

Experiences of Having an Adult Sibling with a Mental Illness: An Interpretative
Phenomenological Analysis.

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by

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Declaration

I declare that **Experiences of Having an Adult Sibling with a Mental Illness: An Interpretative Phenomenological Analysis** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

Signature:

Date:

Abstract

Mental illness has a significant impact on the life of an individual, however not only on the individual but on the family as well. A considerable amount of research has been carried out regarding the experiences of family members internationally. However, in South Africa (SA) there is inadequate information regarding the experiences of families, especially adult siblings, of individuals with a mental illness. Specifically, there is a lack of research investigating individuals' perceptions of their brother or sister's mental illness as well as how this affects the sibling relationship. It is for this reason that the current study aimed at exploring the lived experiences of 'black'¹ isiXhosa speaking individuals who have a sibling with a mental illness. The study employed Interpretative Phenomenological Analysis (IPA) as its qualitative approach. A sample of five participants between the ages of 20-50 years was selected through purposive and snowballing sampling techniques. Semi-structured interviews were utilised and were transcribed and analysed based on the IPA framework. The analysis of the participants' transcripts provided three master themes, which are supported by subordinate themes. The master themes are: 1) experiencing the sibling as a burden post diagnosis, 2) positive experiences from the sibling's mental illness, 3) participant's experiences of their sibling's treatment and the mental health care system. Participants experienced financial burden as well as the burden of caregiving as a result of their sibling's mental illness; these are understood as being subjective and objective burdens. While no change was experienced within the sibling relationship, the siblings' mental illness was experienced as affecting the sibling relationship due to the socioeconomic status of the participants and stigma. The findings support and expand on the growing knowledge of adult sibling relationships and mental illness.

¹ The socially constructed nature of 'race' is acknowledged in this work and the researcher thus uses single quotation marks to connote this signifier. Nevertheless, it is still used as much of South African society is still largely structured by racial categories.

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Keywords: Mental illness, black, sibling, sibling relationship, IPA, phenomenology, experiences, deinstitutionalisation, stigma, caregiving, burden, culture, treatment.

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1. Chapter 1: Introduction

'I think you feel an immediate deep sense of loss. You're shocked and absolutely devastated. You don't believe that what you're hearing is true. Another feeling was, "My God, why us? Why our family?" I went through a full array of emotions. I bargained with God, I was ashamed, I felt guilty. All of this guilt, wondering if there wasn't something more you could have done? I cried and wondered what this was that was happening to us. I was afraid and scared.' – Brother of an individual with a mental illness (Marsh, Dickens, Yackovich, & Wilson, 1993, pg. 29-30).

Mental illness has a momentous impact, not only on the life of the individual concerned, but also on his or her family. The above quotation portrays the deep, emotional impact of having a sibling with a mental illness. It is estimated that 50 to 80 % of relatives with schizophrenia and other psychotic disorders either live with or maintain regular contact with their families (Gibbons, Horn & Powell, 1984; Lehman & Steinwaches, 1998; both cited in McDonell, Short, Berry, & Dyck, 2003). However, there is limited research available that focuses on individuals who have a sibling with a mental illness (Sin, Moone & Harris, 2012). It has been noted that siblings frequently feel like forgotten family members, invisible and abandoned (Lukens, Thorning, & Lohrer, 2004; Marsh & Dickens, 1997; Marsh, 1998).

One of the major changes in the care of individuals with a serious mental illness in the twentieth century is that the process of deinstitutionalisation has shifted the treatment of individuals with a mental illness from public institutions to community care centres. This process had a significant impact on the mental health system and on the families of the individuals with mental illness. (Thompson & Doll, 1982). This shift has largely occurred in the developed world. South Africa, for example, still has instances of institutionalisation, for example at Tower Hospital in Fort

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Beaufort (Eastern Cape) and there are few community care centres. It is argued by Friedrich, Lively and Rubenstein (2008) that the family members who are the most affected and vulnerable, when there is a lack of resources in the community to support deinstitutionalisation, are the siblings of an individual with a mental illness. Thompson and Doll (1982) assert that one of the unintentional effects of the abolishment of state mental hospitals in the United Kingdom has been the increased emotional and interactional burden that families have had to experience on a daily basis in providing critical care to relatives with a mental illness.

Many families are profoundly negatively affected by their new caregiving responsibilities (Clausen & Yarrow 1955; Grad & Sainsbury, 1968; Norbeck, Chafetz, Skoldol-Wilson, & Weiss, 1991; Fisher, Benson, & Tessler, 1990; all cited in Dyck, Short & Vitaliano, 1999). Families may also have additional problems when attempting to access the mental health system (Murray-Swank, Dixon & Stewart, 2007). Often families do not receive support and information from mental health professionals about the illness of their relative; for example, families may not know about the kind of treatment that is being received and the reasons for the treatment (Murray-Swank *et al.*, 2007).

1.1 Significance of the study

Given that there is a dearth of information about the experiences of families, especially adult siblings, and the importance of this stakeholder group in decision-making around the treatment of their relative within the Southern African context, it is essential to study their experiences in a South African (SA) context. Prior research by Smith and Greenberg (2008) has highlighted the importance of investigating the perceptions of siblings regarding their brother or sister's mental illness as well as how their perceptions affect the sibling relationship.

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The sibling relationship has been regarded as the most durable of all family relationships (Smith & Greenberg, 2008). With the parents of the individuals who have a mental illness aging, research has begun to shift away from parents towards siblings as future caregivers of their brothers and sisters (Hatfield & Lefley, 2005; Smith & Greenberg, 2007; Smith, Greenberg & Seltzer, 2007).

Although siblings are considered, to be the logical caregiving replacement for aging parents, it is unclear what their roles will be or how this might affect their lives (Friedrich et al., 2008). Siblings may also experience burdens concerning their brother or sister's mental illness, but little attention has been paid to specific mental health services and programs that could be implemented to reduce the stress experienced by siblings (Friedrich et al., 2008). According to Sin, Moone and Harris (2008), siblings remain invisible to mental health services, because there is inadequate recognition within mental health services of the role that siblings can play. This contributes to inadequate knowledge and skills that are typically needed to manage and cope with circumstances surrounding the illness (Friedrich et al., 2008).

The current research has the potential to enable local researchers within South Africa to determine whether international literature on families and their experiences with mental illness is appropriate for the South African context, in particular, for 'black' isiXhosa speaking individuals, who are the focus of this study. The findings of this study could assist mental health professionals to create appropriate treatment models for South Africa, as suggested by Jonker (2006). Jonker (2006) asserts that the creation of such models will assist South African researchers and mental health professionals in providing an efficient service to families. Furthermore, it is essential to investigate the experiences of family members, as their experiences are crucial for understanding and intervening with family systems. Due to families being

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involved with treatment and caregiving of mentally ill patients after being discharged from hospital (Deal, Wampler & Halverson, 1992).

1.2 The purpose of the study

The purpose of the study is to explore and describe the experiences of 'black' isiXhosa speaking individuals who have adult siblings with a serious mental illness in Grahamstown, Eastern Cape. Individuals with mental illness in this study need to have been hospitalised for a period at a psychiatric hospital or at general hospital due to this mental illness. The objective of the research is to produce an in-depth interpretative analysis of the experiences of individuals who have a sibling with a mental illness. One of the objectives will be to guide mental health care professionals to develop programs and interventions that support and sustain the involvement of individuals in the treatment and care of their sibling with a mental illness in South Africa, as well as creating further research in this area.

1.3 Research Question

The question that the current research endeavors to answer is; how do 'black' isiXhosa speaking individuals experience their sibling relationship with an adult sibling who has a diagnosed mental illness?

Sub questions

- What are the negative and positive experiences of individuals who have a sibling with a mental illness?
- How does the sibling experience the mental health system?

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- What contextual factors impact on how individuals experience having a sibling with a mental illness?

1.4 Contextualising the study

South Africa has experienced oppressive apartheid policies, and due to this, it is burdened by a backlog of social needs and demands, as well as economic shortages, which were created by oppressive apartheid policies. According to Nkosi and Daniels (2007) the fretful economic distance between ‘blacks’ and ‘whites’ which was intensified by political inequities is such that Africans are over-represented in the rural areas where the incidence of various characteristics of socio economic vulnerability are disproportionately intensified. In the absence of inadequate income levels, rural communities find themselves continually trapped in the cycle of poverty (Nkosi& Daniels 2007).

Grahamstown forms part of one of the rural communities of the Eastern Cape. Grahamstown is also known as ‘Rhini’. Rhini is characterised by high levels of poverty and unemployment and low educational levels (Noble, Barnes, Wright & Roberts, 2010). The poverty levels in Makana and Grahamstown are unacceptably high, sitting at 30,303 people or nearly 40% of the population (39. 4%) who fall below the poverty line Socioeconomic Specialist Report, n.d.) Grahamstown has a very high unemployment rate, a grim indication of the social reality that many disadvantaged areas in the Eastern Cape face, and where many families are forced to live below the bread line and about 13, 2 % of family households in Grahamstown has no income (Statistics South Africa, 2014). The majority of the population consists of ‘black’isiXhosa speaking individuals.

1.5 Brief chapter overview

This research report consists of five chapters inclusive of the literature review, research methodology, findings, discussion and the conclusion. The structure of the research report is discussed in more detail below;

The current chapter provides an introduction to the research report; it establishes the motivation and purpose of the study. It acts as a brief synopsis for the reason and the objectives of the study and to provide an understanding of the focus of the research study.

1.5.1 Chapter 2 Literature review. The purpose of the literature review is to provide an overview of relevant and available ideas, knowledge and research related to the experiences of individuals who have a sibling with a mental illness. The literature review begins by placing the experiences of mental illness within the family context. Subsequently the sibling relationship is described within the context of a sibling having a mental illness. Both the negative and positive experiences of the siblings of individuals with a mental illness are described, based on available literature. Siblings' experiences with the mental health system are also explored as well as how culture might influence the way individuals experience having a family member or sibling with a mental illness. Lastly, the literature review contains a section on the available research on how individuals experience stigma, and how it affects the family and siblings.

1.5.2 Chapter 3 Research Methodology. The research questions are presented in this chapter. The research approach and method is described. The study will be utilising an Interpretative Phenomenological Analysis (IPA) approach to answer the research questions. The process of the sampling of the participants is discussed, and relevant details about the participants are provided. The procedures of data collection as well as how the data was analysed will also be discussed. The reliability and validity of the study will also be interrogated. A

section on reflexivity is included in this chapter. Ethical concerns regarding the study, as well as methods undertaken to manage these concerns are discussed.

1.5.3 Chapter 4 Findings. This chapter comprises of the presentation of the research findings. The experiences are categorised, interpreted, and discussed in order to gain a deeper awareness and understanding of the participants' experiences of having a sibling with a mental illness. The findings are first described by using verbatim extracts from the data and subsequently interpreted.

1.5.4 Chapter 5 Discussion. This chapter consists of the discussions of the findings, which are related to existing literature to note areas of similarity and differences.

1.5.5 Chapter6 Conclusion. This chapter is a conclusion to the study; it includes final comments, summary of the findings and various limitations, adding to this possible direction for future research as well as contributions made by the research.

2. Chapter 2: Literature Review

2.1 Introduction

The review of literature will contextualise the current study within available research. This chapter begins with a broad discussion of how family members experience having a relative with a mental illness, as well as a discussion of the concept ‘sibling relationship’. Furthermore, a discussion of the positive and negative experiences of siblings who have a brother or sister with a mental illness is included. The chapter also focuses on the experiences of siblings and adult sibling’s interaction with the mental health system as well as discussing deinstitutionalisation, the mental health system and its consequences for the sibling relationship. The review further engages with the literature that describes the influences of culture on mental illness and how this in turn influences the experiences of siblings within a specific culture. The chapter concludes with how individuals experience the stigma of having a sibling with a mental illness.

2.2 Mental illness and families

In order to understand mental illness and siblings, an understanding of families and mental illness will firstly be explored. The family members of mentally ill individuals are key figures in the support network that often act as a buffer for a patient; this means that families play an important role in the outcome of treatment (Ewertzon, Cronqvist, Lutzen & Andershed, 2012). Jones (2002) also posits that families have been active in shaping responses towards mental illness, in other words families play a role in how services are rendered towards those who have a mental illness. However, the study of families’ experiences with serious mental illness is not adequately investigated in the South African literature. By contrast, the American and European literature offers a wide range of research based on the experiences of families with mental

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illness. For example, Jones (2004) found in a study conducted with 47 families (including mothers, fathers and siblings) who had a relative with a severe mental illness in London, that loss is the central experience of these families. Reinhard and Horwitz (1995), who interviewed 163 parents and siblings of individuals with severe mental illness in the United States of America, found the experience of their mentally ill sibling as a burden is a consequence of dealing with disruptive behaviors and providing instrumental and emotional assistance.

The only available study that focuses specifically on families and how they experience having a family member with a mental illness in SA was conducted in the Free State within Thabo-Mafutsanyana district by Mayaluoe, Mvandaba, du Plessis and Koen (2014). Mayaluoe et al. (2014) found that family members continued to care for their mentally ill family members even though they often felt that they were not competent to play this caregiving role. The study also found that families found it both difficult and painful to live with a mentally ill family member.

According to the National Mental Health Policy Framework (2013-2020) one of the aims for mental health care in SA is to move towards de-institutionalisation. The rationale for deinstitutionalisation was that there was a growing concern for the wellbeing of mentally ill individuals as more reports surfaced exposing mistreatment within psychiatric institutions and the poor conditions in which the patients were being cared for (Turner, 2004). Clinicians are thus increasingly relying on family support for outpatients with mental illnesses. It is therefore important to understand the experiences of families, and this study focuses on the adult siblings of individuals who are mentally ill, so that mental health practitioners can provide appropriate advice and support to relatives. It is pertinent to focus on adult siblings who may provide greater emotional and social support for individuals with mental illness as parents get old and frail. Certainly, Jones (2002) has observed how strong sibling relationships in adulthood can be and

has found that these relationships can be a valuable source of support for mentally ill patients. In order to understand how individuals experience having a sibling with a mental illness, it is vital to explore the sibling relationship, because the sibling relationship has been regarded as the most enduring of all family relationships (Smith & Greenberg, 2008).

2.3 Siblings and the sibling relationship

What is a sibling? The increasing diversity of family structures occurring in most western societies raises a number of issues for the technical fact of who a sister or a brother is. From a perspective that involves taking seriously the interactions between social structures and subjectivity it would seem that social and cultural context play a vital role in how ties between siblings play out (Edwards, Hadfield, Lucey & Mauthner, 2006). Since the current study focuses on 'Black' isiXhosa speaking individuals, it is important to understand how different cultures define siblingship. Various cultures differ in the way the term 'sibling' is used and who is identified as a sibling. In western societies, siblings are identified by genealogical or biological criteria, where full siblings have two biological parents in common and half siblings share only one biological parent. Siblings may also be identified by legal criteria as in the case of step or adoptive siblings (Cicirelli, 1995).

Collectivistic societies (largely found in non-western contexts), however, identify a sibling differently. In the collectivistic societies, siblings may be defined by extension of the term to certain types of blood kin, or by classification on the basis of other criteria other than genealogical criteria alone (Cicirelli, 1995). Depending on the particular society involved, the rules for identification as a sibling may become quite complex. Siblings can be brothers or sisters, blood related or nonblood related, as well as cousins. It is well established in the

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literature that the structure of families in many 'black' communities internationally is multifaceted and complex (Wallace, Hooper & Persad, 2012). The organisational structure of 'black' extended families reveals a close network of relationships within and between family members, who may or may not be blood relatives (Nobles, Goddard, Cavil & George, 1987). From this perspective, sibling relationships, in non-western contexts in particular, are a socially constructed tie: according to Circelli (1995), sibling relationships are the total of interactions of two or more individuals who share knowledge, perceptions, attitudes, beliefs and feelings regarding each other.

The sibling relationship has significant importance as a contributor to the development of other family relationships and family harmony. For example, Lobato, Faust and Spirito (1988) found that siblings could serve as educators for one another, as negotiators of parental attention and control, and as peers with whom to socialise and share experiences. The sibling relationship is a complex and variable social relationship and is highly sensitive to other interfamilial relationships (Sanders, 2004).

Sibling relationships may be viewed as supportive and nurturing relationships and as an alliance between equals. Since siblings are perceived as equals, they share a world that is different to the one shared with parents. Siblings may be the first ones with whom individuals share their concerns, fears and anxieties. The sibling relationship can also be viewed as the first expression of competitive relationships (Sanders, 2004). Dunn, Slomkowski and Beardsall (1994) found in studies of 39 families in England from childhood to early adolescence a warm and supportive relationship with an older sibling was associated with higher perceived self-competence and better adjustment for the younger sibling. When there was a warm relationship between the

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siblings, older siblings helped the younger deal with both minor and major life problems (Dunn, 1994).

Sanders (2004) describe the typical stages of the sibling relationship. In the childhood and adolescent periods, siblings form a companionship. During these times, siblings provide emotional support and share home tasks and care taking. In early and middle adulthood, the sibling friendship and support generally matures compared to that experienced in childhood. The siblings begin to care for their parents and provide emotional support and companionship for the latter as well. Furthermore, in adulthood, siblings may provide long distance support and encouragement to one another. This illustrates that siblings often continue to support, care for one another over their lifespan, and function as caretakers and helpers.

Brody (1998) investigated older siblings' contribution to their younger sibling's development through siblings' interactions. The author found that experiences with academic and social competence demonstrated by an older sibling had a positive effect on the younger sibling's self-regulation behaviors (Brody, 1998). Younger siblings' self-regulation of undesirable behaviors was also positively linked to competent elder siblings that tutored their younger siblings, helped them to solve problems, provided them with social support and discouraged physical, emotional and relational aggression. Whereas an older sibling, 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 sibling with a mental illness, as well as to their parents (Jones, 2002).

Within families' siblings have important roles to perform, however there are variations within different cultural contexts. In western societies, the sibling relationship is typically less important

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than the spousal or parent-child relationship. This is in contrast with non-western societies where siblings may be more important than a spouse and cousins may be considered as siblings (Adams, 1999). Furthermore, siblings in non-western societies carry out important family functions, such as taking care of younger siblings and teaching of household and occupational skills. The latter emphasises interdependence, which is an important characteristic of the group in which they will live in (Weisner, 1982). Nuckolls (1993) also found that support between siblings is taught from a young age and is greatly valued in non-western contexts. Siblings share life crises and rite of passage ceremonies essential to their cultural and social identity, and they take on ritual and ceremonial responsibilities for each other essential to community spiritual ideas. Fulgini, Tseng and Lam (2002) found that the culture of collectivism persists even in the face of social change. A study of adolescents found that youth in Asia (non-western societies) held strong family values and higher expectations regarding their obligations to assist, respect and support their families, which is in contrast to the Europeans (western societies). In addition, siblings are crucial to adult maintenance and support in non-western contexts. Brothers and sisters often share strong economic ties, but even when they do not, they have the right to call on each other for mutual support and assistance at any time. Older siblings take care of younger siblings partly assuming a role that in the western society is usually assigned to parents. This means that children learn nurturance and caregiving much earlier and more intensely both within and outside siblingship in non-western contexts (Nuckolls, 1993).

The differences between the social thought of western and non-western societies, is that western societies view development of individuals into fully autonomous beings as natural. In non-western societies, the individual is not distinguished from his/her status he/she occupies. Shweder (1990) calls this a socio centric definition of a person as opposed to the western

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egocentric definition. The consequences of this socialisation are that it typically creates people with high dependency needs.

In any family, each relationship that a sibling has with another is important, however increasingly, particularly in western contexts. Sibling relationships have become relationships of choice resulting in some siblings no longer having any contact with one another (Barnett, 2005). Although there are positive aspects of a sibling relationship, siblings do experience conflict amongst each other. These aspects will be discussed below.

Rivalry between siblings was assumed to be the most important aspect of sibling relationships. As early as the nineteen hundred, for example (Adler, 1926) showed that birth order and sibling rivalry were related. Sibling rivalry can be described as the competitive relationship or hostility between siblings, blood-related or not. Children tend to naturally compete with each other for not only attention from parents but for recognition in the world. According to Rimm (2002), sibling rivalry is particularly intense when siblings are close in age and of the same gender or when one sibling is intellectually gifted. Sibling rivalry involves aggression and insulting, especially with siblings close in age. Sibling rivalry may continue into adulthood and therefore due to this sibling relationships can change considerably over the years.

Both positive and negative experiences have been noted in relationships with a sibling who has a mental illness (Tanaka, 2011). The subsequent section will focus on the negative experiences that adult siblings go through, as elaborated in the literature, when having a sibling with a mental illness.

2.4 Negative experiences of the siblings of individuals with a mental illness

According to Tanaka (2011) common negative themes among siblings of individuals with a mental illness include feelings of chronic stress and sorrow, grief, loss, neglect, alienation, survivor's guilt, repressed anger and fear of becoming mentally ill themselves. Other negative effects are the responsibilities placed on the individual who has a mentally ill sibling as Siegelman (2001) argues that parents may delegate additional responsibilities to this sibling. In addition, the sibling who does not have a mental illness may have to worry about the future of the sibling who does, when parents can no longer take care of him or her. Siblings may keep these feelings hidden due to a limited number of opportunities to feel special, worthwhile, and important or the centre of positive attention. The studies by Tanaka (2011) and Siegelman (2001) were conducted within the United States of America. The question arises whether similar results would occur within the South African context, where social, financial and emotional strain may be embedded within a relationship?

Siblings may also experience mixed emotions about the diagnosis of their mentally ill sibling. Torrey (1983) describes these mixed emotions as a 'survivor's syndrome' in which siblings blamed themselves for being free of the devastating illness that has affected their siblings. Siblings may blame themselves for the situation, yet simultaneously felt certain that it was not their fault. The siblings feel drawn to the sibling with the mental illness, but at the same time feel rejected by their sibling's bizarre behaviour and a limited impulse control (Torrey, 1983).

Family members may experience grief as well; the significance of grief has been strongly emphasised by those who have looked at the impact of mental illness on families. Jones (2002)

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has emphasised the idea that grief was caused by the incoherence of the relative's behaviour and that these behaviors, such as the unpredictability of their actions and moods, were seen as a negative change. MacGregor (1994) observed that siblings might also experience disenfranchised grief; individuals feel that they cannot communicate their grief, as others do not understand this loss and the shame of mental illness may stop people from talking about their experiences. It has been stated that this type of grief is more difficult to resolve than loss through death, because families are constantly reminded of their loss (MacGregor, 1994; Willick, 1994).

Siblings may also experience having a sibling with a mental illness as a burden, both objectively and subjectively (Maurin & Boyd, 1990), which is supported by Mavundla (2009). The sense of burden is due to care giving. Caregiver burden has been defined as a response to physical, psychological, emotional, social, and financial stressors associated with the care giving experience (Chang, Kim & Rose, 2012). The objective burden refers to the negative effects of the illness on the household and care giving demands. The subjective burden, meanwhile, refers to the caregiver's or family member's personal appraisal of the situation (Maurin & Boyd, 1990). According to Greenberg, Kim and Greenley (1997), similar burdens will mean different things to different people in different contexts. To assist with contextualising the current study within the South African context, the work of Mavundla, Toth and Mphelane (2009) at a community clinic, situated in Makhuduthamaga in Limpopo Province is important. This study described in detail the experiences of informal family caregivers of individuals with mental illness in a rural community in SA. The sample consisted of eight participants, inclusive of five mothers, one father, one sister, and one wife aged between 41 and 65 years (Mavundla *et al.* 2009). This study is relevant to the current research as the latter is also conducted within a rural context and a population who are still perceived as marginalised. Mavundla *et al.* (2009) found that the

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responses of the caregivers were mainly negative conceptualisations of their experiences, despite the neutrality of the questions. The study showed that all of the caregivers focused on the hardships of caregiving and the negative aspects of mental illness. The participants expressed their difficulties with caring for their relatives' physical and emotional needs, and spoke at length about financial burdens. The negative aspects about mental illness were highlighted such as the violence caused by the mentally ill family member as well as inadequate hygiene and uncooperativeness (Mavundla *et al.* 2009). It is believed by Mavundla *et al.* (2009) that the negative conceptualisation of the caregiving experience and mental illness were due to cultural context and beliefs surrounding mental illness in the community and the stigmatisation and marginalisation of such individuals. It should be noted though that the sample was relatively small and included parents and spouses and siblings: the findings may thus not necessarily be more widely representative of siblings and may also not necessarily be generalised to other populations.

There is a need to investigate what these burdens signify in a South African context for 'black', isiXhosa-speaking individuals, which is the focus of the current study. It is only when professionals fully understand the types of caregiver burdens and the impact of the burden on caregivers such as siblings that effective health care services can be delivered to the different types of caregivers (Hatfield, 1994). Although we have explored negative experiences above, siblings have also described positive experiences that have resulted from their sibling's mental illness. The subsequent section will focus on this.

2.5 The positive experiences of the siblings of individuals with a mental illness

According to Tanaka (2011), studies have identified that siblings develop a sense of strength and insight in relation to their brother's or sister's mental illness, including an enhanced sense of self, improved relationship skills as well as greater spirituality. A factor, which contributes to siblings having these positive experiences, includes social support (Cohen, Underwood & Gottlieb, 2000). Siblings may also feel more compassion and tolerance towards others who experience mental illness or they may constructively reassess their life meaning and values (Jewell, 2000). Research has also found that siblings reported that their experience led to a closer sibling relationship and a stronger sibling bond with the individual who has a mental illness. (Sin, *et al.*, 2008).

Family members may find positive meaning from coping with the challenges of having a relative with mental illness. In research conducted by Leith and Stein (2012) family members have indicated feeling a greater sense of purpose, an increased sense of empathy, a greater closeness within their family of origin, and desire to work to improve the mental health system as a result of their experiences with their loved one's mental illness. Having a brother or sister with a mental illness is not an exclusively negative experience; there can be positive aspects too. For example, a sibling may feel more compassionate and tolerant of others who experience mental illness, or they may constructively reassess their life meaning and values (Jewell, 2000). Some siblings report that their experience led to a closer sibling relationship and a stronger sibling bond (Sin *et al.*, 2008). Siblings have also reported benefits related to the family unit, such as more resilience, more cohesive working and more family supportiveness (Sin *et al.*, 2008). They

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may also gain coping skills and knowledge through their experience that they can use to benefit their own lives.

Monyaluoe, Mvandaba, Du Plessis and Koen (2014) conducted a study in the Free State province of South Africa. This study included 14 families, comprising the parents, spouses or siblings of the mentally ill family members, all of whom were Black, Sesotho-speaking adults between 18 and 50 years of age. The mentally ill family members were mainly diagnosed with mood disorders, substance abuse or schizophrenia, and were living with and dependent on their family members.

Some of the positive experiences highlighted by family members included that they have learned to accept and live with their mentally ill relative, even though they often feel that they are incompetent to play their role as a supportive family member (Monyaluoe et al. 2014). Participants also shared that they were supported by community members in looking after their mentally ill relative when they were not around. Participants experienced supporting their mentally ill family member in obtaining treatment as highly important. Education was found to be the one of the most important needs that families had, for example education on the signs and symptoms of relapse and how and when to seek assistance (Monyaluoe et al. 2014) The latter is linked to the mental health system and how individuals experience this, which will be explored below.

2.6 Deinstitutionalisation and the mental health system

Deinstitutionalisation can be described as a process where mentally ill individuals are no longer residing in psychiatric hospitals for long periods of time, with hospitalisation being replaced by brief lodging in smaller and less isolated community-based centres (Bachrach, 1993). The

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rationale for deinstitutionalisation came about in the context of attempts to prevent the inhumane treatment that mentally ill individuals used to endure in state institutions (Lamb & Bachrach, 2001). The push for deinstitutionalisation internationally was made possible by strong political leadership, lobbied by human rights organisations, and caring family members. (Lamb & Bachrach, 2001).

The implementation of the deinstitutionalisation process came much later in South Africa in comparison to North America and Europe, where it took place in 1948 (Porter & Morse, 2001). In South Africa, the process of deinstitutionalisation started to occur around the 1990s. In Gauteng province, the deinstitutionalisation process was motivated by legal imperatives, as the newly appointed judges at that time were skeptical about the mandatory incarceration of people in contracted mental health care facilities, and thus approximately 300 cases of detention were discharged (Strachan, 2000). Strachan (2000) notes that in Cape Town in the 1990s, there were a number of rehabilitation groups for persons with mental illness. Many of the patients who were discharged from state hospitals to the care of their families at home ended up being supported solely by community centres (Strachan, 2000). Some of these state patients attended psychosocial rehabilitation programmes. According to Barton (1999), psychosocial rehabilitation focuses on teaching skills and providing community support for mentally ill individuals in order for them to function in social, vocational, educational and familial roles of their choice, as well as promoting autonomy and independence while decreasing the need for acute care. There are, however, limited or no rehabilitation services for mentally ill individuals within rural areas, with the exception of a smaller number of specialist units, as reported by The Rural Mental Health Report (2015).

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After the democratisation of South Africa in 1994, one of the government's major challenges was to transform services that were previously neglected from the apartheid era. Health care services were ill equipped, lacked necessities and were segregated along racial lines (Schwartz & McGregor, 2002). The latter, segregation along racial lines, may have an influence on how individuals experience having a sibling with a mental illness, in particular taking into account that the current research was conducted with black individuals from a semi-rural context.

It is pertinent at this point to turn our attention to the experiences that the siblings of those with mental illness have had with the health care system in South Africa. Many siblings around the country, for example, have reported that they were not included in caregiving by the mental health system (Riebschlegar, 1991). Mavundla *et al.* (2009) stated that many families reported that they did not understand the causes of the illness of their relative, but that they wished to be educated as they believed that this would provide them with better strategies for care giving.

Lukens, Thorning, and Lohrer (2002), in an American study, have asserted that there is poor recognition of the role that siblings can play in caring for and supporting individuals with mental illness. In South Africa, there are additional challenges, such as cultural values and beliefs that stigmatise mental illness and the socio-economic status of the marginalised, which increases the likelihood of caregiving burden. As found by Mavundla *et al.* (2009), some cultural beliefs in South Africa contribute to the perception of individuals with mental illness as being responsible for or in control of their own conditions, resulting in stigmatisation and family members not assisting with care. The process of and implications associated with taking care of relatives with a mental illness in less-developed societies is not well understood or described fully (Mavundla *et al.*, 2009).

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Although family members may take their relative with a mental illness to the rural clinic to collect medication regularly, the patient may still relapse, due to families being misinformed on how the patient needs to take the medication correctly. It was observed by Mavundla et al. (2009) that when people with mental illness experienced side effects, they often decided to stop taking the medication, without consulting professional help. Mavundla et al. (2009) also found that some patients forgot the instructions for taking medication, while others had negative attitudes towards medication and turned to traditional medicines, for example that provided by faith healers and ‘witch doctors’. This is further supported by Ntongana (1996), who observed that some families felt that their relatives could not be cured and used traditional herbs instead of western medication and psychological interventions. It can be problematic for mentally ill individuals to take herbs without pharmaceutical medicines, as the former may not necessarily assist in treating the symptomology of the condition. Furthermore, there could be contraindications to and potentially severe side effects arising from the use of such herbs, as well as possible interactions with western pharmaceutical medicines that the patient may be taking. The situation is further heightened by misinformation and stigma surrounding mental illness in South Africa, especially in rural areas where traditional explanatory models are still prevalent, such as the mentally ill individual being blamed for their own illness (Ntongana, 1996). These traditional explanatory models may be seen as linked to culture, which is explored below.

2.7 Culture and mental illness

According to Swartz (1998), culture relates to the process of being and becoming a social being; it is about the rules of society and the ways in which these are endorsed, experienced and transmitted. Interpretations of rules change over time with different circumstances, and therefore culture cannot be static. Swartz further argues that it is not possible to draw tight boundaries

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around cultures, as though these are separate entities. The conceptual barrier that biomedicine places between mental and physical health is not one that applies to all systems of thought. It does not make sense to everyone to separate the physical from the mental, and many forms of healing do not make this rigid distinction. Swartz (1998) emphasises the importance of acknowledging that psychiatric illness categories are western cultural constructs; other cultures may not conceptualise distress as illness. The emphasis in western culture on describing distress psychologically is not shared by every culture. In many African cultures, for example, there is a tendency for personal distress to be expressed as bodily pains and problems (Swartz, 1998). Understanding how context can provide a meaning to mental illness is thus important in order to understand the experiences of the siblings of those with a chronic mental illness in context.

South Africa is culturally, linguistically and ethnically diverse. Within the South African context, the concept of ‘culture’ has carried multiple meanings. It has been associated with race, ethnic identity, Afrocentrism, historical tradition, material deprivation and poverty, and often that which is not Western or Eurocentric (Eagle, 2005). In South Africa psychology as a profession has a long history of grappling with culture, ethnicity and diversity as well as seeking to provide a relevant response to needs within an often fractured society (Johnston, 2015). Swartz (2008) has observed that in any attempt to understand mental health and issues of culture, it is pertinent to recognise the interwoven effects of poverty, displacement, inequality and migration on mental illness. Mental disorders accompanying such socio-economic processes have a cultural component, but are also based in the realities of the material aspects of people’s lives. Therefore, it is important to understand how cultural context may influence how individuals experience having a sibling with a mental illness. This is especially relevant because after apartheid, with

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the racial integration of services, new challenges arose in rendering culturally appropriate care (Swartz, 1996).

Cicirelli (1995) has stated that the environmental context has a powerful effect on sibling relations around the world. Considering all the different nations and cultures existing in today's world, the question of whether existing findings about siblings and family relationships in Western societies apply universally is an important one, particularly in the current study, which focuses on 'black', isiXhosa speaking individuals. Lefley (1998) found that different cultural backgrounds address mental illness in different ways; in individualistic countries, individuals provided care based on personal choice and responsibility, whereas mandatory responsibilities and reciprocal obligations to provide care existed in non-western countries. Tanaka (2010) also highlighted that within collectivistic societies; siblings have an obligation to provide care to each other and cannot escape from the caregiving role. It is therefore important to investigate whether the current study, which has been conducted within what can be considered a non-western society has the same findings as according to Nuckolls (1993) as the individuals within the society are community orientated and stresses the priority of group goals will have similar findings to those reported in Western studies.

Sam and Morreira (2012) have proposed that there cannot be mental illness without culture. Culture influences the development, onset, expression, course, outcome, understanding and treatment of mental illness (Sam & Morreira, 2012). Interlinked with the latter, The New Freedom Commission on Mental Health (2003) in SA recognises the importance of studying cultural issues in serious mental illness, as well as related inequalities in mental health care. As mentioned previously, Swartz (1998) has noted that we cannot attempt to understand culture and mental health without considering inequality and poverty.

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Cultural enablement, such as cultural values within family support and spiritual activity, has been identified as a means of recovery from serious mental illness (Primm *et al.*, 2010). The study conducted by Monyaluoe *et al.* (2014) showed that families viewed their relative's mental illness as linked to spirituality and found that some families believed in superstition and witchcraft. There is thus a need for research that evaluates the effects of these cultural factors, such as cultural beliefs about treatment and etiology factors, on mental illness and to use research findings to develop culturally relevant interventions that can assist the family members, including siblings, of individuals who have a mental illness (Primm *et al.*, 2010). Bakshi, Rooney, and O' Neil (1999) have asserted that all communities have culturally embedded attitudes and beliefs that associate mental illness with negative connotations. Therefore, these communities may be prejudiced against individuals with mental illness and their families. This prejudice can be perceived as stigma, which can affect the manner in which individuals experience having a sibling with a mental illness. Stigma and mental illness will be explored below.

2.8 Stigma and mental illness

The study of the relationship between stigma and mental illness has an extensive history. To some, the very existence of the concept of mental illness can be understood in terms of stigmatisation (Jones, 2002). Sociologists Link and Phelan (2001) have provided a model for understanding mental health stigma. These authors recognise that stigma includes a combination of inaccurate or distorted beliefs, negative attitudes and discriminating behaviour. Link and Phelan (2001) have described stigma as a labelling of difference, stereotyping, the separation of 'us' and 'them', followed by discrimination and status loss.

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The model acknowledges that it is easier to discriminate against groups who have less power, such as the marginalised. This is particularly relevant to the current study which focuses on 'black', isiXhosa-speaking siblings in a semi-rural setting who have been historically marginalised and continue to struggle with economic marginalisation. Link and Phelan (2001) have identified different types of stigma, namely: (i) internalised stigma for the individual affected; (ii) social stigma experienced in everyday interactions with friends, family and wider community; and (iii) structural stigma, where the stigma is embedded into legal systems, the media, cultural and business institutions. Families can both stigmatise their relative with mental illness and, in turn, can themselves be stigmatised through association by the community (Link & Phelan, 2001).

Goffman (1963) noted that the effects of stigma are not restricted to those who are directly marked by difference, but also reach those associated with the individual; this is known as 'courtesy stigma'. It is probable that families involved in mental illness will experience stigma and that this may restrict their willingness to seek help and support (Jones, 2002). According to Jones (2002), relatives may experience a threat to their identity by association with someone who is perceived as mentally ill. Furthermore, families within the Western context seemed to experience a direct threat to their own identity, as though their identity were continuous with the person classified as mentally ill. This aspect of identity can be understood as operating at both a psychological and social level (Jones, 2002). Stigma plays a critical role in inhibiting mental health care, as individuals with mental health problems frequently delay help-seeking for the fear of social consequences (Knifton, 2012).

Therefore, the available research strongly suggests that the challenges associated with stigma for the mentally ill individual also affect the family (Jones & Hayward, 2004). Since providing care

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for the mentally ill relative maybe a burdensome experience to many family members, stigma may make the experience even more difficult. Kung (2003) has highlighted that the stigma attached to mental illness and the practical strains involved in caring for a patient are significant sources of stress for the family. Jones and Hayward (2004) have observed that stigma can affect families in ways that would make it difficult for them to support their relatives without fear of feeling uncomfortable or embarrassed at the reactions of others.

According to Hendrikson, Schmal, and Ekleberry (2004), stigma alienates both families and their ill relatives from society and, as a result, many families may withdraw from social networks. This may make it more difficult for them to cope with the illness of their relatives on their own, and families may thus feel trapped in their situations and isolated (Hendrikson, 2004). Scheffer (2003) reports on a survey that was conducted in Canada on employment and mental illness. The survey, entitled “Consumer experience with stigma”, focused on the experiences of individuals with severe mental illness and provided information about the pervasive discrimination in the workplace that often impedes these individuals from reaping their full potential. Seven out of ten participants said that their illness was revealed, and that people treated them as incompetent regardless of their skills that they possessed (Scheffer, 2003). This can have an indirect effect on family functioning, with family members having to bear the financial burden of the stigmatisation of their relative with a mental illness.

Mavundla (2002) also found that general hospital nurses had negative feelings about caring for mentally ill individuals in SA. This is important, as it suggests that health care services and health professionals in SA maintain and further entrench stigma against individuals with mental illness. Such stigma is so widespread globally that the World Health Organisation (2001)(WHO) has identified stigmatisation as one of the major impediments to mental health programme

development, and subsequently embarked on a campaign to alert public institutions worldwide about the importance of this problem. To conclude, it is evident that stigma has an effect on the families, including siblings, of individuals with a mental illness and can, in turn, influence how they experience having a family member with a mental illness.

2.9 Conclusion

The purpose of the literature review in this chapter was to explore how the developments concerning the experiences of individuals who have a sibling with a mental illness have been evolving over time. The review looked at current and historical literature to contextualise the current study. Although there is considerable international research on the experiences of family members with a relative who has a mental illness. There is however, a dearth of research within the South African context that specifically focuses on the experiences of siblings. Siblings may have both negative and positive experiences of their sibling's mental illness. They may experience the mental health system as not providing the essential support that is required in order for better care to take place. Furthermore, siblings may experience stigma due to having a relative with a mental illness. Culture may also play a significant role in the manner in which individuals experience having a sibling with a mental illness. Due to deinstitutionalisation, the relative of an individual with a mental illness may be the primary caregiver. It is only when professionals fully understand the display and types of caregiver burdens, and the impact of these burdens on caregivers, such as siblings, that effective health care services can be delivered to the different types of caregivers who support individuals with a mental illness. This research hopes to contribute to this endeavor.

3. Chapter 3: Research design and methodology

3.1 Introduction

The purpose of the current study is to understand the lived experiences of the adult siblings of individuals who have a serious mental illness living in Grahamstown, South Africa. The study employed a qualitative research design. Qualitative research provides a dense description that gives voice to individual experiences. As noted by Merriam (2009), qualitative research is interested in understanding the meaning people have constructed, that is, how people make sense of their world and the experiences they have in the world. This is different from a quantitative research design, which seeks to explain phenomena by collecting numerical data that can be analysed using mathematically-based methods, in particular statistics (Aliaga & Gunderson, 2000). Qualitative research has been criticised since the results of a qualitative study may not be generalisable to a larger population because the sample group is usually small and the participants were not chosen randomly. However, the research questions of the present study determined the design. The type of qualitative enquiry that was utilised will be interpretative phenomenological analysis (IPA), as this inquiry explores the real, lived experiences of individuals, and the objective of the research question is to explore the lived experiences of the adult siblings.

In this chapter, the IPA method will be discussed, as well as the sampling process that was used. The method of recruitment as well as the kinds of participants for the research will also be detailed. It is vital that every research project be based on ethical considerations, so the ethical guidelines used in this study will also be highlighted. There will also be a section on the validity and reliability of the study, which is based on Yardley's (2000) four principles for quality in an

IPA study. In an IPA inquiry, the researcher is called, on an ongoing basis, to give considerable thought to his or her own experiences and to explicitly claim the ways in which his or her position or experience relates to the phenomenon being researched, a section on reflexivity will thus also be included within this chapter.

3.2 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) was the chosen qualitative approach as it is consistent with the research question framing the study, which probes how individuals experience having a sibling with a mental illness. Interpretative Phenomenological Analysis is committed to the examination of how people make sense of their major life experiences (Smith, Flowers & Larkin, 2009). Larkin and Thompson (2011) describe IPA as an approach to qualitative research with a particular psychological interest in how people make sense of their experience. The outcome of an IPA study includes an element of giving voice; by capturing and reflecting upon the principal claims and concerns of the research participants and by making sense by offering an interpretation of this material-, which is grounded in the accounts but may use psychological concepts to extend beyond them (Smith *et al.*, 2009).

Interpretative Phenomenological Analyses is a relatively new approach and comprises three underlying qualitative approaches, which make up its theoretical foundations, namely: (i) phenomenology; (ii) idiography; and (iii) double hermeneutics, each of these will be explored below. Firstly, phenomenology is a philosophical approach to the study of experience, which means that experiences are examined in the ways in which they occur and on their own terms (Smith *et al.*, 2009). Phenomenology is essentially the study of lived experience or the ‘life world’ (van Manen, 1997). The ‘life world’ is understood as what we experience pre-reflectively, without resorting to categorisation or conceptualisation, and quite often includes what is taken

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for granted or those things that are common sense (Husserl, 1970). The emphasis of this inquiry is on the world as lived by a person, not the world or reality as something separate from the person (Valle, King & Halling, 1989). The current study is therefore concerned with attending to the ways things appear to participants in their lived experience and how participants perceive and talk about their siblings and their mental illness within their own life world.

According to Husserl (1970), researchers should endeavor to focus on each and every particular thing in its own right. Phenomenology involves stepping outside everyday experiences and natural attitudes and into a phenomenological attitude, which requires a reflexive move in order to direct information inward towards our perceptions of objects (Smith *et al.*, 2009). Phenomenological research use descriptions and focuses on the structure of experience, the organising principles that give form and meaning to the life world. It seeks to elucidate the essence of these structures as they appear in consciousness -to make the invisible visible (Kvale, 1996; Osborne, 1994; Polkinghorne, 1983). Interpretative Phenomenological Analysis has an interpretative phenomenological epistemology which is interested in understanding a person's relatedness to the world and to the things in it which matter to him or her, through the meanings that he or she makes (Larkin & Thompson, 2012).

The second foundation of IPA is idiography, which is concerned with particular experiences of particular people in a particular context (Breakwell, Smith & Wright, 2012). Interpretative phenomenological analysis has thus been used in the present study to assist with understanding specifically how 'black', isiXhosa-speaking adults experience having a sibling diagnosed with a mental illness in Grahamstown, South Africa. This is in contrast to an attempt either to produce an objective statement of the event in itself or to examine mental illness in siblings in terms of pre-existing conceptual and scientific criteria. The goal of this research is to provide an

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explorative and interpretive understanding or insight into sibling relationships when there is mental illness in a particular context for particular people; the interpretation is focused on meaning making.

Interpretative phenomenological analysis falls within a social constructivist paradigm that argues that there is no objective reality and that “all knowledge and beliefs about the world are active human constructions and, as such, are mediated by the social, historical, institutional, and economic conditions within which these constructions occur” (Freeman & Mathinson, 2009, p.1.). It takes into account that participants are active in the co-construction of meaning and understanding. The way in which particular contexts are understood thus adds to meaning making, which is in line with idiography.

The third approach underlying IPA is the theoretical stance of double hermeneutics which can be understood as follows: “Participants are trying to make sense of their world, the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2008, p.53). The works of the hermeneutic theorists Schleiermacher, Heidegger and Gadamer are considered to be influential (Smith *et al.*, 2009). These theorists highlighted that access to another person’s experience depends on and is complicated by the researcher’s own conceptions, which emphasizes the importance of an awareness of one’s own biases and preconceptions, and maintaining a spirit of openness (Smith *et al.*, 2009). This perspective recognises that the production of an interpretative account is a function of the relationship between a researcher and participant, and is constructed and shaped by this encounter. The theorists recognises that the production of an interpretative account is iterative, based on the concept of the hermeneutic circle. In other words, during the process of analysis, one moves back and forth through a range of different ways of looking at the data. In order to understand any given part, one looks at the

whole; and to understand the whole, one needs to look at the parts. Therefore, reflexivity plays a large role in double hermeneutics, as the researcher has to be aware of their own biases.

Although IPA is an approach that initially gained momentum within the field of health psychology, its utility has since been demonstrated within clinical psychology research (Pearce, Clare & Pistrang, 2002; Rhodes & Jakes, 2000). Interpretative phenomenological analysis acknowledges that the researcher's engagement with the participant's text has an interpretative element, yet, in contrast to some other methods, such as discourse analysis (DA) (Potter, 1996), it assumes an epistemological stance where through careful and explicit interpretative methodology, and it becomes possible to access an individual's cognitive inner world. A key distinction between IPA and DA is that DA examines the role of language in describing the person's experience while IPA explores how people ascribe meaning to their experiences in their interactions with the environment (Smith, Jarman, & Osborn, 1999). Interpretative phenomenology analysis was thus chosen to explore how individuals ascribe meaning to their experiences of their sibling relationships in their particular contexts.

3.3 Units of Analysis and Sampling Procedures

The proposed study made use of a homogeneous sample, meaning that the sample represents a common particular perspective which is in line with IPA methodological guidelines. The reason for this is that in IPA participants are chosen on the basis that they can grant researchers access to a particular phenomenon. Participants present a perspective rather than a population, and participants tend to have an understanding of the topic at hand (Larkin & Thompson, 2012). Furthermore, the sample can be homogeneous because IPA is an idiographic approach, concerned with understanding particular phenomena in a particular context (Smith et al., 2009).

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In IPA, the sample size is relatively small, because the primary concern is a detailed account of individual experience. The issue is quality and not quantity, and given the complexity of most human phenomena, IPA studies usually benefit from a concentrated focus on a smaller number of cases (Smith, Flowers & Larkin, 2009).

The sampling procedure that was utilised was purposive sampling. This sampling method is used in exploratory research and involves the researcher using his or her judgment in selecting cases with a specific purpose in mind. In the current research, the specific purpose was to explore the experiences of having a sibling with a mental illness. In addition to purposive sampling, snowball sampling was also utilised, which involved the researcher asking participants to identify other individuals that they are aware of who also have a sibling with a mental illness. The reason for using both purposive and snowball sampling was that this increased the probability of finding participants with the criteria that the researcher had in mind.

The sample in the current study consisted of five 'black', isiXhosa-speaking adult siblings of individuals with a mental illness. The participants had not been hospitalised for a mental illness. The reason for focusing on 'black' isiXhosa speaking individuals is that the study is interested in cultural context and low or medium socio-economic status. The reason for this as highlighted by Swartz (2008) is that in attempt to understand mental health and issues of culture, it is pertinent to recognise the interwoven effects of poverty, displacement, inequality and migration on mental health. Given South Africa's history of apartheid, if participants are 'black', they are more likely to have a lower socio-economic status due to the fretful economic distance between blacks and whites. This was intensified by political inequities such that 'black' Africans are over-represented in the rural areas where socio economic vulnerability are intensified (Nkosi & Daniels, 2007). Most 'black' patients in semi-rural and rural areas within the Eastern Cape make

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use of public health care facilities, because they cannot afford the medical care and treatment provided by medical aid schemes and private health care providers. According to Leuner (2000), 78% of the population in South Africa makes use of the state-funded medical care system, while the rest of the population uses private care. It was important to interview participants whose siblings have been through the public mental health sector, as to establish what their experiences have been.

3.4 Participant Recruitment

The sample was recruited through public advertisements asking for individuals who have a sibling with a mental illness in Grahamstown to contact the researcher. The advert in Appendix A was publically displayed on the premises of various Non-Governmental Organisations (NGOs) in Grahamstown, namely St Mary's Development and Care Centre, Lebone Centre, Kuyasa Special School, Family and Marriage Society of South Africa (FAMSA), Child Welfare, Gadra and Joza Youth Centre after permission was obtained from these organisations (letter to the organisations in Appendix B). The intention of displaying the advertisement at NGOs was because some of these organisations often deal with clients who have a sibling with a mental illness or with psychological problems in general.

3.5 Participants

The ages of the participants were mostly young adults with one significantly older participant. This particular age group was selected because the focus of the study was to explore and describe 'adult' siblings' experiences. The middle adulthood group is more likely to have elderly parents who pass on more of the burden of care to the sibling, due to the aging parent having a weakening of capacity to provide care to the mentally ill sibling, as suggested by Hatfield and

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Lefley (2005), Samuels and Chase (1979) and Smith and Greenberg (2008). All participants fell into the low to middle socioeconomic status. Socioeconomic status is an economic and sociological combined total measure of an individual's work experience and of an individual's or families' economic and social position in relation to others, based on income, education, and occupation (Carter, 1999). The table below describes the characteristics of each of the five participants.

Table 1: Characteristics of participants

Characteristics of the Participants*			
Name	Age	Background information	Sibling's diagnosis
Phiwo	23	Student, Phiwo resides with her parents. Her father is a Priest and very respected in the community. The family is Christian. They live in a house and the household consisted of four members. The participant was recruited from FAMSA.	Bipolar mood disorder (He was diagnosed 5 years ago)
Phumla	49	Phumla is an unemployed, dressmaker, Phumla has a daughter and is the sole caretaker of her sister. Phumla resides in a house. Phumla is a Christian. The household consists of 3 members. The participant was recruited from Joza Clinic.	Schizophrenia (Her sister was diagnosed in 1983 after losing her employment)
Lutho	22	Lutho is a student, residing with her parents, her brother is in actual fact her uncle. Lutho resides in a	Schizophrenia (When her brother was at

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		house and the household consist of 4 members inclusive of her parents and sister. The participant was recruited as a snowball sample from FAMSA.	school 10 years ago when he was diagnosed, he passed away in 2012)
Andile	22	Andila is a grade 12 learner; He at some point had to drop out of school to provide financially for his family. Andile resides in a RDP house and the household consists of 5 members. Andile and his family are Christians. The participant was recruited from Joza Youth Centre.	Schizophrenia (His brother was diagnosed when he was still in primary school)
Nomsa	31	Nomsa is an unemployed, part time student. Nomsa is the sole care taker of her brother and previously had to take care of her elderly parents as well. Nomsa resides in a RDP house and the household consist of 3 members. Nomsa and her family are Christians. Nomsa was recruited through the Joza youth centre.	Substance-induced psychosis that led to Schizophrenia (When her brother was 22 years, he started using substances at age 16)

*Pseudonyms were used

3.6 Procedures for Data Collection: Semi-Structured Interviews

Interpretative phenomenological analytic researchers wish to analyse in detail how participants perceive and make sense of the things that are happening to them (Smith, Flowers & Larken, 2009). The best way to collect data for IPA is through the use of semi-structured interviews

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(Smith, Jarman & Osborn, 1999). This is a flexible data collection instrument, in which the researcher and the participants are engaged in a conversation where questions are modified in the direction of the participant's answers. Semi-structured interviews allow for rapport and empathy, thus assisting the researcher to understand the empathic meaning of participants' experiences. However, semi-structured interviews take longer than structured interviews to carry out and to analyse (Smith, Jarman & Osborn, 1999). The interview schedule that was used in the present study is attached in Appendix C. The interview focused on questions pertaining to the sibling relationship, positive and negative experiences, the experience of the mental health system and experiences of stigma, which relates to having a sibling with a mental illness. The interviews were conducted in isiXhosa by the researcher. The interviews were held in the participants' home language, as this made it easier for the participants to express their experiences and the meaning of it. The interviews took place at the Rhodes University Psychology Clinic and were approximately an hour long. Each interview was audio recorded.

3.7 Translation and Transcription

The transcripts were translated and transcribed a week after collection of the data by a professional translator and transcriber, due to time constraints. It was easier to code the data in English, as the data had to be presented in English. However, the translation of the data may have caused it to lose some of its meaning. However, I have listened over the recoding to ensure that the data was transcribed properly. According to Willig (2001), there is no straightforward and word-for-word equivalence between languages. The act of translating data means that the transcript is no longer the original document.

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Willig (2001) further acknowledges that transforming a spoken word into a written word (transcription) is an interpretation in its own right; a transcript can never simply be the mirror image of an interview. It is also important to be cognisant of the fact that there are two common approaches that explain language. The first is the empiricist approach to language, this approach is very pragmatic, translation in this model is the search for appropriate labels for entities which exist in the world, for example providing a label for two languages when translating (Swartz, 1998). The second approach is the hermeneutic or constructivist approach, according to this approach language plays a part in the construction of meaning. This means that language can create its own reality, and that reality is negotiated through language. Therefore, feelings are affected and shaped by the words we use and the vocabulary and sentence construction we have available to us. Different languages develop different systems of vocabulary for emotions and in different ways. The current research employs the second understanding of language rather than the first.

Therefore, I was well aware of these implications, therefore the findings very much represent my interpretation of the participants' meaning making- it is a co-constructed endeavor. Therefore, I was aware that the transcription was completed first in isiXhosa and then translated in English. The researcher also explained this to the translator that the translation had to be as accurate as possible. In IPA the level of transcription is generally at the semantic level, meaning that IPA is interested in the meaning of words. The transcription also made use of transcription conventions such as long pauses and laughter. It is important to state that the manner in which the participants expressed themselves in IsiXhosa at times was not accurately expressed in English as some words in IsiXhosa do not exist in English and vice versa. However, the process of translation has enabled me to be aware of how important non-verbal communication is

because through translation, the verbal meaning might have gotten lost, but the non-verbal communication kept the meaning closer to reality. Therefore, it was important to keep a diary, as well as listening to the recordings when interpreting the data. The next section will discuss this further.

3.8 Procedures for Data Analysis

When you interpret qualitative data, you aim to develop an organised, detailed, plausible and transparent account of the meaning of the data (Larkin & Thompson, 2012). The assumption in IPA is that the analyst is interested in learning something about the participant's psychological world. The participants talk will manifest and suggest beliefs and constructs and this will reveal their psychological world (Smith, Jarman & Osborn, 1999).

In interpretation of qualitative data, the aim is to organise a detailed account of the meaning of data (Smith, Jarman & Osborn, 1999). The researcher started at the beginning level of the individual case, with close line-by-line analysis (coding) (see Appendix D) for an example of line by line analysis) of the experiential claims, concerns and understandings of each participant. I then identified the emergent patterns (themes) within the experiential material from the participant's interviews (see Appendix E). I then grouped the codes into sub-ordinate themes and then into master themes. I then looked at the convergence and divergence, commonality and nuances, for every case and then subsequently across multiple cases. A dialogue developed between the researcher, the coded data and the researcher's psychological knowledge from the literature review, about what it might mean for participants to have a sibling diagnosed with a mental illness (Larkin & Thompson, 2012). I then developed a structure which illustrates the

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relationships between themes in order to make sense of the data. The table below illustrates the Master themes and Sub-ordinate themes, these are represented in Table 2 below.

Table 2: Themes

Master Themes	Subordinate Themes
Experiencing the sibling as a burden post diagnosis	Experiencing financial strain post diagnosis of their sibling.
	Experiencing stigma as a result of their mentally ill sibling.
	Experiencing confusion and conflict with respect to a treatment approach: Taking the traditional, religious or medical path
	Experiencing a strenuous relationship after the diagnosis of their sibling
Positive Experiences from the sibling's mental illness	Experiencing a stronger bond within the sibling relationship
	Experiencing happiness and humour post-diagnosis
	Experiencing having a sibling with a mental illness as helpful
	Gaining knowledge from the experience of having a sibling with a mental illness
Participants experience of their sibling's treatment and the mental health care system	Positive experiences of the mental health system
	Not Knowing

3.9 Reliability and Validity

Smith, Flowers and Larken (2009) posit that Yardley's (2000) four principles of quality is suitable for an IPA study. The four principles consist of sensitivity to context; commitment and rigor; transparency and coherence; and impact and importance. Sensitivity to context may be established through demonstrating sensitivity to the existing literature and theory, the socio-cultural setting of the study (Yardley, 2000) and the material obtained from the participants (Smith et al. 2009). I have endeavored to be sensitive to the literature review and theory by including a section on all of the current available literature and always providing the context in which the literature was conducted. I have also been sensitive to the power dynamics between me and the participants. The manner in which I conducted the interviews, was also empathetic and I ensured that I establish rapport by putting the participants at ease as well as recognising cross-cultural differences between myself and the participants such as believing in ancestry and traditional healers when it comes to illness and sickness.

Commitment involves in-depth engagement with the topic, through developing competence and skill in the method used (Yardley, 2000). Smith et al. (2009) suggest that this may be demonstrated through attentiveness to participants during data collection and taking care over the analysis. Throughout the study I have read extensively on the IPA methodology and have familiarized myself with the data analysis procedures. By rigour, Yardley (2000) refers to thorough data collection and the depth and breadth of analysis. Whilst the rigour of this study will have been affected by my status as a novice qualitative researcher, and also practical

constraints in terms of time and the available sample, I tried my best to carry out the study in a thorough and careful way by drawing on close supervision. I have also carefully documented my data analysis procedures, which I believe demonstrate a systematic and rigorous engagement with the data.

Smith et al. (2009) state that transparency refers to how clearly the stages of the research process are described in the write-up, and that there should be coherence between the research that has been carried out and the underlying theoretical assumptions of the approach being utilised. I have endeavored to enhance the transparency of the analysis by using quotes of the data that I have conducted in the study and have attempted to write up the stages by clearly explaining the stages. Yardley (2000) also includes consideration of reflexivity within the principle of transparency, and I have included a section on reflexivity in the next section.

The final principle of impact and importance reflects that however well or sensitively a research project is conducted, the most decisive way it may be evaluated is in whether or not it tells the reader something interesting and useful (Yardley, 2000). To establish this, the researcher has included the clinical relevance of this study in the Introduction (see 1.2) as well as the Discussion (see 5.2) sections of this thesis.

3.10 Reflexivity

Reflexivity may be defined as both a central component of being human (i.e., the capacity to position the self) and as the ability to reflect on and consider intersubjective dynamics between researcher and data (Finlay & Gough, 2003; Hutchinson & Wilson, 1994); Merrick, 1999; Nicolson, 2003). Owning one's perspective, as reflexivity is described by Elliot, Fisher and Rennie (1999), helps the reader evaluate the researcher's perspective and interpretation of the

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data. Willig (2001) suggests therefore that findings invoke a sense of discovery rather than construction, although Smith and Osborn (2008) argue that IPA is an approach rather than a rigid method, allowing flexibility to meet the researcher's need and context. In order to clarify my perspective, I have made a statement of my own beliefs and assumptions in relation to the study below:

I am 25-year-old Intern Clinical Psychologist currently based at Fort England Psychiatric hospital in Grahamstown. I was born and bred in a town called Komga, a small town in the Eastern Cape, quite similar to Grahamstown where the current study is being conducted, in that it is small and it has a large community of individuals from a lower socio-economic status. I have three siblings and my parents. I am a novice researcher and I do not have a lot of experience of the mental health system. I have a personal interest in the research that I am conducting. In 2014 my brother fell ill, he became disorientated and was not eating and was admitted to hospital. After he was discharged from the general hospital he was referred to Cecelia Makiwane Psychiatric hospital for pharmacological treatment as he had behavioural problems such as aggression, did not have an appetite, was unresponsive and had insomnia. He was placed on various treatments such as anti-anxiety medication, anti-depressants and risperidone. He was given this treatment without our consent, he was 15 years of age, or even an extensive rationale. My family and I experienced the process as quite discouraging as the mental health professionals did not know what triggered my brother's symptoms and I did not find them supportive. The consultations were always just with my parents and we as siblings were not involved, although we were also affected by the situation. The ways in which I have been personally affected by this have included feeling guilty for not being there for my brother. In addition, I had to assist financially for the expenses as we also sought assistance privately for medical services as well as

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psychological. The entire experience saddened and tormented me as my brother changed dramatically - his personality changed and it felt as if he was a stranger. I felt under a lot of strain on me and I often felt hopeless. I mostly had negative experiences as a result of my brother's mental illness and I have been very aware of this during conducting the research as well as my frustration with the mental health system. Therefore, it was not always easy to pose my questions about the mental health system in a good light, I was well aware of this and was very conscious about the manner in which I asked the questions. I have kept a reflexive journal to ensure that I am reflexive about my biases towards the data and to be aware of my interview questioning. I therefore approached this study with openness to multiple constructions, although it may be the case that my own experiences may have influenced how I approached the data, I did my best to reflect on my interpretations and to not overlook positive experiences.

3.11 Ethical Considerations

The current research received ethical approval from the Research Proposal and Ethical Review Committee of the Department of Psychology at Rhodes University (See Appendix F), and it was conducted under the research criteria of Rhodes University. Ethics refers to the moral principles that guide action and are derived from philosophical theories (Harper & Thompson, 2012). 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 in the study. In order for participants to give informed consent, the researcher gave the participants sufficient information about the nature and possible consequences of the research (Harper & Thompson, 2012).

I thus explained to the participants what the interviews entailed and what they could expect from them, as well as informing them about the use of a translator/transcriber. This took place in the

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form of individual information sessions where the participants were provided with a brief outline of the research endeavors, which included the aim and purpose. Furthermore, the importance of the study was provided as well as explaining to them that consent is voluntary and that they can discontinue at any stage of the research, while also raising the awareness of participants that it would not be impossible to withdraw after publication (See Appendix G for the information sheet). The information session was provided in isiXhosa and the informed consent was provided in isiXhosa to make it more accessible to participants. The IsiXhosa and English version of the informed consent are included as Appendix H.

Confidentiality and privacy were also considered: privacy relates to areas of life one wishes to keep private and confidentiality relates to the protection of private information that one has chosen to share for a specified reason (Harper & Thompson, 2012). Confidentiality was ensured by keeping the data in a safe place and by password protecting the transcripts. The translator was asked to sign a confidentiality form (See Appendix I) and deleted the data from her possession once translation was completed. Anonymity refers to the participants being anonymous and that the responses were not being linked to their identities. Therefore, I used pseudonyms to protect the participants' identity and disguised any clearly identifying details. The interviews were recorded by using an audiotape, the participants signed a permission of release form before the interviews were recorded see Appendix J.

The ethical consideration of avoiding harm was also considered. I made it explicit that the participants did not have to talk about things, which might evoke sad emotions. Debriefing was provided by the researcher to participants who felt that they needed to debrief. The ethical consideration of deception was also considered. Harper and Thompson (2012) postulates that power and politics is also another ethical consideration that should be explored, researchers

taking a feminist position have long advocated that researchers engage in some degree of reciprocity to reduce power imbalances and also to build rapport. Therefore, it was important to explore the power balances between the researcher and the participants. I endeavored to explore the latter during the interviews by making it explicit that there were no wrong or right answers to the interview questions. There were power imbalances such as the participants perceiving me as an expert as well as seemingly feeling obligated to attend the interviews after signing the informed consent forms, even though I clearly explained that the research was voluntary.

3.12 Conclusion

In conclusion, the current study utilised an IPA method of inquiry as it is consistent with the research question framing the study which is how individuals experience having a sibling with a mental illness. The IPA method consists of three theoretical underpinnings namely phenomenology, idiography and hermeneutics. In this chapter, I have endeavored to clearly set out all the methodological procedures that were followed in line with IPA requirements including the sampling, recruitment, data collection and data analysis procedures.

4. Chapter 4: Findings

4.1 Introduction

This chapter will describe the findings of the study which was derived from the Interpretative Phenomenological Analysis (IPA) of the five semi-structured interviews focusing on the question: how do individuals experience their sibling relationship with an adult sibling who has been diagnosed with a mental illness. The master themes and subordinate themes have been tabulated (see Table 2 in the previous chapter) and what follows is a description and interpretation of the themes. Verbatim extracts from the semi-structured interviews will be referred to throughout.

4.2 Description and Interpretation of the main themes

4.2.1 Experiencing the sibling as a burden post diagnosis. This master theme aims to capture how participants experience exceptional difficulties after the diagnosis of their adult sibling who has a diagnosed mental illness. The master theme consists of three subordinate themes, which includes financial burden, stigma that is linked to emotional burden and confusion and conflict with respect to a treatment approach, as well as experiencing a strenuous relationship post diagnosis of their sibling.

4.2.1.1 Experiencing financial strain post diagnosis of their sibling.

A common and dominant experience amongst participants was the experience of financial strain post-diagnosis of their sibling with a mental illness. The extract below is from the interview with Nomsa. Nomsa is a 31-year-old woman, who is unemployed and has a 5-year-old son. She is single and studies part time, but is contemplating dropping out of college due to her experience

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of financial strain. Nomsa resides with her elderly parents, she explained that her mother suffered from a stroke and she has to take care of her mother as well as her mentally ill brother.

Extract 1

Nomsa: At the moment, he's fine but our relationship is not that good. Because he(uhm) I don't, I really don't know how to say this but I have to say. Err since I'm this kind of person who is responsible for all of them when they got sick and stuff, so now he is, he's a grant payer yes. Then on his day, nobody is taking his grant or his card whatever. You will see him on the 1st or on the 31st or on the 20-something when the grant day is coming, he will start saying words like, you won't help me, saying to me, you won't help me, you will help your brothers warawara (blah blah). I won't get sick again, something like that. Whereas I did not say anything, I just keep quiet. My dad said, just keep quiet, leave him like that. After a few days when the money is out, hello my sister how are you and then I say hi I'm fine thanks 'ntonintoni' and stop there. (Line 332- 339)

In extract 1 Nomsa describes some of the challenges within her relationship with her brother, challenges linked to financial resources. Firstly, she experiences frustration about having to be the responsible child within her family. Nomsa describes feeling angry with her brother for not assisting with finances, as he receives a grant due to his mental illness. Nomsa feels that it is unfair that she is financially responsible for her brother, yet he does not provide his grant money to assist at home, becoming very elusive when the time draws closer to the date for his grant. Nomsa is conflicted as to how she should act upon her feelings because her father says that she should keep quiet; therefore, to keep the peace she avoids expressing her true feelings. It is possible that her silence is also a function of her gendered position within a fairly traditional family. It seems significant that her brother's mental illness affords him financial resources within an impoverished family, resources that cause conflict in the sibling relationships when they are not used for the communal good.

Extract 2 below is from the interview with Phumla who is 49 years old. She is younger than her sister. Similar to Nomsa, Phumla is formally unemployed but her source of income is providing

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her dressmaking expertise to the community. Phumla has a daughter who is 12 years old and is currently in primary school. With the income from her part time dressmaking, Phumla has to support herself, her daughter and her sister. She also has a responsibility towards her elderly father.

Extract 2

*Nomsa: P: The good things /laughs/ I don't think there is a good thing. always me, always me. I even ask myself sometimes, why God me, always, always, it also disturbs me. It's a lot.... I just wanna feel free and relax maybe two to three months. And I also decided to leave the school, oh maansh*t, everything is on me, do you feel that... Yho it's a burden. (Line 450-455)*

Nomsa in the extract above is responding to the question as to whether there are any positive experiences about having a sibling with a mental illness. Nomsa laughs as if she was asked a very silly question suggesting that she experiences nothing good about having a sibling with a mental illness. She alludes to feeling very alone in taking sole responsibility for her sister: “*everything is on me*”. She describes wanting to be free, suggesting that she is experiencing feelings of suffocation from all the responsibility which is likely to be due to her having to take sole financial responsibility for the family. Furthermore, it seems very significant that she decided to leave school and that she links this to the experience of having a sibling with a mental illness.

Extract 3

Phumla:(sigh) I was very worried because she was very helpful at home, she used to buy furniture, buy clothes even for me you see. Because my mother didn't get paid much, she worked for a student so she didn't earn a lot, so she was very helpful at home. You know though that fathers, my father was working but you know ootata (fathers), they are stubborn, they don't want to spend the money. So she was a breadwinner, I can say that. So I felt very sad, very sad because I knew that I would struggle this much (Line 35-52)

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Phumla firstly described her initial feelings as being worried, post diagnosis of her sister. She sighs before she answers the question emphasising the extent of her difficulty. She describes being worried because her sister was the breadwinner. She furthermore expresses concerned because her sister was not only assisting the family financially, but she also received personal benefits such as clothes from her sister. Significantly, Phumla describes her father as not wanting to spend his money, suggesting that there is a significant gendered aspect to these experiences, which was significant in the first extract. Phumla further describes how she became very despondent regarding her sister's diagnosis, as she did not know that she will "*struggle this much*".

In summary, it can be concluded that the participants experience significant financial strain which they relate to having a sibling with a mental illness. The participants describe feeling overwhelmed by the sense of financial responsibility that they are required to fulfill in the 'gap' left by their sibling. This seems to be an experience despite the existence of a disability grant suggesting that the participants' socioeconomic status is such that the disability grant does not go very far. In addition, it seems that there are gendered dynamics at play such that women in particular carry the financial burden of looking after family members.

4.2.1.2 Experiencing stigma as a result of their mentally ill sibling.

This subordinate theme focuses on how participants experienced their mentally ill sibling as an emotional burden due largely to stigmatisation by the community. The participants described experiencing many negative emotions related to their sibling being mentally ill and the associated stigma, particularly embarrassment, shame and fear.

Extract 4

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Nomsa: Yho it was very, I was feeling so like, I was not like myself because he sometimes embarrassing you, us as a family and then you feel those, and others were laughing., it was like he is doing it for fun. Sometimes he would go outside naked, you know those things. And then we have to, I have to myself, because I was the one, at least not that he listens to me but I was trying to manage. (Line 54-61)

The word 'Yho' utilised by Nomsa emphasises how dire it is too experience having a sibling with a mental illness or how dreadful she feels regarding the experience. Nomsa describes experiencing embarrassment as a result of when her brother was mentally ill. Nomsa describes how this embarrassment stemmed from the laughter/ridicule of the community members highlighting the stigma of mental illness. Nomsa further describes how she tries to manage and cope with his behaviour, emphasising that the responsibility fell to her. The use of "try" emphasises her brother's non-co-operation and also alludes to her not coping well. At this point Nomsa almost broke out in tears and became very emotional, which can emphasise how the experience of having a sibling with a mental illness is very emotionally draining for her.

The next extract paints a similar picture of emotional strain due largely to stigmatisation of the mentally ill sibling by peers. The extract comes from the interview with Andile whose brother was diagnosed with Schizophrenia. Andile is 22 years old and he is a Matric learner. Andile dropped out of school due to financial constraints at home, but he eventually returned to school.

Extract 5

Andile: Mhh for me I will say, having a brother with a mental disease, you face many difficulties. Because while I was growing up I didn't understand, so the other kids were teasing him at the small age. So it wasn't good at that time, it was bad because all the time when we see him, they would start singing songs that are based on him. I'm also part of the group. But to me it's not good and they know that it will be painful to me but they will keep on doing it. (Line 510-516)

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It is interesting how, in Extract 5, Andile refers to his brother's illness as a mental disease, which suggests that he sees his sibling's diagnosis as an ailment and as harmful, possibly even contagious? Andile describes emotional factors such as feeling pain when his friends used to tease his brother about his mental illness. The extract suggests that this was particularly hard because Andile was also part of the group, that is, he wanted to fit in and be accepted by his peers and yet he was associated with his brother's mental illness which was ridiculed.

The next extract deals with a similar theme of shame and embarrassment related to the sibling's mental illness. The extract comes from an interview with Phiwo, a 23-year-old student. She lives with her parents. Her brother is in fact her biological cousin. Her father is a priest and their household is very spiritual.

Extract 6

Phiwo: Mhh (yes) and especially because my father is a priest, so it's like, in my family, nothing embarrassing has happened before. So now we are so scared that he's gonna be the one who's gonna blow us off, he's gonna be the one who's gonna embarrass my father, he's gonna be the one who's gonna, people are gonna say, oh that Quza child is mad. So we are very scared and we are trying by all means to make sure that he doesn't do that. But he does if he wants to. (Line 395-403)

In the extract above Phiwo describes the fear of experiencing embarrassment, of being exposed as having a 'mad' sibling. Phiwo feels this way because her father's role as a priest was felt by Phiwo to give their family a special status. This led to a heightening of the sense of fear or embarrassment that they or he would be discovered as having a relative with a mental illness.

Some of the participants described how they coped with the stigmatisation of their sibling. For example, in the extract below Andile responds to the question regarding the teasing from the community:

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Extract 7

Andile: It makes me feel angry because it's my brother they are talking about, so I won't be ok because I know him better than they do. But I won't say anything I'll just keep quiet. (Line 284-286)

He describes getting angry when community members tease and make fun of his brother. He further describes feeling defensive and states that he knows his brother better than the community members and that is why he does not feel “okay” when they stigmatise him. Nevertheless, Andile states that he will remain silent about his feelings, as he perhaps feels that if he does speak out he may also be ostracised.

Similarly, Lutho describes in extract 8 how she responds to stigmatisation:

Extract 8

Lutho: Most of them were supportive, most of them but others they didn't understand what was going on. They did some them would say ja he's mad ntonintoni (and so on). Oh, sometimes I would get angry but sometimes I would just not listen (124-130)

In the above extract, Lutho responds to stigmatisation in two different ways. It is incredibly interesting that Lutho describes the community members as not understanding. Therefore, for this participant, the stigmatism from the community is rooted in their ignorance. Andile shares this sentiment as he also explained that community members do not understand his brother or his behaviour due to his mental illness. Furthermore, Lutho also describes feeling very angry about the stigmatism, she however, does not listen to the individuals, ignoring them is a form of coping with the stigma. In summary, the participants experience worry, embarrassment and fear due to the stigma of having a sibling with a mental illness.

4.2.1.3 Experiencing confusion and conflict with respect to a treatment approach:

Taking the traditional, religious or medical path. This subordinate theme describes the participant's cultural beliefs as well as their spiritual beliefs and how these informed their experiences of having a sibling with a mental illness. Most participants described that own individual experiences of their culture as significant in their experience of their sibling's mental illness. Only one participant, Nomsa did not mention any traditional or cultural beliefs when talking about her experiences of having a sibling with a mental illness.

Extract 9

Phumla: They're very happy now because they were my relatives, they were just advising me. This woman is supposed to be a sangoma (traditional healer), they were saying to me, this woman is supposed to be a sangoma. I said to them, no my mother tried all of these things but they never helped, so I'll do.... (Line: 448-453)

Phumla in the extract above describes how her relatives and community members would always advise her to take her sister to a traditional healer, as they believed that her sister had the calling to become a sangoma. Phumla felt and still feels differently, she stated that her mother did seek help before she passed away, the traditional way. She describes a non-belief: “*they never helped*”.

Extract 10

Phumla: Mh-h (no) it was the time when my mother was alive. That's why I told them, my mother sent her to the sangoma and that never helped, so I'm going to do things on my own and I just started praying and nothing else. Not really but I do believe, it's because she went there before that's why it was not easy for me to take her back you see. It's not that, and what I see with those sangomathey don't know, they don't go anywhere, they don't help anyone you see. That's why I end up saying my sister is not going there because I don't see any help there you see. (Line 457- 470) I see God worked there because I'm telling you I never took her to the witchdoctors, I just pray and she ended up stopping that thukisa (swearing) and going all over, uhlalaendlini (she stays indoors) as I said that, even at home alone. (Line 187-189)

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Phumla describes deciding to do things her own way by praying and nothing else, because she believed that the traditional healers were not helpful. Phumla drew on her Christian belief rejecting cultural traditions in seeking assistance for her sister.

It can be concluded by Phumla's extract that she believes that it is her prayers alone that has assisted her sister's behaviour to subside as she stated: "*I just prayed and she stopped swearing*". She does not mention the medication as assisting with her sister's symptoms subsiding suggesting a primary understanding of mental illness as a religious or spiritual illness.

In extract 11 below, Lutho (a 22-year-old student) describes a similar experience of traditional methods of healing not being helpful in treating her uncle's schizophrenia (even though he was biological her uncle, Lutho experienced their relationship as one of siblings).

Extract 11

Lutho: mother said to my father maybe he needed something maybe like a traditional ceremony in order for him to ok again. But they made that ceremony but still there was no difference. Family members said that we should take him to the sangoma and we said that we did that and it didn't help, it's just a waste of money cause said he's sick so he's under treatment Yho, my belief? Yes, I do believe in those traditional things because we wanted my uncle to get healed but it didn't help. They said we must slaughter a goat in order for him to be ok, but that didn't help. (Line 41-43)

Lutho describes how her mother suggested a traditional healer, and they conducted a traditional ceremony but it did not help. She sees it as a waste of money, because it does not help. Even though Lutho perceives the traditional ceremonies as unhelpful, she describes reluctance in giving up her traditional cultural traditions. Similarly, Phiwo, in the extract below, describes negotiating an appropriate treatment path for her sibling with the community or family valuing a traditional approach.

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Extract 12

Phiwo: People said that if ever a person puts in those things, they might end up getting mad. So some are saying that no he is mad, the doctor is saying it's bipolar. So we really do not know which is which but mna (I) believe that it's bipolar because when he's eating his treatment he's fine you know. So that divided the family because of that (Line 629-630)

In the above extract, Phiwo describes how some of her family members told them that if a person has spirits inserted (which is what her brother did, he went to a traditional healer and they placed spirits in him to protect him) then those “things” can make her brother “mad”. Here Phiwo seems to be saying that it was possibly the traditional approach that was the cause of his ‘madness’ in this case. The extract suggests that Phiwo and her immediate family are confused as to the etiology of her brother’s mental illness, as the doctor says that her brother has Bipolar Mood disorder and her other family members believe it is a traditional or ancestral problem. However, she believes that it is bipolar, because if her brother drinks his medication, the symptoms subside. However, this belief and getting help from the doctor has divided their family, because some have the belief that he has to seek help from the traditional healer and Phiwo and her family believe otherwise, although they continue to feel confused: “*so we really don't know which is which*”. (Line 630)

In summary this subsection describes how participants continue to rely on spiritual and cultural treatment methods although they frequently describe them as unhelpful they are often confused as to which approach (medical or cultural) to follow which in some cases resulted in conflict in the family.

4.2.1.4 Experiencing a strenuous relationship after the diagnosis of their sibling. The above subordinate theme focuses on what sense the participants make of their experience of a difficult and strenuous sibling relationship post-diagnosis. Nomsa and Andile describe

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challenges in their sibling relationships because of certain behaviours their siblings' exhibit related to their mental illness.

Extract 13

Nomsa: At the moment, he's fine, but our relationship is not that good. (Line 324-325)

Nomsa in the extract above experiences a difficult relationship as she states that her relationship with her brother is not good. This was highlighted in extract 1 that their relationship has become strenuous due to her brother not contributing financially to the family with his disability grant and yet expecting them to support him.

Extract 14

Andile: It will always be him that will come and talk to me and apologise. Because he does these things and laughs and say that you know man I am mentally ill man, don't be like that. Mhh he simply just makes it a joke, he's like that (Line 497-500) Err it's not good, it's bad feeling even though to him it's a joke, because he likes to joke about it. I will laugh but it's not great, it's really not great (Line 502-504)

In the above extract, Andile describes a challenge within his relationship due to his brother behaving badly and being mean. Andile is furthermore describing above his brother's tendency to use his mental illness as an excuse for behaving badly or being mean. He experiences a bad feeling about his brother who is teasing him and being mean towards him. Andile describes laughing with his brother even though in reality he feels sad about his brother's behaviour.

Some participants described a change for the worse in their relationship with their sibling but through no conscious intention from their side. For example, Lutho describes experiencing a strong emotional bond with her brother but she talks about his withdrawal from the relationship.

Extract 15

Lutho: Ja I was a sibling because he came to live with us, I wasn't born yet I think, so he was like a brother Line (52-53) We were close; we had a close relationship then: To me it didn't change, uhm to him it changed because he would push us away (Line 178-179)

Lutho described how her relationship with her brother did not change from her side but rather that she felt that her brother was pushing them away.

To summarise, this master theme focused on negative experiences with respect to the siblings' mental illness. The participants described how they experience financial burden, stigmatisation and, confusion with respect to their cultural/spiritual beliefs due to having a sibling with a mental illness and a deterioration in the quality of the sibling relationship.

4.2.2 Positive Experiences from the sibling's mental illness. This master theme aims to capture the positive aspects of the participants' experiences from their sibling relationship with an adult sibling who has a diagnosed mental illness. The master theme consists of three subordinate themes. The findings, in light of the themes above, seem to be pointing to two possibly contradictory but simultaneous experiences, which is the relationship got emotionally stronger and became more strenuous. The participants further experienced a knowledge gain, from having a sibling with a mental illness. These subordinate themes will be discussed below:

4.2.2.1 Experiencing a stronger bond within the sibling relationship. This subordinate theme focuses on how the participants perceive the sibling relationship after the diagnosis of their sibling, how they describe the bond between them. Many of the participants commented on the stronger relationship that they are experiencing with their mentally ill sibling post-diagnosis

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Extract 16

Andile: Uhm, I would say, if he wasn't ill, we should have been closer than we are now or we shouldn't be closer because sometimes I'm just being with him just to make him feel ok. Especially when I see that he is not in a good mood or good position, I like to just chill with him and take my guitar and play my guitar, I know he like listening to music. And play my guitar. So I would say his illness brought me close to him because as my brother, I always want to be better. (Line 214-217)

Andile in the above extract is displaying conflictual feelings about whether he and his brother have a stronger bond post-diagnosis. He further stated that he at times would just spend time with his brother, because he wanted his brother to feel better. Furthermore, Andile describes how he plays music for his brother as a form of assisting his brother with his mood to alter. He describes how this shared time together has brought them closer as brothers. Phumla, too, in the following extract describes a strong bond with her sister:

Extract 17

Phumla: I thought I would be lonely, but now she is here, she takes my mom's place in my heart. I love her too much. P: Isethe same ngokuaye right (it's still as the same as when she was still well) because she was my best sister. I've got other two sisters but she was the best even before agule(she got sick) and even now you see, we were best friends. We would go to church together and do things together you see (Line 330-350)

Phumla describes no significant changes within her sibling relationship post-diagnosis. Phumla is younger than her sister is, however she has to take care of her older sister because their mother passed away. Phumla further describes how she and her sister are best friends, this can be viewed as the construction of the sibling relationship as a friendship. She further narrates how they share a faith together and do things together which has brought them closer as siblings. Finally, Phumla talks about a sense that sisters can replace parents who die as she states “*she takes my*

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mother's place in my heart". Similarly, in the extract below, Phiwo talks about her relationship with her sibling as not being negatively affected by her brother's mental illness.

Extract 18

Phiwo: No it wasn't affected, maybe if ever I was shouting at him and I was saying Zola do this, maybe it would have changed. But, even the things that he says about me sometimes I just choose to ignore him because I just myself no, because he's got bipolar so I just understand. So it hasn't affected our relationship, I wouldn't say so. (Line 234-239). Became stronger and he's, sometimes he does want to talk but sometimes I just, I don't give him that attention. But I noticed that he's very comfortable talking to me (Line 413-415)

In the extract, she describes experiencing a better understanding between herself and her brother. She describes her brother as feeling comfortable talking to her. At times their good relationship is facilitated by her understanding of his bipolar diagnosis so that she does not always take to heart the bad things he says about her but rather understands this behaviour as being part of his illness.

This section of the findings shows that even though the participants experienced their sibling relationships as stressful and strained as a result of their sibling's mental illness, some participants also described developing a closer relationship because of the mental illness or maintaining a close bond that existed prior to diagnosis.

4.2.2.2 Experiencing happiness and humour post-diagnosis. This subordinate theme focuses on how participants experienced having a sibling with a mental illness as providing them happiness and joy through humour. Both Andile and Lutho experienced their siblings as contributing positively to their lives.

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Extract 19

Andile: Err it's his jokes and I think he has time for people and he likes to keep whatever he has. What I mostly like about him uhm he's someone that he likes to sit in a place where everybody is happy, no one should be quiet (Line 181-191)

In the above extract, Andile describes the positive aspects of having a brother with a diagnosis of a mental illness. He describes his brother's sense of humour, care and interest in others as qualities in his brother that he values. In the extract, below Lutho also experiences her brother's jokes as a positive aspect of having a sibling with a mental illness.

Extract 20

Lutho: (laughs) It's his jokes and when he would see things and we would laugh at him, because we would laugh at him and he would laugh too sometimes (Line 211-216)

In this extract, however, we can read that Lutho laughs when her brother experiences hallucinations. The laughter and humour could also be a defense against her true emotions towards his symptomology, as she and her family would laugh at him when he experiences hallucinations. This experience is in stark contrast with Andile's experience. Andile described how his brother causes them to laugh, by making jokes, whereas Lutho describes how they laugh at her brother's symptoms.

4.2.2.3 The Experience of having a sibling with a mental illness as helpful. An additional theme, which emerged from the analysis, within this main theme, was that participants experience having a sibling with a mental illness as helpful. The helpfulness of their siblings is perceived as something positive by the participants because it is offering help, which their sibling can physically do, and it is tangible.

Extract 21

Phumla: My sister, it's nice to have her because she is the one who is always at home with my kid and she is also very helpful in the house in general, they like playing school. My kid will be a teacher and then sometimes she is a teacher, they teach each other and mark each other's work and my kid shows me. So that's very helpful for my child. She also helps me a lot with the house because she can do chores (Line 303-309)

Phumla describes in the extract above how she enjoys having her sister at home. She is very helpful and she teaches her child and babysits. Phumla perceives her sister as very useful to have around because she can assist with her child's growth and learning. She further experiences her sister as helpful as she helps "a lot" with house chores. In this extract, it is very clear that Phumla's sister is experienced as having a meaningful contribution to make in the family setting, despite her mental illness. Lutho also describes having a sibling with a mental illness as helpful.

Extract 22

Lutho: And well he would help us sometimes with the yard, so he was helpful at times and he would stay with us when my mother is at work and my father is at work, then he would babysit us. (Line 213-216)

She also experiences her brother as helpful, because he used to babysit her and her other siblings. He also assisted with home chores such as gardening.

4.2.2.4 Gaining knowledge from the experience of having a sibling with a mental illness.

This subordinate theme focuses on what the participants have gained from the experience of having a sibling with a mental illness. The most common theme that emerged from the analysis was the participants' experience of having gained knowledge about how to treat other individuals who have a mental illness. The participants describe having learned that individuals with a mental illness are humans as well and should be treated fairly with dignity and respect. Andile describes above how his relationship with his sibling with a mental illness has brought him closer to others who have a mental illness:

Extract 23

Andile: makes me closer to other people who have this illness because almost all of his friends, they are like my friends now. Because even in the streets I holler at them now, hey brother, hello and I stand and I chat and then I go. So it makes me closer to them (Line 258-259)

In the above extract, Andile states that he has become friends with his sibling's friends; he speaks to them even when his brother is not present, and therefore this makes him closer to them. Phumla also experienced having gained understanding regarding other individuals with a mental illness through having a sibling with a mental illness:

Extract 24

Phumla: It has helped me a lot because I now understand a person who has the same condition, it really has helped living with her as well, now I'm not scared if I see someone like her. I also know now what I should do, I understand that she is also a human being and you shouldn't shout when talking to her as though you're talking to a mad person, you must address her as a normal human being. Otherwise they really don't like that, they have a mental capacity like that of a baby, so when talking to her, you must be considerate (Line 243-252)

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Phumla further describes that her growing knowledge of mental illness has assisted her in living with her sister. In addition, she says that she is no longer afraid if she is confronted with someone who has a mental illness. She has also learnt or gained knowledge about how she has to treat and communicate with someone who has a mental illness, “*you should not shout at them and address them as normal human beings*”. Phumla further describes those individuals with a “*mental illness has the mental capacity of a baby*” this suggests that there is still stigmatisation and a lack of understanding of mental illness even while she is proclaiming an understanding.

Extract 25

Lutho: (sigh) best part, the best part was having the experience was seeing someone who is mentally ill because we never had anyone mentally ill except for him. So I think having a person like that in the house, so I think, ja nothing else (Line 254-257) Because uhm, when somebody is sick, maybe our neighbours like my brother, we would not see mad we would know that no he is ill, instead of laughing at the person and making negative remarks, we would understand that the person is sick. (Line 254-257)

Lutho sighs before answering the question, which may indicate that there is a hesitation or difficulty to answer the question, whether there are any positives about having a sibling with a mental illness. For Lutho she experiences the entire experience of having a sibling with a mental illness as positive as this has gained her knowledge on how to deal with neighbours and others in the community who are mentally ill with understanding. The experience further assisted her not to stigmatise others, as she is now aware of mental illness. Phiwo’s experience is quite different in content to Andile, Lutho and Phumla’s experience:

Extract 26

Phiwo: I have gained that Zola has, like I’ve gained from the things that he was speaking about, I have gained the reason why he is angry. I’ve noticed that he is angry at his father, he is angry at the fact that his brother has been cared for in his family and yena

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(he) he is not being cared for in his father's family. And he is also angry at the fact that his father is poor. (Line 357-362)

The above extract suggests that Phiwo attempts to make sense of the reasons for her sibling's mental illness. She places the etiology within the parental, specifically, father-son relationship and she suggests that poverty can be the cause of mental illness.

Nomsa is a negative case analysis, as she had no positive experiences of having a sibling with a mental illness. In the extract below, she laughs at the question she was asked about whether there are any positives of having a sibling with a mental illness. In extract 4, Nomsa already alludes to how much responsibility she feels she has had to take on as a result of her sibling's mental illness. In the below extract Nomsa stated that her brother was not born ill. This could allude to her feelings that he caused his own illness, as he abused substances. She further reveals her feelings of frustration about how she was a caregiver to her parents and her brother. She is unable to do her own things; feeling very confined to what she can do with her personal life. She has to take responsibility for everyone in her family and explained that she at times become '*nervous*'. By nervous I think Nomsa meant that she becomes anxious and worried as her responsibility became overbearing. She further expresses how this also affects her wellbeing as it also disturbs her. Therefore, Nomsa does not experience any positive aspects of having a sibling with a mental illness.

Extract 27

Nomsa P: The good things /laughs/ I don't think there is a good thing. You know he wasn't born like that, it makes me, because we are staying with the, our parents are old, they are all pensioners. My father was born in 1933, my mother was born in 1942 and I became the mother to him now you know. So I can't do my own things you know, I was young and I have to take care of him you know. My mother was attacked by a stroke, sometimes I feel nervous even now can you see. I can say I was a headed child you know,

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because since my mother was sick I was 18 years you know, I took from there. And there was the other brother of mine who died in 2012 at the same time you know. 2012 was the year that my brother, the other brother got sick you know and the cousins you know, always me, always me. I even ask myself sometimes, why God me, always, always, it also disturbs me. (Line 613-619)

It can be concluded that while participants described many negative emotions and experiences related to their sibling's mental illness, they also spoke about positive experiences. Many participants experienced joy and humour as a result of having their sibling in their lives. They further experienced their sibling as very helpful with regards to assisting with house chores as well as gaining knowledge about mental illness as well as how to treat others with mental illness. There was a sense that participants had grown and developed a new understanding of psychological disorders though at times there was still confusion and distress. The participants also commented on how they experienced the mental health system and this is the final section discussed below.

4.2.3 Participants experience of their sibling's treatment and the mental health care system. This main theme focuses on how the participants described their experience of the mental health care system as well as the treatment that their siblings received. Participants described a positive experience with regards to the services of the hospital. There was variation in participants' sense of feeling included by the mental health system regarding information on their sibling's diagnosis and their treatment. This led to a dominant feeling amongst the participants of not knowing, in other words they felt unable to understand the treatment process or the side effects of the treatment.

4.2.3.1 Positive experience of the mental health system. This subordinate theme focuses on how the participants experience the psychiatric hospital services. Three of the participants described experiencing exceptional support from the psychiatric hospital. Phumla

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experienced the doctors as very nice and friendly. Lutho experienced the in treatment facility as especially helpful. Lutho also spoke about how the hospital provided information to her parents.

I have chosen select extracts below to illustrate these findings.

Extract 28

Nomsa: The support, yho very, they were doing a very very good role, I don't know how to thank them because since then, it was only 2 or 3 times that he got sick. Since he is on treatment, I can say two times or three times. (Line 621-623)

Nomsa experiences the mental health care professionals as particularly helpful, as she expressed herself in the extract above with great enthusiasm and this was the only time that her face lit up with hopefulness. The hopefulness is due to Nomsa's experience of the treatment working which has changed the course of her brother's illness.

Extract 29

Phumla: they are fine because when I used to accompany her), oo- (the) sister no- (and) doctor they were very nice (Line 412- 413)

Phumla also experienced the mental health practitioners as very helpful and friendly. It is very interesting that Phumla accompanied her sister to the hospital, as this confirms the significance of sibling relationships.

Extract 30

Lutho: Oh it helped because now he would take his treatment regularly, regularly he would take his treatment because he didn't like Fort England. (Line 395- 398)) Ja they did explain to my parents and they explained it to us, that he would see things, hallucinate and hear voices. Ja so we would understand, but he would take his treatment and he would calm down a bit. (Line 345-351)

Lutho also experienced the hospital as helpful as she was very pleased as her brother became compliant. She further reported that her brother did not like Fort England, which in fact

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promoted his compliance to medication. Importantly, Lutho talks about how the illness was explained to the family by the mental health team.

4.2.3.2 Not knowing. While some participants were very positive about the mental health care system and felt that the illness and treatment processes were explained to them, others describe not knowing about the treatment and the side effects of the treatment. The participants therefore described a variety of experiences. Some felt that they were kept informed of the treatment process and others did not. It is interesting to comment on the differences between these two experiences. The effect of being uninformed was that the participants did not know what the side effects of the medication were and they were uncomfortable talking about their sibling's mental illness. The effect of feeling informed was that the participants described being more comfortable talking to their sibling about his mental illness, especially Phiwo and she was informed that he has to take his treatment without using substances.

Extract 31

Nomsa: Nope, I did go maybe twice or three times a day, I mean a week but nothing they told us about the treatment (Line 624)

Nomsa was involved in the treatment process; however, the treatment was never explained to her. Nomsa was also unable to name the treatment that her brother was placed on.

Extract 38

Phumla: maybe they told my mom, but by the time I took her, she was already in Fort Englandoh no I don't know but it's an injection and some tablets, I meant to bring the tablets with (Line 161-162)

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Phumla also experienced a sense of not knowing, she was unaware about the medication and she could not say what her sister's diagnosis was. Although her mother was informed, she was not informed and she is the primary caregiver at the moment.

Extract 32

Lutho: Did you guys or your parents know what were the side effects of the treatment? 'I didn't know' (Line 353-369)

Lutho also expressed that she did not know about her brother's mental illness. She never went to the hospital to visit, because she mentioned that she was afraid of the hospital.

Extract 33

Phiwo: I wasn't there; I wasn't there because his doctor is in Uitenhage so I was only just told that these are his doctors. So I wasn't there (Line 558-560)

Phiwo also expressed that she was never involved in the treatment process. She was just informed who his doctors were. His doctor was from Uitenhage even though he was residing in Grahamstown. His medication was posted. Although she was never involved, Phiwo was however aware of her brother's illness as seen in extract 13.

Extract 34

No I really don't understand why. I also don't like him to talk about it because sometimes he likes to talk about but I would just go and I would just joke with his friends. It's just that I don't become comfortable when he is talking about it, I just become uncomfortable (Line 238-245)

Andile also experienced a stance of not knowing. He expressed that he did not understand his brother's illness. Andile experienced feeling uncomfortable to talk about his brother's mental illness, as seen in extract 34 above. This could be a form of coping, because he is unable to deal

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with the emotional pain caused by it. There is a contrast with Andile's experience concerning the other participants above, which was that the other participants wanted to know about their sibling's illness. It seems that Andile prefers not talking about his brother's mental illness due to the stigma experienced by Andile regarding his brother's mental illness.

Most of the participants described a positive experience of the mental health system. There was variation in participants' sense of feeling included by the mental health system regarding information on their sibling's diagnosis.

4.3 Conclusion

This chapter has reported on the findings of the study pertaining to the research question. The findings were that siblings experience a burden post-diagnosis of their sibling. The participants experienced a financial burden, which could be related to their socio economic status. The participants further experienced stigma due to the community's attitudes regarding their mentally ill sibling's behaviour. When the participants explained their feelings towards treatment approaches, they experienced confusion and conflict with respect to a treatment approaches, these were between taking the traditional, religious or medical path. The participants did describe positive aspects of having a sibling with a mental illness such as finding humour in hurtful situations, as well as finding their sibling very helpful with practical duties at home. However, the diagnosis of their mentally ill sibling has created a strenuous relationship between the siblings. Factors which were indicated as relating to the difficulty, were financial constraints as well as the stigma from the community. Although some of the participants could not explain their experience of the mental health system, as they were never involved in the treatment process, those who were involved experienced the hospital staff as very friendly and helpful.

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Even though the participants experienced the mental health system as helpful, they lacked knowledge regarding their sibling's mental illness. The next chapter will present a discussion of the main findings of the current research in relation to the literature reviewed.

5. Chapter 5: Discussion

5.1 Overview

Despite the large number of studies regarding the experiences of individuals with a mental illness. There is a dearth of information about the experiences of families, especially ‘black’ isiXhosa sibling’s experiences, within the Southern African context regarding how they experience having sibling with a mental illness. Being aware of the latter, it was hoped that an in-depth understanding of ‘black’ isiXhosa speaking sibling’s experiences of having a sibling with a mental illness would contribute to the existing knowledge within this area.

The master themes as well as the subordinate themes as discussed in the previous chapter will be discussed in relation to the existing literature as presented previously in chapter two. Therefore, this chapter will include a discussion about how the current research findings relate to, extend, replicate and contradict the literature.

5.2 Discussion of the main findings.

The participants’ experiences will be focused on by discussing the main findings of the research. The dominant themes, which developed from the analysis, were that participants experienced financial constraints. There was also an evident gender contrast in terms of caregiving burden, with many of the women participants describing a gendered aspect to the financial burden. The siblings further experienced the feelings of shame and embarrassment due to stigma. Even though the siblings are overburdened by the experience of having a sibling with a mental illness, they do have positive experiences of having a sibling with a mental illness. The latter is

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experienced through humour and laughter as well as the mentally ill sibling providing practical assistance to the siblings.

5.2.1 Financial burden. Grahamstown is known as a semi-rural area, and as alluded to in chapter 1, most of its residents are isiXhosa speaking and from a low socio-economic background. As stated in chapter 3 of the study the participants are 'black' isiXhosa speaking individuals. The main theme, which was derived from the narratives of the participants, is that the participants strongly felt a sense of financial burden even in the midst of the disability grant, which is provided by the government. The link between the financial burdens of having a sibling with a mental illness may be drawn to the context in which the participants from the current study are residing, with all the participants from a low to medium socio-economic background. Even though the participants are from a low-medium socio-economic background, the participants felt that it is compulsory to assist with caretaking, as this was socially required within their cultural context. Lefley (1998) observes the latter; he found that different cultural backgrounds address mental illness in different ways. In western societies, individuals provided care based on personal choice and responsibility, whereas mandatory responsibilities and reciprocal obligations to provide care existed in non- western countries.

Additionally, the theme of financial burden is consistent with studies reporting financial burden in South Africa. A study conducted in SA within a rural context by Mavundla *et al.*, (2009) showed that all of the caregivers focused on the hardships of caregiving and the negative aspects of mental illness. The participants expressed their difficulties with caring for their relatives' physical and emotional needs, and spoke at length about financial burdens. The finding is however slightly in contrast with the current research where the participants do express some positive aspects as will be discussed later.

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Literature regarding burden by Maurin and Boyd (1990) observed that siblings might experience subjective and objective burden. The objective burden refers to the negative effects of the illness on the household and caregiving demands. The subjective burden, meanwhile, refers to the caregiver's personal appraisal of the situation. It is evident from the findings that the latter is replicated within the current study as the participants' experience both subjective and objective burden. The objective burden is the financial burden, which the participants are experiencing, and the subjective burden is the frustration, which the participants displayed due to the caregiving burden.

The sense of financial burden may be viewed as an added stressor upon the participants, as the participants did not only take care of their siblings, but had numerous other responsibilities such as caring for their frail parents. Therefore, the diagnosis of their sibling was an added burden, particularly financially. From the sense of financial burden, a sense of frustration further surfaced due to taking responsibility of their sibling with a mental illness, which was mentioned earlier regarding subjective burden. The sense of frustration and financial burden influenced the quality of the sibling relationship, particularly in a negative way. This was evident when participants elaborated on how they experienced a strenuous relationship due to financial strain even in the presence of the disability grant. The below section will discuss the impact of mental illness on the sibling relationship.

5.2.2 The impact of their sibling's diagnosis on the sibling relationship. The sibling relationship is one of the most enduring relationships within a family. However, what occurs when the relationship is impacted by factors such as a sibling's mental illness? One of the profound findings of the current study was that the participants both felt closer to their sibling and at times felt that there was difficulty within their relationship due to the behaviour of their

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sibling, which was understood to be as a result of their mental illness. Participants experienced a stronger bond, in a sense that they shared mutual activities together as siblings after the diagnosis of their sibling with a mental illness. Literature also observed that siblings reported that their experience led to a stronger sibling bond as seen by Sin *et al.*, (2008). Therefore, this finding does relate to the existing knowledge base.

The findings further demonstrated that siblings within a non-western society do not always share the same parents, but can be a cousin or uncle, but due to relatives living in close proximity, they are viewed as brothers or sisters. The latter relates to international studies by Cicirelli (1995) who found that in non-western societies, siblings may be defined by extension of the term sibling to certain types of blood kin, or by classification on the basis of other criteria other than genealogical criteria alone (Cicirelli, 1995).

Sanders (2004) observed, that siblings often continue to support and care for one another over the lifespan and function as caretakers and helpers. This finding relates to the current research as the participants played the primary role of being a caregiver for their mentally ill sibling. The caregiving provided by the participants were not restricted to financial assistance, but to emotional caregiving as well, as the participants felt personally responsible for make their sibling feel better.

Rivalry between siblings is often assumed to be the most important aspect of sibling relationships within the literature. Therefore, even in the absence of a mental illness sibling relationships have difficulty due to sibling rivalry. In the current study, the participants expressed that their sibling relationship do become strenuous due to the behaviour associated with their sibling's mental illness. The strenuous relationship can be linked to the financial strain, which

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was discussed in the previous section (5.2.1). The reason is due to one of the participants having a difficult relationship with her brother because of his disability grant, she allows him to work with his own finances to establish independence however, and he does not assist her with buying the necessities at home. Therefore, it can be concluded that siblings do engage in rivalry however, this may be intensified due to factors such as one of the siblings having a mental illness.

5.2.3 Gendered roles. Literature has indicated that there are gender differences concerning care giving. Traditionally women are known to be the caretakers. Bedini and Phoenix (2004) reports that about 80 percent of people who provide informal caregiving are women. In the current study, it was found that the women within the study experienced frequently described gendered aspects to their roles suggesting that they experienced higher caregiving burden than the men in their families. Literature has proposed that female caregivers experience higher burden and distress due to lack of available social support. According to Wallsten (2000), women who care for the elderly are less likely to seek or receive support, because of the restrictions imposed on them by their caregiving roles. The latter was evident as the narratives from the women within the current study narratives pointed to gendered experiences related to caregiving.

5.2.4 Stigmatisation. There has been an extensive history of discriminatory behaviour being associated with mental illness. As proposed by Jones (2002) the very existence of the concept of mental illness can be understood in terms of stigmatisation. One of the definitive findings of this research is that participants described significant experiences regarding stigma. It is clear from the findings that stigma is still very prevalent and explicit within this South African community. The individuals who have a mental illness experience the stigma, but it further

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affects the entire family inclusive of siblings. The participants largely experienced emotional strain due to the stigma. The emotional strain included shame and embarrassment due to stigma by the community members. The shame and embarrassment can have a cultural component as cultural beliefs of mental illness are at times linked to 'spirits and witchcraft'. The study conducted by Monyaluoe et al. (2014) showed that families viewed their relative's mental illness as linked to spirituality and found that some families believed in superstition and witchcraft. The latter can then furthermore play into the stigma. The latter is interwoven with the current study's findings where participant's first sought traditional assistance because of their cultural beliefs regarding the casual factors of their sibling's mental illness. The findings also evidently show that the participants believe in traditional customs and that is their first preferable choice as discussed above, as the traditional explanatory models in SA are still prevalent. Therefore, the cultural context as well as the socio economic background of the family and the sibling is of utmost important as observed by Swartz (2008). In any attempt to understand mental health and issues of culture, it is pertinent to recognise the interwoven effects of poverty, displacement, inequality and migration on mental health.

The stigma associated with mental illness as found in the current study is due to community members lacking understanding of what mental illness is as well as the etiologies of a mental illness. The findings also show that the participants chose to ignore the community members. This could be because the participants themselves lacked information regarding their sibling's mental illness. This perpetuates the cycle of stigma, because if the participants were informed about their sibling's illness extensively, they would be able to fight against stigma and not blatantly ignore it.

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The participants further expressed anger towards this stigmatisation. While the participants experience stigma, this does not refrain them from seeking support and treatment at the hospital. This is in contrary to what Jones (2002) has observed that the stigma may restrict the families' willingness to seek help and support. Although the participants sought assistance from the hospital, many of them described seeking traditional treatment first. This can be linked to culture and the participants' cultural beliefs that may stigmatise the western form of seeking help. Therefore, it can be concluded that the participants do experience stigma, and they cope with the stigma by ignoring it and does not affect their support and help seeking

5.2.5 Positive Experiences. Despite the turmoil concerning financial strain and having a strenuous relationship, participants display resilience and do experience positive aspects of having a sibling with a mental illness. The findings from the current study suggest that participants found humour and happiness in the midst of all the caregiving burden and financial constraints - they laugh at the jokes, which their siblings make. The participants further expressed how helpful their sibling are at home, they regarded this as one of the positive aspects of having a sibling with a mental illness. This is good because it can be perceived that the participants do experience their siblings as normal human beings. This is related to the next positive aspect that is participants experienced. Treating individuals who have a mental illness with dignity and respect is one of the aspects that the participants have acquired from having a sibling with a mental illness. The participants further described how having a brother or sister with a mental illness has assisted them with gaining knowledge about how to handle or treat other individuals in the community who has a mental illness. The latter relates to the literature from Jewell (2002) who stated that siblings might feel more compassion and tolerance towards others who experience mental illness. This finding was particularly insightful for the current

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researcher, as written in the reflexivity section (3.10) I was aware not to project my own negative experiences upon the participants when asking about their experiences with having a sibling with a mental illness.

5.2.6 The mental health system. The mental health system has changed drastically as reviewed in chapter one from institutionalisation to deinstitutionalisation which occurred in the 1990's in order to prevent the inhumane treatment that mentally ill individuals used to endure in state institutions (Lamb & Bachrach, 2001). The findings of the current study suggest that the participants experienced the mental health services positively. However, some of the participants described not being involved in the hospital process. This relates to the literature as many siblings around the country, for example, have reported that they were not included in caregiving by the mental health system (Riebschlegar, 1991). This is important, as the siblings within this study are at times the sole caretaker of their sibling and therefore should be involved in order for them to get educated about their sibling's mental illness. Literature from Mavundla *et al.* (2009) stated that many families reported that they did not understand the causes of the illness of their relative, but that they wished to be educated, as they believed that this would provide them with better strategies for care giving. The latter relates to the current study as the participants showed the desire to be informed or educated about their sibling's mental illness. The participants of the current study displayed confusion as to which treatment model to utilise. Education about their sibling's mental illness might assist with the confusion.

6. Chapter 6: Conclusion

6.1 Overview

This study has explored the ways in which ‘black’ isiXhosa individuals experience their sibling relationship with an adult sibling who has a diagnosed mental illness. A small sample of five participants were interviewed with regard to the research question. It has to be acknowledged that this research in no way claims to provide an exhaustive understanding of participants’ experiences of having a sibling with a mental illness. Nevertheless, three major themes were identified across the experiences of the five participants, namely; experiencing the sibling as a burden post diagnosis, positive experiences from the sibling’s mental illness, participant’s experience of their sibling’s treatment and the mental health care system. The implications for policy interventions, limitations and future research will be discussed within this chapter.

The theme of financial burden due to the diagnosis of their sibling was strongly noted in the experiences of all the participants. Participants felt overburdened financially and with caregiving responsibilities. This was consistent with the literature, for example Mavundla *et al.*, (2009) conducted a study in a rural context and found that participants experienced financial burden. Furthermore, the participants also experienced caregiving burden associated with the multiple responsibilities that they have and this is particularly associated with non-western societies, where care taking is obligated as observed by Lefley (1998). The participants furthermore experienced both subjective and objective burden, which was consistent with the literature founded by Maurin and Boyd (1990).

The experiences regarding the sibling relationship was contradictory. Participants expressed feeling that they had both a stronger bond as well as a strenuous relationship with their sibling.

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The sense of financial burden was felt to have negatively affected the sibling relationship. Furthermore, the findings suggested a strong gendered component to the experience of burden. It is clear from the findings that stigma is still very prevalent and explicit. The stigma experienced by the participants was associated with shame and embarrassment. The shame and embarrassment can have a cultural component as cultural beliefs of mental illness are at times linked to 'spirits and witchcraft'. This was consistent with Monyaluoe *et al.* (2014) observing that families still showed belief in superstition and witchcraft. In addition, participants experienced having a sibling with a mental illness as having assisted them with gaining knowledge about how to handle or treat other individuals in the community who has a mental illness. This was consistent with Jewell's (2002) findings that participants become compassionate and tolerant towards those individuals who have a mental illness. This was significant because even though the participants experienced excessive burden financially they found positive aspects of having a sibling with a mental illness. The latter is not consistent with the literature. Lastly, it can be concluded that the participants were at times not involved in the treatment process. This was consistent with Riebschlegar (1991) who found that siblings have reported that they were not included in caregiving by the mental health system. Therefore, although this study included a sample of mixed diagnoses, the findings provided a contribution to an understanding of individual's experiences who have a sibling with a mental illness in a semi-rural South African context.

6.2 Limitations of the research

The researcher acknowledges a number of limitations of the study. Firstly, multiple interviews with each participant as an alternative could have been utilised as well as to conduct a pilot interview to develop the interview schedule further. This approach was not considered in the

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current study, as there were limited participants who were interested in participating within the study as well as time constraints. The limited interest of the participants could be related to the stigma associated with mental illness as well as them wanting to keep the diagnosis of their sibling as a secret.

Secondly, the current researcher is a novice researcher to the IPA methodology, although there was extensive reading and supervision, the latter could have influenced the manner in which data was collected as well as the interpretations made. Thirdly, the current study had a homogenous sample, and consisted of 'black' isiXhosa speaking individual, which means that the findings of the study cannot be generalised to other populations, however the findings are transferrable. Furthermore, another limitation is the issue of language, and the translation of the data from IsiXhosa to English. Some of the meaning of the data might have been lost during translation, although the current researcher was aware of this and asked the translator to keep the translation very close to the data. As has been explained before, the interviews were conducted in IsiXhosa but some of the participants were both fluent in IsiXhosa and English, and their narration gravitated towards English. Therefore, they may not have been able to articulate their stories fully in English. A further limitation could be objective responses, with which participants responded, instead of providing at all times subjective experiences. This means that the participants at times spoke in abstract terms instead of talking about their own personal experiences, in retrospect the researcher should have made it explicit that they should provide their personal experiences. A chief limitation of the data obtained is that the information is based solely on self-report. This is not a problem in itself, but no responses, without further confirmation, can be seen as representing the truth of what has happened. All accounts are

affected by participants' memory and by how they chose (consciously or otherwise) to present themselves to the researcher.

Although the research has limitations, the findings do present certain implications for practice and policy. These will be discussed below.

6.3 Implications of the findings

In light of the findings of the current research, there are a number of implications for practice and policy. Firstly, regarding the finding of financial and caregiving burden, the siblings of individuals could be supported emotionally in the form of a support group for siblings or families who have a mental illness. This will provide a safe space to reflect upon their thoughts and feelings. Regarding the disability grants, the government may have to attempt to control the mishandling of funds by the grand collectors so that the family can benefit from the funds to assist with alleviating the financial constraints.

Secondly, stigma may not be entirely abolished however, the cycle that perpetuates the stigma can be broken. The cycle may be broken by creating awareness in society of mental illness. This may be done through educational campaigns and possibly siblings and family members of individuals with mental disorders (including these individuals themselves) have an important role to play here. Another form of education may be through incorporating mental health education in the life orientation subject at school. This will assist with being misinformed and may contribute to assisting with stigma.

Thirdly, regarding the findings about the participants firstly seeking traditional assistance as well as their cultural beliefs about the traditional explanatory models. It is evident that cultural

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context should be taken into consideration as it still has an influence even in the 21st century. Therefore, mental health practitioners should be culturally sensitive and should make use of cultural interpreters as well as professional interpreters who will provide a verbatim translation and who will be able to provide a thorough explanation of the cultural components.

Finally, the findings regarding the participants not being involved in the treatment process as well as not completely being educated regarding their sibling's mental illness having important implications. It can be concluded that the participants were not well informed about medication and were not fully informed about the mental illness of their sibling. Therefore, mental health practitioners need to ensure that siblings are involved, or at least find out who the primary caregiver is and if there are multiple caregivers to ensure that all these caregivers are involved in the treatment process. A systematic intervention to involve all the family members and caregivers and provide them with an elaborative explanation of the etiology of mental illness, explanation of the diagnosis and the side effects of the medication should be provided.

6.4 Areas of further research

The current study found that experiencing financial burden was a prominent experience for many participants due to having an adult sibling with a mental illness. It would therefore be informative to repeat this research with other individuals, focusing on one specific diagnosis. Additionally, conducting a larger/quantitative study to get a sense of how prevalent this experience of the mental illness of a family member being an additional financial burden. The current study has also highlighted the particular need for the phenomenological study regarding caregiving burden. A longitudinal study would also assist to accurately capture the past and current experiences of participants. Another area for future research as highlighted by the current

research is the need to study a specific aspect of the sibling relationship, and how it is influenced by having a sibling with a mental illness.

6.5 Study Reflections

It is important to reflect on the research process as I was carrying dual roles, being a researcher and a clinician. Therefore, during the research I was mindful of any issues regarding the confusion that might have arisen regarding the above roles. I started my internship after conducting the interviews with the participants at the same hospital, which the participant's siblings attended. Therefore, I was cognisant of the fact that I had to be objective at all times. It was a new experience for me to undertake a research interview and I tried my utmost best to ensure that I asked questions regarding my research focus and that I did not act as a therapist. Furthermore, I wondered if my status as master's student might have influenced how the participants responded to my questions and what they disclosed and kept to themselves. I was aware of my position of having experienced both sides, being a service user of the mental health system (through my own experiences as a sibling) and providing a service for the mental health system and not letting this cloud my judgment during analysis of the data and making the interpretations.

6.6 Concluding remarks

The primary aim of the current study was to gain an in depth understanding of the experiences of having an adult sibling with a mental illness. The findings suggest that the participants experience financial burden, caregiving burden, stigma, an impact on the sibling relationship, positive experiences such as humour and joy and they further experienced the mental health practitioners as friendly, however they at times were not involved in the rehabilitation process.

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Limitations of the study have been discussed and the areas of future research were explored to focus on a more homogenous group, focusing on one diagnosis. The findings further provided implications for practice and policy.

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Appendices

Appendix A: Poster English

DO YOU HAVE A SIBLING WITH A MENTAL ILLNESS?



RESEARCH PARTICIPANTS WANTED TO PARTICIPATE IN A STUDY ABOUT THEIR EXPERIENCES OF HAVING A SIBLING WITH A MENTAL ILLNESS.

RESEARCH PARTICIPANTS WILL BE INTERVIEWED ABOUT THEIR LIVED EXPERIENCES OF HAVING A MENTAL ILLNESS FOR APPROXIMATELY AN HOUR

Place of interviews: Rhodes University Psychology Clinic

- ❖ **REFRESHMENTS WILL BE AVAILABLE**
- ❖ **TRANSPORT EXPENSES FOR THE DAY WILL BE REIMBURSED**

Are you between the ages of 35-60 years of age?

Do you have a sibling with a mental illness?

Would like to participate?

Kindly contact Raylene Flannigan Cell: 0833964559

The research is to complete my Masters in Clinical Psychology under the supervision of Prof Lisa Saville Young. The research has received ethical approval. Thank you

IsiXhosa Poster

**KUFUNWA ABANTU ABAZOTHATHA INXAXHEBA KUPHANDO,
NGEMO YOKUHLALA KWABO NABANTU ABAGULA NGENGQONDO**



Indawoyovavanyo: Rhodes University Psychology Clinic

- ❖ **ABATHATHA INAXHEBA UKUTYA KUZOBAGONA KANTI NEMALI UMNTU
AYISEBENZISILEYO UKUZA APHA NOKUGODUKA IZOBUYISWA**

Ungabauneminyakaephakathiko 35 no 60?

Uhlalanesizalwanaesigulangengqondo?

Uyafunaukhuthathainxaxhebakoluvavanyomibuzo?

Uthethalsixhosa?

*Ncedauxulumanen no Raylene Flannigan Inombolngu: **0833964559***

Appendix B: Permission to post advertisement

Permission to post advertisement

REQUEST FOR PERMISSION TO POST AN ADVERTISEMENT TO RECRUIT INDIVIDUALS WHO HAVE A SIBLING WITH A MENTAL ILLNESS.

Dear Sir/Madam

My name is Raylene Flannigan, and I am a Masters in Clinical Psychology student at Rhodes University. The research I wish to conduct for my Master's thesis; involves exploring the lived experiences of individuals who have a sibling with a mental illness. This project will be conducted under the supervision of Professor Lisa Saville Young

I am hereby seeking your consent to place an advertisement to recruit individuals who has a sibling with a mental illness on your premises.

I have received ethical approval to conduct this research from the Department of Psychology at Rhodes

If you require any further information, please do not hesitate to contact me on 0833964559 or email: Rayleneflannigan@gmail.com. Thank you for your time and consideration in this matter.

Your permission to place the advertisement on your premises will be greatly appreciated.

Raylene Flannigan

Trainee Clinical Psychologist

Rhodes University

Prof Lisa Saville Young

Supervisor

Rhodes University

Appendix C: Interview Schedule (English)

Adult Siblings and Mental Illness: An Interpretative phenomenological analysis.

Semi- structured interview schedule

1. How did you first find out about your siblings' illness?

Possible prompts: When did you first out? What was it like when you first heard the news? Did you understand the illness/diagnosis?

2. Can you tell me about your experiences of having a sibling with a mental illness?

Possible prompts: How do you feel about it, how you cope?

3. How would you describe the support from extended family members?

Possible prompts: And from the general community? How would you describe stigmatizing within the community?

4. How would you describe living with a sibling who have been diagnosed with a mental illness?

Possible Prompts: What are the negatives? What are the positives?

5. How would you describe the impact of your sibling's illness on your relationship?

Possible prompt: Does it impact your other relationships' as well? How might this be?

6. How would you describe the relationship after finding out that your sibling has a mental illness?

Possible Prompt: How do you feel about these changes?

7. What has been the best part of having a sibling with a mental illness?

8. What has been the most difficult times for you, to have a sibling with a mental illness?

9. How has your experience of the helping professions at the hospital been?

Possible prompts: How would you describe the support? To what extent were you involved in the treatment and decisions about the treatment?

IsiXhosa Interview Schedule

Siblings and Mental Illness: An Interpretive phenomenological analysis.

Semi- structured interview schedule

1. Wazivakanjani wokuvangesimoso kukhubazeka somntakwenu?

Prompts: Waqalaniniukuvangesimosakhe? Wazivanjaniemvenikokwaziswangezindaba?

Wawuyaziukubayintoni le imphetheyo?

2. Ungandibalise langamava akhowokubano mntakwenu okhubazekileyongengqondo?

Prompts: Ikuphathanjani lento kwayeyintoni eyenza izinto zibelulakuwe?

3. Ungandibalise langenkxaso evelakwiza lamanezakho?

Prompts: Inkxaso evelaekuhlaniyona? Lunjani ucalucalulolona esixekweniohhlakuso?

4. Ungathikunjani ukubanomntakwenu okhubazekileyongengqondo?

Prompts: Zintoniezenzanzima? Zintoniezenzakubemnandi?

5. Ungathi esisigulosi buchaphazelen janiubudlelanebenu?

6. Lwabanotshintshonaubudlelanebakhonomntakwenuemvenikobauvileubaugulangengqondo?

Possible Prompt: Uzivanjaningolutshintsho?

7. Yeyiphi into eyenzakubemnandiukubanomntakwenuophazamisekileyongengqondo?

8. Leliphielonaxeshaowevakunzimangalo?

9. Nizivanixhasiwenangogqirhanomongikaziesibhedlexakufunekeniyile?

Symptoms of illness

Appendix D: Initial Analysis (Line by Line)

1

chizu phureh'ia

1 Interview Substance Induce Psychosi

2 R: Ok thank you for coming, you said your name is
3 Nolu....

4 P: Nolubabalo

5 R: Nolubabalo ok, how old are you?

6 P: 31 years

7 R: Ok and you say that, you told me that you are
8 currently studying or are you?

9 P: Yes I am currently studying

10 R: But you are unemployed?

11 P: Yes

12 R: Ok, uhm and ok so uhm you know that there is
13 no right or wrong answer and whenever I ask you
14 something that you are not willing to share then just
15 let me know and I'm gonna state that. Uhm and ja
16 so be free to tell me to me anything and if you have
17 anything to ask me, be free to ask me anything. Uhm
18 so you say that your brother has got a mental illness,
19 can you tell me more about that?

20 P: Yes we he became uhm he became
21 entally il sinc

(we) collectivistic
Discovery

22 R: 2012

23 P: Yes and the thing is, we are, I took him to the
24 hospital, the thing is, he was a substance abuser Dagga,
25 he was smoking dagga and all sorts of things and then
26 we found out that, as a family, he used those substance
27 ings at an early age, 16/17 years. So then he

Substance
abuse
Family: collectivistic

28 became in that situation, and then we took him to the
29 hospital...

situation difficulty describing?

30 R: Ok, before you continue, what happened, can you
31 tell me what were the symptoms?

32 P: The symptoms, yho, he was drinking paraffin, he was
33 eating cemen, one day he took his ID photo and painted
34 it with a petrol until it became faded and black. He was
35 doing some things that were like that and I was maybe
36 28 years by then. So I got the elders, I can say that, One
37 day I decided to take him to the hospital, before I took
38 him to the hospital, there was this man who was a friend
39 of mine, he was a police man and then I asked him just
40 so that he can go, because if I took him by myself he
41 wouldn't go there. Then he took him, he took us to the
42 hospital, we got there and then he went to, until he went
43 to Fort England and then he stayed about 3 months.

When she couldn't handle it anymore (one day)

doesn't see herself capable to take him to hospital

long term

44 R: At Fort England?

45 P: At Fort England

46 R: Ok, so you said that he smoked weed, dagga

47 P: Yes

48 R: All those substances...

49 P: All those other substances...

50 R: And he got sick because of that?

51 P: Yes

52 R: And uhm he stayed in the hospital about 3
53 months, how did you feel about all of this?

(yho) = emphasis of how bad it is / how bad she felt

loss of sense of self

embarrassment to her "you" (me) + W [family] (collectivist) everyone is embarrassed

54 P: Yho it was very, I was feeling so like, I wasn't like
55 myself because he sometimes embarrassing you us as a

(Stigma)

56 family and then you feel those, and others were
 57 laughing it was like it he is doing it for fun. Sometimes
 58 he would go outside naked, you know those things. And
 59 then we have to, I have to myself because I was the one
 60 at least, not that he listens to me but I was trying to
 61 manage. [At the point she almost cries]

People finding it humorous
 Personal (I) responsibility
 Trying: Tried to be OK
 (Coping)

62 R: So you were the one that, so you were staying
 63 together?

64 P: Together yes

65 R: Uhm and how was your relationship as brother
 66 and sister, how was your relationship before he got
 67 sick?

68 P: Before he got sick we were like, he used to drink, not
 69 that much of dagga but when he is drunk and he is
 70 moaning and be rude and using vulgar language before.

speaking with disappointment
 Rude + disrespectful
 before illness

71 R: Uhm I'm talking about your relationship

72 P: Relationship, it wasn't.....

73 R: Your relationship with your brother

74 P: Ok

75 R: Ibinjani(how was it)?

76 P: (It wasn't that) it was like a brother and sister
 77 sometimes..

L: hesitant
 Not sure
 Uncertainty about the relationship
 not that close

78 R: Was it close, how would you describe it?

79 P: Mhh it was, yes I was closer with him but not that
 80 close because the4re are so many of my siblings.

81 R: Ok, but then after the mental illness, how would
 82 you describe the relationship after he got sick, do

83 you see any change in the relationship, how would
84 you describe that?

85 P: There is no change, there is no change because he is
86 still that person now. He is still that person. But I think
87 Fort England has done a lot for him because there's no
88 more being naked and vulgar languages now, he's just a
89 person. Because maybe is because of the treatment.

Difference
(Treatment)
Just a person's
didn't see him as
a person before?

90 R: Ja, what would you say the negatives of having a
91 brother with a mental illness?

92 P: Embarrassment. I feel embarrassment.

Embarrassment
feeling embarrassed
Repetition of the
word, emphasis.

93 R: Mhh, how do you feel about...

94 P: About myself?

95 R: Ja, can you tell me more about the
96 embarrassment

97 P: Like sometimes he comes in front of your friends and
98 doing some funny things. Funny things like, he came
99 with his dagga sometimes and put it in a plate or
100 something like that. And in front of your friends, maybe
101 we are sitting entertaining ourselves. Maybe let's say
102 eating sandwiches, one day I was in front, we were
103 sitting outside in front it was hot. And then he came with
104 this plate of dagga and then he said, I'm smoking this,
105 I'm this kind of person, nobody is going to change me.
106 And then I just keep quiet because I don't want to argue
107 in front of my friends and then I said, keep calm my
108 brother, don't do this and that. And then he just stood
109 up with his plate and put it there and then I just took
110 that plate with the weed and threw it away after some
111 few minutes, not in front of him.

Embarrassment
in front of friends

Keep quiet +
not argue

112 R: Ok, so you say that you feel embarrassed and it
113 also sounds like you felt sad

114 P: Sad

115 R: Sad ja mhh

116 P: Sadness sometimes

At times feel
(Sad)

117 R: So you felt also sad?

118 P: Mhh

119 R: So what are the positives of having a brother with
120 a mental illness, what would you say are the
121 positives?

122 P: In which way?

123 R: In a way that maybe uhm, what are the good
124 things?

125 P: The good things /laughs I don't think there is a good
126 thing.

laugh; defend
against
the hurt?
Doesn't think there
is a good thing?

127 R: What makes you say that?

128 P: You know he wasn't born like that, it makes me,
129 because we are staying with the, our parents are old,
130 they are all pensioners. My father was born in 1933, my
131 mother was born in 1942 and I became the mother to
132 him now you know. So I can't do my own things you
133 know, I was young and I have to take care of him you
134 know. My mother was attacked by a stroke, sometimes I
135 feel nervous even now can you see. I can say I was a
136 headed child you know, because since my mother was
137 sick I was 18 years you know, I took from there. And
138 there was the other brother of mine who died in 2012 at
139 the same time you know. 2012 was the year that my

?? Angry??
Upset? Sad?

Responsibility
Responsibility

could not live her
life
Core giver
Role

Nervous/anxiety
Child headed
home

feeling
anxious

140 brother, the other brother got sick you know and the
 141 cousins you know, always me, always me I even ask
 142 myself sometimes, why God me, always, always, it also
 143 disturbs me.

Repetition
Emphasis of
frustration?

Question God
(Disturbing)

144 **R: So you also feel that it's quite difficult for you**
 145 **and you also feel sad and it's a lot...**

146 **R: It's a lot..**

147 **R: And you can't do what you want to, do you have**
 148 **your own children probably do you want it or you**
 149 **feel like you can't because you already have..**

150 **P: My brother, my older one. But I do have my**
 151 **daughter, she's 3 years now.**

152 **R: So it does sound like it's a lot but I'm just**
 153 **wondering how you cope, how do you cope with**
 154 **having a brother with a mental illness?**

155 **P: Yho...**

156 **R: What makes it easy for you, what do you use as**
 157 **your coping mechanism?**

158 **P: Yho, have (no) I think only God, I can say my**
 159 **boyfriend sometimes. If I get sad or somebody has hurt**
 160 **me, I talk to him.**

spiritual
spirituality/
Religion
(Partner)
Yho (difficulty)
what can make
it easy?!

161 **R: Ok so it's nice that you have support from him**

162 **P: Yes and then he shows me no it's not the end of the**
 163 **world and stuff and stuff. I even now decided to go to**
 164 **Port Elizabeth whereas I know I am unemployed and**
 165 **then the person whom I'm going to is also unemployed.**

166 **I just wanna feel free and relax, maybe two to three**
 167 **months. And I also decided to leave the school, (oh)**
 168 **maansh*t, everything is on me, do you feel that..**

feeling
suffocated??
wanting to be
free

Swearing = level of
frustration
everything is on her

Appendix E: Example of emergent theme table from one participants

Emergent Theme	Original Transcript	Exploratory comments / (Interpretation)
Symptomology of the diagnosis (Green)	<p>P: Yes and the thing is, we are, I took him to the hospital, the thing is, he was a substance abuser. Dagga, he was smoking dagga and all sorts of things and then we found out that, as a family, he used those substance abuse things at an early age, 16/17 years. So then he became in that situation, and then we took him to the hospital...</p> <p>The symptoms, yho, he was drinking paraffin, he was eating cement, one day he took his ID photo and painted it with a petrol until it became faded and black</p> <p>Sometimes he would go outside naked, you know those things</p> <p>He would go outside naked</p> <p>Like sometimes he comes in front of your friends and doing some funny things. Funny things like, he came with his dagga sometimes and put it in a plate or something like that.</p> <p>Yes, he hears things, he sees things, yes he hears and talking to no one</p> <p>P: I think his problem is on brain</p>	<p>Substance causing the mental illness?</p> <p><i>'As a Family':</i> (collectivistic?)</p> <p><i>'Became in that situation'(difficult to describe the situation??)</i></p> <p><i>"Yhothe severity of her brothers behaviour?"</i></p> <p>Embarrassment in front of friends.</p> <p>Funny things= Not usual things to do.</p>

	<p>R: Is it, is he slow?</p> <p>P: Very very slow</p> <p>R: Ok</p> <p>P: He's very very slow because even now he is on treatment. I can say he is very stable now, but he is sometimes feeling so lonely, he wanna sleep alone, doing his things alone, doesn't wanna talk sometimes. So it was before, before it was very very difficult. He nearly burnt himself one day, he took a lighter and then burnt his bed, curtains <i>ntonintoni</i>, HomeChoice duvet when he started. And then my parents said ok, he mustn't use some, like electric appliances like the kettle in his room. He must come to the house when he wants something and match, he mustn't use it.</p>	<p><i>'Very very slow'</i> emphasis on his intellectual state: how the substances have had an effect on his brain.</p>
<p>Feelings and understanding of treatment and feelings towards the hospital(Dark Blue)</p>	<p>there's no more being naked and vulgar languages now, he's just a person. Because maybe is because of the treatment.</p> <p>The support, yho very veryvery, they were doing a very veryvery good role, I don't know how to thank them because since then, it was only 2 or 3 times that he got sick. Since he is on treatment, I can say two times or three times.</p>	<p>Treatment making a difference.</p> <p><i>"Now he is just a person"</i> didn't see him as human when he is ill??</p> <p>Excellent support and services from the hospital.</p>

	<p>Nope, I did go maybe twice or three times a day, I mean a week but nothing they told us about the treatment</p>	<p>Not involved in treatment decisions.</p>
<p>Emotional responses to the diagnosis of sibling (Blue)</p>	<p>Yho it was very, I was feeling so like, I wasn't like myself because he sometimes embarrassing you, us as a family and then you feel those, and others were laughing</p> <p>R: Ja, what would you say the negatives of having a brother with a mental illness?</p> <p>P: Embarrassment, I feel embarrassment</p> <p>P: Sad</p> <p>R: Sad jamhh</p> <p>P: Sadness sometimes</p> <p>P: The good things /laughs/ I don't think there is a good thing.</p> <p>always me, always me. I even ask myself sometimes, why God me, always, always, it also disturbs me.</p> <p>It's a lot</p> <p>I just wanna feel free and relax maybe two to three months. And I also decided to leave the school, oh maansh*t, everything is on me, do you feel that...</p>	<p>“Yho” Emphasis of how bad she felt</p> <p><i>‘I wasn't like myself’</i>: Loss of sense of self</p> <p><i>‘Embarrassment’</i> to her and her family (collectivist)</p> <p>Embarrassment repetition of the word: emphasis that it is really embarrassing.</p> <p>At times she feels sad</p> <p>Laugh: defending against the hurt. Doesn't think there is a good thing?</p> <p><i>“Always me always me”</i> emphasis on her frustration: Questioning GOD.</p> <p><i>It's a lot</i> (Burden??)</p> <p>Feeling suffocated, wanting</p>

	<p>I am not okay, not at okay at all because from 18 years, that is 18, 19, 20 until 32 years is a lot. My mother, from 18, from that 18 years was attacked by stroke, I was doing matric. So I decided to leave school at the early age whereas I've got my elder sister you know, who was able to look after my mother but she didn't you know. And then I decided to leave school since then, I failed my matric and it was my first time to fail. I didn't even.....</p> <p>Yho it's a burden, more of what's happening?</p> <p>then my environment would be fine but there's just more and more</p> <p>P: Yho I was crying, crying crying but not in front of</p> <p>: I feel so worried, I was so worried because we didn't let him to do that.</p>	<p>to be free.</p> <p>Swearing: level of frustration</p> <p>Everything is on her (Burden)</p> <p><i>"I am not okay, not at okay at all"</i> Repetition (severity of not being okay) a lot to handle</p> <p>Decided to leave school: Sacrifices.</p> <p>"Yho" Exclamation agree it is a burden.</p> <p>"More and more" : feels like it is never ending</p> <p>Crying feeling hopeless</p> <p>Feeling worried about what others will say about her brother??</p>
Experiences of the	P: It wasn't that, it was like a brother	<i>Hesitant</i> sometimes... not

<p>sibling relationship post diagnosis (Red)</p>	<p>and sister sometimes...</p> <p>There is no change, there is no change because he is still that person now, he is still that person.</p> <p>At the moment, he's fine but our relationship is not that good. Because <i>hee</i>(uhm) I don't, I really don't know how to say this but I have to say. Err since I'm this kind of person who is responsible for all them when they got sick and stuff, so now he is, he's a grant payer yes. Then on his day, nobody is taking his grant or his card whatever. You will see him on the 1st or on the 31st or on the 20-something when the grant day is coming, he will start saying words like, you won't help me, saying to me, you won't help me you will help your brothers <i>warawara</i>(blah blah) I won't get sick again, something like that. Whereas I did not say anything, I just keep quiet. My dad said, just keep quiet, leave him like that. After a few days when the money is out, hello my sister how are you and then I say hi I'm fine thanks <i>ntonintoni</i> and stop there.</p> <p>No, I really don't blame, I love my siblings, I do take care of them. And whereas he's like that to me, I still don't have that, because he is my brother. I keep telling them that you are going to bury me, I'm going to bury you, you are my brother we are coming from the same womb. You can do whatever you want to but we are the same blood. So they know</p>	<p>sure? uncertainty about the relationship. (close but not that close)</p> <p>No change in the relationship</p> <p>Strained relationship due to grant money.</p> <p>Love her siblings and they are genetically bonded.</p>
--	--	---

	me by that.	
Forms of Coping (orange)	<p>I was trying to manage.</p> <p>P: Yho, <i>hayi</i>(no) I think only God, I can say my boyfriend sometimes. If I get sad or somebody has hurt me, I talk to him.</p>	<p>Trying to manage</p> <p>Her faith helping her cope.</p>
Feelings towards stigma (Pink)	<p>and others were laughing, it was like it he is doing it for fun</p> <p>P: Yes I do, there is a stigma but some rumours, nobody is coming to you directly and saying that they said that and that</p> <p>P: I really don't care as long as I'm caring for him and the family is caring for him I really don't care. I'm just doing what is right for him and the family.</p> <p>my father <i>akanangqondo</i>(is mad) and then I say, God will sometime help him my son, leave them alone.</p>	<p>Others finding it humorous (stigma??)</p> <p>Stigma about the illness.</p> <p>Don't care attitude towards stigma (feelings towards stigma).</p> <p>Stigma saying brother is "mad"</p>
Caregiver/ Helper (sense of self) (Black)	<p>I can't say no, I am always a helper</p> <p>Yes I would have been, not because he is my brother because I like to help, I'm a helper even in the community.</p>	<p>Sense of self</p> <p>Like to help, always a helper</p>
Sense of responsibility	<p>One day I decided to take him to the hospital, before I took him to the hospital, there was this man who</p>	<p>She had to take him to hospital</p>

<p>(Purple)</p>	<p>was a friend of mine, he was a police man and then I asked him just so that he can go,</p> <p>because if I took him by myself he wouldn't go there</p> <p>So I can't do my own things you know, I was young and I have to take care of him you know</p> <p>for some things. So then I became the mother of the child, of the house – doing chores that I wasn't supposed to be doing</p> <p>I have this responsibility. It's my responsibility since then</p>	<p>Responsibility to take care of him, became the mother.</p> <p>“Can't do my own things” Could not live her life.</p> <p>Responsibility</p>
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Appendix F: RPERC Letter



RHODES UNIVERSITY

Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT Tel: (046) 603 8500/8501 Fax: (046) 603 7614 e-mail: psychology@ru.ac.za

RESEARCH PROJECTS AND ETHICS REVIEW COMMITTEE

3 June 2015

Raylene Flannigan
Department of Psychology
RHODES UNIVERSITY
6140

Dear Raylene

ETHICAL CLEARANCE OF PROJECT PSY2015/24

This letter confirms your research proposal with tracking number PSY2015/24 and title, 'Siblings and mental illness: An interpretative phenomenological analysis', served at the Research Projects and Ethics Review Committee (RPERC) of the Psychology Department of Rhodes University on 3 June 2015. The project has been given ethics clearance.

Please ensure that the RPERC is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators.

Yours sincerely

A handwritten signature in black ink, appearing to read 'J. Marx'.

Dr Jacqueline Marx
CHAIRPERSON OF THE RPERC

Information to the participants

Dear Prospective Participant

This is an opportunity to participate in a research study about siblings and mental illness. This study is being conducted by Raylene Flannigan at the Rhodes University under the supervision of Professor Lisa Saville Young.

Purpose of the study


The purpose of the study is to explore the experiences of individuals who has an adult sibling with a mental illness. I am interested in how you first found out about your siblings diagnoses. I am also interested about your experiences, both negative and positive of having a sibling with a mental illness as well as how your experiences has been with the mental health system.

What is expected from the participant?

Your participation will include an interview at the Psychology clinic. You will be reimbursed for transport to and from the clinic on the day of the interviews. The interviews will be an hour long and refreshments will be provided. The interviews will be recorded, and all the interviews will be transcribed. You will have to sign a consent form before participation in the study. Participation in the study is voluntary and no one will be forced to participate. Participants can withdraw from the study at any point

The information gathered will be confidential and will not be shared with anyone other than the supervisor. You can be assured that you will not be identified in any way in the report of the study. Everyone involved in the research will sign confidentiality forms.

If you do get emotional and overwhelmed by talking about your experiences, you will be debriefed by me and I can refer you to the Psychology Clinic for further counselling.



If you have any other questions, please feel free to contact me.

Cellphone: 0833964559

Email: RayleneFlannigan@gmail.com

Thank you for considering to participate.

Professor Lisa Saville Young (Clinical Psychologist)

Raylene Flannigan (Trainee Clinical Psychologist)

Appendix H: Informed consent (English)



RHODES UNIVERSITY

Grahamstown • 6140 • South Africa

PSYCHOLOGY CLINIC • Tel: (046) 603 8502 • Fax: (046) 603 7203 • e-mail: y.scheepers@ru.ac.za

INFORMED CONSENT

I _____ (participant's name) agree to participate in the research project of Raylene Flannigan on the experiences of individuals who has an adult sibling with a mental illness.

I understand that:

1. The researcher is a student conducting the research as part of the requirements for a Master's degree at Rhodes University. The researcher may be contacted on 0833964559 or Rayleneflannigan@mail.com (email). The research project has been approved by the relevant ethics committees, and is under the supervision of Prof Lisa Saville Young in the Psychology Department at Rhodes University, who may be contacted on 046 603 8047 or l.young@ru.ac.za

2. The researcher is interested in the experiences of individuals who has an adult sibling with a mental illness. What

3. My participation will involve undergoing an interview for a maximum of 1 hour and I am aware that the interviews will be recorded and transcribed by a transcriber.

4. I may be asked to answer questions of a personal nature, but I can choose not to answer any questions about aspects of my life which I am not willing to disclose.

5. I can tell the researcher any concerns I have about my participation in the study, or consequences I may experience as a result of my participation. The Psychology clinic may be contacted for further support if needed.

6. I am free to withdraw from the study at any time – however I commit myself to full participation unless some unusual circumstances occur, or I have concerns about my participation which I did not originally anticipate.

7. The report on the project may contain information about my personal experiences, attitudes and behaviors, but that the report will be designed in such a way that it will not be possible to be identified by the reader. I will not be identified by name.

8. I am aware that I will not receive any feedback from the researcher. And I am aware that the report might be published and shared with other health professions.

Signed on (Date):

Participant: _____ Researcher: _____

Informed consent (IsiXhosa)



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Iphepha lesivumelwano

U----- uyavuma ukuthatha inxaxheba kuphando olwenziwa ngu Raylene Flannigan kubantu abahlala nabaphilisana nabantu abaphazamisekileyo engqondweni.

Ndiyaqonda ukuba:

1. Umphandi ngumfundi owenza uphando ngokwemfuneko nokulindelekiyo eyenzela I Master's degree yake kwiDyunivesithi iRhodes. Umphandi lo uyafumaneka kule nombolo – 0833964559 okanye Rayleneflannigan@gmail.com (incwadi ye-intanethi). Olu phando lusemgangathweni ofanekeliyo, lipasiwe ziikomiti ezifanelekileyo and luphantsi kweliso lika profesa Lisa Saville Young kwiSebe lezeSayikholoji kwiDyunivesithi iRhodes ofumaneka kule nombolo – 046 603 8047 okanye l.young@ru.ac.za
2. Umphandi unqwenela ukwazi ngezinto abantu abaphilisana nabantwakwabo abaphazamisekeleyo ngokwasengqondweni abahlangabezana nazo
3. Ukuthatha inxaxheba koluphando kuthetha ukuya kudliwano-ndlebe yeyure, kwaye zonke iinkcukacha zizakurekhodwa zibhalwe na phantsi.
4. Ndisenokubuzwa iimibuzo ephathelene nam ngqo, kodwa ndisenokukhetha ukungaohenduli xa ndingakhululekanga.
5. Ndisenomxelele umphandi izinto ezindihluphayo malunga noluphando, okanye imiphumela yokuba yinxenye koluphando. Iziko lesayikholoji lisenokuthintwa xa kuko uncedo oludingekayo.
6. Ndivumelekile ukurhoxa koluphando nanini na xandifuna, kodwa ndiyazimisela ukuthatha inxaxheba ngaphandle kokuba kukho iimeko ezingapha kwamandla ezindivikelayo, okanye ndinokuhlalaba okuvukuayo ngokuthatha unxaxheba kwam ebendingakhange ndikuqonde ngexesha ndivuma ukuzindakanya nophando.
7. Uchazo malunga nophando olu lungase luqulathe iinkcukacha zezinto endidlula kuzo, indlela endive ngayo kunye nendlela endenza ngayo, kodwa izobunjwa ngendlela apho lowo uyifundayo akazukwazi ukubona ukuba ndim. Igama lam aluzuchzwa.

8. Ndiyaqonda ukuba anduzufumana nkcazelo kumphandi kwaye uphando olu lungahle lupapashwe futhi lubonwe ngabanye abasebenzi kumaziko ezempilo.

Ityikitywe ngolusuku.....

Lo othatha inxaxheba.....Umphandi.....

Appendix I: Transcription and translation confidentiality form

CONFIDENTIALITY AGREEMENT:

Transcription and Transcription Services

I, _____, (name of transcriber/ Translator) agree to maintain full confidentiality in regards to any and all audio recordings and documentation received from Raylene Flannigan related to her research study on Siblings and Mental Illness: An Interpretive Phenomenological Analysis.

Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents;
2. To not make copies of any audiotapes or computerized files of the transcribed interview texts, unless specifically requested to do so by Raylene
3. To store all study-related audio recordings and materials in a safe, secure location as long as they are in my possession;
4. To return all audio recordings and study-related documents to Raylene in a complete and timely manner. To ensure that I password protect the recordings and transcriptions.
5. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audio recordings and/or files to which I will have access.

Transcriber's name (printed) _____

Transcriber's signature _____

Date _____

Rhodes University — Department of Psychology

**USE OF TAPE RECORDINGS FOR RESEARCH PURPOSES
PERMISSION AND RELEASE FORM**

Name of participant			
Participant's contacts details	Email address: Phone number:		
Name of researcher			
Level of research	Honours	Masters	PhD
Brief title of project			
Name of supervisor			

DECLARATION

(Please initial/tick blocks next to the relevant statements)

1.	The nature of the research and the nature of my participation have been explained to me.	verbally	
		in writing	
2.	I agree to be interviewed and to allow recordings to be made of the interview.	audiotape	
		videotape	
3.	I agree to _____ and to allow recordings to be made.	audiotape	
		videotape	
4.	The tape recordings may be transcribed	without conditions	
		only by the researcher	
		by one or more nominated third parties	
5.	I have been informed by the researcher that the tape recordings will be erased once the study is complete and the report has been written. OR I give permission for the tape recordings to be retained after the study and for them to be utilised for the following purposes and under the following conditions		

Signature of participant: _____

Date: _____

Witnessed by researcher: _____

Date: _____