

A Phenomenological Study of Primary Caregivers of Patients Living With Schizophrenia in

Gauteng Province, South Africa

by

Nopfumbada Tracy Tshilidzi

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Supervisor: Dr M Makgahlela

Co-Supervisor: Prof S Govender

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## **Declaration of Originality**

I, Nopfumbada Tracy Tshilidzi declare that the dissertation, “A Phenomenological Study of Primary Caregivers of Patients Living With Schizophrenia in Gauteng Province, South Africa”, hereby submitted to the University of Limpopo, for the degree of Master of Arts in Clinical Psychology has not previously been submitted by me for a degree at this or any other university; that is, it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

Nopfumbada Tracy Tshilidzi

Signature: .....

Date:.....

## **Dedication**

Humbly dedicated to my parents Zandile (*bhele, Mbikazi, nontandakuphakanyiswa, mafu, qunta, ndabezitha, langa lokulunga*) and Maluta Nephumbada, for their unconditional love, support, and patience. Your support will forever be heartfelt.

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## **Abstract**

The study sought to explore and describe the lived experiences of caregivers involved in support groups whilst caring for a family member diagnosed schizophrenia in Johannesburg South, Gauteng province. A qualitative study was conducted among primary caregivers of family members diagnosed with schizophrenia and involved in support groups. Members were selected using purposive sampling and ten participants were interviewed (eight parents and two siblings of diagnosed family members). Data were collected using semi-structured interviews and analysed using interpretive phenomenological analysis (IPA).

Common themes regarding the experience of caring for a family member diagnosed with schizophrenia were clearly delineated. Findings of the study revealed that the participants experienced psychosocial, emotional, and economic challenges in caring for their relatives diagnosed with schizophrenia. The findings point to problems such as psychological distress, extensive worry, subjective burden and significance of support in caring for ill family members. Findings also highlight challenges such as financial constraints and cultural factors which negatively impact the quality of caregiving for the participants' ill relatives.

The study further revealed the coping mechanisms that caregivers adopt to cope with the difficulties of caring for their schizophrenic family members. Religion and support groups were some of mechanisms a majority of participants found to be helpful for them in coping. The present study found that family members involved in the group program demonstrated improved family communication, greater confidence in their ability to help their loved ones, reduced burden and improved subjective quality of life.

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## **Chapter 1: Background of the Study**

### **1.1 Introduction**

Mental illness is a global health concern. The World Health Organization (2010) estimated that one out of four families worldwide will have at least one member suffering from a form of mental disorder by 2020. Among several mental health conditions that are chronic and debilitating is a psychotic condition called schizophrenia (Combs & Mueser, 2017). Schizophrenia is a psychotic disorder characterised by abnormal thinking, perceptual disturbances, and diminished or exaggerated emotional expression (Weimand, Hall-Lord, Sällström, & Hedelin, 2013). Its symptoms include the experience of delusions, hallucinations, disorganised thinking, grossly disorganised motor behaviour, and its aetiology is largely attributable to genetic inheritance and biochemical imbalances in the brain (Sadock & Sadock, 2011). Several studies have found that cognitive impairment is one of the core features of schizophrenia with resultant impairments in social, personal, and occupational functioning (Millier et al., 2014).

The impact of the disorder is not only limited to the individual diagnosed, but also affects their families, neighbours, and the community as a whole (Hayes, Hawthorne, Farhall, O'Hanlon, & Harvey, 2015; McFarlane, 2016). Immediate family members have been reported to suffer emotionally, psychologically and financially (Millier et al., 2014; Hayes et al., 2015). In particular, the condition has a negative impact on the sufferers' social, psychological, and occupational functioning which makes it challenging for caregivers to manage (Freeman & Garety, 2014). Because of this, interventions directed at the illness are all encompassing; that is, they target bio-psycho-social aspects of the illness. The social aspect encompasses efforts (e.g., psychotherapy, formal support groups) directed at family members (Millier et al., 2014).

Psychoeducational support groups have been particularly recommended for families as their involvement in the management of patients is key ( Millier et al., 2014; Urizar et al., 2014). The support groups empower families in dealing with the challenges that come with caring for a family member living with the condition. Research suggests that families, especially those from low socioeconomic backgrounds, experience high levels of stress and burden (Urizar et al., 2014; World Federation of Mental Health, 2010). Amongst other challenges, family members living with schizophrenia experience being stigmatised, shamed, and ridiculed, and thus they suffer emotionally. Additionally, families are shunned and accorded little to no support by the community (Wankiiri, Drake, & Meyer, 2013). Lack of support leaves families, who are key role players in the care of patients, overwhelmed and mentally distressed. South African studies have also found that challenges confronting caregivers of mentally ill persons impact on their quality of life (Brooke-Sumner, Petersen, & Lund, 2014; Monyaluoe, Mvandaba, Plessis, & Koen, 2014).

## **1.2 Problem Statement**

For better care of people living with schizophrenia, support from family and relatives is paramount. The World Federation of Mental Health (2010) highlighted the important role played by families in the care of mentally ill patients. The support offered by families and relatives may be in the form of emotional and/or material support and the support may be implicit or explicit. In all cases the literature has suggested that support is one area of importance contributing to the better care of mentally ill patients (Brooke-Sumner et al, 2014; Monyaluoe et al., 2014). There is empirical evidence, for example, that family support, in addition to other factors, can help prevent relapses (Asher, Patel, & De Silva, 2017; Brooke-Summer., 2015; Millier et al., 2014), thereby increasing patients' overall quality of life (Hayes et al. 2015; Mendenhall et al., 2014; Monyaluoe et al., 2014). Moreover, relevant to the current

study, Urizar et al. (2014) concluded that there is greater benefit of social support to ill relatives especially coming from relatives who also participate in psychosocial support groups.

In spite of the notable importance of social support, multiple socio-cultural and economic challenges often get in the way, and prevent family members from providing optimal support to the mentally ill relative (Deshpande, Dewani, Sirkhot, & Veerkar, 2018; Opoku-Boateng et al., 2017; Urizar et al., 2014). For example, one of the common themes in the literature is the financial burden that comes with caregiving (Deshpande et al., 2018), and another is the stigma of mental illness.

Although there are many studies that have reported on the importance of social support in easing the challenges confronted by caregivers, similar studies in developing and underdeveloped countries are lacking (Monyaluoe et al., 2014). In South Africa, studies focusing exclusively on caregivers' lived experiences and/or needs are scarce (Brooke-Sumner et al., 2014; Monyaluoe et al., 2014). In view of this notable omission, this study, sought to investigate the lived experiences of primary caregivers including their coping strategies. The study results could contribute towards an understanding of caregivers' challenges and needs and how best to respond to them. This would also benefit relatives living with schizophrenia.

### **1.3 Purpose of the study**

#### **1.3.1 Aim of the study**

The study sought to explore and describe the lived experiences of caregivers involved in support groups whilst caring for a family member diagnosed and living with schizophrenia.

#### **1.3.2 Objectives of the study**

The study objectives were:

- To identify the psychological and emotional experiences of caregivers in their caring role for a family member living with schizophrenia.
- To establish the economic and sociocultural challenges that caregivers experience in their caregiving role.
- To appraise caregivers' coping mechanisms including their experiences of support groups they are part of as part of their caregiving role.

#### **1.4 Significance of the Study**

This study provided significant information on the experiences of primary caregivers living with persons or members diagnosed with schizophrenia. The study also identified challenges families are faced with when caring and living with a member diagnosed with the condition. Information on these challenges and dynamics can assist in providing guidelines for comprehensive intervention. In addition, the study will contribute towards expanding understanding of the role of families in the treatment process of their ill relatives and how caregivers can be better assisted with difficulties they are faced with. It will also add to the literature relating to the significance of families in the treatment of schizophrenia, particularly in the South African context where information is currently limited.

#### **1.5 Operational Definition of Concepts**

The following concepts are used throughout this study.

**Family:** In the context of this study, a family is understood to mean a group of people in a household who are attached emotionally, interact regularly, and share concerns for the growth and development of individuals and the group (Lefley, 1996). Since all family members are

assumed to share concerns for each other, the term family will be used interchangeably with caregivers. Caregivers which refers to someone who takes care of someone who has a chronic illness or disease (Lefley, 1996).

**Primary caregiver:** A primary caregiver is the person who takes primary responsibility for someone who cannot care for themselves. It may be a family member, a trained professional or another individual (Lefley, 1996). However, in this document, primary caregiver refers to a family member and the word primary caregiver is used interchangeably with family member.

**Schizophrenia:** Schizophrenia is a chronic and severe mental disorder that affects how a person thinks, feels, and behaves, and the symptoms can be quite disabling. Persons diagnosed with schizophrenia depict thoughts or experiences that seem out of touch with reality, disorganised speech or behaviour and decreased participation in daily activities (Sadock & Sadock, 2011).

**Support group:** In the context of this study, a support group is where people with similar burdens, issues or challenges come together and share their experiences and coping strategies to feel more empowered and for a sense of community support. The process of helping each other may take the form of providing and evaluating relevant information, relating personal experiences, listening to and accepting each other's experiences, providing sympathetic understanding or establishing a social network (Schopler & Galinsky, 2014).

## **1.6 Outline of the Dissertation**

In the current chapter, the study background including a statement of the problem is provided. The study purpose, that is the aim and objectives, are detailed. Chapter 2 is a review of the literature related to the lived experiences of primary caregivers of patients living with schizophrenia. Towards the end of the chapter, the study's frameworks are elaborated. In

Chapter 3, a detailed discussion of the research methodology is given. Chapter 4 consists of a presentation of the study findings. In the last chapter, an integrated discussion is offered. The results of the study are discussed in the context of existing empirical studies and theory. In the same chapter, the study implications are discussed, and recommendations and conclusions are provided.

## **Chapter 2: Literature Review**

### **2.1 Introduction**

This section will begin by presenting a review of literature starting by providing an overview of schizophrenia as a psychotic disorder. This review will also include an African perspective on schizophrenia and a discussion of different interventions available for people living with schizophrenia, including support available to their families. Finally, the socioeconomic and cultural factors that have implications on providing support to the patients are presented.

### **2.2 Psychosis and Schizophrenia**

Psychotic disorders are a group of mental conditions that cause abnormalities in thinking and perception (Combs & Mueser, 2017). A defining feature for psychotic conditions is the experience of a severe breakdown in mental functioning (Sadock & Sadock, 2011). The American Psychiatric Association's diagnostic manual classifies psychotic disorders (schizoaffective, schizophreniform, delusional disorder, and brief psychotic disorder) and schizophrenia under one umbrella, and they are all defined by abnormalities in one or more of the following domains: delusions, hallucinations, disorganised thinking (speech), grossly disorganised or abnormal motor behaviour (catatonia) or negative symptoms (American Psychiatric Association, 2013). Schizophrenia is often diagnosed before the age of 25 and persists throughout an individual's life (Sadock & Sadock, 2011).

Schizophrenia has a worldwide lifetime prevalence of about 1% irrespective of culture, social class, and race (Sadock & Sadock, 2011; Pharoah, Mari, Rathbone, & Wong, 2010). Schizophrenia is characterised by positive and negative symptoms. Positive symptoms include

the experience of hallucinations and delusions whilst negative symptoms may be in the form of emotional numbness and self-absorption (Combs & Mueser, 2017; Sadock & Sadock, 2011). Studies show that cognitive impairment is one of the core features of schizophrenia, and, unlike other symptoms of psychosis that can be suppressed with medication, cognitive impairment is not amenable to treatment (Keefe & Harvey, 2012; Schaefer, Giangrande, Weinberger & Dickinson, 2013). Cognitive impairment in schizophrenia is substantial across multiple domains. It includes, amongst others, deficits in declarative memory, working memory, language functions, executive functions, and slower processing speed (American Psychiatric Association, 2013). Personality and emotional changes are also a common experience for sufferers, and this compromises their social functioning (Kring & Elis, 2013; Turner, van der Gaag, Karyotaki, & Cuijpers, 2014).

## **2.3 Aetiology of Schizophrenia**

### **2.3.1 Biomedical explanations**

From a western perspective, several biomedical factors have been proposed as being linked to schizophrenia, including genetic, psychological, endocrinological, metabolic, environmental, virologic, and auto-immunological factors, as well as neurotransmitter systems and structural disorders of the brain (Tamminga & Medoff, 2000). All may act as predisposing, triggering, or functionally modulating factors. This biological approach has been largely used for explaining and understanding the aetiology of schizophrenia and is said to be based on empirical evidence (Butcher, Mineka, & Hooley, 2013).

### **2.3.2 Psychological explanations**

Psychodynamic theories assume that mental illness is a result of unconscious psychological conflicts originating in childhood. Sigmund Freud suggested that most mental processes are unconscious, and that three different parts of the psyche control human behaviour (namely, the id, ego and the superego). According to the Freudians, some types of abnormal upbringing (particularly if there is a cold, rejecting, 'schizogenic' mother) can result in a weak and fragile ego that struggles to combat the id's desires, leading to development of psychopathology (Winnicott, 1960; Freud, 1940). Although much research continues to implicate a disturbed upbringing as a risk in schizophrenia onset and relapse, some research has showed that the mother's personality is not a reliable predictor of mental illness (Butcher et al. 2013).

In contrast to those who adhere to psychodynamic theories, behaviourists attribute mental illness to a lack of effective behaviour or behaviour that does not help the individual in coping with the environment (Corey, 2005). Social cognitive theorists, for example, have argued that a lack of self-efficacy could lead to the development of abnormal behaviour (Meyer, Moore, & Viljoen, 2003). A theoretical analysis of schizophrenia based on a cognitive model integrates the complex interaction of predisposing neurobiological, environmental, cognitive, and behavioral factors with the diverse symptomatology (Beck & Rector 2005). The impaired integrative function of the brain, as well as domain-specific cognitive deficits, increases vulnerability to aversive life experiences, which in turn leads to dysfunctional beliefs and behaviors.

### **2.3.3 African indigenous explanations**

Although much is known regarding schizophrenia from a western point of view, studies show that the conceptualisation of schizophrenia is greatly influenced by culture (Chidarikire, Cross, Skinner & Cleary, 2018; Mbuyo, Ndeti, Mutiso, & Khasakhala, 2013; Mokgobi, 2014; Monteiro. 2015). This is because culture regulates perceptions of normal and abnormal, and endorses certain behaviours as right or wrong (Chidarikire et al., 2018). In Africa, ideas about the causes and effects of mental illness, including schizophrenia, remain conflictual (Chidarikire et al., 2018). However, a widely accepted belief is that mental illness has its root cause in witchcraft or ancestral possession/calling rather than chemical imbalances in the brain ( Mokgobi, 2014; Mosotho Louw, & Calitz, 2011). Therefore, cultural background influences the definitions and sociocultural meanings attached to schizophrenia; these meanings are shaped by norms, beliefs and values (Matsumoto & Juang 2016).

In Africa, empirical studies (e.g., Campbell et al., 2017; Chidarikire et al., 2018; Opoku-Boateng et al., 2017) prove that it is believed that people with jealousy are capable of bewitching others, and to the detriment of the afflicted suffering from a mental illness such as schizophrenia. Mokgobi (2014) lends support by stating that in African cultures schizophrenia symptoms can be identified as witchcraft or an ancestral calling that can only be addressed through traditional means. These explanations align well with the understanding of jealousy-induced witchcraft in Southern African communities and highlights the important role that culture plays in the understanding of mental illness. In addition, Bignall et al. (2015) highlights that people come to comprehend mental illness through their cultural beliefs, which in turn influence their course of action.

Whatever the belief, Kalra, Bhugra, and Shah (2012) argued that it is crucial to consider cultural variations in the understanding of bio-psycho-social models of aetiology and management of psychiatric conditions such as schizophrenia. Monteiro (2015) proposed the

extension of the biopsychosocial model to include sociocultural-spiritual dimensions of conceptualising illness and treatment. This is important because, clearly, cultural beliefs may have a significant impact on how schizophrenia is explained and understood, and, as such, may well influence help-seeking behaviours, effectiveness of treatment and medication compliance.

## **2.4 Interventions for Schizophrenia**

Interventions for schizophrenia are broad, and often include medical, cultural and psychosocial interventions. Material and emotional support from families and communities is equally important.

### **2.4.1 Medical interventions**

Medically, there are a variety of treatment approaches that can be used. Antipsychotic drugs are the first line of treatment for schizophrenia. Clinical guidelines have demonstrated the effectiveness of the drugs in terms of reducing the psychotic symptoms (Morrison et al., 2014). Although medical interventions have been found to be effective, studies have indicated that non-adherence to antipsychotic medication is a frequent challenge in the management of schizophrenia, and can lead to increased risk of relapse, reduced quality of life as well as higher economic costs for inpatient care. Non-adherence not only has implications for patients, but also frustrates families who themselves need care and support (Haddad, Brain, & Scott, 2014; Higashi. Medic. Littlewood. Diez. Granström & De Hert, 2013).

Despite evidence the effectiveness of medication in reducing psychotic symptoms, studies have shown that there is no standard treatment for cognitive deficits in schizophrenia (Lett, Voineskos, Kennedy, Levine & Daskalakis, 2014). Cognitive deficits can profoundly impact on an individual's insight and judgement of their condition as well as their social and

occupational functioning (Turner et al., 2014). In this regard, studies have described advances in psychosocial interventions that target social cognitive deficits (Moncrieff, 2015).

## **2.4.2 Psychosocial interventions**

Studies have provided evidence that psychosocial interventions are an important component in the treatment and care of schizophrenic patients and their families. Psychosocial interventions include group therapy, cognitive rehabilitation, psychoeducation and social skills training (Brooke-Summer, 2015; Moncrieff, 2015). Moncrieff (2015) stated that a combination of pharmacological and psychological interventions promises better outcomes when treating people with schizophrenia, and seem to improve their prognosis and have positive impact on families as well.

### ***2.4.2.1 Psychosocial interventions for patients***

Psychosocial interventions for persons diagnosed with schizophrenia have been reported to have the potential to reduce the number of relapses, reducing hospital readmission and promoting medication adherence (McFarlane., 2016). In particular, Brooke-Summer (2015) stated that cognitive behaviour therapy and other forms of psychosocial intervention were found to have potential in improving personal and social functioning for diagnosed persons, although a study showed that, in the case of CBT, they did not have significant effect on reducing the amount of distress associated with psychosis (Jauhar et al., 2014). It is important to note, moreover, that these interventions are proposed as adjuncts rather than alternatives to drug treatments.

### ***2.4.2.2 Psychosocial interventions for caregivers***

Schizophrenia exerts a substantial burden on caregivers because they provide support in many ways including emotional, physical and financial (Wankiiri et al., 2013). Studies have

suggested that a lack of social support for families is associated with high level of psychological distress (Kate, Grover, Kulhara, & Nehra, 2013; McFarlane, 2016). Perhaps unsurprisingly, then, psychosocial interventions for families are reported to effectively improve the experience of caring and the quality of life of caregivers of people with schizophrenia, reducing their psychological distress (Yesufu-Udechuku et al., 2015). Despite this, Hayes et al. (2015) found, in a study of quality of life and social isolation among caregivers of adults living with schizophrenia, that families continue to live with negative caregiving experiences and poor quality of life because of lack of assessment of their needs which has led to few or inappropriate services being rendered.

In South Africa , several studies have emphasised that appropriate community-based psychosocial rehabilitation interventions are a crucial element of social support for families and for mental health service development (Brooke-Sumner et al., 2014; Monyaluo et al., 2014). Of particular interest to this study, however, Brooke-Summer (2015) suggested that further mobilisation of families or caregivers in such interventions would improve the current psychosocial interventions available. Participation in support or psychosocial groups has been particularly mentioned as benefiting families (Urizar et al., 2014).

Maura and de Mamani (2017) stated that group therapy is another form of psychosocial intervention that has attracted interest as it has been deemed more time- and cost-effective. They report that it allows a greater number of individuals to be treated simultaneously, and that it is more efficacious and promotes greater interpersonal relationships than other psychotherapeutic interventions. However, although group-based psychosocial treatments have been found to provide benefits to patients and their families, studies have also shown that there are very few culturally-informed group treatments for schizophrenia and even fewer programs attend to the needs of both patients and family (Asmal, Mall, Emsley, Chiliza, & Swartz., 2014; Maura & de Mamani, 2017; Segredou et al., 2012).

Literature on the effectiveness of group cognitive behavioural therapy (CBT) and group-based psychoeducation for individuals with schizophrenia and their families has found that family members involved in the group program demonstrated improved family communication and greater confidence in their ability to help their loved one and reduce the burden of care (Segredou et al., 2012; Maura & de Mamani, 2017). It has further indicated effectiveness in terms of improving subjective quality of life. In South Africa, Asmal et al. (2014) also found that family group therapy was effective for individuals with schizophrenia and their families. Similarly, Sin and Norman (2013) conducted a review of group psychoeducational interventions for family members of individuals with schizophrenia which showed improvements in knowledge about the illness and coping. However, their study also reported less consistent findings regarding the impact of psychoeducation on family burden and expressed emotion, a measure of criticism, hostility, and emotional support.

Notwithstanding promising findings on the impact of group-based psychoeducation on patient and family member functioning, these interventions appear to be limited as very few programs include both patients and family members in treatment simultaneously (Segredou et al., 2012). Furthermore, Brooke-Summer, (2015) argued that the acceptability and feasibility of what interventions do exist are compromised by material inappropriate for clients' language and level of education, as well as a lack of consideration of clients' traditional explanatory models of illness and significance of religion as a coping mechanism. In addition, Owen et al. (2015) also emphasised limitations in the methodological quality of studies regarding the effectiveness of group-based intervention due to the inconsistency of a results and a lack of clarity as to whether the effects persist over time. This study will assist in expanding understanding of the role of families in the treatment process of their ill relatives and how caregivers can be better assisted with difficulties they are faced with

## **2.5 Challenges Associated with Living with a Person with Schizophrenia**

Schizophrenia is a multidimensional psychiatric diagnosis which has been explored in almost all cultures and socioeconomic groups throughout the world (Marsella & White, 2012). Caring for a relative with schizophrenia is associated with multiple challenges including emotional, financial, and sociocultural challenges (Opoku-Boateng et al., 2017). These challenges have a negative impact on the quality of care provided by families to their ill relative, and also affect family members' adjustment and coping with the caregiving process (Bignall, Jacquez, & Vaughn, 2015). These challenges are explored in more detail below.

### **2.5.1 Psychological and emotional challenges**

The World Federation of Mental Health (2010) issued a report arguing that caring for those with chronic conditions requires tireless effort, energy, empathy, and unquestionably impacts greatly on the daily lives of families. A study which focused on the psychosocial problems of families caring for relatives with mental illness (Iseselo, Kajula, & Yahya-Malima, 2016) found, amongst other things, that families experience daily stress due to the unpredictable and bizarre behavior that accompany a family member's mental condition. Additionally, due to the stigma attached to mental illness, affected families experience feelings of isolation, frustration, guilt, and become conflicted about their caregiving role (Iseselo et al., 2016). Frustrations also abound due to a lack of emotional and social support (Hayes et al., 2015).

Koujalgi and Patil (2013) conducted a comparative study on family burden of patients with schizophrenia and depressive disorder, and found that the family burden is significantly higher in patients with schizophrenia compared to that experienced by families caring for individuals with other mental or physical health problems. Caring for a family member with schizophrenia often results in high degrees of self-conscious emotions (shame and guilt/self-

blame), burden, and other serious mental health consequences such as depression (Weisman de Mamani., & Suro, 2016). All these challenges impact on the quality of care (Ozkan, Erdem, Ozsoy, & Zararsiz, 2013). Lack of psychological support for families or caregivers of patients may therefore compromise their quality of support towards their ill relative.

In South Africa, studies have similarly showed that families living with people diagnosed with schizophrenia experience serious psychosocial and emotional problems (Hogan & John-Langba, 2016; Lippi, 2016). Monyaluoe et al. (2014) conducted a study in Free State Province on the lived experiences of families living with mentally ill relatives and found that lack of community-based mental health services, rejection, and stigma by the community made caring difficult and resulted in psychological and emotional problems for families.

Research has indicated that certain cultural practices and values (e.g., spirituality, collectivism) may assist family members in coping with the self-conscious emotions and burden associated with caregiving (Deshpande, et al. 2018; Opoku-Boateng et al. 2017). However, studies on the lived experiences of families living with a mentally ill patient and attending support groups are generally lacking, although one study by Hogan and John-Langba, (2016) has found that one of the most common coping mechanisms used by families was attending support groups. It is against this background that the present study explored the lived experiences of families who are also attending support groups.

### **2.5.2 Gender differences in caregiving**

Recent studies on caregiver-burden in schizophrenia have mainly focused on parents (usually mothers), followed by spouses and siblings of patients (Opoku-Boateng et al. 2017; Urizar et al., 2014). Evidence from this research has indicated a significant correlation between gender in caregiving and the level of burden. A number of these studies (Ae-Ngibise, Doku, Asante & Owusu-Agyei, 2015; Geriani., Savithry., Shivakumar., & Kanchan, 2015; Urizar et

al., 2014) have reported higher levels of caregiver-burden, stress, burnout, psychological morbidity and poorer quality of life among female caregivers of those with schizophrenia. In their review of caregiver-burden in schizophrenia, Urizar et al. (2015) noted that being female, being unemployed and more time spent in caregiving were all associated with higher burden. However, other studies have found no gender differences in overall burden, objective burden, subjective burden, worry, fear, or stigma (Geriani et al., 2015; Sharma, Chakrabarti, & Grover, 2016)

Several theories have been advanced to explain gender differences among caregivers. Sociological explanations have emphasised expectations of traditional gender roles, in which women are expected to adopt the role of a caregiver (Sharma et al., 2016). According to this view, this is ingrained in females through their social and cultural experiences starting from childhood, and leads to a different approach to caregiving compared to men. Sharma et al. (2016) argued that men may also be less adept at expressing their difficulties or emotions. Additionally, theories of segregation of labour have argued that, since women are more likely to stay at home, it is natural for them to take up the caregiver role (Fitzsimons. 2017).

### **2.5.3 Socioeconomic challenges**

Study results have revealed that financial constraints, lack of social support, disruption of family functioning, stigma, discrimination, and patients' disruptive behaviour are some of the major challenges families are faced with (Opoku-Boateng et al., 2017; Monyaluo et al., 2014). However, some study findings have highlighted financial constraints as posing a greater burden than other areas mentioned above (Ae-Ngibise et al., 2015; Laidi et al., 2018). Socioeconomic status seems to have significant correlation with high level of burden or negative experience for caregivers. Studies conducted in Nigeria and Ghana support this claim

in that households with low income caregivers were found to experience extra burden due to competing needs of their ill relative and their inability to be gainfully employed.

These findings are in line with scholars who have argued that mental ill health and poverty interact in a negative cycle within low- and middle-income countries (Lund et al., 2011) whereby mental illness can inhibit socioeconomic attainment and lead people to drift into a lower social class or never escape poverty (Mossakowski, 2014). For example, people with schizophrenia are unable to hold a job due to the limitations brought about by the condition, especially the cognitive impairment. In these cases, families are required to financially support their ill relatives (Turner et al., 2014). However, their own low economic status may make that difficult and add to their already significant burdens.

A longitudinal study conducted by Ran et al. (2017) demonstrated that persons with schizophrenia from low family economic statuses during the 14-year follow-up period had a significantly higher rate of homelessness and lower rate of survival than those in families with a high economic status. Other studies have similarly indicated that schizophrenic patients with low family economic status had significantly higher rates of living alone, being homeless, being unmarried, having fewer family members, and a greater lack of support than those with high family economic status (Lund et al., 2010; Ran et al., 2017).

Moreover, low socioeconomic status families suffer not only from the burden of caring but also struggle with material support (Donisi et al., 2013). Furthermore, Urizar et al. (2014) hypothesised that socioeconomic status negatively correlates with symptom-severity for people with schizophrenia as well as psychological distress for families. In South Africa, despite the financial support that the South African Social Security Service Agency (SASSA) provides for mental health care users in the form of disability grants, studies have shown that families of the recipients continue to experience challenges caused by living in poverty (Lippi, 2016;

Monyaluoe et al., 2014). Seemingly, Turner et al., (2014) have also argued that the sums allocated are not sufficient to meet the mentally ill's basic needs.

#### **2.5.4 Cultural belief as a challenge**

Research studies suggest that ethnic and cultural factors strongly influence the manner in which family members comprehend and respond to mental illness (Abbo, Okello, Musisi, Waako, & Ekblad, 2012; Bignall et al., 2015; Matsumoto & Juang, 2016; Sorketti, Zainal, & Habil, 2012). Several studies have highlighted the importance of understanding patients and their family's cultural background when treating psychiatric conditions. Hassim and Wagner (2013) have argued that cultural beliefs and attitudes towards schizophrenia are substantially different in South Africa as compared to western societies, and that, consistent with international literature, that those beliefs influence how people respond to mental illness.

It has been demonstrated that, due to negative attitudes and cultural beliefs, patients living with schizophrenia and their families are often stigmatised and ostracised (Hassim & Wagner, 2013; Singh, Mattoo, & Grover, 2016). The causes of psychiatric stigma identified include misconceptions about mental illness, as well as traditional, religious and medical explanatory frameworks (Yang et al., 2013; Nxumalo, & Mchunu, 2017). As a consequence, mental illness stigma results in damaging internalisation of stereotypes, concealment of illness, and other harmful psychological outcomes for both mental health care users and their caregivers (Zolezzi, Alamri, Shaar, & Rainkie, 2018). A major concern is that stigma associated with mental illness leads to delays in help-seeking and threatens adherence to treatment (Nxumalo, & Mchunu, 2017; Burgess, 2016). In addition, Burns, & Tomita (2015) suggest that individuals who seek help for mental disorders from traditional and religious healers tend to delay access to western form of intervention.

## **2.6 Theoretical Frameworks**

According to Creswell (1994), the choice of a theoretical framework should provide a common worldview or lens from which one supports the research problem and analysis of data. In this study, two lenses were adopted. Firstly, Bowen's family system theory provided a perspective on the influence of family dynamics in relation to caregivers' experiences, whereas coping theory assisted the researcher in understanding coping strategies employed by those living and caring for a family member diagnosed with schizophrenia.

### **2.6.1 Bowen's Family System Theory**

Bowen's family system theory is a theory of human behaviour that views a family as an emotional system and uses a system's thinking to describe the complex interactions in the unit (Haefner, 2014). This theory's basic assumption is that a family is an interrelated system, and that an individual within it cannot be understood in isolation. Bowen posited that families are not simply groups of independently functioning individuals, but rather a system wherein changes in one-part influence other interrelated parts (1966). Therefore, when one family member's behaviour changes, it often produces changes or heightened tension/anxiety in other members. Family members could react either positively or negatively to this change. Accordingly, changes that occur in families during times of heightened tension may lead to conflict, dysfunction, impairment, and/or emotional distancing between family members (Bowen, 1966). This theory helps in the understanding of family interactions or dynamics' influence on the onset or perpetuation of mental illness in families (Goldenberg & Goldenberg, 2012).

Bowen (1966) hypothesised that schizophrenia is a manifestation of a process that involves the entire family system, i.e., it is the reciprocal functioning of all the members of the family which contributes to the emotional intensity of the patient. In essence, the emotional

symptoms of an individual are an expression of dysregulated emotions in a particular family, which are often embedded in patterns of behaviours from past generations. Accordingly, families play a role both in terms of aetiology and treatment of conditions such as schizophrenia.

In the context of this study, the application of the theory assisted in the understanding of changes brought about the ill family member to his/her family system. The theory assisted the researcher to understand the impact of the patient's mental condition on his/her caregiver. This included understanding primary caregivers' lived experiences, including coping mechanisms. Amongst other issues that this framework enabled the researcher to understand is how caregivers in response to the stress and anxiety of caring for an ill family member express their experiences and communicate the distress. In essence, this theory helped the researcher to understand caregivers' experiences as a direct outcome of systemic changes brought about by a family member's mental condition.

### **2.6.2 Coping Theory**

Folkman and Lazarus (1988) proposed one of the most comprehensive theories of stress and coping in psychological literature. In this model coping is defined as the use of effortful strategies to adequately adapt to particular situations appraised as overwhelming to one's normal resources. Based on these appraisals, individuals develop adaptive and/or maladaptive coping strategies to deal with the condition (Folkman & Lazarus, 1988). In contrast, stress is viewed as a dynamic relationship in that it continues to change as a function of the person acting on the environment and the environment acting on the person (Folkman & Lazarus, 1988). In evaluating an event, individuals use both primary and secondary appraisals. With primary appraisal, individuals assess whether a transaction with the environment is caring, challenging, or threatening, while with secondary appraisal, individuals evaluate what

resources and choices they have in the context of the transaction. The overall process is not considered to be one unfiltered stream of consciousness but rather one in which each concept can influence another (e.g., knowledge of an adequate coping strategy may lessen the perceived threat). In conjunction, the behavior of coping with an environmental stressor occurs regardless of whether or not the coping behavior is successful in relieving the threat (Lazarus & Folkman, 1984).

Pearlin, Mullan, Semple, and Skaff (1990) used this framework in developing their model specific to the context of caregivers and their stressors. Within the caregiver stress model, stressors are the varying experiences and situations that caregivers struggle to adapt their resources to adequately handle the stress. The stressors involved in caregiving include primary stressors (e.g., behavioral disturbances, dependence of activities of daily living, cognitive status) that directly influence the relationship between the caregiver and the person cared for, while secondary stressors (e.g., economic strain, occupation or social conflicts) are experienced indirectly by caregivers. Pearlin et al. (1990) described coping strategies (along with seeking social support) as mediators in the coping process or caregiver health outcomes. Therefore, the caregiver stress model suggests that problems that are not adequately addressed will increase the likelihood of a lower quality of life and declines in caregiver health (Pearlin et al., 1990).

Lazarus and Folkman (1984) outlined two predominant strategies or forms of coping which are categorized as “problem-focused” or “emotion-focused” strategies. Problem focused coping strategies rely on implementing behaviors that involve manipulating or changing the stressor(s) within the environment. This may include strategies such as seeking others for help, confrontation of a stressor, changing behaviors in a situation and removing (or adding) influential elements to the environment (Lazarus & Folkman, 1984). In contrast, emotion-focused coping strategies are expressed inwardly as a person tries to attenuate the emotional

distress considered to be brought on when in contact with a stressor (Lazarus & Folkman, 1984). For example, strategies such as avoidance or distancing of unwanted emotions, venting of emotions to friends, support groups and acceptance of feelings in unchangeable situations (Folkman & Lazarus, 1984). Applying the theory's basic tenets, the researcher was better placed to understand how caregivers cope.

## **2.7 Summary**

This chapter gave a general overview of the literature reviewed for the study. In particular, empirical studies on schizophrenia, its aetiology, and management have been presented. A greater detail has been on the interrogation of the lived experiences of caregivers involved in support groups whilst caring for a family member diagnosed with schizophrenia. Subsequently, the focus was on the theoretical frameworks (i.e., Bowen's family system theory and Folkman and Lazarus's coping theory) which guided the study. Towards the end, the review focused on challenges associated with caring for persons diagnosed and living with schizophrenia.

## **Chapter 3: Methodology**

### **3.1 Introduction**

The present chapter outlines the study methodology. The following methodological issues are discussed: the study paradigm, research design, and the methods of sampling, data collection and data analysis employed. Study quality criteria and ethical considerations are also covered in this chapter.

### **3.2 Research paradigm and design**

A research design is “a plan or procedure for research that covers methods of data collection and data analysis, and it involves the intersection of theoretical assumptions and strategies of inquiry” (Creswell & Zhang, 2009, p.95). Considering that the study aim was to explore the views, meanings, and interpretations of participants, the study was guided by the interpretivist paradigm. Interpretivism asserts that reality consists of people’s subjective experiences of the external world; thus, interpretivists may adopt an inter-subjective epistemology and the ontological belief that reality is socially constructed (Willis, Jost, & Nilakanta, 2007). In line with the basic tenets of this paradigm, the researcher was able to qualitatively explore the world of human experience through the participants’ rich insights, interpretations, and descriptions (Willis et al., 2007).

Methodologically, the qualitative approach was found suitable in that it allowed the researcher to “systematically and empirically inquire into participants meaning creation” (Ospina, 2004, p.1279), with the aim of achieving an understanding of how the participants made sense of their lived experiences (Merriam, 2009). Qualitative approaches often result in

the rich reports that are necessary for interpretivists to fully understand contexts (Willis et al., 2007).

For generation of knowledge, a hermeneutic phenomenological design was employed as it is concerned with the life worlds or people lived experiences. With this design, the focus is on enlightening details and seemingly unimportant aspects within experiences that may be taken for granted in people's lives, with the goal of creating meaning and achieving a sense of understanding (Wilson & Hutchinson, 1991).

### **3.3 Study setting and sample**

The study participants were caregivers involved in support groups either at the Talisman Foundation or Thandanani Care Centre in the Gauteng Province. The Talisman Foundation is a psychosocial rehabilitation centre which was established in 1979. It is a non-governmental facility situated at The Hill, south of Johannesburg. The foundation accommodates up to 200 people diagnosed with mental health conditions such as schizophrenia, depression, bipolar mood disorder, and personality disorders (Talisman Foundation, 2017). Their services include vocational skills training as well as support groups for both residents and their families. In contrast, Thandanani Care Centre is a non-governmental organisation which was established in 2001. The centre is licensed to accommodate 65 people diagnosed with severe mental disorders such as schizophrenia and bipolar mood disorder (Thandanani centre, 2016). The centre also provides psychosocial support for both residents and their families.

### **3.4 Population and sampling**

The targeted population was primary caregivers of persons diagnosed with schizophrenia and currently attending support groups either at Talisman Foundation or Thandanani Care

Centre. Sampling was conducted from the two settings. A sample in qualitative research consists of cases or units of elements that will be examined, and are selected from a defined research population (Patton, 2002). In this study, the researcher used purposive sampling method to select caregivers of a relative diagnosed and living with schizophrenia, specifically those who participated in support groups offered within the two centres. According to Silverman (2015), in purposive sampling, a particular case is chosen because it illustrates some features or elements that are of interest for analysis. A total of 14 primary caregivers were initially identified for inclusion from the target population. However, after contacts were made, only 10 agreed to participate in the study.

### **3.5 Data collection tool and procedure**

Data were collected using individual semi-structured interviews that utilised an interview guide (see Appendices 1A, 1B and 1C) and the content of interview guide were translated into Setswana and Isizulu. The use of interviews in qualitative research provides a deeper understanding of social phenomena than would be obtained from purely quantitative methods such as questionnaires (Terre-Blanche, Durrheim & Kelly, 2006). A total of ten semi-structured interviews were conducted with consenting participants. Before participants could be approached, the researcher gained permission by consulting both centres to request approval to conduct the study (see Appendices 3A and 3B). Upon gaining permission, a list of caregivers meeting the study criteria (i.e., being a caregiver to a family member diagnosed and living with schizophrenia, and also being involved in a support group offered in one of the centres) was compiled and given to the researcher by the centres' registered counsellors. Subsequently, the researcher contacted all ( $n = 14$ ) caregivers on the list provided to request their participation, and informed them about the study purpose.

Out of the 14 contacted, only 10 volunteered to participate in the study. Face-to-face individual appointments were then scheduled with the 10 participants. The interviews took place in their households, occupational settings, and some at the health care centres. Four interviews were conducted in English, another four were a combination of English and Zulu and the other two were a combination of English and Setswana. During the interviews, the researcher also took field notes. All interviews were audio recorded and later transcribed verbatim. The researcher translated all interviews into English with the assistance of Zulu- and Setswana-speaking registered counsellors in the facility. The researcher was in the company of an assistant (a registered counsellor) in all scheduled appointments for debriefings in the event that some participants needed such services. Seven participants made use of the debriefing services after the interviews.

### **3.6 Data analysis**

Interpretive Phenomenological Analysis (IPA) was used to derive meaning from the transcribed individual interviews. The aim of IPA “is to give evidence of participants’ making sense of the phenomenon under investigation and at the same time document the researcher’s perception” (Pietkiewicz & Smith, 2014, p. 7). Following Pietkiewicz and Smith (2014), the following four IPA steps were employed:

**Step 1: Multiple readings:** In the first step, the researcher familiarised herself with the data by reading through the transcripts and listening to the recordings. The researcher read through the texts several times while attempting to suspend presumptions and judgments in order to focus on what was actually presented by each interviewee.

**Step 2: Transforming notes into emerging themes:** In the second step, the researcher continued to read through the text whilst identifying themes that best captured the essences

reflecting the phenomenon under investigation. Furthermore, the researcher identified themes from within each section of the transcripts, and sought possible connections between them. This process was done with the research objectives in sight so as to ensure that the data truly addressed the set study aim.

**Step 3: Seeking relationships and clustering themes:** The third stage involved attempting to identify the holistic context that informed the participants' narrative of their lived experiences. The researcher provided an overall structure to the analysis by relating the identified themes into 'clusters' or concepts. For instance, the researcher marked concepts in the text with different colors. The aim, at this stage, was to arrive at a group of themes and to identify categories that suggested hierarchical relationships between them. The themes were therefore arranged in an ordered system that identified the main features or concerns identified by the participants. Excerpts to illuminate the themes were also isolated.

**Step 4: Writing up an interpretive phenomenological analysis:** The last stage involved the writing up of a narrative account of the study (refer to chapter 5). This stage involved transforming the participant's expressions into expressions appropriate to the scientific discourse supporting the research (Pietkiewicz & Smith, 2014, p.8). In this step, the researcher drew attention to the main aim of qualitative research, which is interpreting the subjective opinions of research participants from a contextual point of view. The researcher also compared the obtained data with that outlined in the literature review outlined in Chapter two.

### **3.7 Quality criteria**

Qualitative approaches have been widely recommended for studies of this type; however, they have been criticised for lacking accuracy and rigour. Therefore, for a qualitative study,

trustworthiness becomes a crucial aspect that needs to be addressed. Shenton (2004) recommended that, for a qualitative study to be trustworthy, it should satisfy the quality criteria of credibility, transferability, dependability, and confirmability. These qualities were observed in this study as outlined below so as to improve the study trustworthiness.

### **3.7.1 Credibility**

Tracy (2010) stated that credibility refers to the trustworthiness and plausibility of the research findings. Credibility of research findings is earned through reliability, replicability, consistency, and accuracy (Golafshani, 2003). To ensure credibility in the present study, the researcher followed appropriate steps in data gathering, data analysis, and reporting to ensure that the findings reflect the aims of the study. In addition, due to the diversity in language among participants, the researcher consulted with Zulu- and Setswana-speaking professionals for translation to English to ensure credibility.

### **3.7.2 Transferability**

Quality also emerges through a study's potential to be valuable and applicable across a variety of context or situations (Tracy, 2010). De Vos et al. (2011) described transferability as another method to ensure external validity or generalisability. To ensure transferability in the present study, the researcher has provided sufficient detail of the context of the study for a reader to be able to decide whether the prevailing environment is similar to another situation with which he or she is familiar.

### **3.7.3 Dependability**

Dependability refers to stability over time. Guba and Lincoln (1985) argued that, if the work was to be repeated in the same context with the same methods and participants, similar results should be obtained to ensure reliability. By clearly stating the steps followed in the

present study, which included obtaining ethical clearance and approval from the psychosocial rehabilitation centres, the researcher sought to provide a measure of dependability. The researcher further ensured dependability by audio-recording the interviews as well as taking field notes during the entire data collection process.

#### **3.7.4 Conformability**

Anney (2014) stated that confirmability refers to the degree to which the findings of the study can be confirmed or verified by other researchers. Confirmability ensures that data and interpretations of the findings are not figments of the researcher's imagination but are clearly derived from data (Shenton, 2004). In the current study, the researcher followed recommended steps in analysing and reporting the data. Furthermore, the results were analysed and reported in conjunction with existing literature.

### **3.8 Ethical considerations**

#### **3.8.1 Permission for the study**

The researcher obtained ethical clearance from the University of Limpopo's Research and Ethics Committee (Ref: TREC/363/1018: PG) before the study was conducted (see Appendix 4). The researcher also approached the two-mental health rehabilitation centres (Talisman Foundation and Thandanani Care Centre) and sought permission before interacting with consenting participants (see Appendices 3A and 3B for letters of request).

#### **3.8.2 Informed consent**

Before the interviews ( $n = 10$ ) were conducted, the researcher sought and obtained written informed consent from each of the participants. Participants were informed that

participation was voluntary, that they were free to withdraw from the study at any time, and that there would have been no implications should they have withdrawn their participation at any given point (See Appendices 2A, 2B and 2C). For instance, the researcher respected some of the participants who initially were approached but declined participation.

### **3.8.3 Privacy, anonymity and confidentiality**

Privacy, anonymity, and confidentiality were maintained and adhered to throughout the study taking into consideration the best interest of each participant. The tape recordings and notes taken during the interviews were accessed only by the supervisor and the researcher. The researcher assured the participants that in all documents they would be referred to by number and demographic characteristics such as ethnicity, gender, age, occupation would be used rather than names to ensure anonymity, privacy and confidentiality.

### **3.8.4 Aftercare for the participants**

Due to the nature of the study, it was expected that it might evoke unpleasant emotions. In view of that, an arrangement was made with the facilities' registered counsellors for containment and debriefing. As mentioned above, the researcher was assisted by a registered counsellor in all scheduled appointments for the containment and debriefing of all participants who needed the services.

## Chapter 4: Results

### 4.1 Introduction

In this chapter, study findings are presented. The term *participant* is used instead of the real identity of the individuals participating in the research. To ensure that participants can be easily differentiated in the research without being identified, they have each been given a number. In the first part of the chapter, the demographics of participants and cared-for patients will be presented. This will be followed by a presentation of the emergent themes and subthemes.

### 4.2 Demographic Profile of Participants

Table 1: Demographic information of caregivers and cared-for patients

Caregiver Characteristics	#	Cared Patient Characteristics	#
<b>Gender</b>		<b>Gender</b>	
Female	9	Female	2
Male	1	Male	8
<b>Age Range</b>		<b>Age Range</b>	
35-45	1	20-35	3
45-55	1	35-45	7
55-65	6		
65+	2		
<i>n = 10; Mean; 57.2; S.D = 10.7</i>		<i>n = 10; Mean; 36.2; S.D = 6.6</i>	
<b>Ethnicity</b>		<b>Ethnicity</b>	
Black	7	Black	7
White	2	White	2
Indian	1	Indian	1
<b>Marital Status</b>		<b>Marital Status</b>	
Single	2	Single	8
Married	3	Married	1
Widowed	2	Widowed	0
Divorced	3	Divorced	1
<b>Education</b>		<b>Education</b>	
Junior	0	Junior	1
Senior	6	Senior	3
Tertiary	4	Tertiary	6
No formal education	0	No formal education	0
<b>Occupational Status</b>		<b>Occupational Status</b>	
Employed	3	Unemployed	10
Self-employed	0		
Pensioner	5		
Unemployed	2		

<b>Caregiver Characteristics</b>	<b>#</b>	<b>Cared Patient Characteristics</b>	<b>#</b>
<b>Relationship to Patient</b>		<b>Relationship to Caregiver</b>	
<i>Biological Parent</i>	8	<i>Siblings</i>	2
<i>Biological Sibling</i>	2	<i>Son/Daughter</i>	8
		<b>Duration of diagnosed condition</b>	
		<i>0-5 years</i>	2
		<i>10 years and above</i>	8
		<i>n = 10; Mean; 8.7; S.D = 2.6</i>	

Table 1 reveals that a total of 10 caregivers (Females = 9; 35-65yrs.; mean age 57.2yrs.; S.D of 10.7) participated in the study. In their majority ( $n = 8$ ), participants were biological mothers to the cared patient. Seemingly, most ( $n = 5$ ) were pensioners followed by those who were employed ( $n = 3$ ). Their ethnicity distribution was dominated by blacks ( $n = 7$ ), followed by Whites ( $n = 2$ ) and Indians ( $n = 1$ ).

With regard to the demographic characteristics of cared patients ( $n = 10$ ; males = 8; 20-45yrs.; mean age 36.2; SD of 6.6), most of them were single ( $n = 8$ ) while all the ten were unemployed. This was despite six of them having a tertiary qualification. In their majority ( $n = 8$ ), they have been diagnosed and living with schizophrenia for more than 10 years.

### 4.3 Emergent themes

Three main themes, each with related subthemes, emerged from data analysis. The super-ordinate themes to emerge were the following: a) psychological and emotional challenges, b) challenges associated with caregiving, and c) caregiver coping mechanisms. These, along with their subthemes, will be described below with supporting participant interview extracts provided in italics.

### **4.3.1 Psychological and emotional challenges**

The analysed data revealed that caring for a family member diagnosed and living with schizophrenia is a psychologically distressful experience. This was reported by all participant caregivers. This finding is presented under two subthemes: a) psychological distress, fear, and anxiety, and b) caregiver burden.

#### ***4.3.1.1 Psychological distress, fear and anxiety***

Caregiving was reported to be an experience which comes with a plethora of psychological and emotional difficulties. Caregivers experienced the process as painful, and they associated it with a constant experience of psychological distress. Amongst some of the emotional experiences reported were feelings of anxiety, anger, sadness, hopelessness, and frustration. Participants reported that caregiving and the resultant psychological distress ended up interfering with their day-to-day functioning. Some of their experiences are captured below:

*It is so painful for me as a parent to see my daughter's future fading, I don't understand this schizophrenia, I don't think she is like other schizophrenic people.*

*I am a nurse I know schizophrenia; I have seen people go crazy. And, she is difficult sometimes I almost got admitted for depression.. (Participant 10, 58 yrs. Female)*

*I was fighting a losing battle. I was getting sick I was going through depression and like I said my son couldn't help, my daughter couldn't do it on her own..*

*(Participant 4, 68 yrs. Female)*

A 30-year-old female carer to her 37 year-old-sister expressed that the caring role was emotionally overwhelming, and, in her case, family relations were also strained following witchcraft accusations directed at her mother. She reported that some family members blamed her mother for her sibling's mental illness. She said:

*It has caused a lot of stress, a lot of heartbreak, you know when you think about it sometimes. What can I do to make all of this to go away and sometimes you can think of committing suicide. It makes me very sad because I didn't get to experience having an older sister, I had to grow fast to become her elder sister instead.*

**(Participant 8, 30 yrs. Female)**

Some caregivers seemed frustrated by not knowing what caused their family members' condition. Added to this, they recounted experiences of stress and fear experienced due to unpredictable aggressive behaviour associated with their family member's mental condition, especially since some of the violent behaviour was directed at family members and their property. This finding is further supported as follows:

*There are so many challenges and stress that we have been experiencing, because he just changes unexpectedly without our understanding of what is happening, he gets aggressive, he does not listen when spoken to, he wants to fight us and his siblings also did not understand him and they were impatient with him.*

**(Participant 3, 66 yrs. Female)**

*When he starts getting aggressive especially at night I would wake up and sneak out and then leave for an hour or two, and park my car at the police station. I take a blanket with and I would stay there an hour or 2 and then I would come back to the house then I think he's probably okay. I would also be thinking to myself that I am not sure whether I was going to be the one to be killed or what. It is stressful and frustrating I don't want to lie, before he sleeps sometimes he will wake up and break things, windows, car windscreen. (Participant 1, 47 yrs. Female)*

*We fear for our lives when he is unwell he threatens to kill us, he breaks windows and he becomes very violent, uncontrollable, and we always have to call the police for assistance. (Participant 7, 57 yrs. Female)*

*The challenge is that I own nothing, I own nothing ...I have a car but I watch it being damaged every time, it's not on...I ended up giving it up and am now using public transport. (Participant 1, 47 yrs. Female)*

The findings also revealed that caregivers were not only stressed and concerned about their own safety but also the safety of their ill relative. This is because their relative would often disappear from home, act on their delusions, and at times, be assaulted by community members or get arrested.

*He has a tendency of disappearing which worries me, there was a time 2-years ago that we looked for him everywhere, hospitals, mortuaries, and prisons. How do you eat and sleep not knowing where your child is? You worry of his safety? (Participant 7, 57 yrs. Female)*

*As it is, I am worried I don't know where he is, I haven't seen him in weeks. He is not safe out there. (Participant 1, 47 yrs. Female)*

*As a parent I had to be strong, but I am always stressing, if he goes out I am not sure how he will be when he comes back, if he is safe, or if he will get into fights. (Participant 3, 66 yrs. Female)*

#### **4.3.1.2 Caregiver burden**

A further analysis revealed that most caregivers experienced caregiving as burdensome. The majority of them intimated that the burden significantly impacted on their quality of life. One female participant aged 43 years-old and caring for two siblings living with schizophrenia had this to say:

*It is a burden, am not going to lie, it is a burden because to some degree I feel that I should have been far in life, I never wanted to stay in place where I grew up for the rest of my life. Whenever I step in my mother's house I get frustrated because it was never my dream to live in there forever. Not that it's a bad house but it was just never my dream and but if she was allowed to create her dream, why am I not? - This is the only sad thing. (Participant 1, 47 yrs. Female)*

*I gave up most of my time because I was going back and forth almost the whole week to the education campus for him. And then I would go to a library and sit there until he's done with his classes. This also cost me petrol and affected my relationship with my wife. (Participant 6, 61 yrs. Male)*

*It is the responsibility I had to assume after the passing of my father, I worry all the time about when will I have a life of my own, what would happen if for instance I get married. My sister and my mother do not get along at all. (Participant 8, 30 yrs. Female)*

Another burden reported had to do with the amount of time caregivers had to devote to caring for an ill relative. One respondent reported the frustration associated with the sporadic disruptions that come with the illness, and by which one's daily routine gets affected. How caregivers' daily living becomes burdened by the relative's condition is further elaborated as follows:

*I went to Mauritius for two weeks because my father was turning 105 years old. I recently got a message from relatives in Mauritius saying that things are bad, my father might die any time in the next month or two months. So I had to go, but I worry about leaving my wife alone with all this burden because we cannot all go and leave my son alone. (Participant 6, 61 yrs. Male)*

*When he is here, in the house, there must be someone that is looking after him. And it is difficult for me because I am self-employed and I need to work the whole day.*

***(Participant 2, 67 yrs. Female)***

Another source of burden reported had to do with the mentally ill persons' inability to live an independent life. Consequently, their survival is fully dependent on the carers. Carers had to provide for their basic needs including offering them support. Due to this, most of the participants reported constantly worrying about the sustenance of their relatives in the event that they died. This was expressed more by elderly women whose sons were still young. This is despite their sons being educated because they were unemployable because of their mental illness.

*I also worry a lot as parent that he would never be able to take care of himself or be independent, and I am growing old. (Participant 3, 66 yrs. Female)*

*Who's going to support him throughout his life? We try to economize a bit, we economize for the day we die, so that he can have a little bit of money left. (Participant 6, 61 yrs. Male )*

*One thing you certainly realise is that he is going to be your responsibility and your financial burden forever. I've got another son you know, so we have to put him as a trustee, and he will have to oversee the finances. Because he [ill son] got absolutely no idea". (Participant 5, 59 yrs. Female)*

Caregivers also reported the burden of having to constantly be dealing with emergencies involving the police or hospitals due to the unpredictable nature of the illness. Most caregivers reported travelling between hospitals and prisons to look for or visit an ill family member. This was echoed by a 67-year old mother to a 41-year-old son who disappeared from home and was

later arrested acting on his delusions. She further reported traveling between hospitals and prisons looking for him. This is what the caregiver had to say:

*I went twice to Boksburg and they told me that he was not there. I even went to the head - offices and they went through all their books and computer records and he was not in the system. I even asked them to check the hospital files or whatever. I returned home, and that's when he called and said; I am in Boksburg and I am going to court. The ups and downs are tiring, frustrating, and costly you know.*  
**(Participant 2, 67 yrs. Female).**

Another caregiver told a similar story:

*It is too much work, sometimes you spend the whole month looking for him, running up and down hospitals and prisons. I stopped working because I was forever not at work and I cannot divide myself into two, he is a full time job, a difficult job.*  
**(Participant 7, 57 yrs. Female)**

### **4.3.2 Challenges associated with caregiving**

Study participants identified four key challenges associated with caring for a family member living with schizophrenia. These are, a) a lack of social support, b) socio-economic challenges, c) substance abuse and non-adherence to treatment, and d) cultural beliefs as a challenge.

#### **4.3.2.1 Lack of social support**

Caregivers reported a lack of social support as one of the challenges they encountered in caring for a family member living with schizophrenia. This is because caring for a mentally ill person is both emotionally and financially overwhelming and, thus, they are in need of constant social support. This is expressed below:

*I am all by myself, I have no support and we do not have a father figure which makes it more difficult and stressful. (Participant 2, 67 yrs. Female)*

*His father does not want to offer support in anyway, is just me and my daughter. (Participant 4, 68 yrs. Female)*

The benefits associated with having some social support were reported coming from being a recipient of empathy and encouragement, as expressed below:

*I used to consult with a very good Indian lady, she was very supportive, she used to explain things about his sickness, and she used to counsel me. And all that helped me because I was not coping. It's been 18 years, it's a long time of struggle and stress but now that he is in Talisman there is a peace of mind". (Participant 4, 68 yrs. Female)*

*Look, on my side, from time to time, you know I call my brother in Mauritius and talk to him and my sister about everything, and they ask to see how it's going with him, so I have a bit of support from my family in Mauritius. (Participant 6, 61 yrs. Male)*

The lack of support was not only limited to immediate family members but also extended to the community and government health care facilities. This societal and institutional lack of support resulted in the experience of frustration and difficulties in the caring role. One participant was caring for her two brothers, and one of the brothers was a victim of life Esidimeni tragedy; she shared her experiences as follows: “*The system failed my brother, I found him after sometime somewhere in Soshanguve, the place was horrible, I couldn't recognise him*”. She also remarked as follows about the police officials whenever one of her brothers became aggressive; “*I stopped calling the police when he starts breaking the windows*

*because they do not come, if they do, they would tell me to take him to the Sangoma.*

*(Participant 1, 47 yrs. Female)*

#### **4.3.2.2 Socio-economic challenges**

Financial constraints were reported to be another major challenge in caring for an ill relative. Some caregivers had to rely on government social grants and instrumental support provided by some of their relatives since they were unemployed. The little financial support received went towards sustaining themselves, including providing basic needs (e.g., food, clothes, and cigarettes) for an ill relative. This is what some participants had to say:

*We're struggling financially, he is unemployed and I am trying this business of selling kitchen things, but I have accepted as a parent that I will have to take care and provide for him forever. (Participant 3, 66 yrs. Female)*

*I always worry about finances because it's hard for my daughter, she looks after me, I'm a pensioner, and she's a widow. So I always worry about the financial part of things even though she works very hard. (Participant 4, 68 yrs. Female)*

*Financially, there's much to consider. You know it's not just yourself, you have to consider the third person as well. Definitely a big impact. (Participant 6, 61 yrs. Female)*

Another source of financial challenge had to do with caregivers having to spend money on unplanned travelling costs. This is because caregivers had to constantly travel long distances to hospitals and prisons to visit the cared-for person. Some of the reported unplanned costs included replacement of damages caused by an ill relative whenever mentally unstable. What pained many caregivers the most was that their ill relatives were graduates yet unemployable because of their condition. One reported that it seemed they have wasted money funding their son's studies; instead, they felt they could have saved the monies for their retirement,

*It is a struggle and I had to spend a lot of money travelling. I could not take cooked food from the house to prison. I have to buy food from prison, and prison food is expensive. Whenever I go there, all my money would be spent there. But financially it is hard. When he was transferred to Sterkfontein, it's far, and things got worse.*

**(Participant 2, 67 yrs. Female)**

*And you know also inconsideration that he has graduated, he has an honours in English. If he had done well, he would've been working and we wouldn't have to care for him. All this money we have spent we could have put it aside for our old age. (Participant 5, 59 yrs. Female)*

#### **4.3.2.3 Cultural beliefs as a challenge**

Although some participants reported cultural beliefs as positively influencing their process of caregiving, some reported negative experiences associated with traditional African beliefs. Below are some quotations illustrating their views:

*In my culture my daughter's problem is ancestral, I consulted with Sangoma because I know my daughter does not need this medication and worse part is that it makes her gain weight. She has become a zombie because of this medication.*

**(Participant 10, 58 yrs. Female)**

*It is clearly not a medical issue because when I go to the clinic to handle it the medical way I see no results. Whenever it's his Doctor's appointment they would ask if he is taking his medication, yes! They would ask him, so, why are you being violent? Why are you doing this and that? And he cannot answer.... It is like you are bothering him because is not him that is doing that [being aggressive and claiming that he's an ancestor] so seriously, I do not believe that this sickness is clear cut. (Participant 1, 47 yrs. Female)*

These participants reported that the illness was caused by the patient's ancestors and hence the medication was not working. On the one hand, some families and patients reported that the illness was orchestrated by witches. A sibling caring for her ill sister reported that, as a family, they believed that her sister was bewitched. Consequently, it was difficult for the family to get the appropriate treatment whilst it was also difficult to convince the sibling to adhere to the treatment she received from hospital. She had this to say:

*It is difficult, my sister strongly believe that my mother bewitched her because she is a Sangoma and like I said they don't get along because of that and then more burden and problems for me. Again, my sister does not believe she's sick hence she defaults treatment because she believes that she has a calling, I don't know how many rituals were done to try sort this, I am tired. (Participant 8, 30 yrs. Female)*

There were those participants who expressed that their ill relatives perceived their illness as a calling to become sangomas. However, getting the appropriate intervention was difficult because the patient or their families adopted Christianity which discourages such beliefs and related treatment approaches. Participants, including a sister caring for her two brothers, expressed the frustration of balancing Christianity and ancestral beliefs as follows:

*Both my brothers believe that they have a calling to become Sangomas and my family has a strong history of ancestral practice. My grandmother was a Sangoma. I don't believe in these things, they don't exist. I am a Christian; I believe in Jesus. (Participant 1, 47 yrs. Female).*

*I do not know how many churches and traditional healers we have visited, others said he was possessed with evil spirits, his father thought it was ancestral calling and he never gotten better until now that he is medication. It is difficult you know. (Participant 7, 57 yrs. Female)*

#### **4.3.2.4 Substance abuse and non-adherence to treatment**

Substance abuse and non-adherence to treatment were also reported to have negative implications on the quality of caregiving. Most participants reported unpredictable aggressive behaviours when their ill relatives defaulted on treatment or abused substances. Consequently, caregivers would be distressed by their relative's perceived irresponsible behaviour. The following quotes illustrate this:

*He used to stay in extension 10 in his house and that's the worst area for drug addicts. And they used to let him smoke dagga, and he would relapse and become very aggressive towards me. (Participant 4, 68 yrs. Female).*

*He used to be very aggressive, he would be disorganised, dirty, walk around the streets asking for money, always in taverns drinking alcohol, and it seemed like he has given up on his life, he did not care. It is very stressful; it was bad for his sibling. (Participant 3, 66 yrs. Female)*

*I have to give him R5 every day for cigarettes which is too much. And what I have noticed is that, if I don't give him the money he end up asking for a smoke from everyone and some people give him dagga and I am the one who suffer the consequences of dagga. Whenever he starts becoming aggressive I know that he smoked dagga. (Participant 1, 47 yrs. Female)*

*The trouble starts when he does not take his treatment, and starts using marijuana then our lives become hell, back to square one and it is draining emotionally and physically. (Participant 9, 59 yrs. Female)*

Non-adherence to treatment was also attributed to psychotropic medication's side effects. For some participants, non-adherence was associated with the lack of insight into their mental condition and some cultural beliefs. These experiences are shown in the quotes below:

*He complains that his medication affects his emotions, and that he puts the blame on his medication and not on the illness. As far as I know, it's the illness that is at least partially responsible for his lack of emotions. He was getting better, and then again he would stop his medication, then he relapses again and again. (Participants 5, 59 yrs. Female)*

*And he stayed in several hospitals because, he was becoming better, and then stopping his medication and default. Not pretences, but you know, he was convinced that God is going to help him, so he thought he didn't need his medication. And another time, he chose wrong friends who told him that he must not take his medication. (Participant 6, 61 yrs. Male)*

*It just seems to me that after eight years he still doesn't have the insight that it's not the medication that's making him ill you know, and that he is suffering from a serious mental illness. I don't think he has accepted that. (Participant 5, 59 yrs. Female)*

### **4.3.3 Caregiver coping mechanisms**

Caregivers adopted various coping strategies to deal with the burden of taking care of their mentally ill relatives. Identified coping strategies included a) spirituality and religiosity, b) counselling and psychotherapy, and c) the use of recreational centres and caregiver support groups.

#### **4.3.3.1 Spirituality and religiosity**

Spiritual and religious beliefs and strategies were indicated as some of the mechanisms employed to cope with the burden and challenges of caring for ill relatives. Most caregivers reported having become more religious and spiritual. In terms of religiosity, several caregivers

reported finding prayer and religious groups to be helpful. These ideas were expressed as follows:

*It's tough and difficult but I just pray, I don't want to lie. I pray and get strength and comfort from God. (Participant 2, 67 yrs. Female)*

*I know somehow that God is looking out for me.... you understand. I have always spiritualised the whole saga and I think that's what has helped me cope in a way, that's what would make me not get the negative side of it cause as much as I am not safe, I am safe. (Participant 1, 47 yrs. Female)*

*I am a Christian and I believe that people were created by God and sometimes things we do not understand happen to us like being mentally disturbed and only God know why and we trust in him with all these difficulties. (Participant 3, 66 yrs. Female)*

Beliefs held about the illness also appeared to serve as a coping mechanism for some participants. Among the participants, a mother caring for her schizophrenic son held a spiritual view which, according to her, helped her cope. This is what she had to say:

*Whatever he was talking about it is real in the spiritual realm and it is not real in our realm. In my mind, I always relate his experience to that guy [Luke chapter 5] and as much as those things are weird but whatever he is talking about it is real in the spiritual realm but not real in our realm. Even though this is tormenting him, he is seeing things from the other side. So for me is not that stressful because there is something am referring to that gives me a different understanding and these has been helping me to survive if I can put it like that. I am looking at it from a totally different perspective, my interpretation of everything. (Participant 1, 47 yrs. Female)*

#### **4.3.3.2 Counselling and psychotherapy**

Some caregivers reported relying on counselling and psychotherapy to deal with the distress that came with caregiving. Some indicated that counselling and psychotherapy helped them cope with feelings of depression, guilt, anxiety, and other negative emotions, as the following quotes show:

*They allowed me six sessions free. Which I did with a private psychologist, which my medical aid arranged, but I didn't have to pay, it came from that and it helped me a lot because I was depressed. (Participant 9, 60 yrs. Female)*

*I used to go for sessions regularly there, the psychologist used to counsel me and everything, and she used to ask me things about him [ill son] and all that. And as time went along I adapted, I started getting used the illness because before I wasn't clued up on it. I was struggling. (Participant 4, 68 yrs. Female)*

*At the clinic they were supportive, I used to see the social worker for counselling every month, even though sometimes she was not there it helped me with stress and to deal with problems. (Participant 3, 66 yrs. Female)*

#### **4.3.3.3 Recreational centres and caregiver support groups**

The participants appraised rehabilitation centres favourably in that the centres not only offered services to their ill relative but also provided support groups to them. Additionally, the centres assisted in the better care of their relatives, thus preventing relapses. Participants further intimated that they experienced peace of mind and less stress knowing that their ill family members were in a safe space whilst being offered the best treatment.

Another finding was that, although some participants reported getting support from family and friends, they found the support groups to be beneficial in that they helped them cope with the burden of caregiving. Most caregivers highlighted that the support groups provided

them with a safe space to express their fears, anxieties, frustrations, and needs. Additionally, the spaces were identified as helpful in that caregivers were able to connect with other caregivers who shared similar experiences, and who understood the challenges that came with caring for a family member with mental illness. This finding is illustrated by the following quotations:

*I attended a couple of sessions but due to finances I could not continue. You know, when you are in the group you realise that you are not alone other people are also going through similar difficulties, and you get courage and be consoled through talking. It really helps but the problem is that is far. (Participant 3, 66 yrs. Female)*

*There was this group in TARA hospital, I met some people there who taught me something. Maybe simply to know their problems with their children or member of their family etc., so basically that's the only support group and it was insightful. (Participant 6, 61 yrs. Male)*

*But now that he is in Talisman is better, when he was here [at home] he would drink alcohol and refuse to take treatment, and it was difficult to control him but now in Talisman they supervise his adherence to medication better. (Participant 3, 66 yrs. Female)*

*At one time I felt I was fighting a losing battle. However since he's been here there is an improvement. I am alright. I see great improvements. I think he only had one relapse I feel that there's been a great improvement with him. It's what we wanted. We're at peace, he's got everything. And I'm looking towards the future. I'm not saying it's going to be smooth, but it's going to be better, because he is taken care of. We have peace of mind, he's got food, he's got a roof over his head, he's not*

*walking in the streets; he's not walking away from home. (Participant 4, 68 yrs. Female)*

#### **4.4 Summary of findings**

This chapter presented the study results. The findings revealed that caregivers experience psychological distress, fear and anxiety in caring for a family member diagnosed with schizophrenia. Findings further revealed numerous challenges caregivers experience in caring for their relatives diagnosed with schizophrenia. Amongst some of the challenges identified were financial constraints and cultural beliefs which negatively impact the quality of caregiving for their ill relative. The study further revealed coping mechanisms that caregivers adopt to cope with difficulties of caring for their schizophrenic family members. Religion, support groups, and psychosocial rehabilitation centres were some of mechanisms a majority of participants found to be helpful to their ability to cope.

## **Chapter 5: Discussion**

### **5.1 Introduction**

This chapter offers an integrated discussion of the study findings. The findings are discussed in line with previous empirical studies, with convergences and divergences with those studies noted. The study findings are also discussed in line with the chosen theoretical frameworks.

### **5.2 Psychological and emotional Challenges**

This study revealed that caring for a family member diagnosed with schizophrenia is associated with the experience of emotional and psychological distress. Similar results have been reported before both in South Africa (Hogan & John-Langba, 2016; Lippi, 2016) and Ghana (Opoku-Boateng et al. 2017). In the current study, caregivers reported the experience of fear, anxiety, and depression amongst other distressful reactions. From a family systems perspective, Bowen posited that families are not simply groups of independently functioning individuals, but a system, wherein a change in one-part influences other interrelated parts of the system (Bowen 1966). Thus, when one family member suffers from a mental condition (in this case, schizophrenia), it often produces heightened tension or anxiety in other family members who might either react positively or negatively.

#### **5.2.1 Psychological distress and fear**

Most caregivers in this study reported experiencing difficulties in caring for their family members diagnosed with schizophrenia which for most participants triggered unpleasant feelings or psychological distress which in turn made it difficult for them to cope and carry on

with normal day-to-day activities. Caregivers of persons diagnosed with schizophrenia commonly expressed feeling overwhelmed, depressed, hopelessness, and helplessness which impacted not only their quality of life but also the quality of care for their ill relative. This is in concordance with both a World Federation of Mental Health's (2010) report and a randomised-controlled experimental study that was conducted to determine the effects of psychoeducation on emotional expression, depression and family burden of primary caregivers of the schizophrenic patients (Ozkan et al., 2013).

Caregivers in this study often faced daily stressors and sometimes feared their family members' unpredictable and bizarre behavior. Caregivers also expressed concerns and extensive worry about the risk of being injured or killed by their violent and aggressive ill relative. Frequent destruction to property was also reported, seemed to be a devastating experience for most caregivers, negatively impacting on the quality of care. Monyaluoe et al. (2014) reported similar findings, indicating that caregivers are constantly worried about their ill relative's physical aggression and destructive behaviour which makes it difficult for them to offer the necessary support. A study by Hanzawa et al. (2013) in Asia also established psychological impact of trauma from patient's violent behaviour.

Caregivers were not only stressed and concerned about their personal safety from a relative's unpredictable aggressive behaviour but also experienced distress and fear related to the safety of their ill relative because, due to the nature of the condition, ill relatives tend to act on their delusions, and disappear from home. What this finding suggests is that caregiving is a mentally demanding role associated with constant worry and fear of injury to the integrity of both caregivers and ill-relatives. These finding echoes that of a study by Brain, Kymes, DiBenedetti, Brevig, and Velligan (2018). However, it is in contrast to some past studies in which caregivers have been found to be concerned only about their own safety (Monyaluoe et al., 2014; Hanzawa et al., 2013).

### 5.2.2 Caregiver burden

Caregivers experience enormous a burden associated with caring for their family members diagnosed with schizophrenia. The burden of caring for an ill relative has a significant impact on their quality of life. The higher levels of burden were also significantly related to all four domains of quality of life which included physical health, psychological health, social relationships and environmental health. Caregiver burden is an area that a number of studies have specifically focused on, and the findings of the present study are in concordance with those reported in the past (Geriani et al., 2015; Opoku-Boateng et al. 2017; Urizar et al., 2014).

In this study, it was found that the burden is related to the amount of time needed to devote to caring for ill relatives, abrupt disruptions brought about by the illness to caregiver's daily plans and living, and unexpected financial expenditures. Other caregivers were forced to adjust or give up their lifestyle and dreams in order to accommodate their ill relative's needs. This finding supports much of the available literature (Deshpande et al., 2018; Geriani et al., 2015; Gupta. Solanki. Koolwal. & Gehlot. 2015; Opoku-Boateng et al. 2017; Urizar et al., 2014). However, a study conducted in Ghana by Ae-Ngibise et al. (2015) revealed that the major burden was mostly reported to be related to financial constraints.

Noteworthy was that the burden of caring seemed to be assumed by mostly by the elderly mothers of ill patients. For instance, the majority of participants ( $n = 8$ ) in this study were elderly females in their late 50s to 60s. Similarly, recent studies on schizophrenia caregiver-burden have found that the majority of caregivers were mainly parents (usually mothers), followed by spouses and siblings of patients (Geriani et al., 2015; Opoku-Boateng et al. 2017; Urizar et al., 2014). In addition, evidence from the research has indicated a significant correlation between gender in caregiving and the level of burden. A number of these studies (Ae-Ngibise et al 2015; Geriani et al., 2015; Urizar et al., 2014) have reported higher levels of caregiver-burden, stress, burnout, psychological morbidity and poorer quality of life among

female caregivers of those with schizophrenia. This study's finding seems to contradict other studies that have found no gender differences in overall burden, objective burden, subjective burden, worry, fear, or stigma (Geriani et al., 2015; Sharma., Chakrabarti., & Grover. 2016).

### **5.3 Caregiver Challenges Associated With Caring for a Mentally Ill Relative**

In this study, caregivers identified four key area of challenge in caring for a person living with schizophrenia. These were a) the lack of social supports, b) socio-economic challenges, c) socio-cultural challenges, and d) substance abuse and non-adherence to treatment. These findings will be discussed below.

#### **5.3.1 Lack of social support**

In addition to the psychological and emotional challenges experienced, caregivers in the present study reported a lack of social and financial support as a challenge in caring for a person living with schizophrenia. This is in line with literature that has suggested that caring for a mentally ill person is both emotionally and financially overwhelming (Kate et al., 2013; McFarlane, 2016). One study in Australia found that families continue to live with negative caregiving experiences and poor quality of life because their needs are not well assessed and addressed, and also because they lacked social support (Hayes et al., 2015).

Although social support was not always available to the participants in this study, those who received it experience being a recipient of empathy and encouragement as a source of relief. Other studies have also found that psychosocial interventions are an important component of social support for both diagnosed people and their primary caregivers (Brooke-Summer,2015; Moncrieff, 2015 Yesufu-Udechuku et al., 2015; Urizar et al., 2014)

### **5.3.2 Socio-economic challenges**

Inadequate financial support is one of the key challenges associated with caring for persons living with schizophrenia (Ae-Ngibise et al., 2015). This has a negative impact on caregivers and compromises the quality of the caring afforded to the affected person. In the current study, financial constraints were associated with caregivers being pensioners who relied on social grants and support from other family members to support ill relatives who were always unable to provide for themselves despite having qualifications because of their mental illness. This is in accordance with studies conducted in Nigeria and Ghana where it was found that caregivers from households with low income had to carry an extra burden due to competing needs of their ill relative and their inability to be gainfully employed (Ae-Ngibise et al., 2015; Opoku-Boateng et al., 2017).

Of noteworthy, is the resentment expressed by one participant denoting that it is wasteful to invest economically in a child who would turn out to be unproductive, and a burden on parents on the basis of mental illness. This is an area that may need further exploration. Nonetheless, care givers also burdened by financial constraints related to travelling long distances between hospitals and prisons looking for and visiting their ill relatives. Caregivers also reported financial implications related to replacing broken windows and other goods their ill relative broke when they were aggressive or in relapse.

### **5.3.3 Cultural beliefs as a challenge**

Emerging evidence suggests that culture and ethnicity play a significant role in the stress and coping process for primary caregivers (Bignall et al., 2015). Cultural background also influences the definition and socio-cultural meanings attached to schizophrenia (Matsumoto & Juang, 2016). Certain cultural beliefs were prominent among African black participants in the present study which caused a conflict between psychiatric interventions, Christianity and

African beliefs and cultural practices. For instance, in the present study, some caregivers reported their relative to be ill due to an ancestral calling, and for some others, it was related to other forms of spirituality such as witchcraft.

This finding is in accordance with Mokgobi (2014) who stated that in African cultures schizophrenia symptoms can be identified as an ancestral calling, a condition that can only be addressed through cultural means such as consultations with traditional healers. Some other African studies have also found that traditional healers, particularly in Sudan and Uganda, attributed the causes of psychosis to supernatural causes such as demons, evil spirits, and witchcraft (Abbo et al. 2012; Sorketti et al. 2012).

It is against these held beliefs that treatment and adherence to psychotropic drugs by patients will always be a challenge, especially with black African patients. Phan (2016) reported that cultural beliefs had an influence on adherence to treatment resulting in relapses, and negative experiences for caregivers. This was also observed in the current study where caregivers whose ill relatives believed that the condition was related to ancestral calling had multiple admissions or relapses due to non-compliance with prescribed medication. Clearly, cultural beliefs have a significant impact on how schizophrenia is explained and understood as well as influencing patients' and their families' help-seeking behaviors. It is therefore paramount to support increased inquiry into adaptations of mental health interventions and cultural interventions (Griner & Smith., 2006; Degnan et al., 2018; Segredou et al., 2012).

#### **5.3.4 Substance abuse and non-adherence to treatment as a challenge**

Substance abuse and treatment non-adherence have been reported to have negative implications in the quality of caregiving. Phan (2016) also reported that non-adherence was common among patient with schizophrenia, and that it led to decompensation or exacerbation of symptoms, relapses, rehospitalisation or greater use of emergency psychiatric services,

functional decline, and increased risk of death. In the present study, most participants reported unpredictable aggressive behaviours when their ill relatives abused substances or defaulted treatment. These result in high levels of stress, living in fear, and difficulties in managing or controlling ill relatives.

In the present study non adherence to treatment was associated with medication side effects. Non-adherence was also associated with cultural and religious beliefs of both the caregiver and their ill relatives as well as a lack of insight into and knowledge about their ill relative's condition. Non-adherence was found to have negative impact on the caregiving experience in this study; however, most studies have focused rather on the impact of non-adherence on health system (Higashi et al., 2013; Phan. 2016).

#### **5.4 Caregiver Coping Mechanisms**

Caregivers adopted various coping strategies to deal with the burden of taking care of their mentally ill relatives. Folkman and Lazarus's (1988) coping theory emphasises a coping process in which individuals evaluate potential stressors and, based on these evaluations, develop adaptive and/or maladaptive coping strategies (Folkman & Lazarus, 1988). In the context of this study, based on the caregivers' appraisal of caregiving as distressful, burdensome, and a challenge, their adopted coping strategies included spirituality and religiosity, counselling and psychotherapy. In addition, they relied on the care provided by recreational centres, including the provided in-house social support groups. More attention is devoted to each of the coping strategies below.

##### **5.4.1 Spirituality and religiosity as coping mechanisms**

Spiritual and religious coping methods seemed relevant and adaptive among most caregivers for dealing with the stress of caring for a person with a mental illness. In general,

caregivers reported high levels of religious involvement and frequent use and perceived helpfulness of religious coping strategies. Some caregivers also perceived the condition of their relative from a religious perspective which also helped them to cope with the stress and difficulties of caring for a schizophrenic family member. This finding is similar to that of a similar study conducted by Ae-Ngibise et al. (2015) in Ghana where most caregivers reported relying on prayers offered by pastors and other divine instructors, and hoping for miracles. It also echoes a study conducted by Deshpande et al. (2018) in India which had similar results.

#### **5.4.2 Counselling and psychotherapy**

For some caregivers, the burdens of living and caring for ill relatives can become overwhelming and beyond what is possible to cope with in a healthy way without professional intervention. Participants reported that counselling and psychotherapy had helped them cope in safe and healthy way with the distress, guilt, anxiety, and other negative emotions triggered by taking care of a loved one. Jauhar et al. (2014) also found psychotherapy to have potential in improving personal and social functioning among caregivers. These findings tend to support McFarlane's (2016) conclusion that psychotherapy aimed at supporting and educating families about the illness and its management should be considered as part of the treatment process.

#### **5.4.3 Recreational centres and caregiver support groups**

The study found that recreational centres offered support both to persons diagnosed with schizophrenia and to their caregivers. Support groups were one form of support provided in these facilities, and the participants found these to be a helpful platform to learn and share experiences as caregivers. The present study also found that family members involved in the group program reported better understanding of their ill relative, confidence in their ability to help their loved one, improved quality of life and reduced burden. This is in accordance with much of the literature which has indicated that psychosocial interventions, including group

therapy, cognitive rehabilitation, psychoeducation and social skills training, are an important component of care for schizophrenic patients and their families (Brooke-Summer, 2015; Moncrieff, 2015; Monyaluoe et al., 2014; Urizar et al., 2014; Yesufu-Udechuku et al., 2015). It also may support Asmal et al.'s (2014) conclusion in a South African study that family group therapy was effective for the individual with schizophrenia and their families.

## **Chapter 6: Conclusions and Recommendations**

### **6.1 Conclusion**

The current study sought to explore and describe the lived experiences of caregivers involved in support groups whilst caring for a family member diagnosed and living with schizophrenia. The objectives of this study were:

- To identify the psychological and emotional experiences of caregivers in their caring role for a family member living with schizophrenia.
- To establish the economic and sociocultural challenges that caregivers experience in their caregiving role.
- To appraise caregivers' coping mechanisms, including their experiences of support groups they were taking part in.

The study was qualitative in nature and comprised of ten primary caregivers of family members diagnosed with schizophrenia and involved in support groups. Key study findings were that caregiving was experienced as psychologically and emotionally distressful. In addition, caregiving was experienced as burdensome because of the multiple challenges (e.g., financial constraints, lack of social support, non-adherence to treatment) that come with it. Because of the interplay of the multiple negative experiences associated with caregiving, caregivers felt that caregiving compromised their quality of life. In order to cope, caregivers had to rely on several coping mechanisms including religiosity, spirituality, and support groups offered in recreational centres. Rather than other similar studies that have explored experiences of caregivers of those diagnosed with schizophrenia, the present study found that family members involved in support groups demonstrated improved family communication, greater

confidence in their ability to help their loved one and reduced burden. It further indicated effectiveness in terms of improving subjective quality of life.

## **6.2 Study Recommendations**

This study identified significant psychosocial and economic issues associated with caregiving. It therefore becomes critical for the identified issues to be addressed because the quality of care given to those living with schizophrenia depends on their primary caregivers. It thus becomes essential to plan interventions that would reduce their burden of care and improve their psychological well-being.

Addressing the challenges that caregivers are faced with should be a collaborative effort involving health care facilities, providers and all spheres of government so that these difficulties can be addressed accordingly. Professional assistance in the form of counselling, public awareness of mental illnesses in general, and economic support by all stakeholders including the government, private sector, and non-governmental organisations are all vital in addressing the challenges faced by caregivers of persons diagnosed with schizophrenia. Psychoeducation about schizophrenia and psychotropic drugs is of paramount importance for both patients and their caregivers to alleviate non-adherence. Establishment of dual diagnosis rehabilitation centres to address substance use problems among those diagnosed with schizophrenia are also recommended to alleviate the challenges caregivers are faced with.

It is also crucial to support increased inquiry into adaptations of mental health interventions and cultural interventions in order to address challenges associated with cultural beliefs. In addition, mental health care practitioners should be encouraged to familiarise themselves with different cultural backgrounds so as to intervene effectively.

Participants reported positive experience with community-level interventions such as the psychosocial rehabilitation centres, they were involved with. Therefore, recreational centers similar to the Talisman Foundation and Thandanani Care Centre should be established and decentralized to other areas for broader interventions. Psychosocial support and other intervention mechanisms should also be made available in primary health facilities. It is further recommended as a result of the findings from the current study that further research be conducted in other areas in South Africa. This will enable policy developers to improve the mental health care system for both patients and caregivers.

### **6.3 Limitations**

The following are some of the limitation that could be associated with the present study:

- Translating the interview data from Zulu and Setswana into English may have led to omissions or inappropriate substitution of original material provided by the participants.
- The study was conducted in only two psychosocial rehabilitation centres in Johannesburg, Gauteng Province. The current findings may therefore not be generalisable beyond the places where the study was conducted.

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## Appendices

### Appendix 1A: Interview Guide (English Version)

Objective	Interview questions
<p>1.To explore caregivers’ psychological and emotional challenges experienced in living with a family member living with Schizophrenia.</p>	<p>a) How do you understand your family member’s mental condition?</p>
	<p>b) What negative emotional and psychological challenges come with caring for a family member living with Schizophrenia?</p>
	<p>c) What positive emotional and psychological benefits come with caring for a family member living with Schizophrenia?</p>
<p>2. To establish and describe the challenges they are confronted with in living with an affected family member.</p>	<p>d) What are some of the challenges that come with living and caring for a family member diagnosed with Schizophrenia?</p>
	<p>e) What specific economic or financial related challenges are family members confronted by when living and caring for an affected family member?</p>
	<p>f) What specific cultural challenges are family members confronted by when living and caring for an affected family member?</p>

<p>3. To explore caregivers' coping mechanisms including their experiences of support groups as part of living with an affected family member.</p>	<p>g) How have you been coping with living and caring for an affected family member?</p>
	<p>h) What specific coping mechanisms do you rely on as part of your coping with the caring of a family members' condition?</p>
	<p>i) What are your experiences of the support groups you have been part of since you started participating as part of living with an affected family member?</p>

**Appendix 1B: Dikaelo tsa Dipotso (Setswana Version)**

Maikaelelo	Dipotso tsa katiso
<p>1.Go sekaseka maikutlo a batho ba ba nnang le maloko ba ba naleng bolwetse ba Schizophrenia.</p>	<p>b) O thaloganyana jwang maemo a tshaloganyano a ba leloko la gao?</p>
	<p>b) Ke maikutlo a fe a a sa lokang a o kopanang le ona fa tlhokomela mong wa leloko yo a naleng bolwetse jwa Schizophrenia?</p>
	<p>c) Ke maikutlo a fe a tlhomamiso a o kopanang le ona fa o tlhokomela mong wa leloko yo a naleng bolwetse jwa Schizophrenia?</p>
<p>2. Go supa/simolodisa le go tshala di kgwetlho yase batho ba kopanang le tsona go dula le mongwe wa leloko yo a naleng bolwetse jwa schizophrenia.</p>	<p>d) Ke di kgwetlho di fe tse di tlang fa o dula le go tlhokomela mong yo a naleng bolwetse jwa Schizophrenia?</p>
	<p>e) Ke matsapa a feng a botshelo la a ditshetele a malapa a iphitleng a lebane le ona fa ba tlhokometse ba lelapa b aba amedileng kgotsa ba ba leng mo mathateng.?</p>
	<p>f) Ke matsapa a feng a moetlo/setso a malapa a iphitleng a lebane le ona fa ba tlhokometse ba lelapa b aba amedileng kgotsa ba ba leng mo mathateng?</p>

<p>3. Go sekaseka dilo tse di thusang batlhokomedi le kitso e ba e fitlhelang go tswa go setlhopeng sa tshegetso jaaka bontlhabongwe ba go dula le mongwe wa leloko yo a naleng bolwetse jwa Schizophrenia.</p>	<p>g) O ntse o kgona jwang go dula le go tlhokomela mong yo a naleng bolwetse jwa Schizophrenia?</p>
	<p>h) Ke ditse kgotsa mokgwa yo o o dirisang gore o kgone go ithusa le go ithusa le go thusa mongwe wa lelapa yo o amegileng?</p>
	<p>i) Ke eng se o se ithutileng a sale o o nna mongwe wa tirelo thuso ya tshedimosetso jaaka o na le molesika yo amegileng?</p>

### Isengezo 1C: Isiqondiso Senhlolovo (Ushicilelo lwesiZulu)

Inhloso	Imibuzo yenhlolovo
<p>1. Ukuhlaziya izinselelo zabanakekeli zangokwengqondo nezangokomphefumulo abahlangabezana nazo ngokuphila nelunga lomndeni eliphila nokuphazamiseka engqondweni</p>	<p>c) Usiqondisisa kanjani isimo somqondo welunga lomndeni wakho?</p>
	<p>b) Yiziphi izinselelo ezingezinhle ezihambisana nokunakekela ilunga lomndeni eliphila nokuphazamiseka engqondweni?</p>
	<p>c) Yiziphi izinzuzo ezinhle ngokomphefumulo nangokwengqondo ezihambisana nokunakekela ilunga lomndeni elinokuphazamiseka engqondweni?</p>
<p>2. Ukwazi ukuthola kanye nokuchaza izinselelo ababandakanyeka kuzo ngokuhlala nelunga lomndeni eligulayo.</p>	<p>d) Yiziphi ezinye zezinselelo ezilethwa wukuhlala nokunakekela ilunga lomndeni elihlonzwe njengelinokuphazamiseka engqondweni?</p>
	<p>e) Yiziphi izinselelo ngokomphakathi nangokomnotho amalunga omndeni abhekana nazo ngenkathi ehlala futhi enakekela ilunga lomndeni eligulayo?</p>
	<p>f) Yiziphi zinselelo eziqondile ezimayelana nomphakathi namasiko amalunga omndeni abhekana nazo ngenkathi ehlala futhi enakekela ilunga lomndeni eligulayo?</p>

<p>3. Ukuhlaziya amasu wabanakekeli okwazi okubhekana nesimo, ukuhlanganisa ulwazi lokuba semaqenjini asizayo njengxenye yokuphila nelunga lomndeni eligulayo</p>	<p>g) Ukwaze kanjani ukumelana nokuhlala kanye nokunakekela ilunga lomndeni eligulayo</p>
	<p>h) Yimaphi amasu aqondile okubhekana nesimo owaphendulayo njengxenye yakho yokubhekana nokunakekela isimo selunga lomndeni wakho?</p>
	<p>i) Yiluphi ulwazi oluthole emaqenjini elekelelayo nosube yingxenye yawo selokhu uqale ukubamba iqhaza njengxenye yokuhlala nelunga lomndeni eligulayo?</p>

## **Appendix 2A: Consent Form (English Version)**

### **Consent form**

I \_\_\_\_\_ hereby agree to participate in a Master's research project that focuses on the lived experiences of caregivers living with individuals diagnosed with Schizophrenia and attending support groups at Talisman Foundation/Thandanani Care Centre Johannesburg Gauteng province.

The purpose of this study has been fully explained to me. Furthermore, I understand that I am participating freely and without being forced in any way to do so. I also understand that I can terminate my participation in this study at any point should I wish to do so, and that this decision will not affect me negatively in any way.

I understand that this is a research project, whose purpose is not necessarily to benefit me personally. I understand that my details as they appear in this consent form will not be linked to the interview schedule and that my answers will remain confidential.

## **Appendix 2B: Fomo Ya Tumellano (Kgaolo ya Setswana)**

### **Fomo ya tumellano**

Nna \_\_\_\_\_ ke dumellana o tsaya karolo mo tirong ya dipatisisomorero tsa masters tse lebeneng le diphithelo tsa batlhokomeli ba ba phelang le batho ba ba sa itekalenang mo tshaloganyong (Schizophrenia) le go nna teng mo ditlhopheng tsa tshegetso ko Talisman Foundation/Thandanani Care Centre Johannesburg Gauteng province.

Morero o na wa thuto o tshalositswe sintle mo go nna go feta mo ke mtlhaloganyana gore e tseyana karolo ke sa gapeletsiwe. Ke tshaloganya gape le gore nka gona go emisa go tsaya karolo mo thutong e ka nako nngwe le nngwe fa ke batla le gore diphithlelelo di ka se nkame ka mogwa o o seng maleba gothlelele

Ke tshaloganjya go re sena ke merero ya dipatlisiso tse merero ya o ne e seng botlhokwa mo go nna. ke utlwisisa gore dintlha tsa ka tse ditlhagang mo fomong ya tumellano di ka se amagane le kemiso ya dipuisano le gore dikarabo tsa ka di tla nna sephiri.

## **Isengezo 2C: Ifomu Lemvume (Ushicilelo lwesiZulu)**

### **Ifomu lemvume**

Mina \_\_\_\_\_ ngiyavuma ukubamba iqhaza emsebenzini wocwaningo lwemastazi ogxile olwazini lwabanakekeli abahlala nabantu okutholakale ukuthi banokuphazamiseka engqondweni futhi baya emaqenjini anakekelayo eTalisman Foundation noma eSikhungweni Sokunakekela eThandanani, esifundazweni saseGauteng.

Inhloso yalolu cwaningo ichazwe ngokugcwele kimi. Ngaphezu kwalokho, ngiyaqonda ukuthi ngibamba iqhaza ngokukhululeka nangaphandle kokuphoqwa nganoma iyiphi indlela ukwenza lokho. Ngियाqondisisa futhi ukuthi ngingakwazi ngingayeka ukubamba kwami iqhaza kulolu cwaningo noma yinini uma ngifisa ukwenza njalo, kanjalo nokuthi lesi sinqumo ngeke sibe nomthelela omubi nganoma iyiphi indlela.

Ngियाqonda ukuthi lona ngumsebenzi wocwaningo, inhloso yalo okungekhona ukuzuzisa mina siqu. Ngियाqonda ukuthi imininingwane yami njengoba ivela kuleli fomula lemvume ngeke ixhunyaniswe nohlu lwenhlobo futhi nezimpendulo zami ziyohlala ziyimfihlo.

**Appendix 3A: Letter to Request Permission: Talisman Foundation**

Department of Psychology  
University Limpopo (Turffloop )  
Private Bag X1106  
Sovenga  
0727

Talisman foundation  
58 Plinlimmon road  
The Hill extention Ext  
Johannesburg  
2197

Dear sir/madam

Re: permission to conduct research on experiences of caregivers living with a member diagnosed with Schizophrenia and currently attending support group in your facility.

I, Tracy Tshilidzi Nopfumbada, am currently a registered student for a Master of Clinical Psychology at the University of Limpopo. I hereby request for permission to conduct the study amongst caregivers living with members diagnosed with Schizophrenia as a requirement for a Master's degree in the Department of Psychology.

My research topic is: A Phenomenological Study of Primary Caregivers of Patients Living with Schizophrenia in Gauteng province, South Africa

Your assistance will be greatly appreciated

Yours faithfully

TT Nopfumbada

\_\_\_\_\_  
Dr Makgahlela M  
Supervisor

-----  
Prof S Govender  
Co Supervisor

\_\_\_\_\_  
Date

-----  
Date

**Appendix 3B: Letter to Request Permission: Thandanani Foundation**

Department of Psychology  
University of Limpopo (Turfloop Campus)  
Private Bag X1106  
Sovenga  
0727

Thandanani foundation  
56 Rose St, Florida,  
Roodepoort,  
1709

Dear sir/madam

Re: permission to conduct research on experiences of caregivers living with a member diagnosed with schizophrenia and currently attending support group in your facility.

I, Tracy Tshilidzi Nopfumbada, am currently a registered student for a Master in Clinical Psychology at the University of Limpopo. I hereby request for permission to conduct the study amongst caregivers living with members diagnosed with Schizophrenia as a requirement for Master's degree in the Department of Psychology.

My research topic is: A Phenomenological Study of Primary Caregivers of Patients Living with Schizophrenia in Gauteng province, South Africa

Your assistance will be greatly appreciated

Yours faithfully

TT Nopfumbada

\_\_\_\_\_  
Dr Makgahlela M  
Supervisor

\_\_\_\_\_  
Date

-----  
Prof S Govender  
Co Supervisor

-----  
Date

## Appendix 4: Ethical Clearance



University of Limpopo  
Department of Research Administration and Development  
Private Bag X1106, Sovenga, 0727, South Africa  
Tel: (015) 268 3935, Fax: (015) 268 2306, Email: anastasia.ngobe@ul.ac.za

### TURFLOOP RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

**MEETING:** 27 November 2018

**PROJECT NUMBER:** TREC/363/2018: PG

**PROJECT:**

**Title:** A Phenomenological Study of Primary Caregivers of Patients Living with Schizophrenia in Gauteng Province, South Africa.

**Researcher:** TT Nephumbada

**Supervisor:** Dr M Makgahlela

**Co-Supervisor/s:** Prof S Govender

**School:** Social Sciences

**Degree:** MA Clinical Psychology



**PROF. TAB. MASHEGO**

**CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE**

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: REC-0310111-031

- Note:**
- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
  - ii) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

*Finding solutions for Africa*

## Appendix 5: Letter of Permission



Talisman Foundation

LIVE YOUR LIFE

58 Plinlimmon Road  
The Hill Park,  
Gauteng 2197  
Tel: (011) 435-0727  
Fax: (011) 435-1186

Department of psychology

University of Limpopo

Sovenga

0727

Dear /madam

**Re: letter of permission to conduct research study on of primary caregivers of patients living with schizophrenia at Talisman Foundation.**

This letter serves to confirm that Ms Tracy Nopumbada has been given permission to conduct a research study at Talisman Foundation.

The facility has no objection

Regards

A handwritten signature in black ink, appearing to be 'M. M.', written over a horizontal dotted line.

Management