and to ensure accuracy. Participation is completely voluntary, and you will not be advantaged or disadvantaged in any way for choosing to participate or not participate in the study. Your decision to participate is entirely your decision, and this decision will not affect your access to the organization. Given that the study uses face-to face interviews, anonymity cannot be assured, but confidentiality will be protected. That is, every effort will be made to ensure the confidentiality of your name and identity. In the handling of data, you will be represented by a number, so that your identity is known only to the researcher. However, direct quotes may be taken from the interview content, and used in the research report, but this content will be stripped of any identifiable information.

Because the schizophrenia of a family member is a very difficult topic to talk about, you only have to answer the questions that you want to, and you can stop the interview at any time. Furthermore, you may withdraw from the study at anytime. My supervisor and I are the only people that will listen to the tapes or see the tape

transcriptions. These audio tapes will be stored in a secure place with restricted access until the study is examined, or for two years after publication

This study has been given clearance by the Human Research Ethics Committee at the University of the Witwatersrand. This means that the University has given permission for this research to be carried out. The results will be written up in the form of a research report, and possibly a research publication. If you would like, a one-page summary of the results will be made available to you at the organisation, or you may contact the researcher. Please remember that whether you take part or not, it will not affect your access to support in any way. It is not anticipated that there are any direct risks to participating in the study. However, you will be debriefed on your experience of the interview process and should it be found that you have experienced any distress as a result of your participation in the study, contact details for relevant and free counselling services have been provided on this form.

If you choose to participate in the study please complete the Interview Consent Form, attached. Alternatively I can be contacted telephonically at 083-947-7289 or via e-mail at zesty.lisa@gmail.com. My supervisor, Ms. Tanya Swart, may be contacted on (011) 717-4586 or via e-mail at Tanya.Swart@wits.ac.za. If you have any more questions about the research, please feel free to contact me, or my supervisor.

Kind Regards,

_____

Ms. Lisa Kallmeyer

Masters student in community-based counselling psychology
Department of Psychology, University of Witwatersrand

Free Counselling Services – Contact Details

Lifeline – 0861 322 322

SADAG (South African Depression and Anxiety Group) – (011) 262-6396

South African Bipolar and Schizophrenia Association (SABDA)- (011) 463-9901

APPENDIX F: Consent from for participants

I _____ have read the information sheet and I am aware of the nature of this study. I hereby voluntarily consent to being interviewed by Lisa Kallmeyer for her study on the perception of sibling relationships affected by schizophrenia. I understand that:

Please tick

- ☐ Participation in this interview is completely voluntary.
- ☐ I may refuse to answer any questions I would prefer not to.
- ☐ I may withdraw from the study at any time.
- ☐ I understand that there are no direct risks or benefits to participating in the study.
- ☐ No information that may identify me will be included in the research report.
- ☐ The researcher may use direct quotes taken from my interview, in the research report, provided no information that may identify me is included.
- ☐ I will receive a summary of the research results if requested.
- ☐ The researcher will assist me in contacting relevant counselling services should I feel that I require such services as a result of my participation in this study.

Signature:_____

Date:_____

APPENDIX G: **Audio-recording and transcript consent form**

I, _____ hereby voluntarily consent to my interview with Lisa Kallmeyer for her study on the perception of sibling relationships affected by schizophrenia, being audio-tape recorded, and transcribed. I understand that:

- The tapes and transcripts will only be heard by the researcher and her research supervisor, and will only be processed by the researcher.

- All tape recordings and transcripts will be kept in a secure location, which only the researcher will have access to.

- All tape recordings will be destroyed after the research is completed and examined.

- No identifying information will be used in the transcripts or the research report.

Signature:_____

Date:_____

APPENDIX H: Ethics Clearance Certificate