An exploration of the psychosocial experiences of Tswana caregivers of people living with schizophrenia in Mafikeng, North West

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Mini-dissertation submitted for the degree of Master of Health Science in Clinical Psychology at the Mafikeng Campus of the North-West University

Supervisor: Prof C.A. Oduaran
Co-Supervisor: Ms P.S. Kolobe

Graduation ceremony April 2019
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Declaration

I, Thato Seseane declare that this mini-dissertation for the award of Master of Social Science in Clinical Psychology degree at the North West University has not been previously submitted by me for a degree at this or any other institution. I hereby submit this mini-dissertation, and it is my own work in design and execution. All the reference materials contained herein have been duly acknowledged.

April 2019

T.S Seseane

Date

Preface

The candidate opted to write a dissertation, with the support of her supervisors.

Supervisor: Prof Choja Oduaran

-- Date: --

Prof C Oduaran

Co-Supervisor: Ms Patricia Kolobe

-- Date: --

P S Kolobe

Dedication

I hereby dedicate this research to all the people who have supported me, to those who participated in the study, and to those who inspired me.

Above, I dedicate it to all of my family, my mentors, and my friends.

Acknowledgements

I would like to extend my heartfelt gratitude to the following:

- A big thank you to the God Almighty for His grace upon my life and studies. God, I am nothing without you. Indeed you are a way-maker and a promise-keeper.
- Special thanks to the greatest woman I know, my mother, Malebo Seseane. Thank you Mama for your prayers, for always believing in me, and for your support.
- Warm thanks to my Father. Even though you are not here to witness this Papa, I know how much you believed in me and prayed for this.
- To my younger brother Tseko, thank you for your continuous encouragement.
- To all my family and friends, thank you.
- Prof Oduaran. I thank you for your guidance, supervision and mentorship. Thank you for the contribution you have made in this study, and may God bless you even further.
- To Ms Kolobe, you have played numerous roles in my life and in my studies. Thank you for being a mother, supervisor, mentor, counsellor, prayer partner, and many other things. I thank God for your life, and may God continue to glorify himself through you.
- Thank you to the BHO team for the on-going support and to my sponsors.
- Puleng, my friend, my sister, my motivator, thank you.
- To all my lecturers and classmates. Thank you for the impact you have made in my studies.
- Thank you Miranda Mnadawe for your assistance with regards to helping me with technicalities.
- A big thanks to all those who took their time and participated in this study. May God guide you and bless you for the great role and tasks that you are faced with.

- To Mr Mokolobate, thank you for your support.
- Thank you Tshepang Molale for all your help.
- To my partner, thank you for your support, and for walking this journey with me.
- Finally, Thati, my little angel in heaven, you motivated me to push through this. I love you angel.

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List of Abbreviations

WHO	World Health Organization
NIMH	National Institute of Mental Health
SES	Socio-Economic Status

Abstract

Schizophrenia is deemed to be one of the utmost severe mental disorders that disrupts the functioning of both the persons living with it, and those around them (Mosotho, Louw,& Caltz, 2011). This much-misunderstood disorder can be disabling and can impair one's life functioning to such a degree that the people living with it may need care from the people around them. Caring is a process, and within that process different caregivers may be exposed to different psychosocial experiences. It places a significant physical, cognitive, and emotional burden (stigma, anxiety, depression etc.) on the person living with the disorder and on their caregivers, and furthermore, it also has enormous financial consequences for those involved (McEvoy, 2007). The lack of research pertaining to the psychosocial experiences of caregivers of people living with schizophrenia in the North West province of South Africa led the researcher to conduct a study of this nature in the North West, particularly in Mafikeng. The researcher utilised a phenomenological design, which is considered to be a qualitative research approach. The study used snowball sampling, a sampling technique whereby participants introduce the researcher to other possible participants, and in this way, the study sample comprised six female Tswana caregivers aged 19-64 years. Data was analysed thematically, whereby the researcher linked the participants' feelings, beliefs, and experiences in order reach understanding and to create meaning. Although two major themes were derived from the data, the findings revealed stigmatisation as the dominant principal observation leading to these two themes. The results also revealed that even in the face of challenges in the process of caregiving, resilience and their belief in God serve as caregivers' coping strategies.

Key words: Caregivers, schizophrenia, psychosocial, experience

Chapter 1

1.1 Introduction

According to Schatzberg and Nemeroff (2009), schizophrenia is regarded asthe most acclaimed mental disorder globally. This disorder does not exist in isolation, by only affecting people living with it, but it also affects the broader social system, such as the caregiver/s (i.e. family), the community, the government, and the economy. It is a globally recognised disorder and yet many people still have very little knowledge about it (Molefi & Swartz, 2011). Moreover, schizophrenia is well regarded as one of the utmost austere mental disorders that disrupts the functioning of the person who is affected as well as the people around theaffected person (Mosotho, Louw,& Calitz, 2011).

It is known as an overwhelming disorder that is depicted by a wide-ranging spectrum of cognitive and emotional dysfunction, which includes delusions, hallucinations, disorganised speech and behaviour, and inappropriate emotions (Barlow & Durand, 2012). This mental illness, or psychological disorder, as psychologists and other health care professionals refer to it; can affect people from all walks of life, regardless of their racial group, gender, socioeconomic status, and/or religion (Hanzawa, Bae,& Tanaka, 2010).

The nature of this disorder can be disabling and can impair one's life functioning, to the extent that these affected people are likely to need care from people whom are close to them in most cases. Caring is a process, and within this process, different caregivers may be exposed to different psychosocial experiences. Caregivers are regarded as either voluntary or paid people (mostly family) who assist affected individuals with their activities of daily living.

Globally, caregivers encounter different psychosocial experiences in their day-to-day lives, and these experiences may differ from one person to the other. This means through these experiences, their own life and their interrelations with other people may be affected.

These forms of interrelation may be related to issues of love, care, social support, and a sense of belonging (Kirch, 2008).These psychosocial experiences may certainly include the psychological and social attributes of a person's life that may influence their thoughts, feelings, behaviours, health, functioning, well-being, and/or quality of life (Hanzawa, Bae,& Tanaka, 2010). The psychological components comprise cognitions, emotions, and personality, while the social factors include the economic standing (socio-economic status), religion, culture, and educational background, and social support (Geriatric Fellowships, 2010). The proposed study focuses on Tswana caregivers.

1.2 Background of the Study

According to Molefi and Swartz (2011), schizophrenia is an incapacitating mental illness that is estimated to affect at least 1% of the general population in all cultures. It affects equal numbers of people regardless of their gender, race, and/or economic status, however the onset is regarded to be later in women than in men. This mental illness is categorised by negative and positive symptoms. Positive symptoms include hallucinations associated with senses and delusions that often include paranoia orparanoid behaviour (Schultz, North,& Shields, 2007). Negative symptoms comprise, among others, the flattened affect, loss of sense of pleasure, loss of will or drive, and social withdrawal. In co-operation, the negative and positive symptoms affect patients' families (Schultz et al., 2007).

According to the World Health Organization (WHO) (2008), around 40-90% of patients with schizophrenia reside with their families. In developing countries, the family provides care for these patients in face of inadequate mental health facilities. Furthermore, the WHO (2008) states that the latest changes in family structures and an on-going economic decline in developing countries tends to temper and threaten the support available to patients with chronic mental illnesses such as schizophrenia.

Schizophrenia is a devastating mental disorder that does not only affect the person who has been diagnosed with it, but also affects the immediate caregivers and the community at large (Mosotho et al., 2011). In some communities, people living with this disorder are perceived as being a burden to many: the government (public health services); caregivers; and the community. People who are affected by schizophrenia as well as their caregivers are likely to be confronted with numerous challenges (Mosotho et al., 2011).

Schizophrenia is universally considered to be one of the most severe mental disorders. Furthermore, globally, it has been identified as the eighth most prominent cause of disability adjusted life years in the age group 15 to 44 years (Mosotho et al., 2011). In most cases, if not all, families are the ones who provide care for their family member or relative living with serious mental disorders such as schizophrenia(Mosotho et al., 2011). People living with this disorder/illness most often need people who will take care of them (caregivers) because of the disabling nature of their disorder (Awad & Voruganti, 2008).

In recent years, the global process of deinstitutionalisation shifted the locus of care of people with mental illness from mental institutions to their families (Molefi & Swartz, 2011). As a result, more than 50% of the people with this disorder live with and are reliant on their families to care for them. This leads to caregivers of people with schizophrenia having to face major challenges, which mainly include financial constraints and emotional burdens. Moreover, these caregivers and their family members who live with schizophrenia are also reported to experience stigma of a misunderstood disorder. This illness does not only affect the person living with it but it also has a direct negative impact on their caregivers, and it can place an enormous burden on their lives, and consequently they also experience the stigma that is associated with their affected relative. It also reported that the caregivers have limited time for leisure and socialising and, as a result, they experience heightened symptoms of psychological distress (Molefi & Swartz, 2011).

Approximations highlighted in research data from European countries suggest that somewhere between 50% and 90% of people with chronic mental disorders live with their families (Awad & Voruganti, 2008). In New Zealand, it is estimated that 10% of the population are caregivers to family members with mental disorders such as schizophrenia (Jorgensen, Parsons, Jacobs,& Arksey, 2010). Even when not living with their family, people with schizophrenia still require significant emotional and financial support (Awad & Voruganti, 2008). Caring for a person with a severe, long-term, and disabling mental disorder places significant demands on caregivers. However, on a more positive note, the relationship between the caregiver and the person living with schizophrenia may also grow as they spend more time together (Jorgensen et al., 2010).

In the past few years in the care of patients suffering from mental disorders, there has been a perceptible shift from institutional to community care. In South Africa, the new Mental Health Care Act (No 17 of 2002) promoted the deinstitutionalisation of psychiatric patients, and as a result the role of family caregivers has gained importance. The deinstitutionalisation of patients means that caregivers (family, relatives, etc.) are now the ones who are assuming the role of looking after their family members or friends with schizophrenia, and as a result, caregivers of persons with schizophrenia suffer from substantial stress (Mhaule & Ntswane-Lebang, 2009).

When the process of deinstitutionalisation was implemented, family members and friends or relatives who were willing to take in the individual affected by schizophrenia were the ones who were expected to take care of these individuals every day, and this undoubtedly disrupted their well-being and day-to-day routines. Some caregivers perceive it as a burdensome role, especially if they have little or no support from their community, friends, and family (Uys & Middleton, 2010).

Schizophrenia not only adversely affects the affected person, but also the people caring for them. The caregiving may also have positive effects, as the caregiver may grow closer to the person living with schizophrenia, since they spend a lot of time together.

1.3 Statement of the Problem

Schizophrenia is one of the most overwhelming forms of mental illnesses that leads to long-standing and progressive disability, which may result in impairment in several areas of an individual's functioning (Kaplan, Sadock,& Sadock, 2015).

Schizophrenia places a great deal of physical, cognitive, and emotional burden on the person living with the disorder, their family members, in this case caregivers, and it also has enormous financial consequences for those involved, as well as for the country (McEvoy, 2007). Schizophrenia is also one of the most stigmatised mental disorders, which leads to a vicious cycle of social discrimination and the breakdown of social networks for people living with the disorder and their caregivers (Rössler, Salize,& Riecher-Rössler, 2007).

Estimations reveal that at least 1% of the South African population suffers from schizophrenia, and this amounts to an amount of almost 500 000 people suffering from this disorder at any given time (Mosotho et al., 2011).

According to Molefi and Swartz (2011), people affected by schizophrenia, especially in the psychotic phase, can behave and act in disorganised, abnormal, and strange ways, ranging from silly, childish behaviour to aggressive outbursts to the extent of violent acts such as burning houses, killing people and animals, etc., and this is mainly due to disturbed perception that makes schizophrenia sufferers view the world differently to the way normal people do. Therefore, this disorder needs serious attention. However, caregivers mostly provide this care, because this illness impacts upon the person living with it (Igberase, Morakinyo, Lawani, James,& Omoaregba, 2010). The process of caregiving can be extremely stressful and place an enormous burden on caregivers, and their safety is at risk because Schizophrenia patients can be harmful to themselves and to others (McEvoy, 2007).

This study explored caregivers' experiences, and therefore, an exploration study is predominantly about one trying to understand people's experiences from their frame of reference and their lived experiences in order to get and in-depth and rich understanding of a phenomena, which in this case refers to the psychosocial experiences of caregivers of people living with schizophrenia.

Although existing studies that have been conducted on caregivers of people living with serious and severe mental illnesses such as schizophrenia, statistics regarding the caregivers of people living with schizophrenia in South African provinces, more especially in the North West town of Mafikeng, have not been recorded, even though these caregivers primarily provide care for affected individuals.

Furthermore, in most studies done in South Africa and other countries globally, researchers have focused on people living with mental illnesses; while less research has been carried out on the experiences of people who take care of these patients. These caregivers play a major role in these patients' lives, and this may lead them to experiencesignificant burdens. In the North West province, no research has been conducted pertaining to the psychosocial experiences of caregivers of people living with schizophrenia, and hence the proposed study will help to focus on Mafikeng in the North West province of South Africa. Therefore, the study focused on exploring the psychosocial experiences of the Tswana caregivers caring for people with schizophrenia in Mafikeng.

1.4 Aim of the Study

The aim of the study was to explore the psychosocial experiences of Tswana caregivers of people living with schizophrenia in Mafikeng, in the North West province of South Africa.

1.5 Research Questions

I. What are the psychosocial experiences of caregivers of people living with schizophrenia?

II. How do caregivers of people living with schizophrenia cope?

1.6 Research Objective

I. To explore the psychosocial experiences of caregivers of people living with schizophrenia; and

II. To determine the coping strategies of caregivers of people living with schizophrenia.

1.7 The Significance of the Study

I. Although there is extensive literature on schizophrenia, few studies have been conducted in relation to Tswana caregivers in Mafikeng. The study contributes to literature in Mafikeng in the North West province of Mafikeng. The study provides a better understanding and gives more insight into the experiences of caregivers of people living with schizophrenia.

II. The findings of this study can aid the development of intervention techniques for society, institutions, people living with schizophrenia, their caregivers, and families regarding how to support them with their challenges and experiences.

III. This study's findings have the potential to increase or promote or enhance the existing policies; and implementation and formulation thereof that can assist these caregivers to enhance their wellbeing.

1.8 Scope of the Study

The study was conducted in Mafikeng, in the Ngaka Modiri Molema District, in the North West Province in South Africa. The sample included six adult Tswana caregivers.

Chapter 2

2 Theoretical Background

In the study the operational definitions of terms were used to articulate the operationalizations of the terms that were broken down to understand the exploration of the psychosocial experiences of Tswana caregivers of people living with schizophrenia in order to understand the nature of the phenomenon in question.

2.1 Operational Definitions of Terms

2.1.1. Psychosocial- Psychosocial refers to the relationship between one's psychological development in, and interaction with, a social environment (Kirch, 2008). The term psychosocial suggeststhat there is a link between a person's psychological state and their social state as they can directly influence one another (Kirch, 2008).

2.1.2. **Experience-** Experience is considered to be the concrete acquaintance of any subject, which is accomplished using experimental, extended, and wide-ranging observation (Buxton, 2013). The Collins English Dictionary (2015) and McEvoy (2007) describe experience as face-to-face subjective observation; a specific occurrence or sentiment that a person has undertaken; and gathered knowledge of concrete subjects.

2.1.3. **Psychosocial experiences** – Psychosocial experiences collectively refer to what an individual goes through and experiences in a psychological state that will affect their social life (Kirch, 2008).

2.1.4. **Schizophrenia**– Schizophrenia is a distressing disorder that is categorised by a broad spectrum of cognitive and emotional dysfunction that includes delusions, hallucinations, disorganised speech, and inappropriate emotions (Barlow & Durand, 2012). It is also regarded as a chronic mental disorder that affects cognitive functioning, and perception, and it is characterised by delusions, hallucinations, disorganised speech, disorganised behaviour, and negative symptoms (National Institute of Mental Health (NIMH), 2013).

2.1.5. Caregiver - A caregiver or carer is a voluntary or remunerated individual who assists another individual with impairment with their activities of daily living (Roick, Heider,& Toumi, 2006). A caregiver is someone who provides care for someone who is in serious need of it, by taking care of that particular person and ensuring that their basic needs are being provided (Hanzawa et al., 2010).

2.1.6. Tswana people – Tswana people are Bantu-speaking people that may include all the Sotho or Tswana clans living either in Botswana, Lesotho, or South Africa (Buzz South Africa, 2013).

2.2.Theoretical Framework

2.2.1 Caregiver experience and impact framework

The study adopted the conceptual framework known as the family caregiver experience and impact framework from Rungreangkulkij and Gillis (2000). The model is based on the following concepts: caregiver's characteristics; subjective experiences; and objective experiences that may be influenced by coping skills and social support (Kidula, 2010). The family caregiving experience framework is illustrated as in Figure 1hereunder.

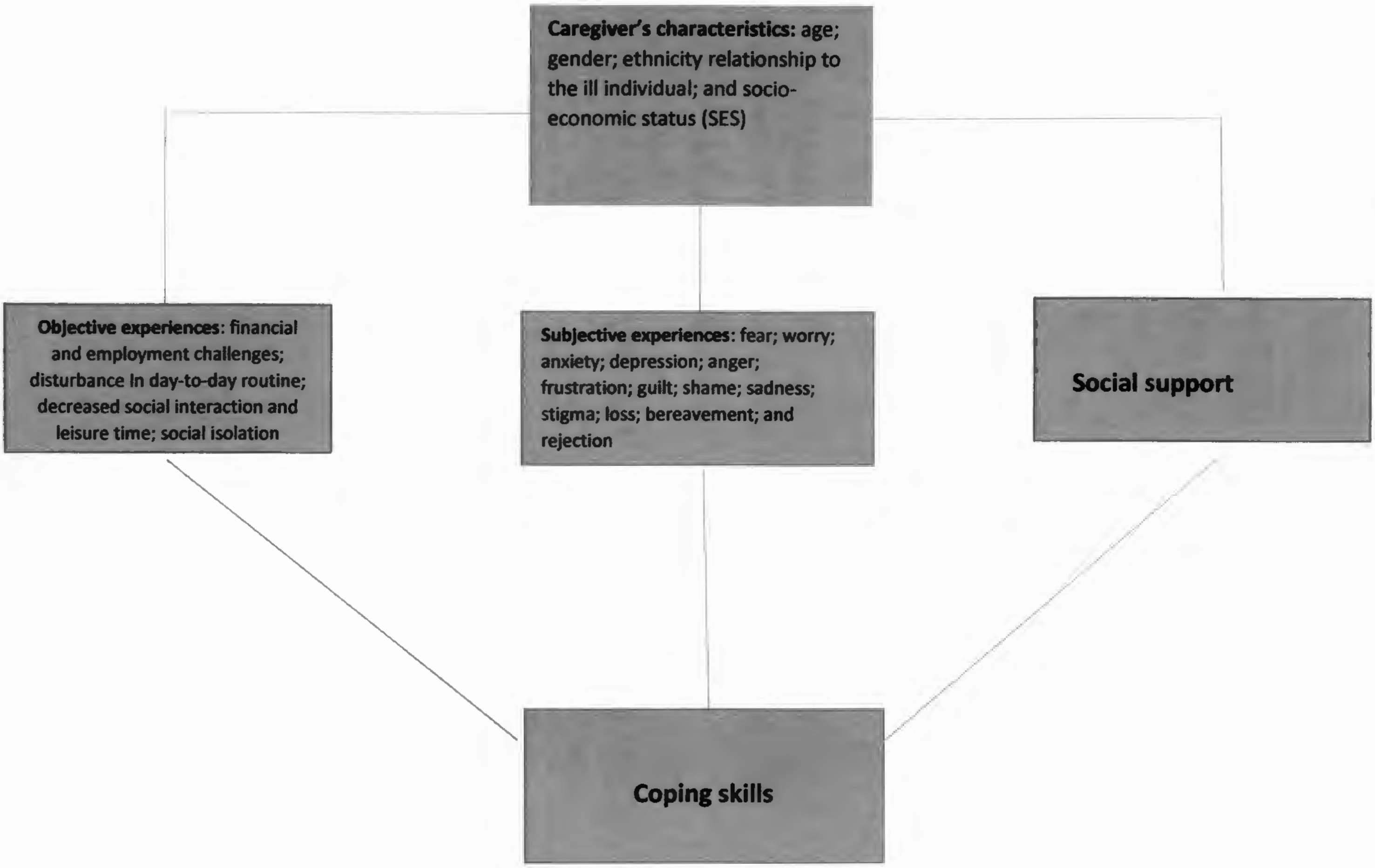

Figure 1: The family caregiving experience framework

Objective experiences in the study are characterised as those that demonstrate behavioural phenomena such as negative interference in day-to-day routines, social activities, and leisure time; social isolation; financial burdens; and employment impediments. Subjective experiences are defined as the individual's judgement of a situation and the extent to which caregivers perceive their experiences, therefore subjective experiences comprise fear, sadness, anger, guilt, worry, stigma, loss, rejection, bereavement, and frustration.

The process of caregiving may have different meanings or may have universal characteristics, regardless of culture, economic status, gender, and level of relationship to the affected person. Caregivers may have both subjective and objective experiences in the process of caregiving. The level of social support in the process of caring also has an impact on caregivers' experience in terms of caring for their loved one. Furthermore, the caregiver's level of coping skills is likely to play a significant role in how the caregiver experiences and perceives the process of caring for their affected loved one. Additionally, coping skills may also be determined by the level of support the caregiver receives from people and the community, and their perceived experiences during the process of caring for the individual living with schizophrenia.

2.3.Theoretical Perspective

2.3.1 The Bowen Family Systems Theory

Bowen (1974) describes his theory as a phenomenon that is based on human behaviour. He further states that the family is an emotional constituent and he utilises the systems philosophy to label the multifarious relationships within this component. It is within the system of a family that its members are strongly connected emotionally.

Families have an overwhelming emotional impact on their member's thoughts, feelings, and actions, to the extent that it often appears as though people are living under the same emotional skin. Family members seek out one another's attention, approval, and support, and react to one another's needs, anticipations, and disappointments. This connectedness and responsiveness results in the inter-reliance of family members. Therefore, an interruption in one family member's functioning is certainly followed by the subsequent changes in the functioning of other family members.

The system's mutually emotional reliance is developed to promote the cohesiveness and support that families need, such as shelter, affection, and protection. Conversely, intensified tension can impact negatively on development that encourages harmony and co-operation, and often, if not always, lead to complications. Once family members become anxious, this anxiety could intensify and spread amongst all family members. Equally, when anxiety increases, family members' emotional connectedness intensifies rather than being soothing. Ultimately, other parts of the system (family members) may feel overwhelmed, isolated, or threatened. In a nutshell, carers are those individuals that help and comfort the affected family member, in order to diminish the strain in others. It is a mutual interaction, for example, whenan individual takes on an excessive amount of responsibility to diminish the agony of others inarelationship, they often have unrealistic expectations of themselves, or a person submits to others who tell them what to do. The person who is the most accommodating of the affected family member, literally becomes engaged in the caregiving and is consequently the person that is most susceptible to problems such as depression, alcoholism, affairs, or physical illness.

This theory simply states that if one part of the system is disturbed, the entire system is also disturbed. An individual's illness, in this case schizophrenia, affects other family members. Families need support from each other, but this can be compromised and overwhelming. When one party of the family is mentally ill, this disrupts the family. Other parts of the system or family members who take care of their ill relatives may experience burdens, and their psychological wellbeing (thoughts, emotions, and behaviour) may also be affected due to the burden of looking after people affected by mental disorders.

2.3.2 The Stress-coping Theory

Lazarus and Folkman's (1984) Stress-coping Theory proposes that family members or caregivers experience stress as a reaction to their family member's mental disorder. The caregiver's own life state contributes significantly to how they will address and meet the challenges of providing care for a family member with a mental disorder. The social and economic status of caregivers may vary, as does the period of the individual and the family's life-cycle, for example, a strong financial state may allow family members to be able to afford the safe care and resources that their affected family member requires.

The family member's mental disorder emotionally impacts differently on other family members, depending on their role within the family, and the experiences and responsibilities of parents differ from those of the affected member's spouses, siblings, or children. The ill family members' conduct, incapacities, and seeming disruptions on the caregivers' lives are the stressors that are reduced by the caregiver. The caregiving experience may be intellectualised as an evaluation of the stressors and burdens that the caregiver has to endure.

Caregivers experience the process of caregiving differently. Some caregivers may not find the situation threatening to their wellbeing because they are not very close to the affected person, and as a result they may feel that they are not obliged to be overly responsible for the caregiving role of the affected individual. However, other caregivers may perceive the situation as very demanding and consider the caregiving to be a significant stressor that compromises their wellbeing. During this phase, the caregiver's coping capabilities play a dominant role in their efforts to recover a state of balance in their lives.

Coping skills are the caregiver's problem-solving, cognitive, and emotional exertions in an effort to cope with the demanding circumstances. These various approaches of coping are limited, and they can be used at the same time or successively to cope with a problematic situation. The various influences, such as caregiver's persona, attitude towards coping, or the degree of social support and existing services are likely to impact on the caregiver's experience of caregiving. A caregiver's state of wellbeing is the consequence of their coping stratagems. If a caregiver's coping mechanism is inadequate to reduce their stress, they experience psychological or physical illness. The coping process takes place within the cultural expectations of caregiving, the society's economic status, and the country's existing social and health policies.

2.3.3 The Ryff Model of Psychological Well-Being

According to Ryff (1989), psychological well-being refers tohow individuals evaluate their lives. These appraisals can be in the manner of thoughts or in the form of affect. The cognitive part is a knowledge-based appraisal of one's life, that is, when a person gives a mindful, evaluative judgment about their satisfaction with their life as a whole. The affective part is a hedonic evaluation in terms of how people experience pleasant/unpleasant moods in response to their lives. The postulation behind this is that most individuals evaluate their life as either good or bad, so they are usually able to offer judgments. Additionally, people habitually experience moods and emotions, which have either a positive or a negative effect on their well-being.

Well-being is a dynamic notion that consists of idiosyncratic, social, and psychological dimensions, as well as health-related components. The Ryff Model of Psychological Well-Being is a tentatively established mechanism that precisely focuses on measuring various features of psychological well-being. These facets comprise self-acceptance, the establishment of quality ties to others, a sense of autonomy in thought and action, the ability to manage complex environments to suit personal needs and values, the pursuit of meaningful goals, a sense of purpose in life, and continued growth and development as a person.

Self-Acceptance

High Self-Acceptance: this is when a person embraces a positive outlook toward themselves, recognises and accepts various characteristics of their lives including mutually good and bad qualities, and feels positive about their past life.

Low Self-Acceptance: when an individual has a sense of dissatisfaction with their life, they are disenchanted with what has transpired in their past life, are distressed about certain personal qualities, and wish to be different than what they are.

Personal Growth

Strong Personal Growth: when a person has feelings of consistent development, see themselves as developing and expanding, are open to new experiences, have the sense of realising their potential, see improvement in themselves and behaviour over time, and are changing in ways that reveal more self-knowledge and efficiency.

Weak Personal Growth: when a person has a sense of personal stagnation, they lack a sense of development or growth over time, they feel bored and indifferent about life, and feel unable to develop new attitudes or behaviours.

Purpose in Life

Strong Purpose in Life: when a person has goals in life, they are eager about life and have a sense of direction, they feel there is value to their present and past life, they embrace beliefs that provide life purpose, and they have goals and intentions for living.

Weak Purpose in Life: when individuals display a lack of sense of meaning in life, they have few goals or aims, they lack a sense of direction, they do not see the purpose of their past life, and they have no attitudes or beliefs that give meaning to their lives.

Positive Relations with Others

Strong Positive Relations: when an individual has sincere, satisfying, trusting relationships with others, they are concerned about the well-being of others, they are capable of empathy, affection, and intimacy, and they can comprehend the reciprocal relationship of human relationships.

Weak Relations: when an individual has few close, trusting relationships with others, they find it challenging to be warm, open, and concerned about others, they are isolated and frustrated in their interpersonal relationships, and they are unwilling to make compromises to cement important relationships with others.

Environmental Mastery

High Environmental Mastery: when an individual has a sense of mastery and proficiency in handling the environment, they are able to control a multifaceted range of outward activities, make effective use of allied opportunities, and are able to choose or create settings suitable to their personal needs and standards.

Low Environmental Mastery: when an individual has difficulty managing everyday activities, they feel incapable of changing and improving the contexts in which they operate, they are ignorant of allied opportunities, and they lack a sense of control over the external world.

Autonomy

High Autonomy: when a person is self-determined and independent, they are able to resist social pressures to think and act in certain ways, they can control behaviour from within, and they can evaluate themselves according to their personal standards.

Low Autonomy: when an individual is certain of the expectations and evaluations of others, they rely on judgments of others to make important decisions, and conform to social pressures to think and act in certain ways.

According Oshodi, Adeyemi, Aina, and Umeh(2012), taking care of a person with schizophrenia often affects both the caregiver's psychological and social wellbeing, which leads to emotional strain such as anger, depression, sadness, bereavement, guilt, fear, shame, loss, stigma, and rejection.

This study focuses on three characteristics and compares them to existing literature and the study's later findings.

- Acceptance

There is little research on the positive experiences of caregiving, but there are some people (caregivers) who not only experience the negative aspects of caregiving but also the positive ones, and these aspects include benefits, such as social support, acceptance of the disorder, and the benefits available in certain societies (Oshodi et al., 2012).

There are different coping strategies that caregivers usually adopt, and one of them is acceptance. Some caregivers accept the nature of their affected relative's mental health state, and this acceptance helps them to foster a positive outlook on life, and in doing so, the process of caring becomes easier.

- Purpose in life

In certain cases, the burden of caring placed on caregivers, in particular, can have significant adverse effects on their ability to manage their own lives, which will in turn manifest as psychological distress, including grief, anger, depression, suicidal ideation, and anxiety (Bailey & Grenyer, 2013; Ulstein et al., 2008; Zauszniewski & Bekhet, 2014).

Some individuals who care for people living with schizophrenia, often have a questionable sense of a purposeful life, and they may perceive their purpose in life as unpleasant and from a negative perspective due to the burden and challenging nature of caring for their mentally affected relative. The psychological wellbeing of these caregivers may well be disrupted and they could end up experiencing depression, anger, anxiety, and suicidal thoughts. They are often unable to enjoy themselves, to focus on themselves, to engage in social activities, or to reach their educational or vocational goals.

- Personal growth

Caregivers may feel stuck as the result of caregiving because they often focus and concentrate on the individual with schizophrenia, and they neglect their own needs because their focus in entirely on providing care for their affected relative. Some caregivers cannot maintain romantic relationships, and are unable to get married. Other caregivers have to leave their jobs, while others do not even have the time to empower themselves by furthering their education and/or seeking employment(Oshodi et al., 2012).

Chapter 3

3. Literature Review

3.1 Introduction

Schizophrenia is one of the most relentless, persistent, and stressful forms of psychotic and mental disorders (Oshodi et al., 2012).This mental disorder is chronic and often results in psychotic behaviour that may be characterised by inadequate thinking and difficulties in information processing and interpersonal relationships, and problem-solving abilities. It can also be said that schizophrenia disrupts one's integrity or privacy of the self, together with loss of autonomy, or sense of being in control and independent (Mhaule & Ntswane-Lebang, 2009).

As a chronic illness, schizophrenia may be long term and progressive. This disorder does not only affect the person diagnosed with it, it also affects their caregivers. Caregivers around the world may have different ways in which they experience the process of looking after and taking care of their affected child or relative living with schizophrenia, because experience is subjective (McCann, Bamberg,& McCann, 2015). The experience of caring for schizophrenic family members differs from caregiver to caregiver, to the extent that some may have negative experiences and others may have positive ones, and even these experiences are likely to differ across cultures (Mosotho et al., 2011). This study investigated the psychosocial experiences of caregivers of schizophrenic people. Caregiving is often accompanied by challenging encounters and intermittent stress, because the role of caring stresses every part of the caregiver's life, which may lead to caregiver burden (McCann, Lubman,& Clark, 2011).

3.2 Schizophrenia

Schizophrenia is one of the most common and severe chronic psychotic mental illnesses in the mental disorder spectrum. It is known to be an overwhelming disorder that is categorised by a wide-ranging spectrum of cognitive and emotional dysfunction, which includes delusions, hallucinations, disorganised speech and behaviour, and inappropriate emotions (Sadock, Sadock,& Ruiz, 2015).

3.2.1 Characteristics

When this disorder is active, it may be categorised by episodes in which the person is unable to make a distinction between real and unreal experiences. As with any other disorder, the severity, duration, and frequency of symptoms may vary; but, in people living with schizophrenia, the occurrence of severe psychotic symptoms frequently decreases throughout the person's lifetime (Schatzberg & Nemeroff, 2009). Poor compliance to treatment and substance use (e.g. drugs and alcohol), and stressful situations are likely to increase symptoms (Schultz et al., 2007).

3.2.2 Symptoms of schizophrenia

Schizophrenia manifests in several symptoms.

- Positive psychotic symptoms

Positive symptoms include thoughts, behaviours, or sensory perceptions present in a person with a mental disorder, but not present in people in the normal general population (Schatzberg and Nemeroff, 2009), they include:

  - Hallucinations: seeing; hearing; or smelling things that are not really there;
  - delusions: belief and ideas that are not based on reality;
  - disorganised behaviour: abnormal behaviour that is not culturally expected and accepted, and behaviours that do notfit the situation; and
  - disorganised speech: derailment of sentences, loose association between ideas, incoherence, illogical statements, excessive detail, and rhyming of words.

- Negative symptoms

Negative symptoms reflect a decrease in, or loss of normal function (Schatzberg & Nemeroff, 2009).

- Alogia, which is the poverty of speech;
- avoliation, which is a decrease in the motivation to initiate and perform self-directed purposeful activities;
- affective flattening, which means that the person does nothave the full range of emotional expression that others do; and
- anhedonia, which is the inability to experience pleasure.

3.2.3 Diagnostic criteria

The Diagnostic and Statistical Manual of Mental Disorders (5th edition, 2013) found that the following is a diagnostic criteria tool

A. Two (or more) of the following, each present for a significant period of time during a one-month period (or less, if successfully treated). At least one of these must be present:

1. delusions;
2. hallucinations;
3. disorganised speech (e.g. frequent derailment or incoherence);
4. grossly disorganised or catatonic behaviour; and
5. negative symptoms (i.e. diminished emotional expression or avolition).

B. For a significant period of the time, since the onset of the disturbance, the level of functioning in one or more major areas, such as work, interpersonal relations, or self-care, is markedly below the level achieved prior to the onset (or, when the onset is in childhood or adolescence, there is failure to achieve the expected level of interpersonal, academic, or occupational functioning).

C. Continuous signs of the disturbance persists for at least six months. This six-month period must include at least one month of symptoms (or less if successfully treated) that meet Criterion A. (i.e. active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms, or by two or more symptoms listed in Criterion A present in an attenuated form (e.g. odd beliefs, unusual perceptual experiences).

D. Schizoaffective disorder and depressive or bipolar disorder with psychotic features have been ruled out because either:

1) no major depressive or manic episodes have occurred concurrently with the active-phase symptoms; or

2) if mood episodes have occurred during active-phase symptoms, they have been present for a minority of the total duration of the active and residual periods of the illness.

E. The disturbance is not attributable to the physiological effects of a substance (e.g. a drug of abuse, a medication) or another medical condition.

F. If there is a history of autism spectrum disorder or a communication disorder of childhood onset, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations, in addition to the other required symptoms of schizophrenia, are also present for at least one month or less if successfully treated (The Diagnostic and Statistical Manual of Mental Disorders, 2013).

3.2.4 Coping mechanisms for people living with schizophrenia

According to (Stuart, 2009), in the acute phase of psychosis, the individual living with schizophrenia may use numerous unconscious defence mechanisms in an effort to defend themselves from the startling experiences, such as their disturbed perceptions (e.g. seeing things or even hearing voices that other people cannot, which are known as hallucinations) that are triggered by the disorder. These people frequently experience regression associated with the problem of processing information. This usually consumes an enormous quantity of their own energy to cope with the anxiety, which may leave them with reduced energy for activities required for their day-to-day functioning. Projection often occurs in an attempt to alleviate their own bewildering perceptions, by projecting accountability for their conduct to someone or something, and this usually manifests in symptoms such as paranoia and persecutory delusions (Stuart, 2009).

Their withdrawal behaviour emerges largely in an inactive form, and during this process, the person usually avoids interaction with others, and their interpersonal skills are severely impaired (Uys & Middleton, 2010).

3.2.5 Self-care deficits

Individuals living with schizophrenia devote little attention to their personal appearance. A reduced drive, flat affect, and confusion of thoughts and cognitions are evident in patients who appear to be incapable of taking responsibility for their self-care. These individuals typically disregard their personal hygiene, such as neglecting and refusing to bath, changing their clothes, or attending to day-to-day grooming responsibilities, such as combing their hair or shaving their hair, or even cutting their nails. People living with schizophrenia can wear apparel that is inappropriate in the current season and weather conditions (Kneisl & Trigoboff, 2009).

The neglect for their general appearance and cleanliness may spread to the patient's home and the patient may fail to preserve a hygienic and secure living space. These individuals may be unable to maintain and take care of their personal possessions and may also misplace them easily (Kneisl & Trigoboff, 2009).

3.2.6 Deinstitutionalisation

According to Stuart (as cited in Bayini, 2012), deinstitutionalisation is the process of transferring patients that are hospitalised for extended periods of time to a community setting. The mental health care system applies this process in order to release long-term institutional care into community care, which is complemented by discharging long-term patients to a home setting, and by circumventing redundant admissions back to the institutions (Mental Health Care Act 2002; Stuart, 2009).

The majority of mentally ill patients in South Africa reside with their families, and this system of care was put in place to reduce hospitalisation, and so that a schizophrenic patient could spend more time in the community than in a hospital, to assist in aiding their day-to-day functioning (Uys & Middleton, 2010).

Despite the fact that the process of deinstitutionalisation achieved a reduction in beds, admissions in hospitals increased, due to the increased number in the recurrence of criminal offenders and emergency departments processing severely psychotic patients. Insufficient community resources also resulted in patients demanding to be re-admitted so that their basic needs could be met in a hospital (Stuart, 2009).

Deinstitutionalisation usually means that relatives, friends, or immediate family members have the responsibility of assuming the role of caring for their loved one affected by schizophrenia (Uys & Middleton, 2010).

3.3 Caregiver Experiences

Caring for someone with a mental disorder means different things to different people. Individuals are regarded as unique beings; no person is the same as another; people may go through the same experience, but they may not experience that particular situation in the same manner. Similarly, in the journey and process of caring, carers may have different experiences, views, and sentiments regarding the provision of care to a person with a mental illness or, in this instance, schizophrenia (Mhaule & Ntswane-Lebang, 2009).

In Nigeria, one study argued that mental disorders have a major impact on both caregivers and patients. Caregiving on its own results in a number of difficult encounters and occasional stress, as the role of caring affects every aspect of the caregiver's life (Oshodi et al., 2012; Akinbiyi, Yusuf,& Nuhu, 2009; Sefasi, Crumlish,& Samalani, 2008).

3.3.1. Subjective burden experience of caregiving

Several studies (Oshodi et al., 2012; Akinbiyi, 2009; Sefasi et al., 2008) have signposted that caregivers have subjective and objective experiences when taking careof their affected relative or family member with schizophrenia. The subjective experiences refer to the psychological consequences encountered by the caregivers, and these experiences include their personal judgment of the situation and its perceived severity.

Caregiving for a person with schizophrenia often affects both the caregiver's psychological and social wellbeing, which leads to emotional strain such as anger, depression, sadness, bereavement, guilt, fear, shame, loss, stigma, and rejection (Kenny, Sarma,& Egan,2012).

According to Mhaule and Ntswane-Lebang (2009), caring for someone with a mental disorder possibly means different things to different people. Individuals are different, no person is the same as any other; people may go through the same experience, but they may not experience that particular situation in the same manner, and similarly, in the journey and process of caring, people may have different experiences, views, and sentiments with regard to providing care to a person with a mental illness, or in this instance, schizophrenia.

3.3.1.1 Concern and guilt experienced by caregivers

In most cases of the caregiving process, caregivers have been found to be very concerned about difficult behaviours, negative symptoms, attempts at self-harm and harm to others. Caregivers often feel guilty and concerned, and they may blame themselves for the illness of the affected person that they are taking care of (Oshodi et al., 2012).

In most cases, caregivers who are mothers of the person with schizophrenia, express misconceptions about God or claim that their ancestors are punishing them for something wrong they might have done in the past. Caregivers also believe that the lack of improvement in their family members's condition is due to them as caregivers not doing as much as they could (Mhaule & Ntswane-Lebang, 2009).

3.3.1.2 Anxiety and depression

According to Oshodi et al. (2012), a Nigerian study claimed that approximately one third of caregivers experience severe anxiety or depression associated with their caring roles. The stress concomitant with the role of caregiving can put enormous strain on caregivers and may lead to depression.

Providing care to a mentally ill individual with a severe and chronic mental disorder such as schizophrenia can come at great personal cost to a caregiver's well-being. Primary caregivers of people living with schizophrenia may experience unpleasant effects on their own physical, emotional, and social well-being (Kenny et al., 2012), with approximately one in five caregivers of people with mental illness reporting that caring for an individual with a mental illness has a reasonable to significant contrary effect on their general well-being. Furthermore not only is the caregiver's health affected adversely, the whole family's physical and emotional well-being is affected, and as a result, the family's day-to-day functioning becomes disrupted and somewhat dysfunctional (Kenny et al., 2012).

In certain circumstances, the burden of care placed on caregivers, can have substantial adverse effects on the caregiver's ability to cope with their own lives, manifesting as psychological distress, including grief, anger, depression, suicidal ideation, and anxiety (Bailey & Grenyer, 2013; Zauszniewski & Bekhet, 2014). Caregivers also often feel isolated

(McGarry & Arthur, 2001) and are unable to express their needs and adversities to others (Digiacomo, Delaney, Abbott, Davidson, Delaney,& Vincent, 2013). The role of caregiving for a person with schizophrenia also reduces the amount of time they have for themselves, and affects their social life adversely (Peraica, Vidovic, Petrovic & Kozaric-Kozaric,2014) and their family relationships (McCann et al., 2011; Stjernsward & Hansson, 2014), causing further stress and strain.

3.3.1.3 Stigmatisation

According to Uys and Middleton (2010) the term 'stigma' comes from the mark branded on a slave, and refers to an accusation against one's reputation. In addition, it is something that labels an individual negatively in the eyes of society. Semple and Smyth (2009) state that 'stigma' is a Greek word meaning 'mark', and initially referred to a symbol that marked delinquents or conspirators in order to publically identify them. In a more contemporary definition, stigma refers to the sense of shared disapproval and group of negative views attached to particular people, such as mentally ill people.

The stigmas attached to mental illness and the everyday stresses involved in caring for a patient are significant sources of stress. Minority families with a mentally ill relative are said to experience a double stigma: from both the illness and their minority status (Mohammad, Subhi, Jusoff, Wan Azreena, Chong, Fauziah, Lukman, Sarnon, Nen, Hoesni & Alavi, 2011). Some families prefer that their mentally ill family member be admitted to an institution rather than being cared for in the home, or they hide them from the eyes of the world to avoid what they perceive to be a social stigma. The generalisation of stigma to families is an additional source of psychological risk and stress for both the mentally ill patients and their family members (Ae-Ngibise, Christian, Doku, Asante,& Owusu-agyei, 2015).

Many caregivers experience stigmatisation in their societies; the reality of stigma associated with their affected relatives' illness affects them.

3.3.1.4 Anger and frustration

According to Mhaule and Ntswane-Lebang (2009), some caregivers acknowledge that they love the individuals with schizophrenia that they care for, and wish that they would recover from their illness, but the caregivers admitted to being frustrated at not having the means to cope with the caring process. Other caregivers expressed anger and frustration towards the government for poor service delivery, such as not building enough psychiatric hospitals to accommodate their affected relatives and to provide for their needs. Several studies (Frisch, 2006; Martens & Addington, 2001) have noted similar feelings of anger and frustration when describing caregiver's experiences of caring for their schizophrenic family members. They maintain that living with a schizophrenic relative can be very stressful and distressing. In another study, some participants stated that they wished their affected relative was dead or never born, these expressions were a result of their frustrations and anger (Oshodi et al., 2012).

3.3.2 Objective burden experiences and caregiving

Objective experiences involve outward measurable demands placed on the caregivers. The experiences faced by caregivers include financial difficulties, strain on interpersonal relationships, a reduction in social support, physical violence, disruptions to the caregivers' routines, in their households, and to their leisure time (Yusuf, Nuhu,& Akinbiyi, 2009).

3.3.2.1 Violence and aggression

According to Mclefi and Swartz (2011), caregivers experience aggression from the schizophrenic people that they are taking care of. This often happens in their psychotic states, and these people tend to be verbally aggressive towards their caregivers, e.g. they shout at their caregivers without provocation, and sometimes they act violently towards them and threaten to harm them. As a result of these acts, caregivers are always looking over their shoulders and always feel uneasy because they are scared that the people they're caring for might harm them.

One study established that one of the indicators that participants found predominantly challenging was the verbal abuse they experienced from their affected relatives. The participants conveyed feeling distraught and helpless, and taking on too much tension as a result of their affected relatives' disturbing behaviour. Others reported that that they had experienced elevated blood pressure due to the verbal abuse they encountered (Molefi & Swartz, 2011).

3.3.2.2 Substance abuse

Caregivers are predominantly concerned about habits that their affected relatives have or habits that they have picked up. They claim that their relatives with schizophrenia have major problems of substance abuse, such as heavy alcohol consumptions and the use of dangerous drugs such as tik (Molefi & Swartz, 2011). One caregiver believes that it is her son's use of tik that triggered his illness. Several participants complain that because of substance abuse their affected relatives began to display negative symptoms, act violently, threatened to harm them, became paranoid, and decreased their medication adherence (Mhaule & Ntswane-Lebag, 2009; Molefi & Swartz, 2011).

3.3.2.3 Access to and quality of health care

The issue of health care services and provision is a pressing and devastating issue in developing countries, especially in Africa. People have to travel long distances to access health services, many don't even have the means to travel, some claim that even if they travel these long distances they arrive at the clinics and receive poor service, such as unhelpful attitudes from staff members, and incomplete medication(Mhaule & Ntswane-Lebag, 2009; Molefi & Swartz, 2011). South African families, especially using those that use public mental health facilities, face many challenges, for instance there is a shortage of mental health facilities, and accessibility of these services is problematic. Cultural and racial differences between families and service providers also pose major challenges, and there may be difficulties with families and service providers speaking different languages and adhering to vastly differing world-views (Molefi & Swartz, 2011).

3.3.2.4 Financial difficulties

In Africa, most of the people living with schizophrenia are from poor backgrounds, you find that in countries with a low socio-economic status, unemployment and illiteracy compound the care of people with schizophrenia.

Caregivers sometimes are forced to quit their jobs to look after their affected relative, some have not worked at all and rely on social grants. In a large family the grant money does not even provide for the affected relative's basic needs. Where caregiver families are on the lower end of the economic scale, they are almost entirely unable to cater for their affected relative's needs.

3.3.2.5 Culture

Several studies (Mhaule & Ntswane-Lebang, 2009; Mosotho et al., 2011; Oshodi etal., 2012) indicate that in African cultures, some people believe that supernatural powers and possession by evil spirits are responsible for their relatives developing schizophrenia, while other people may believe that their relative's schizophrenia was caused by bewitchment, and as a result, they turn to traditional healers or doctors as their first point of reference for consultation.

3.3.2.6 Caregivers' knowledge of schizophrenia

According to Sefasi et al. (2008), caregiver burden correlates positively with schizophrenia knowledge, this means that the more the caregiver knows about the illness or the disorder of the person they are taking care of, the more burdens will be experienced.

Other studies (Graham, Ballard,& Sham, 1997) propose that it is possible that higher levels of knowledge are associated with higher levels of stigma, and state that stigmatisation has been reported to contribute to burdens among caregivers of mentally ill patients in Africa. This means the lesser you know, and the less contact you have with an affected person with schizophrenia, the lesser the burden.

3.3.2.7 Age, gender, and caregiving

Usually in African culture, females are considered the natural caregivers no matter what age they may be. In African communities, they are the ones who usually look after their affected patients, in this instance patients with schizophrenia. Commonly, female caregivers who participate in caregiving are reported to experience most of the burden, but in a Nigerian study Nigeria (Oshodi et al., 2012), males, rather than females, were identified as the ones who appeared to experience more of the burden. It was concluded that this might have been because of the negative caregiving appraisals from men who are traditionally not involved in caregiving roles (Oshodi et al., 2012). Shama, Chakrabarti, and Griver (2016) also suggested that all over the world women are the foremost providers of caregiving and thisis mainly due to societal and cultural demands that compels them to adopt caregiving roles.

3.4 Positive Experiences of Caregiving

Little research has been carried out regarding the positive experiences of caregiving, but there are some people who not only experience the negative aspects of caregiving, but also experience the positive ones, and these aspects may include rewards like social support, acceptance of the disorder, and benefits in certain societies (Oshodi et al., 2012).

3.5 Coping Strategies of the Caregiver

Even in adverse conditions of caring, caregivers tend to adopt coping strategies that help them with the demand and burden of caring for their mentally affected relative with schizophrenia. The role and demands may be assimilated into their regular family responsibilities Sefasi et al. (2008). In most cases, the caregivers develop different kinds of coping strategies to deal with the burden of caregiving. The coping strategies are usually categorised into two groups: Emotion-focused and problem-focused strategies. The objective of emotion-focused strategies is mainly to lessen the negative emotional impact of the stressor, and they may include avoidance, denial, fatalism, hope, or looking to religion (e.g. God). On the other hand, the problem-focused coping strategies refer to direct actions that an individual uses to change their situation. These include problem-solving or seeking social support to resolve the stress of caregiving (Oshodi et al., 2012)

According to Chadda (2014), it is imperative to understand caregivers' coping mechanisms for tackling their burdens, because it affects the caregivers' day-to-day functioning. The burden is a perpetual source of stress, and how the caregivers cope with it affects the course of the person in their care's illness. The burden and the coping methods also influence the caregiver's physical and mental health, and hence their further efficacy as a caregiver.

In Chadda, Singh, and Ganguly's (2010) study, it was stated that emotion-focused coping has been associated with the perception of higher burden, whereas primarily problem-focused and fewer emotion-focused coping strategies lead to a reduced perception of burden. Caregivers' positive evaluations of their coping strategies is associated with reduced distress levels and positive attitudes toward the patient (independent of symptoms and levels of burden). Problem-solving strategies have been reported as being associated with improved functioning(Chadda et al., 2010).

It has been established that caregivers use several coping strategies, including positive emotions like compassion, hope for a better future, developing faith in God, participating in religious practices, helping others with a similar problem, and taking advice from experts and health professionals (Chadda et al., 2010).

Caregivers of people living with schizophrenia usually express a spectrum of emotions in their caregiving roles, ranging from concern, confusion, frustration, fear, sadness, grief, anger, resentment, and guilt, to hope, caring, compassion, sympathy, and love(Mohammad, 2011). According to Onwumere, Smith, and Kuipers (2010), emotions vary from time to time during caregivers' care of their relatives. Mutually positive and negative emotions are reflected at different times. Positive and compassionate approaches and supportive handing of the mentally ill individuals are common methods of coping and caregiving.

Acceptance of the mental illness as it exists is another strategy that is usually used. Most caregivers have one common experience when dealing with the behavioural disturbances of their affected relative, and this has been reported as follows: "Whenever she stops treatment, she loses temper, breaks things and shouts when her demands are not met". It was reported that when caregivers accept the behavioural outburst as a result of their relative's illness, they feel better able to cope with it (Mohammad, 2011).

Igberase, Morakinyo, Lawani, James, and Omoaregba (2010) state that in most instances, caregivers are hopeful of a good future. One father of a young male with schizophrenia stated: "If good things change, so do the bad things, and therefore our bad time will also pass away". The mother of another schizophrenic said, "If things are not good today, tomorrow will be better".

Many caregivers stated that their faith in God was an important coping strategy (Chadda, 2014). Most caregivers felt that they were duty-bound to take care of their relatives with an illness, and stated that they must provide these relatives with the best treatment possible and leave everything else for God to attend to. According to Onwumere et al. (2010), religion is often a source of support. Most caregivers believe in God and believe that He will help them out of the situation that they have to cope with.

Mohammad (2011) established that caregivers of people living with schizophrenia develop approaches that assist them in coping with the responsibility of caring for their mentally ill family member, mainly by using hope and faith, practical coping mechanisms, emotional coping systems, detachment, and cultural coping methods.

- Hope and faith

To continue with the caring of the patient, family caregivers use hope and faith to motivate them in long-term situations.

- Practical coping

It was established that caregivers take practical action by sharing their problems with other interested individuals, such as mental health professionals, because they believe this will help them to solve the problems that they experience when caring for their mentally ill relatives.

- Emotional coping.

Some caregivers use positive and constructive thinking to cope with the negative emotions they experience. They believe that they have a commitment and responsibility to remain positive in their relationship with their mentally ill family member.

- Detachment.

Detachment is identified as another coping mechanism used by caregivers, and this is achieved by thinking of other matters instead of focussing only on the mentally ill individual.

- Cultural coping.

Caregivers implement cultural care-giving methods, which include traditional coping mechanisms when dealing with mental illness, due to existing cultural beliefs and the availability of resources in the community.

Mohammad et al. (2011) study further reveals that caregivers view their experience positively when they receive continuous social support from mental health professionals, their family members, and their closest friends.

3.6 Summary of the Empirical Review of Literature

Studies that explore the psychosocial experiences of caregivers of people living with schizophrenia in the North West province are under-researched, and in Mafikeng not a single study of this nature has been conducted.

Studies have shown that caregivers do not only go through negative experiences as is expected, but some caregivers have had positive experiences in the process of caregiving. Literature has proven that many researchers have a single perspective regarding the subjective and objective aspects that many caregivers of people with schizophrenia experience.

Chapter 4

4. Research Methodology and Design

4.1 Introduction

The chapter focuses on the methodology that was used in this study. Features of the research methodology are discussed, and they are the qualitative methodological approach of the study, the research design, the data collection methods, and the method of analysis.

4.2 Research Method

A qualitative research approach is research conducted using a range of methods that use qualifying words and descriptions to record and investigate aspects of social reality (Bless, Higson-Smith,& Kagee, 2011. The qualitative approach has been used to answer questions about the complex nature of the phenomena (experiences of taking care of people with schizophrenia), with the purpose of describing and understanding phenomena from the participants' perspective (Leedy & Ormrod, 2005). Ingleton and Seymour (2001) further explain that the main aim of qualitative research is to produce detailed and systematic accounts that plausibly and credibly explain events or phenomena. The qualitative approach was appropriate for this study as the approach provides an in-depth and subjective view on the psychosocial experiences of the Tswana caregivers of people living with schizophrenia.

4.3 Research Design

According to Cresswell (2014), a phenomenological study is a study that describes the meaning of a lived experience of a phenomenon or concept for several individuals. The core of phenomenology is the intent to understand the phenomena under study on the participants' terms, and to provide a description of human experiences as the subjects themselves experience them. In this study, the phenomenological design has been used to study people's perceptions, perspectives, and understanding of a particular situation, in this case the people are adult Tswana caregivers (Cresswell, 2014). The phenomenological research design is an appropriate design for the study based on the fact that this study sought to explore the experiences of caregivers of people living with schizophrenia.

4.4 Research Context and Participants

The study was conducted in Mafikeng, in the Ngaka Modiri Molema District, in the North West province of South Africa. The study intended to include a maximum of 12 Tswana caregivers, as 12 is the maximum entry requirement to conduct a focused group (Stewart & Shamdansani, 2014). According to Stewart and Shamdansani (2014), a focus group is supposed to include between six and 12 participants. However, the researcher managed to get six female Tswana caregivers to participate because the study utilised the snowballing sampling method, and therefore the number was dependent upon referrals received.

4.4.1 Inclusion and exclusion criteria

Inclusion criteria – participants had to be:

I. caring for an individual with schizophrenia who meets the DSM-V criteria (at least a month and upwards; and

II. Tswana-speaking.

III. Willing to participate

Exclusion criteria – participants had to be excluded if they:

IV. were unable to give informed consent; and

V. were not a caregiver.

4.5 Sampling Method and Procedure

The study used the snowball sampling method. According to Bless et al. (2011), snowball sampling is a sampling method that involves approaching a single case that is involved in the phenomenon to be investigated in order to gain information on other persons with similar experiences. This sampling method produces a study sample through referrals made among people who share or know of others who possess some characteristics that are of research interest. The method is well suited to a number of research purposes, and is particularly applicable when the focus of study is on a sensitive issue, possibly concerning a relatively private matter, and thus requires the knowledge of insiders to locate people for the study (Levy, 2014).

According to Suanders et al. (2017), saturation should be operationalised in a way that is consistent with the research question(s) and the theoretical position and analytic framework adopted. In line with this argument, an exhaustive recording of seven to eight hours during focus group discussions allowed data collection to be consistent with all research questions and the theoretical position of this study. The research used open-ended questions and made extensive follow-ups based on the participants' responses to ensure saturation.

The study was dependent upon referrals of people who are providing care for people living with schizophrenia, and the participants had to be willing and capable to share their views and experiences on the subject matter, which is caregiving to individuals with schizophrenia. Moreover, during the process, others refused to participate because of complexities relating to the stigma and prejudices of being related to someone with schizophrenia.

Noy (2008) states that the snowball method is a technique that aids researchers to find or track down rare and difficult to find characteristics that are required for the sample that the researcher desires. In this technique the researcher relies on the subject that they were able to identify, by so doing the researcher depends on that subject to elicit information of the next subject who possesses the same characteristics as they do, and which the researcher needs. For example, if the researcher manages to find and identify one respondent, the researcher depends on the next respondent who was tracked down using the information from the first respondent to get a referral to the next respondent, and so on until the desired sample size is achieved.

The researcher intended for the study to consist of both Tswana female and male caregivers of people living with schizophrenia, however the snowballing method only led to six caregivers of people living with schizophrenia, all of which were female, ranging from 19 to 64 years of age. Creswell (2007) states that samples in qualitative research are commonly small in size. Therefore, the fact that participants in this study consisted of six Tswana females is not uncommon.

4.5.1 Sample size

In qualitative studies the aim is not to be representative of the population. The validity, meaningfulness, and insights generated from such studies have more to do with the information richness of the cases selected, and the analytical qualities of the researcher, rather than the sample size.

According to Levy (2014), there are no rules for sample size in qualitative research. It depends on what one wants to know, the purpose of the study, and the practical factors, and each focus group size can have a minimum of six and a maximum of 12 respondents (Levy, 2014; Steward & Shamadansani, 2014).Qualitative researchers often refer to the redundancy criterion, which is when no new information is forthcoming from new sampled participants; in such cases the researcher can stop collecting data (Levy, 2014).

One can also use practical criteria in defining a sample size, considering the amount of time it costs to do and transcribe the interviews and the number of sub-groups from which one will select participants (Levy, 2014). Although the sample size was intended to have 12 Tswana caregivers (where six of them would be male and another six would be female), the study only had six female Tswana caregivers. This was because other possible participants refused to participate due to the stigma and prejudice ascribed to the role of providing care to someone living with schizophrenia.

4.6 Data Collection Strategies and Procedures

A letter of permission to conduct the study was applied for and granted by the North-West University. The researcher then made contacttelephonically with one participant who referred her to others, up until she reached the number that could make up the focus group. Although initially 12 participants were the target sample, the researcher did not manage to achieve the target that was initially proposed, and she then continued with the minimum number that is required to conduct a focus group, namely six (Steward & Shamdansani, 2014). The researcher and the participants scheduled a suitable appointment for the focus group interview. The objective and aims of the study, and issues that concern flexibility and confidentiality of participation were conveyed clearly to the participants who were later given consent forms to complete and sign. The researcher explained to the participants what thestudywas all about and what it meant to sign the consent forms, and thereafter participants were given 30-45 minutes to study the consent form and to ask questions related to the consent forms they were to sign, and the focus group ran for an intensive 7-8 hours, where by participants were giving rest breaks and refreshments in-between.

4.6.1 Focus group interviews

A focus group interview was conducted for the participants who are all caregivers of people living with schizophrenia. The member-checking technique was utilised during the group discussions to ensure trustworthiness of interpretations that were provided. The technique permits the researcher the opportunity to comprehend the participants' descriptions by providing other participants with the opportunity to rectify inaccuracies and to challenge what they view as incorrect interpretations. Other participants offered to provide supplementary information by repeating the process of questioning, giving the researcher an opportunity to summarise primary findings and results, in addition to sanctioning certain features of the data (Fusch & Ness, 2015). This provided all members in the group with an opportunity to provide a broader range of responses and descriptions and explanations with regard to providing care to people living with schizophrenia.

4.6.2 Audio recordings

In addition, during the interviews, a tape recorder was used to capture all the interview sessions, and permission was elicited from the participants who were assured that the recordings would be held in a safe place to ensure participant security and confidentiality. The interviews used open-ended questions. A seven and eight-item survey (Appendix C) was administered in order to collect basic demographic data from the participants. In addition, during the interview, field notes were taken to ensure that every non-verbal detail was recorded.

The researcher, the expert researcher, and the six participants were seated in a private conference room, at a circular table that accommodated 10 chairs. The researcher ensured that everyone was comfortable. The session began with the researcher introducing herself and the expert researcher, and asked everyone to introduce themselves. This was done to ensure that everyone felt welcome and comfortable. Thereafter, the researcher thoroughly explained the purpose of the session at hand. This was followed by an explanation of the purpose of the consent forms and why they needed to be signed. Participants were further given 30 minutes to study the consent form and ask questions in relations to the consent form, which was available in both English and Tswana. Thereafter the signed consent forms were retrieved from the participants, and then the researcher began posing open-ended questions pertaining to their experiences of caregiving to people with schizophrenia. This question was posed in such a way that it did not limit them in terms of expressing their experiences:

“You are taking care of somebody who has schizophrenia, we may not know for how long, but think of the experience around that, what is it that you can tell us about the experience of a caregiver of that person?”

Follow up questions were based on the participants’ responses.

After the focus group discussion, a debriefing session took place,it was done by the psychologist that was invited by the researcher to come and provide debriefing services, this topic is extremely sensitive, and in some it opened wounds.

4.6.3 Field notes

Polit and Beck (2010) state that a researcher uses field notes to record unstructured observations that were made in the field, together with an interpretation of those observations. The field notes taken during the data collection were instantaneously written down after the interview and were then followed by descriptive and eloquent explanations that the researcher impartially and empirically documented in terms of the proceedings that took place during the interview.

In this study, field notes were taken and used to assist the researcher to recall and extract information from the interviews. The following are the crucial points that were followed in the field note taking, namely the researcher’s emotions, interpretations, views, or perceptions, preconceptions, and observations. The field notes helped the researcher to transform the above aspects into the end product. Initially, observation was the technique used for information gathering throughout the interview. This technique provided the researcher with an opportunity to simplify multifaceted issues that were unusual and complex.

4.6.4 Data capturing

Data was captured with the aid of a tape recorder and field notes in order to obtain the information from participants during the focus group interview.

4.7 Procedure for Data Analysis

This section of the study details how data obtained from the focus group discussion was analysed. Data analysis is defined as the process of bringing order, structure, and meaning to a mass of collected data (Van De Vos, Strydom, Fouche,& Delport, 2011).

The study analysed the data by using significant statements, meanings, and textual and structural descriptions of their experiences as a guide. A thematic analysis is a method that emphasises organisation and rich description of the data set. Thematic analysis goes beyond simply counting phrases or words in a text, and identifies implicit and explicit ideas within the data. Thematic analysis is also related to phenomenology, in that it subjectively focuses on the human experience (Braun & Clarke, 2006).

Braun and Clarke (2006), opined that thematic analysis means capturing identifying key ideas from the data to provide answers to the research questions. This form of analysis was used to produce new insights and comprehension regarding themes, truths, and facts. In an effort to analyse the data, the researcher used a thematic analysis to link the participants' feelings, beliefs, and experiences to create understanding and meaning.

Braun and Clarke (2006) further propose that thematic analysis offers a flexible research instrument that is capable of offering a comprehensive, rich, and multifaceted description of data. It is also regarded as a technique that identifies, analyses, and reports patterns that are regarded as themes. Thematic analysis also interprets several characteristics of the research topic; and it reports on meanings, realities, and experiences of participants.

Howitt and Cramer (2011) determined the steps in the thematic analysis as follows:

Step 1: Familiarisation with the data

During this stage the researcher becomes actively involved with the data. The researcher formulates ideas about what was being said in the interview. The interview data is transcribed from the recording because this aids in more intense processing of the data. This is also the best way to familiarise oneself with data (Howitt & Cramer, 2011).

Step 2: Initial coding generation

This is the process through which themes are generated. The initial coding process involves working through the data systematically, making suggestions of what is happening in the data. Since this research study analysed caregivers' conversations, which did not have detailed consistency, initial coding was intended to capture the essence of a segment of the text (Howitt & Cramer, 2011).

Step 3: Searching for themes based on the initial coding

During this step themes are basically obtained by linking the coding in a meaningful way. Consequently, the process of initial coding involved the researcher formulating descriptive suggestions for interesting aspects in the data that was obtained. One way of identifying themes was to write down each of the different initial codings onto separate pieces of paper or card, and then the initial coding was sorted into piles of coding that seemed to be related (Howitt & Cramer, 2011).

Step 4: Review of themes

In this step, the researcher has a set of themes, which help to expedite the understanding of what appears in the transcription. Nonetheless, these themes need to be retested against the original data, at they might not yet be refined at this stage (Howitt & Cramer, 2011).

Step 5: Theme definition and labelling

A researcher refines the themes in order for this step to be objective. At this stage, the researcher identified sub-themes, which made it easier to define and label themes accurately. Defining and labelling themes also took place in relation to the data. When a researcher does this, the encoded data is coded using refined themes, which makes it easy to understand the material (Howitt & Cramer, 2011).

Step 6: Report writing

The final report requires that a researcher illustrate their analysis using extracts from their data. This was a stage for reflection on the researcher's analysis. The final report provided the researcher with an opportunity to discuss the analysis in the light of the literature review. The researcher found innovative ways in which to analyse and evaluate aspects that had not been discussed by previous researchers (Howitt & Cramer, 2011).

4.8 Trustworthiness

According to Merriam (2009), trustworthiness is the word used in a qualitative methodology and design to measure the quality of the research. The process of ensuring trustworthiness is illustrated in Table 1 below.

Table 1: The process of crystallisation to ensure trustworthiness

Principles	**Strategies**	**Application**
Complex interpretations	Data Collection	During this stage several qualitative methods were utilised, such as focus group interviews and field notes
Data collection	Focus group interview, observational fields notes, audio data, and member-checking	Member-checking was performed throughout the focus group interview in order to check the findings, particularly in terms of obtaining feedback on data, interpretations, and conclusions from the participants themselves

Analysis	Code recorder procedure	The study used thematic analysis. Once the researcher completed the thematic analysis, peer evaluation was carried out, whereby the researcher gave another researcher, a qualitative researcher, the opportunity to examine issues of bias and to compare analyses in order to confirm that this study used thematic analysis. Once the researcher completed the thematic analysis, a peer evaluation was carried out, whereby the researcher gave a qualitative researcher an opportunity to examine issues of bias, and to compare analyses in order to confirm credibility. The researcher also gave an expert researcher the analysis so that they could evaluate and examine whether or not the analysis and findings were credible. The purpose of the application of these numerous methods was to retrieve rich data in order to produce a

		phenomenological and complete representation of the findings.
	Paradigms	The study findings were presented as patterns and themes to aid the researcher to understand and interpret the participants' versions of various ways in which the research problem was understood.
Variety of presentations	Multiple text	When the data was subsequently gathered by means of an audio data recording, field notes, conversations, member-checking, and expert evaluation, the researcher incorporated the findings of every single collection in a story in a connected manner.

Trustworthiness was ensured using the process of crystallisation, whereby it makes use or combines multiple forms of analyses and genres of representation into a coherent text or a series of related texts that build rich and open, partial accounts of a phenomenon (Merriam, 2009). This technique aided the researcher to reflect reality out of unrelated points (Eillingson, 2009). It also helped the researcher to understand and gain insight into the research topic.

Crystallisation assists in building richness in a study; the factor that aided in building richness was the use of various data collection methods, in this case, the consolidation of numerous methods in the research, which included the use of audio data, member-checking, observational field notes, peer analysis, expert evaluations, and confirmation and validation of findings with the participants. By using the crystallisation technique, the researcher guaranteed and ensured the study's trustworthiness. Trustworthiness is considered to be the element that provides soundness, elevates the quality of the study, and is a significant measure of ethical research (Merriam, 2009).

4.9 Ethical Considerations

A letter requesting permission to conduct the study was requested, and ethical approval for the study was obtained from the North West University's Ethics Committee to proceed with the research study titled: An exploration of the psychosocial experiences of Tswana caregivers of people living with schizophrenia in Mafikeng, North West.

According to Cresswell (2009), the researcher is obliged to conform to and respect participants' needs, rights, desires, and values. In this study, all the participants' rights to privacy, confidentiality, anonymity, fair treatment, and protection from harm and discomfort were respectfully adhered to. The researcher ensured that the participants understood the objective of the study in which they agreed to participate, what would take place in the research process, and they were also reminded that participation was voluntary. As a result, the researcher created a consent form that appears as an addendum in the study, and was based on Strydom's (2011) recommendations as well as the guidelines for informed consent (Weathington, Cunningham,& Pittenger,2010).

Informed consent was explained to the participants, and a detailed description of what the study entailed was provided. After explaining the study to them, they were given an informed consent form, which was available in English and Setswana, to complete and sign if they agreed to participate in the study. The researcher explained that participation in the study was completely voluntary. Additionally, the interview questions were presented in a nonthreatening manner, which respected the wellbeing of the participants.

In support of Thompson and Chambers' (2012) recommendation that participation may subsequently be withdrawn at any stage without the participant providing the researcher with any reason whatsoever, the researcher advised the participants that they could withdraw from the study at any time during the interview/study if they experienced discomfort. Further to another of Thomson and Chambers' (2012) recommendations, intervention was provided and made available to participants who experienced emotional trauma. The researcher also emphasised that there would be no remuneration to participants in the study, as participation in the study was totally voluntary.

Privacy and concealment was ensured in the study by hosting the focus group interview in a private conference room. Thereafter, the audio tape recorder was stored in a safe and locked filing cabinet (cupboard) in the researcher's office. Strydom's (2011) concept of confidentiality and anonymity implies that all of the participants' information is treated in confidential manner was adhered to by keeping the names of the participants confidential and unidentified, and by not disclosing them to anyone. Human dignity (Ubuntu) moralities were upheld by the researcher towards the participants, in order to achieve collaboration and co-operation from participants and other relevant participants who were involved in the study.

Nestor and Schutt (2012) state that debriefing participants after research interviews is both imperative and necessary. During and after the focus group interview, the researcher and the psychologist assessed participants' individual reactions in the interview, to examine the likelihood of re-traumatisation and the necessity for any psychological interventions. After the interview the researcher gave participants the opportunity to reflect on the interview and to talk about their experiences regarding participation in the study. The researcher undertook to make the outcomes of the research at the final completion of the study available to participants. The method in which the researcher will make the findings available to the participants will be via telephonic discussion due to their limited accessibility.

Chapter 5

5. Research Findings and Data Analysis

5.1 Background Overview of the Study

A focus group interview was conducted with six female caregivers of people living with schizophrenia in the Ngaka Modiri Molema District in Mafikeng, in the North West province of South Africa. All the participants are black women ranging in age from 19 to 64 years. One woman is married, one is divorced, and four are single.

Participant	Age	Gender	Relationship	Marital status	Duration of caring
1	48	Female	Girlfriend	Single	Four months
2	19	Female	Daughter	Single	+5 years
3	27	Female	Daughter	Single	+12 years
4	64	Female	Wife	Married	17 years
5	39	Female	Daughter	Single	22 years
6	50	Female	Mother	Divorced	3 years

Brief background information of Participant 1

A female of 48 years of age. She takes care of her boyfriend and they have been together for almost a year. Its four months since the participant became aware of the patient's disorder. The patient was hospitalised for four months, and was released on the day of the interview.

Brief background information of Participant 2

Participant 2 is a 19 year-old single lady who takes care of her mother.

Brief background information of Participant 3

Participant 3 is a 27 year-old single lady who takes care of her mother, who has been sick since before she and her siblings were born, and she is the oldest child.

Brief background information of Participant 4

Participant 4 is a 64 year-old married woman who takes care of her husband. Her husband has been sick since 2013, and the participant has been taking care of him for four years.

Brief background information of Participant 5

Participant 5 is a 39 year-old woman who takes care of her mother, who has been sick since the participant completed Grade 10 in 1995. The participant has taken care of her mother for 22 years without any assistance from any family member.

Brief background information of Participant 6

The participant is a 50 year-old woman who takes care of her 21 year-old son. Her son has been sick since he was 18 years old. The woman has been taking care of him for three years without anyone's help.

5.2 Introduction to the themes

Two major themes emerged from this study. The themes described the psychosocial experiences that the caregivers have been subjected to as a result of their negative communal and social experiences, due to the stigmatisation of schizophrenia and due to their inadequate coping skills. The themes are: communal and social experiences; stigmatisation of schizophrenia and coping.

Theme 1: Communal and social experiences: Stigmatization of schizophrenia

THEME	SUB-THEME	SUB-SUB THEME
Communal and social experiences: Stigmatisation of schizophrenia	Excessive rejection	- Family members' withdrawal *(siblings, children, parents, relatives)* - Community withdrawal *(churches, friends)* - Discrimination - Humiliation and assault *(Name-calling, negative labelling)*
	Isolation	Social isolation Self-isolation
	Lack of support	- Organisational support *(hospitals, professionals)* - Familial support - Financial support - Social support
	Emotional distress	- Humiliation and embarrassment - Excessive pain *(It's very painful)* - Lack of interest in mutual relations

		- Suicidal ideation
	Loss	- Jobs
		- Financial stability
		- Materials
		- Interpersonal relations
		- Social relations
		- Social identity
		- Good health
		- Hope

Table 2 shows theme 1 extracted during data analysis, which is communal and social experiences

5.3. Themes to emerge from data analysis

5.3.1 Communal and social experiences

Stigmatisation of schizophrenia

The caregiver's communal and social experiences appear to involve stigmatisation of the condition itself.

"My son said 'mama, there is serious stigma about this sickness...it's like one has leprosy and is smelling...' You know, I sometimes think I could have left my son to kill himself the other time to avoid all this pain around us caused by stigma". [P6]

"I say it's like leprosy, because people reject you and reject the one who is sick ... the sick person.... You will feel the pain when your child tells you that 'mama no one wants to see me, no one wants to be close to me... no one wants to associate with me..'. No one comes to see him ... no one ... not even one... not one that is from the mother's side, from the father's side it is the same... no one" (stressing the words repeatedly with anger). [P6]

"*...what people have told themselves about me and my schizophrenic mother is known only to them.... The stigma is bad.*" [P3]

Another participant interrupted P3 to add, *"I am telling you, really this stigma is there ... it makes you lose interest in life; life becomes meaningless"*. [P6]

"Stigma and rejection by everyone makes the pain unceasing". [P5]

"*My other son, not the sick one, was assaulted and humiliated just because of stigma*". [P6]

"You know, this stigma will make life miserable for you". [P1]

"[the] pain of the stigma is unbearable ... it never leaves you." [P3]

According to the findings of this study, this stigmatisation is reflected towards all the people associated with the schizophrenic person, including their caregivers, leading to all of the experiences stated as sub-themes bellow.

Excessive rejection

The caregivers face rejection in all forms from people around them.

"*Rejection by everyone makes an unmovable pain... Mama, rejection is so painful,* (crying) *I am rejected... The only people I link with nowadays are those that are new in my life, those that I have not told them about my situation... not even neighbours"*. [P6]

The caregivers together with their affected family members face excessive rejection from the society around them, no matter how close they are to them.

Family members' withdrawal

"*The sick person is rejected... you will feel pain when your child say to you mama, no one comes to check on me, just imagine... I mean on the mother's side, on the Father's side.... No one.."*. [P6]

Siblings

"I stayed with my siblings after my mother became sick with no one to help ... even up to today no one is helping us... (Crying bitterly) ... even her siblings" [P5].

"...like my mother, she has her own brothers and sisters, they just don't care ... they don't exist at all in our lives ... they are just not there. It's only me and my sister who see to it that she finds kind of help..". [P3]

*"...the way my mother's siblings are, they just do not care... even her twin sister... (*Twin sister, does she have a twin sister?*) Yes she does... even if I call her to say 'Speak to your twin sister', she doesn't respond.... Her blood sister and a twin sister for that matter ... the one who bears the resemblance to her ... she is ashamed of her sister ... she has got siblings who do not care at all about her life".* (more sobbing) [P5]

Parents

The rejection seems to be worse when it comes from the affected person's parents *"...I and his father are divorced, last time I said to him (the father), 'Sir, I never said I want to come back into your life... what I want is for you to help me with help your own son' ... Do you know what he said to me? He said 'It's like I am someone who is dead, because nobody can go see a dead person in the grave".* [P6]

Relatives

The participants stressed the absence of relatives

"*...relatives, your closest brothers your sisters, those that you thought would be there for you, will be nowhere... not one.* [P3](Strongly).

"My son stayed three months (stressing), *three months in the hospital, they never came, it's only me who comes to the hospital.... They do not want to associate themselves with us ... truly they reject us like people who have leprosy".* [P6]

"I ran around going in and out of the hospital alone with this man, and no one, I mean none of his own blood relatives, assisted me anywhere ... I don't even know what they are planning". [P1]

Community withdrawal

"I became stressed and could not sleep at night, people would laugh at me and say, 'You see this mad man of yours is going to kill you', and I told them that it's okay, death is for everyone". [P1]

Churches

"The church has the most stigma, they will make life miserable for you ... I am now attending a certain church not because I wanted to ... not because I wanted to be a member, but because of the situation I am in.... The church I used to go to has deserted me; they are all gone; they see me as a sinner, a mad person, the mother of a mad person". [P6]

Friends

"Some people wouldn't even talk to me.... When I get to their places ... I mean my best friends, they spit on my face, mock me, and tell me to leave their houses because if I still stay with the mad man... ". [P1]

Discrimination

Humiliation and beatings

Some family members experienced beatings from the community purely because they are related to the schizophrenic person.

"My other son was humiliated and nearly killed last time by people who know him very well ... they call him the brother of a mad guy. I mean people who know us, I even talked to their mothers, and they just said' sorry'". [P6]

Others would beat the schizophrenic person.

"Her sisters in-law beat her up". [P3]

Others experienced name-calling and negative labelling.

"They call him the brother to this mad guy ... this has affected him seriously, to an extent he can't even eat, and he has lost a lot of weight" (Sobbing).[P6]

Isolation

Social isolation

The participants stated social isolation as one of the painful experiences the have encountered.

"I just don't trust anybody, the same people you think you trust are the one[s] who will laugh at you and mock you.... People chase her (mother) away saying 'Get out of here you are smelling bad', and they are referring to us because she doesn't comprehend anything.... When you find people seated, they leave, and you will be left alone". [P3]

Self-isolation

The social isolation experienced by the caregivers results in them isolating themselves in order to avoid the embarrassment of the communal isolation.

"My sibling is a quiet person who communicates only with me and my mother ... she doesn't socialise with other young people, she isolates herself from people because she wants to save herself from humiliation and embarrassment". [P3]

Lack of support

Organisational support

"There is no support from anyone, even the churches do not have anything to support people who go through these pains; the community is busy stigmatising us instead of giving us support and bringing us closer to them". [P3]

"Even the government is not doing anything to support us ... we are just by ourselves, no one around us, we just cry alone". [P5]

Hospitals and the professionals

"The hospital doesn't even try to help us go through this problem, they just take these people and forget that we also need help, just at least a support group to heal, because we are the most affected here". [P3]

Familial support

The lack of familial support is another form of stigmatisation and rejection from those are even much closer, i.e. their families.

"My uncle, her brother, rejects my mother. Whenever I seek help from him he tells me that my mother is married and it's not his burden ... nobody cares to support us". [P5]

In response to the question"Tell me, what makes you cry so bitterly throughout?" P5 responded by saying, *"I cry like this because I have been all by myself in my mother's life, and raising up my siblings. This hurts me deeply...* (sobbing bitterly). *...She has got siblings who do not care at all about her life or just give us her children support... (more sobbing).*

Financial support

Because of the problems they face as individual caretakers, these caregivers have no one to support them financially, and they take each day as it comes.

Social support

"I think of Job in the Bible saying to his three friends, 'You miserable comforters, instead of bringing hope to me you bring judgement, pain and hurt to me' ... people in church will hurt you most instead of building you up". [P6]

Emotional distress

The participants shared their experiences of emotional distress as a result of all their communal experiences and as behaviour of the schizophrenic people themselves. This psychological experience has resulted in humiliation and embarrassment, excessive pain, suicidal thoughts, a lack of trust in people, and a lack of trust in mutual relations.

Humiliation and embarrassment

"There was once some celebration next door to us, my husband went there and undressed in front of everyone. His children brought him home. I got so hurt mama, more that the word hurt, not even knowing what to do... it was a real shame to me as the wife.... That on its own showed me that we are really humiliated before the whole world". [P4]

"It's painful, because when she is naked like that, some immoral people laugh and say 'See how that mad woman is humiliating herself' ... saying it in your presence, knowing that this woman is my mother ... and you can't even help because she is very strong and the people you expect help from are the ones laughing at you, saying they did not feed from a mad woman, it's really painful.. ". [P3]

"It's very painful, just imagine one guy came very angry [with] me one day, saying my mother knocked at his door the previous night, it was really embarrassing, and I just say sorry to this man not knowing what to say". [P3]

Relational level

The data revealed that although all the participants experience unbearable pain associated with their caregiving, the pain differs depending on the level of relationship they have with the sick person they take care of. It was established that those caregivers who were much closer biologically to the schizophrenic person experienced deeper pain than other caregivers. The participant taking care of her son felt significant pain, as did those who take care of their mothers. Those who take care of their husbands seemed to be able to control their emotions; they responded calmly to the questions, and indicated that they had the most sophisticated coping strategies.

It is very painful

The pain of their experiences was the main experience participants alluded to throughout the discussion.

"It's very painful". [P6]

"It's very painful ... we grew up to find our mother sick. She never raised us up; we never went to school like other children. We have been all by ourselves, growing up like motherless children". [P3]

In response to the question, “How can you describe strongly the pain you are going through in just one word?” the participants emphasised the following phrases:

- *Uncontrollable pain*
- *Unacceptable pain*
- *Unbearable pain*
- *Unmovable pain*
- *Unstoppable pain*
- *Established pain*
- *Excessive pain*
- *Heavy pain*
- *Piercing pain*
- *Continuous pain*
- *Makes one helpless*
- *Pain that kills your faith.*
- *So deep you lose hope of life*
- *So painful you lose interest on life*
- *So painful it cuts me deep into my whole being.*
- *Worst pain in the entire body that even makes your bones ache*
- *The more you try to accept it, the more the pain increases because of the stigma and rejection by everyone.*

Lack of interest in relationships

The single participants stated that because of the pain they experience, they are not interested in any relationship, as it may add to the pain they already experience.

"It's true, I'm not interested in any relationship now. How can I with all the stress that I have and all the pain? It means I will be putting more pain on myself. I really fear relationships at the moment". [P6]

"The father to my kids died. He understood my situation.... I have stress... I'm not interested in any relationship now. How can I, with all the stress that I have and all the pain makes an addition. It means I will be putting more pain on myself. I really fear relationships". [P5]

Suicidal ideation

Thoughts and suicidal statements became one of the indicators of emotional distress.

"The other time I wanted to kill myself, behind the hospital, thinking of the word this boy was saying "stigma" is the real truth". [P6]

"...like me, I nearly committed suicide the other day thinking 'What do I live for? It's painful'" [P3]

"I wanted to take some tablets and die, because there is no need to be alive". [P5]

Loss

While stating their experiences of stigmatisation, the participants described their sense of loss. According to the findings of this study, stigmatisation of schizophrenic patients and their caregivers has led to excessive rejection that has resulted in the participants experiencing isolation, a lack of support, and severe emotional distress, resulting in caregivers experiencing a deep sense of loss.

Jobs

"I am a financial advisor, I get good jobs. I lose them because I am always unproductive when I think of my son.... Sometimes when I relate my son's condition, people just feel I will not be able to cope [and] just because of that, they don't hire me" [P6]

"I am not working. I failed matric because of my mother's condition" (crying). [P5]

"I ended up leaving my job because of my husband ... things became bad and life became tough". [P4]

Financial stability

Being alone without any financial support, has resulted in severe financial losses for the participants.

"All the money I got finished as I was paying; medical aid also got finished ... I don't have anything, as I speak ... I have turned into nothing". [P6]

Materials loss

"I no longer live the life that I used to live; I live in a shack as I speak... (tears rolling down)*... my house has been repossessed, it's painful mama, serious (*crying even more*) I can't even bear the pain... I could be somewhere, up there in life as a financial advisor, but I don't have anything"*. [P6]

Social relations

"All of my friends have left me because they urged me to leave him and I told them it's not possible". [P1]

Social identity

"People call you 'The mad one, the mother of the mad guy'. Sometimes you forget, you search for your phone while it's in your hand and visible, being very forgetful". [P5]

"*They call you a mad person; it affects you as well... You become the mad person they say you are, and lose yourself... My identity is gone, that strong woman, financial advisor who used to go [with her] head held high is no longer there in me... I don't know who I am anymore"*. [P6]

Health

Participants experience a decline in their health.

"This situation has even brought sickness on me, it has affected me... I'm now sick and have high blood pressure, which I never used to have until this pain came into me. I am depressed and don't even like myself". [P6]

Hope

"The pain is so deep you lose all hope of life". [P6]

"You can't even pray. When you try to pray, you don't even understand what you want to say; the prayer even fades on the way". [P3]

Theme 2: Coping

THEME	SUB-THEME	SUB SUB-THEME
Coping	Self-motivation	- Belief system *(hope in God, the word of God, prayer)* - Self motivation *(focus on the family and avoiding unhealthy competition in the community)* - Involvement in social clubs - Love for the schizophrenic person *(unconditional positive regard)*

- Previous painful experiences

(resilience)

Table 3 shows theme 2, coping, which was extracted during data analysis.

5.3.2 Coping

It has been revealed that generally, most of the participants still experience deep pain that makes coping difficult for some of them. In this case, the caregivers exhibit different coping styles, except for their belief systems.

Belief system

The participants have emphasised their belief systems as the major aspect of their coping strategies.

"The truth is, it's only God who is keeping me". [P6]

Hope in God

"Truly speaking, hope and strength is from the Lord". [P4]

The word of God

"Whenever the pain comes I just go to God my father.... When I am too hurting, I just read the bible and my heart heals". [P2]

"*There is a verse that I always read, 1 Peter Chapter 1, the one that talks about trials and tribulations; that whatever we are going through, He, God, knows.... You know, those things are the ones that keep on bringing me back to life...".* [P6]

"I believe what the Bible says; those who have put their trust in the Lord shall never be brought to shame. I believe this shame will one day be gone".

Prayer

"It's only that I trust in the Lord who is alive, I'll go and pray and ask Him 'Where are you God?'" [P6]

"I would be patient and pray. I told myself, I will just stay under prayer, because nobody will take me anywhere, let me take God inside me.... When he is sober, he will tell me that 'You know what my wife, I am strong because of you, you go to church and pray. and my life is held by you...'. I strongly stay in prayer ... I don't have a sisters, I don't have a brother, I don't have a mother or a father. I am just by myself". [P5]

Self-motivation

Acceptance of the situation

Some of the participants have learned to accept their situation, which has led to self-acceptance.

Self-acceptance

"The only thing that I have told myself is I want to accept myself, I have accepted myself... because if you don't accept yourself it will be painful (repeatedly saying it)... *I don't want to lose hope, I don't judge myself or say I have sinned more than everybody, or say, God does not see or hear me, no ... I never try to compare my life and compete with anybody's life out there, but I am only myself, I don't compare and compete [against] anyone"*. [P4].

"...there is an English saying that says, 'an injured soldier is better than a dead soldier', so I always tell myself at least he is still alive, although injured. I will wait, maybe one day he will just miraculously be healed ... I am also not dead, maybe one day I will be no longer that miserable woman as I am today". [P6]

Involvement in social clubs

"There is this social club [where] I am a member; there we talk, laugh, and share in our meetings, and when I get home I feel good. I come back healed because I have met other people out there". [P4]

Love for the schizophrenic person

Unconditional positive regard

"They urged me to leave him.... I told them it's not possible because I loved this man ...when two people are in love, you stand strong; those talks mean nothing to me". [P1]

"...and you know what, we love these people with all our hearts... My husband does not want to bath, I pour water for him and talk to him nicely to come and [I] bath him nicely and I become very happy and he becomes very clean and I become so happy about it (speaking with a smile). *I love him and treat him nicely; I even try to teach him how to behave".* [P4]

Previous painful experiences

Resilience

"After my siblings and my mother passed on, I was left alone. I told my relatives when I arrived with my mother's corpse that no one should pity me. I hate pity and that's what made me ... have strength [later] when my husband became sick. I remembered what I ha[d] gone through. I told myself I have no one to be there for me, and decided to stand strong. Whenever pain comes, I tell myself that if I was able to stand the pain of all my family members passing, and I am left alone, then I can stand this pain as well ... and I don't want to lose hope". [P4]

5.5 Summary of the Results

Themes that surfaced from the collected data revealed various findings. Although there were negative experiences associated with caregiving, the findings also revealed positive experiences, such as having faith in God and loving their loved ones unconditionally.

Caregivers also had common experiences regarding the process of caregiving for their loved one with schizophrenia. With regard to the above-mentioned experiences, the study also revealed that there were also various dynamics in terms of coping in the process of caregiving. Finally, these findings will be discussed in relation to the literature reviewed and theoretical viewpoints.

Chapter 6

6.1 Discussion, Conclusions, and Recommendations

6.1 Introduction

The principal intention of this study was to explore the psychosocial experiences of Tswana caregivers caring for people with schizophrenia in Mafikeng, in the North West province of South Africa. The study findings revealed two themes that describe the phenomenology of caregivers who care for people living with schizophrenia. The following discussion was achieved by using these themes and being guided by the literature review and the theoretical perspectives.

6.2 Discussion

This study focused on six female Tswana caregivers of people living with schizophrenia and the crucial point was to explore the psychosocial experiences of these Tswana caregivers caring for people with schizophrenia. The universal outcome of the study was in agreement with some previous research findings, namely that the process of caregiving places an enormous burden on caregivers caring for people with schizophrenia, and the burden manifests in both psychological and social aspects of the caregivers' lives (Oshodi et al., 2012; Akinbiyi, 2009; Sefasi et al., 2008)

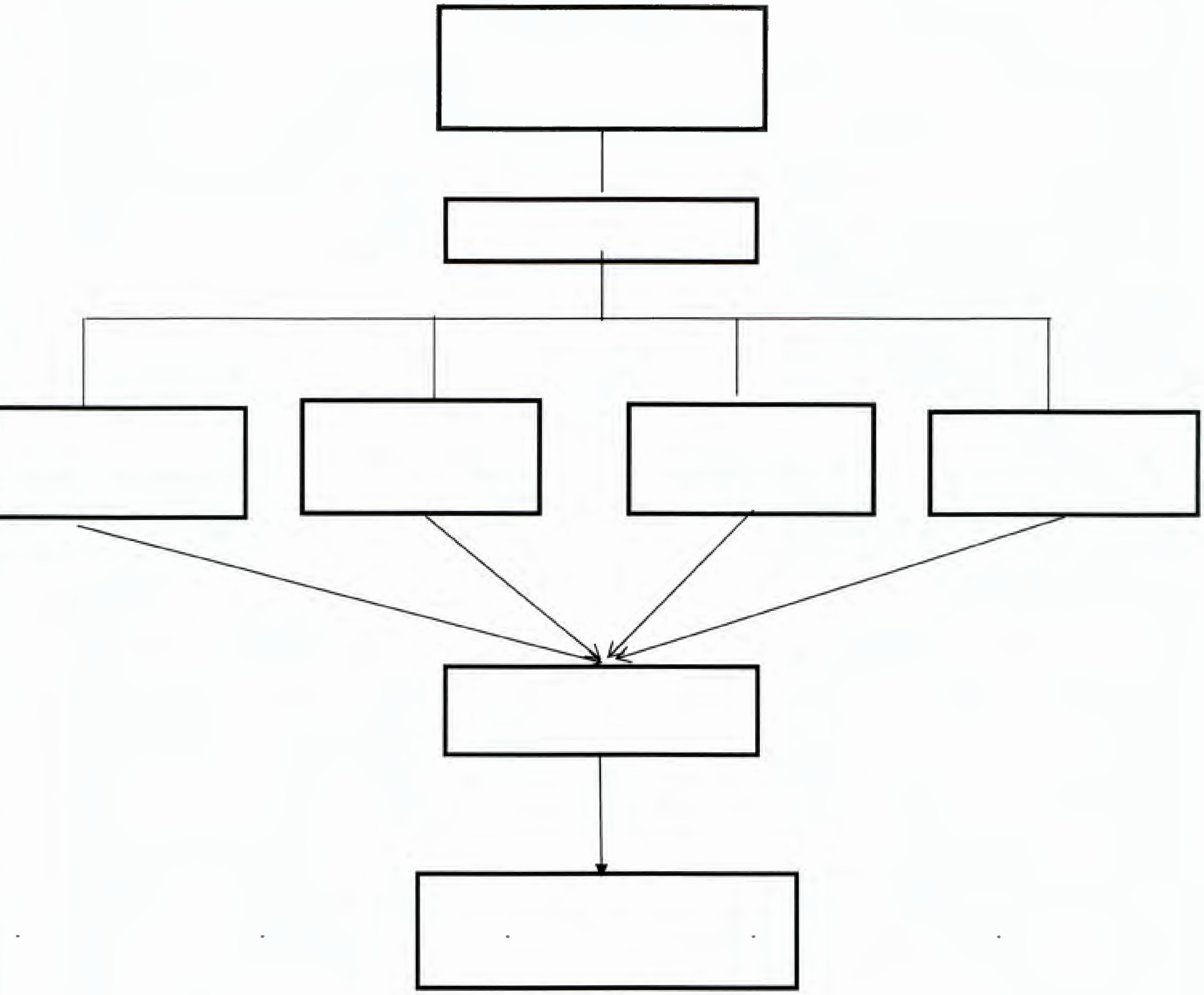

Figure 2: The psychosocial experiences of caregivers of people living with schizophrenia

Although two significant themes were derived from the data, the findings revealed stigmatisation as the dominant principal theme leading to these two themes. It was revealed that there is stigmatisation of schizophrenia, and this attitude results in stigmatisation towards schizophrenic persons, their caregivers, and people related to them. As a result, stigmatisation has led to negative psychosocial experiences among the participants, irrespective of their age, their levels of education, the duration of their caregiving, and their socioeconomic status.

Secondly, it was discovered that due to this stigmatisation, the family members of people living with schizophrenia are humiliated and physically assaulted for the mere fact that they are related to persons living with schizophrenia. The findings also revealed the participants' level of relationship with the schizophrenic loved one has a significant impact on the participants' emotional experiences. That is, biologically-related caregivers experience emotional experiences more deeply than caregivers who are not biologically related. Themes will be discussed in detail hereunder.

Theme 1: Communal and social experiences: stigmatisation of schizophrenia

Excessive rejection

This sub-theme encompasses sub-sub themes, which include family members' withdrawal, community withdrawal, discrimination, humiliation, and beatings experienced by the caregivers.

In the study it was evident that most caregivers experience excessive rejection, and this excessive rejection emanates from the withdrawal of other family members, and community members, and society at large. Caregivers elaborated on how they experienced rejection, stigmatisation, and discrimination due to their loved one's illness. Participants further revealed that even if their family members, who they believed they could turn to in the face of their challenges, especially siblings and relatives, had turned their backs on the participants and their loved one affected by schizophrenia. They stated that people rejected them to the extent that they feel these people no longer even view them as human beings.

Furthermore it was brought to light by the caregivers in this study that their family members, including their schizophrenic loved ones, seldom experience humiliation, name-calling and assaults (beating) in their communities, and from their relatives. However, it was revealed that the community goes to the extent of assaulting individuals who are related to the schizophrenic persons, just because they are related. Some schizophrenic individuals similarly experience beatings from their own relatives, such as siblings and neighbours. Little has been found in literature in regard to this finding, instead this corroborates Molefi & Swartz's (2011) findings, which claim that schizophrenic persons often behave in a hostile manner towards their caregivers and the community due to their perceptual disturbances.

Isolation

This section will describe the caregivers' experiences of isolation during their caregiving journey.

Participants stated that social isolation is one of the most painful experiences they have had to endure. The study also revealed isolation (social isolation and self-isolation) that emerges as a result of the community and society's stigmatisation and the discrimination towards the caregivers. The study revealed that these caregivers resort to isolating themselves from the community and society, not only because of the isolation and the lack of support, but also due to excessive rejection and stigmatisation emanating from the people closest to them, such as family members, friends, church members, and neighbours. This was also discussed by Bowen in his Family Systems Theory (1974), which states that when one part of the system is disrupted, other family members may suffer as well and experience unpleasant feelings or face challenges to the extent that they feel overwhelmed, isolated, or out of control.

Lack of support

Caregivers expressed the impact of the lack of support in their lives, because the community and family have withdrawn from them, and the caregivers have no one but themselves to rely upon. Participants stated that they cannot even reach out to people for support because of the rejection, stigmatisation, and discrimination. Lack of societal, organisational, financial, and familial support leads to caregivers isolating themselves from the community and the society. Participants stressed that churches, communities, and the government are failing them and are not supporting them in any way. This finding correlated with the studies done by Stjernsward and Hansson (2014), Digiacomo et al. (2013), McCann et al. (2011), Angermeyer et al. (2006), and McGarry and Arthur (2001), which revealed that caregivers frequently feel isolated and are unlikely to express their needs and difficulties to others because of the stigmatisation and the negative rejection they receive from people.

Emotional distress

Participants stated that their emotional wellbeing is severely affected which results in the burdensome nature of emotional distress. The caregivers further stated that they experience excessive pain, to the degree that the pain is "uncontrollable, unacceptable, unbearable, established, and continuous pain". The emotional distress that they experience has resulted in them being unable to show any interest in seeking out relationships with other people because of the burden of that caring results in. Most of the participants admitted that they no longer go out with their friends, or attend funerals or family gathering, because they have to look after their affected relative 24 hours and because of the unpredictability of the nature of their loved one's illness. The study also revealed that in some cases the caregivers are placed in emotionally uncomfortable positions, and they feel embarrassment due to the behaviour of their loved ones affected by schizophrenia. Sometimes these individuals with schizophrenia behave in a disorganised and socially unacceptable manner; sometimes they undress themselves in front of people, and this type of unpredictable behaviour results in embarrassment and shame for their caregivers.

This study established that some caregivers experience anger at the fact that they are the caregivers. For example, one participant stated that she sometimes wonders why, and what she did to deserve a mother with schizophrenia. She further admitted that having to care for her mother sometimes resulted in her becoming excessively angry because of the psychosocial burden and the severe stigmatisation she encounters. Mhaule and Ntswane-

Lebang (2009), Frisch and Frisch (2006), and Martens and Addington (2001) reported that caregivers grow angry and frustrated when they are unable to cope with the process of caring, and that living and caring for a person with schizophrenia is stressful and upsetting, and participants admit to their anger by stating that they wish that their affected relative was dead or had never been born. However there is no existing research to establish whether or not caregivers have suicidal ideations when the burden of caregiving becomes too onerous.

Loss

The data reveals that the experiences of loss is a result of the participants' experiences with stigmatisation. This study's findings supports the research that states that the stigmatisation of schizophrenia leads to excessive rejection that results in the participants experiencing isolation, a lack of support, and emotional distress, which leads the caregiver to experience loss.

The caregivers of people living with schizophrenia are aware that their interpersonal relations have changed, as have their social relationships, in terms of the fact that they are no longer able to interact with others (e.g. go out with friends, attend funerals, or attend family gatherings) because they have to look after their affected relative 24 hours a day because of the unpredictability of the nature of their illness. Other caregivers are not involved in romantic relationships due to the painful experience, they neglect their partners and only focus on their affected loved ones, and their romantic partners might add to the pain they are already experiencing. Caregivers may feel stuck as the result of caregiving, because they often focus and concentrate on the individual with schizophrenia and neglect their own needs because their focus in entirely on providing care for their affected relative. This finding is in agreement with the Ryff's Theory of Wellbeing (1989), under the personal growth aspect, which deals with people with weak personal growth, who usually have a sense of personal stagnation, and are unable to carry out other tasks and activities.

It was further revealed that caregivers are unable to get married and maintain romantic relationships due to their responsibility of taking care of their relative, and because no other person helps or supports them in the caretaking of their affected relative. The studies carried out by Peraica et al. (2014) and Digiacomo et al. (2013) highlighted that the role of caring also reduces the amount of time caretakers have for themselves, and this affects their social lives adversely.

In the study it was found that a caregiver's social identity is also affected because of their experiences with the treatment from the community and society. There is no literature available regarding the social identity of caregivers of people living with schizophrenia, however the study did establish that the caregivers' social identity is also affected in a sense that that caregivers cannot find a place in society, because of what they are experiencing in terms of stigmatisation on a daily basis. Some caregivers reported that because of what they are going through, society perceives them in a distorted way and they have become laughing stocks in community. Another participant stated that she does not feel a sense of belonging in her community. Perhaps more research should be conducted to explore the aspect of social identity in the process of caregiving

Caregivers' health was another concern that arose out of the study. The study established that the challenging nature of caring for a person living with schizophrenia takes its toll on caregivers and leads to them having hypertension (high blood pressure) and severe somatic pains. Although Molefi and Swartz (2011) stated that the role of caregiving could lead to the development of high blood pressure, their study did not report on any other medical problems, such as the development of bodily pains or somatic symptoms. The study revealed that some participants experience such deep pain that they lose faith in the power of prayer, while some participants revealed that they felt that God is their only hope.

Theme 2: Coping

The study revealed that generally, most of the participants still experience deep pain that may compromise their coping skills. Thus caregivers exhibited different coping styles, except for their belief systems.

The study revealed that in the face of their adverse situations, caregivers tend to self-motivate, and this self-motivation gives rise to self-acceptance. This is only achieved when the caregivers no longer care how others perceive them and their affected relative, and they also avoid unhealthy competition in the community. This factor has not been revealed in existing literature that focuses on coping strategies of caregivers of people with schizophrenia. Some participants stated that they participate in social clubs to vent and release their stress.

It was also revealed that loving the patient unconditionally by having unconditional positive regard for them and accepting their loved one with schizophrenia also helps caregivers to cope with the difficult process of caregiving. Resilience was another factor that arose out of the study, the demanding and stressful burdens of their everyday lives has resulted in the caregivers growing even stronger. However, Aakiriti, and Dweep's (2014) study revealed that caregivers' resilience is promoted by support from family and friends, and their resilience reduces and controls the negative consequences of caregiving. Similarly, Amagai, Takash, and Amagai (2016) revealed that one needs resilience to defeat the burden of caring, and the support from family and friends is imperative in boosting the caregiver's resilience. They further stated that resilience fosters empowerment, decreases burnout, and preserves caregivers' physical and mental health.

Finally a factor that was common to all participants was their belief system. Participants proclaimed that God kept them going, and they stated that their faith in God and the word of God are their pillars of strength. They further stated that their hope that their lives would one day improve encouraged them not to give up on God. The study established that caregivers' faith in their belief system is universal in the sense that they all believe that God will pull them through their challenging situations. This finding is in agreement with the other studies (Chadda, 2014; Mohammad et al, 2011; Onwumere,2010) where it was established that people use emotion-focused strategies to lessen the negative emotional impact of the stressors, which includes avoidance, denial, fatalism, hope, or looking to religion (e.g. God).

6.3 Conclusion

In conclusion, the study revealed that two major themes were derived from the data. The findings revealed that stigmatisation is the leading, dominant principal observation that lead to these two themes. It was revealed that people with schizophrenia, their caregivers, and people related to them experience significant stigmatisation. This stigmatisation has led to negative psychosocial experiences among the participants, irrespective of their age, their levels of education, the duration of their caring, and their socioeconomic status.

In addition it was established that due to this stigmatisation, the family members of people living with schizophrenia are humiliated and assaulted for the mere fact that they are related to the persons affected by schizophrenia. The findings also revealed that the relationship with the schizophrenic person has a prominent impact on the level of the participants' emotional experiences. That is, the biologically-related caregivers encounter more negative emotional experiences than other relatives as it was reflected on the finding that most participants that were biologically related to the ill person were one whom reported negative emotional experiences, i.e. the girlfriend to the ill person did not report to have more negative experiences, but however expressed her love towards the ill person and also expressed that she has accepted his condition.

Finally, even though caregivers experience challenges in the process of caregiving, they also have coping strategies that shield them during the process of caregiving; their belief systems help them to cope. Some caregivers tend to self-motivate and exhibit unconditional positive regard towards the person that they take care of. Their past negative experiences help some caregivers to be resilient during caregiving, and other caregivers simply engage socially at social clubs to relieve their stressors.

6.4 Recommendations of the Study

In the Mafikeng area in the North West province of South Africa, radio programmes with psychologists and psychological interventions should be implemented to deal with caregivers who raise children with special needs. Such interventions could provide caregivers with support groups to voice their frustrations regarding the prevalence of schizophrenia and caregiving in this geographical area. This could lead to other caregivers who share similar experiences coming out and seeking professional help, when they realise that there are people with similar experience to their own, and would help to alleviate the isolation they feel.

Based on this study's findings, the following recommendations are proposed:

1. It is recommended that the results of this study be used to inform policy makers in health care sectors, mainly the Ngaka Modiri Molema District in the Mafikeng area of the North West province of South Africa, which caters for all health-related issues in Mafikeng and neighbouring areas, so that the policy makers can develop intervention strategies that will help health care professionals to support caregivers of people with schizophrenia.
2. This study also recommends that the communities should be educated about schizophrenia to reduce the stigma attached to caregivers, people living with schizophrenia, and the disorder itself.

The above-mentioned should also be aligned to the implementation of effective services and support structures to empower the caregivers with skills and knowledge on caregiving.

Government and relevant stakeholders need to provide psychological interventions to caregivers of people affected by schizophrenia, as the study highlights the psychological impact of caregiving.

Studies on the caregivers' burden should be carried out in other areas within the North West province.

Research should give more attention to the humiliation and stigmatisation related to the caregivers' negative experiencesbecause it is under researched, more especially within the North West Province.

6.5 Limitations of the Study

The data collected in this study were limited to six female caregivers in a family setting, with ages ranging from 19 to 64 years of age, in the Mafikeng area of the North West province of South Africa. Other families, especially male family members, refused to participate in the study, which is why there are no male views presented in the study.

However, due to the complex nature of the study, as well as complexities relating to stigmatisation and prejudice, the researcher understood their reasons for being unwilling to participate, and therefore found it sufficient to continue collecting data from those who had agreed to participate, even though they represented only one gender group (i.e. females).

In addition the study brings forth gender bias as it was limited to a single gender orientation (i.e. females) and as a result lacked males.This may have been due to the fact that all over the world women are the foremost providers of care (caregiving) and this is mainly as a result of societal and cultural demands that compels them to adopt caregiving roles as suggested by Shama, Chakrabarti, and Griver (2016).

The caregivers' experiences were subjective, and as a result, it is not possible to represent the views of all caregivers from across the whole of North West province and South Africa. The study restricted its attbention to the psychological and social processes that the caregivers experienced.

6.6 Implications for Future Research

The literature on caregiving within South Africa, particularly rural areas such as Mafikeng, is scarce. This study recommends that researchers conduct future studies to contribute to the theoretical understanding of caregiving within the South African context.

It is recommended that contributory factors that could influence caregiving be explored, including the caregivers' quality of life, the burden of caregiving, cultural factors, and financial factors. Additionally, the severity of the diagnosis should also be considered. It may be necessary to consider exploring the positive experiences of caregivers in an African cultural context to achieve a deeper understanding of such experiences.

It is crucial that qualitative and quantitative studies are carried out and explore whether caregivers experience challenges due to multiple diagnoses or the severity of the diagnosis.

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Appendix A

Ethical Clearance Certificate

NORTH-WEST UNIVERSITY
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Institutional Research Ethics Regulatory Committee
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ETHICS APPROVAL CERTIFICATE OF PROJECT

Based on approval by the **Human Sciences Research Ethics Committee (HSREC)** on **13/02/2017**, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) hereby approves your project as indicated below. This implies that the NWU-IRERC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: Exploration on the psychosocial experiences of the Tswana caregivers of people living with schizophrenia in Mafikeng, North West.

Project Leader/Supervisor: **Dr C Oduaran & Ms P Kolobe**
Student: **TS Seseana**

Ethics number: N W U - 0 0 3 3 8 - 1 7 - A 9

Institution	Project Number	Year	Status
NWU	00338	17	A9

Application Type: Master's
Commencement date: 2017-02-13 **Expiry date:** 2020-02-13 **Risk:** N/A

Special conditions of the approval (if applicable):

- Translation of the informed consent document to the languages applicable to the study participants should be submited to the HSREC (if applicable).
- Any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the HSREC. Ethics approval is required BEFORE approval can be obtained from these authorities.

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- *The project leader (principle investigator) must report in the prescribed format to the NWU-IRERC via HSREC:*
  - *annually (or as otherwise requested) on the progress of the project, and upon completion of the project*
  - *without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.*
  - *Annually a number of projects may be randomly selected for an external audit.*
- *The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the HSREC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.*
- *The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-IRERC via HSREC and new approval received before or on the expiry date.*
- *In the interest of ethical responsibility the NWU-IRERC and HSREC retains the right to:*
  - *request access to any information or data at any time during the course or after completion of the project;*
  - *to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process.*
  - *withdraw or postpone approval if:*
    - *any unethical principles or practices of the project are revealed or suspected,*
    - *it becomes apparent that any relevant information was withheld from the HSREC or that information has been false or misrepresented,*
    - *the required annual report and reporting of adverse events was not done timely and accurately,*
    - *new institutional rules, national legislation or international conventions deem it necessary.*
- *HSREC can be contacted for further information via Estie.Emtoch@nwu.ac.za or 018 289 2873.*

The IRERC would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the IRERC or HSREC for any further enquiries or requests for assistance.

Yours sincerely

Prof LA Du Plessis
Digitally signed by Prof LA Du Plessis
Date: 2017.02.21 15:49:04 +02'00'

Prof Linda du Plessis
Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)

Appendix B

Consent Form

I, ________________________________ hereby agree to take part in the study, by voluntarily participating in the study on **"ANEXPLORATION OF THE PSYCHOSOCIAL EXPERIENCES OF TSWANA CAREGIVERS OF PEOPLE LIVING WITH SCHIZOPHRENIA LIVING IN MAFIKENG, NORTH WEST"**

I understand what is written in this form.

I understand that participation is voluntary and I can withdraw from the study at any time, with no negative consequences.

I understand that the session with the researcher will be recorded (video and/or audio) and I agree to this.

I understand that all information will be kept private and no identifying information will be used.

Signed: ____________________ Date: ____________________

Witness: ____________________ Date: ____________________

Appendix B1

Consent form (Tswana)

Nna, ………………………………………………… Ke dumela go tsaa karolo mo patlisisong e e umakilweng **"AN EXPLORATION OF THE PSYCHOSOCIAL EXPERIENCES OF TSWANA CAREGIVERS OF PEOPLE LIVING WITH SCHIZOPHRENIA IN MAFIKENG, NORTH WEST"**

Ke tlhaloganya se se kwadilweng mo papetlaneng ee.

Ke tlhaloganya gore botsaya karolo ga bo patelediwe, ebile nka tlogela nako ngwe le ngwe, ntleng le ditlamorago dipe.

Ke tlhaloganya gore kopano ya patlisiso ee e tla gatisiwa.

Ke tlhaloganya gore tshedimosetso ee ke abelaneng ka yona e tla nna ya sephiri.

Mosaeno: ____________________ Letlha: ______________________

Paki: ____________________ Letlha: ______________________

Appendix C

Biographical Questionnaire

Biographical data of caregivers

1. Age
2. Gender
3. Race
4. Marital status
5. Qualifications
6. Employment status
7. Relationship to the person with schizophrenia
8. Duration of caring

Biographical data of people with schizophrenia

1. Age
2. Gender
3. Race
4. Marital status
5. Qualification
6. Employment status
7. Period of mental illness

Appendix D

Certificate of Editing

WRITERS & EDITORS

CORPORATE * ACADEMIC * LITERARY EDITING

TEL: 08104686501
EMAIL: isabellaza@hotmail.co.uk

10 May 2018

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

CERTIFICATE OF EDITING – T S Seseane

I hereby confirm that in May 2018 I edited Ms T S Seseane's dissertation: **An Exploration of the Psychosocial Experiences of Tswana Caregivers of People Living with Schizophrenia in Mafikeng, North West** for the degree of Master of Social Science in Psychology at the Mafikeng campus of the North West University.

I have not had final sight of the document accepting or rejecting editorial changes made.

Sincerely

M. I. MORRIS

Isabella Morris

Professional Editor

Associate Member of the South African Professional Editors' Group