

**The experiences amongst caregiver of mental health users with schizophrenia in the
Nankudu District, Namibia.**

By

Veronika Mudumbi

17276919

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Supervisor: Dr N.J Bila

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DECLARATION OF ORIGINALITY


Name of the student: Veronika Mudumbi

Student number: 17276919

Topic: The experiences amongst caregiver of mental health care users with schizophrenia in the Nankudu District, Namibia.

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ABSTRACT

Student: Veronika Mudumbi (17276919)

Supervisor: Dr. N.J Bila

Degree: MSW- Health Care

Department: Social Work and Criminology

Topic: The experiences amongst caregiver of mental health users with schizophrenia in the Nankudu District, Namibia.

In Namibia, mental health is considered as a low priority health concern hence resources are instead diverted to life threatening illnesses. Furthermore, it is estimated that about 15% of the Namibian population suffers from mental health, with schizophrenia being the most common mental disorder. Despite the limited resources, The Ministry of Health and Social Services seeks to promote the extension of health for the care of people living with mental disorders to the family and community at large; however, such services are not yet in existence. Consequently, the responsibility of caring for the mental health users is shifted to the family caregivers who tend to be negatively affected. Additionally, only a few mental health users receive adequate mental health services and this places even more burden on the caregivers (MoHSS, 2005:5; MoHSS, 2010:13).

It is against this background that the present study was conducted. The goal of the study was to explore the experiences among the caregivers of mental health users with schizophrenia in the Nankudu District, Namibia. The study was explorative in nature hence the qualitative research approach was used. Furthermore, the study adopted the case study design to explore the lives of caregivers in a modern restricted system through interviews to gain in-depth data and to understand of their lives. One on one, semi structured interviews were used to collect data from ten caregivers of mental health users with schizophrenia in Nankudu district. The purposive sampling method was used to select the participants for the study.

The findings revealed that the caregivers experience physical, psychological, emotional, social and financial burden as a result of their caregiving roles and responsibilities towards the mental health users. The psychotic episodes for instance were negative experiences for all the caregivers. The caregivers adopted various roles and responsibilities towards the care of persons with schizophrenia such as overall involvement in their treatment plan, seeking for

alternative traditional medicine and daily functional support of the mental health users. Moreover, they also experienced stigma from the community members and it constituted to more social and psychological effects. The study further revealed the lack of community based mental health care services and social work services for the mental health users and caregivers. Subsequently, the caregivers rely on other family members, friends and neighbours and interestingly, police officers for support. The study also highlighted some positive experiences encountered by caregivers such as acceptance of their caregiving role, good support system and the mental health user's adherence to medication and recovery.

Due to the highlighted findings, it is recommended that the Ministry of Health and Social Services should establish and implement family psychoeducational programmes for the caregivers and mental health users with schizophrenia to ensure their active involvement in the treatment plan, improve the quality of care and their well-being. Moreover, the Ministry of Health and Social Services should expedite the implementation of community based mental health services to offer support to the mental health users and caregivers as highlighted in the National Mental Health policy. Lastly, health professionals such as Social Workers should provide continuous psychosocial support to the caregivers in order to help them to address their negative experiences.

List of Keywords

Experiences, Caregivers, Mental health users, Schizophrenia

List of Acronyms

MoHSS	-	Ministry of Health and Social Services
CSWA	-	Canadian Social Work Association
MHCUs	-	Mental Health Care Users
WHO	-	World Health Organisation
WFMI	-	World Federation of Mental Health
NIMH	-	National Institute of Mental Health

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CHAPTER ONE

GENERAL INTRODUCTION AND STUDY BACKGROUND

1.1 Introduction

Mental health illness has become a global concern affecting individuals, families, communities and nations worldwide. The World Health Organization [WHO] (2011:13) asserts that mental disorders are estimated to account for 13% of the global burden of diseases worldwide. In 2004, the WHO estimated that 26.3 million people were diagnosed with schizophrenia (WHO, 2008:43).

The *African Regional Health Report* (2006), revealed that the mental health problem increases due to factors such as conflict, post conflict situations, breakdown in the traditional family structure, the high prevalence of communicable diseases (such as HIV/AIDS), poverty, and alcohol and drug consumption. The report further indicates that it is hard to address the mental health burden in African due to insufficient financial and human resources. In South Africa for example, the number of psychiatrists per 100 000 populations is 1.2 and 4.5 is the number of psychiatric beds per 100 000 populations (WHO, 2006:70).

Namibia, as a developing and middle-income country, regards mental health service as a low priority area of health concern and resources are directed towards communicable and life-threatening diseases (MoHSS, 2005:5). The limited focus on mental health implies that a small percentage of mentally ill persons are properly diagnosed and receive mental health services in the country. The National Mental Health Policy in Namibia refers to the demographic health survey that was conducted by the Ministry of Health and Social Services [MoHSS] in 1992 which reported a total number of 7360 people that were diagnosed of a mental illness. The Namibian National Census in 2001 also reported that 5.6% of the population suffers from mental disability. The noted surveys indicate that there was an increase in mental illness between the year 1992 and 2001. According to the National Health Policy Framework for Namibia, the leading mental health diagnosis for outpatients is schizophrenia which is likely to be associated with disability due to its effects on the individual (MoHSS, 2010:13). The National Health Policy Framework for Namibia further indicates that international figures estimate that about 15% of the Namibian population are sufferers of mental illness: 3% being major or serious mental illness, 10% common mental disorder and 2% of children with serious mental health problems, learning difficulties and behavioural problems (MoHSS, 2010:13).

Namibia has established a National Mental Health Policy with a goal “to achieve and maintain a high standard of mental health and well-being amongst the population of Namibia and minimize stigma against people with mental disorders” (MoHSS, 2005:10). The established goal can be achieved through the implementation of a mental health care system into Primary Health Care activities. Furthermore, the National Mental Health Policy promotes the extension of care for people with mental disorders to the families, communities and when necessary to health facilities as a way to achieve successful outcomes of the mental health users (MoHSS, 2005:10). The current situation in Namibia is that such a policy is not fully implemented as there are no existing programmes in the communities to support the mental health users (MoHSS, 2010:13). Furthermore, the caregivers are also not fully integrated into the treatment care plan and this is evidenced by the fact that mental health users end up defaulting treatment.

The aspects outlined in the policy and statistics of mental illnesses, prompted the present researcher to explore the field of mental illness focusing on the experiences amongst caregiver of mental health users with schizophrenia in the Nankudu District, Namibia. The family care givers were the unit of analysis for the research because they are the primary care givers of the mental health users; providing them with emotional, physical, social and financial support associated with the care and treatment (Crowe & Brinkley, 2015:286). Nankudu is a Health District Hospital situated in the Kavango Region, Namibia. The research was conducted in this District Hospital, because it attends to all mental health cases that are referred from Clinics and Health Centres.

The report is divided into four chapters; chapter 1 focuses on the overview and background of the study, chapter 2 focuses on the literature review, chapter 3 is on the research methodology and empirical findings, and lastly chapter 4 focuses on the key findings, conclusions and recommendations.

The researcher defines the key concepts of the study as follows:

Experience: The Oxford South African Concise Dictionary (2015:411) defines ‘experience’ as “the event or occurrence which leaves an impression on one”. For the study, experience refers to what the caregivers of mental health care users with schizophrenia go through when caring for the patient, and how their lives have changed as a result of the burden of caring.

Caregiver: The term caregiver is defined as “the key person who generally provides the most care and support to the patient” (Awad & Voruganti, 2008:152). In the conducted study, the

caregiver refers to the family member providing care and support to the person suffering from schizophrenia. The family caregiver should reside in the same house hold with the patient.

Mental health care users: The WHO (2011:58) defines a mental health care user as “a person receiving mental health care services”. In the present study, mental health care users are those diagnosed with and are receiving treatment for schizophrenia at the Nankudu District Hospital.

Schizophrenia: Barlow and Durand (2012: 455,456), define schizophrenia as “a severe mental illness that is characterized by broad spectrum of cognitive and emotional dysfunction”. The condition is severe, disabling and affects the individual’s daily functions (Barlow & Durand, 2012:455-6). The study only focusses on caregivers of mental health users diagnosed with schizophrenia.

1.2 Theoretical framework

The study was informed by the biopsychosocial approach which is rooted in the general systems theory. Therefore, the researcher initially discusses the general systems theory and subsequently provides a detailed discussion of the biopsychosocial approach.

1.2.1 General systems theory

The general systems theory developed by Ludwin Von Beralanf in the 1960s attempts to apply the biological systems theory to the social world when dealing with complex interactions in all types of systems (Healy 2014:117). The theory is linked to the science of wholeness and in order to understand mental health challenges, the systems perspective advocates the need to focus on transactions between the person and the environment rather than focusing on individual psyche (Healy, 2014:117). Friedman and Allen (2010:7) add that the systems theory enables the understanding of the dynamics of client systems, with its relationships and interactions with other systems to explain growth and change in living organisms. The ideology of wholeness changed the people’s perceptions of the systems theory and led to the theory’s core concepts of open and closed systems, entropy, boundary, haemostasis, inputs, outputs and feedback that occur when there is interaction between the systems and the environment (Friedman & Allen, 2010:7).

Beder (2000:41), defines a system as “a holistic, organized unit of interdependent, transacting and mutually influencing parts (individual or collectives and their subunits) within an identifiable (social-ecological) environment. Beder (2000:41) adds that the systems are those elements in lives that relate and interrelate, which also have a contact and impact on the ability to function. The theory focuses on shifting attention from the cause-and-effect relationship between

variables to a person/situation as an interrelated whole in order to understand human behaviour in the social environment (Beder, 2000:41).

The theory was applicable to the study because it enabled the researcher to holistically view and understands the experiences of the caregivers of mental health users with schizophrenia in conjunction with their environment in order to determine the impact of caregiving on their functionality as caregivers. The systems theory allowed the researcher to look at the relations and interrelations that exist between the caregivers and other subsystems in the environment and how the relations influence their concept of the caregiving burden and their role as caregivers. The theory for instance enabled the researcher to look at the stigma that derives from the environment of caregivers and its influence of their experiences of caring for mental health users with schizophrenia.

1.2.2 Biopsychosocial approach

The study was informed by the biopsychosocial approach proposed by George L. Engel in 1977. According to Endozien (2015:900), the biopsychosocial approach considers the biological, psychological and social factors and their complex interactions in understanding health and illness. Hatala (2012:52) adds that the biopsychosocial approach builds on the biomedical model which has assumptions that relate illness and healing primarily to physiological aspects, overlooking the social, psychological, moral and political dimensions. In the context of the present study, the biopsychosocial approach unlike the biomedical model enabled the researcher to not only focus on the mental health users but also looked at their relations with family members who are the focus of the conducted study. To understand the impact of caring of mental health users with schizophrenia, Hatala (2012:51) is of the opinion that one needs to look at the social aspects (such as the family relations, support system and socioeconomic status, national policies, cultural aspects and community support); psychological and behavioural aspects (such as lifestyles, health belief and experiences); and biological aspect (such as genetics, prepositions and heredity) as they are all implicated in the various stages of the well-being of the caregivers. Friedman and Allen (2010:3) concur with Hatala (2012) and indicate further that the assessment and the development of appropriate intervention strategies for a particular client requires considerations of the individual in relation to a larger social context. In the context of the present study, the biopsychosocial assessment enabled the researcher to holistically view and understand the impact of caregiving on the lives of caregivers of persons with schizophrenia in their environment.

Endozien (2015:900) states that the biopsychosocial approach borrows from the general systems theory which is of the opinion that a system is characterised by the intentions of components, these interactions being complex than straight forward. Hatala (2012:53) also adds that the theory entails multiple systems at work in any phenomena and they interact with one another based on certain principles of norms and values that unify the systems. Just like the general systems theory, the approach advocates for a holistic or comprehensive view of health and diseases and this enabled the researcher to focus on different aspects of family caregivers which is the closest system to mental health users and this can have a direct or indirect influence on the treatment outcomes (Hatala, 2012:51). Hatala (2012:59) concludes that the continual maturing of the BPS model depends on the extent to which any and all of these levels such as the genetics, biological, psychological, sociality, ecology, culture and spirituality are involved and intersect within even the simplest intervention. Therefore, unlike the medical model which focuses on biological aspects as the health determinants for mental illness, the biopsychosocial model gave the researcher the platform to explore how the caregivers of mental health users with schizophrenia are affected in a larger social context and thereby devise some recommendations on the appropriate intervention strategies for social workers when rendering services to the caregivers. Lastly, this approach enabled the researcher to explore the biological, social and psychological impact of schizophrenia on the caregivers due to its holistic nature of understanding health and illness.

1.3 Rationale and problem formulation

The researcher explored the experiences amongst caregiver of mental health users with schizophrenia in Namibia. The National Mental Health Policy in Namibia identifies the lack of resources such as mental health facilities and rehabilitation, specialized health care professionals, updated legislation, lack of follow up and after care services, and inaccessibility of mental health services (MoHSS, 2005:8) as the current challenges. The Nankudu district hospital is also affected by limited resources as experienced in the country at large, therefore, caregivers take up all the responsibility to care for the mental health users which results into various psychosocial implications that were explored by the current researcher.

The literature that was reviewed confirmed that there is a lot of research that was conducted on the experiences of caregivers of mental health care users in other countries. In South Africa, Mavundla and Mphelane (2009) conducted a study on caregivers' experiences in mental illness based on the perceptions of the respondents from the Makhuduthamanga Local Municipality in Limpopo. The study revealed negative experiences of caregivers in providing physical,

psychological, emotional, and security needs. A similar study was conducted in 2007 by Fan and Chen in Taiwan on factors associated with the care burden and quality of life amongst caregivers of mental health users. Both studies associated caregiving of mental health care users with negative experiences (Fan & Chen, 2011; Mavundla, Toth & Mpheleane, 2009). These studies are very informative; however, the results cannot be replicated in a Namibian context due to the differences in socioeconomic imperatives, cultural/traditional beliefs and mental health care systems in the countries. Moreover, the conducted study focused on a specific mental illness which is schizophrenia and not on all mental disorders; therefore, experience might differ for caregivers of individuals with schizophrenia.

Through consultations, no research has been conducted in Namibia on the experiences of caregivers of mental health care users with schizophrenia. Therefore, this motivated the present researcher to conduct the current study in order to find out the experiences of caregivers for mental health care users with schizophrenia with the hope that the findings may inform policy makers to improve the status of caregiving for mental health users. Moreover, the findings may devise strategies for intervening with caregivers of mental health care users to ease the burden of care since the policy acknowledges the importance of caregivers for mental health users in the health system. With the above noted, the core question for the research is: What are the experiences amongst caregivers of mental health users with schizophrenia in the Nankudu district, Namibia?

1.4 Goal and objectives

The following are the goals and objectives of the research:

1.4.1 Goal

The goal of the research was to explore the experiences amongst caregiver of mental health users with schizophrenia in the Nankudu District, Namibia.

1.4.2 Objectives

- To describe the phenomenon of schizophrenia in Nankudu District, Namibia, from a systems theory perspective.
- To explore the biopsychosocial experiences of caregivers for a person living with schizophrenia.
- To ascertain the tasks and roles of caregivers in caring for a person living with schizophrenia.

- To explore the intervention and support provided to the caregivers of a person living with schizophrenia.
- To suggest strategies for social workers on intervening with caregivers of mental health care users with schizophrenia in the Nankudu district, Namibia.

1.5 Overview of the research design and methodology

The study utilised the qualitative research approach to explore the experiences of the caregivers of mental health users with schizophrenia in the Nankudu district, Namibia (Fouché & Delport, 2011:65). An applied research type was utilised as the study sought to make recommendations to address obstacles experienced by the caregivers to the Ministry of Health and Social Service and to the social workers for implementation during their interventions with the caregivers. A case study design was utilised to enable the researcher to explore the lives of caregivers in a contemporary bounded system through interviews to gain in-depth data and an understanding of their circumstances (Fouché & Schurink, 2011:321). An instrumental case study design was used because it correlated with the research goal. The study population comprised of all the caregivers of mental health users accessing health care services from Nankudu district in Namibia. The researcher was not aware of the total number of the caregivers hence a non-probability sampling approach was applied to get the caregivers with the most characteristics to generate the information needed for the research (Rubbin & Babbie, 2016:220-221). One on one, semi-structured interviews were used to collect data from the participants. The interviews were audio recorded with permission from the caregivers. To analyse the data, the researcher utilised the five steps of data analysis by Cresswell (Schurink, Fouché & De Vos, 2011:397). Ethical considerations such as avoidance of harm, informed consent, violation of privacy and confidentiality and the publication of findings were applied throughout the research process. A detailed research methodology is presented in chapter three.

1.6 Limitations of the study

Despite meeting the research objectives, the researcher encountered the following limitations during the research process:

- Most of the participants could only communicate in Rukwangali, therefore all the recordings were translated into English during the transcribing process.
- The researcher used the non-probability sampling technique; however, most of the participants ended up being female and their experiences might be different from their male counterparts.

- Some caregivers who were interviewed were caring for mental health users who had defaulted their treatment plan.
- The sample that was interviewed did not represent the entire district because the participants were mostly from the nearby areas to Nankudu district. Those who were staying far could not be traced by the researcher due to a lack of contact details.
- There was a lack of cultural diversity in this study because the majority of the participants were from the Kwangali ethnic group and this implies that the findings could be culturally biased.
- A qualitative research approach was used and a small sample size took part in the study, therefore, the findings were contextual and cannot be generalised to the entire population of caregivers of mental health users with schizophrenia.

1.7 Chapter outline

The research report consists of four chapters.

Chapter one: The chapter provides an introduction of the study, the rationale, and the problem statement that prompted the research. The research question, the goal, and objectives of the study are also presented in the chapter. Furthermore, the theoretical frameworks informing the study such as the general system theory and biopsychosocial perspective are also discussed in the chapter. Lastly the chapter briefly highlights the research design and methodology and the limitations of the study.

Chapter two: The chapter focuses on the relevant literature review relating to the experiences of the caregivers of mental health users with schizophrenia.

Chapter three: This chapter discusses in depth details of the research methodology and the ethical considerations that were applied during the research. It also presents a summary of the findings of the study using themes and sub themes generated from the study. The chapter also presents the quotes from the interviews and literature to proffer the findings.

Chapter four: This is the last chapter of the report and it discusses the extent to which the objectives of the study were met. The chapter also concludes and makes recommendations to relevant programmes, practice and policy based on the findings.

In the following chapter, an in-depth literature review on the experiences of the caregivers of mental health users with schizophrenia is explored.

CHAPTER TWO

LITERATURE REVIEW ON THE EXPERIENCES OF CAREGIVERS OF MENTAL HEALTH USERS WITH SCHIZOPHRENIA

2.1 Introduction

The study focused on exploring the experiences amongst caregiver of mental health users with schizophrenia. Although similar studies have been conducted in other countries, the conducted study was the first to explore the experiences of the caregivers of mental health users with schizophrenia in the Namibian context and through this study; the researcher managed to fill the knowledge gap.

In order to give perspective to the study, the present chapter reviews relevant topics pertaining to the experiences of mental health users with schizophrenia. The chapter firstly explores the overview of the mental health problem especially schizophrenia, with a specific focus on the prevalence of the condition, the aetiology of schizophrenia, the diagnostic symptoms and the treatment. The topic on traditional medicine and mental illness is also explored to understand other treatment alternatives for mental health users in different communities. Furthermore, the experiences of family caregivers of persons with schizophrenia are discussed intensively focusing on the caregiver's concept of burden and the roles and tasks of caregivers. The impact of stigma on the family is also discussed. The chapter also explores evidence-based interventions and services relevant to the needs of the caregivers in minimizing the burden of care. Lastly, the barriers towards an effective provision of mental health care in Namibia and the social worker's intervention in mental health care are presented.

2.2 Overview of mental health: Schizophrenia

The researcher is of the opinion that it is important to understand the aspects of schizophrenia by looking at its prevalence, causes, the diagnostic symptoms and treatment in order to understand its disabling nature that poses a burden to the caregivers.

Awad and Voruganti (2008:152), assert that schizophrenia is a chronic disabling condition affecting approximately 1% of the population with a prevalence range of 8.3 cases per 1000 population worldwide. The Diagnostic and Statistical Manual 5 [DSM 5] adds that schizophrenia emerges in the late adolescent stage and the mid-30s, with onsets before adolescent being very rare. The lifetime prevalence of schizophrenia is about 0.3 to 0.7%; however, there is a reported variation based on the sex, migration status, urbanity, economic status, latitude, and

spectacular trends on incidence, prevalence, and mortality (American Psychiatric Association [APA], 2013:102; McGrath, Saha, Chant and Welham, 2008:67). Awad and Voruganti (2008:152) concur with the APA (2013:102) on the fact that schizophrenia has characteristic symptoms that range from cognitive, behavioural and emotional dysfunction with no symptoms of pathognomonic of the disorder. The authors further indicate that the symptoms have functional/occupational and social disabilities and they are further associated with direct and indirect costs towards the mental health user, family members and society at large (Awad & Voruganti, 2008:152; APA, 2013:100).

Regarding the mortality rate, McGrath et al. (2008:68) state that studies have shown that individuals with schizophrenia are twice as likely to die compared to the general population. The APA (2006:577,578) adds that suicide is a leading cause of premature deaths amongst persons with schizophrenia with an estimation of 30% suicide attempts, about 4-10% deaths and about 20-40% estimated rates of suicidal behaviour. The increased mortality of schizophrenia is further associated with the high rates of comorbid conditions such as substance related disorders, anxiety disorders, panic attacks, mood disorders, schizotypal and paranoid personality disorders. The comorbid and side effects of treatment (such as weight gain, diabetes, metabolic syndrome, cardiovascular and pulmonary diseases) generally reduce the life expectancy of the individual (APA, 2013:106; McGrath et al., 2008:68).

2.2.1 Etiology of schizophrenia

Hadlich, Kirov and Lapinen (2010:4), indicate that the causes of schizophrenia are defined by modern models: the biopsychosocial model and the stress vulnerability model. Hadlich, Kirov and Lapinen (2010:4), add that the biological, psychological and social factors all contribute to the development of schizophrenia, while the stress vulnerability model identifies environmental stressors as factors that initiate the predisposition of individuals to become schizophrenic. The factors outlined cause schizophrenia, trigger schizophrenic episodes and cause the disorder to persist. Barlow and Durand (2012:466-474) agree with the models and identify genetic, neurobiological, psychological and social influences as causations of schizophrenia. Barlow and Durand (2012:475), and Hadlich et al. (2010: 5) agree that genetics are responsible for the vulnerability of some individuals into becoming schizophrenic. The authors further add that there is no specific gene that causes schizophrenia; however, studies on twins found higher levels of heritability and this has led to the suggestions that gene factors are the main causes of the disease. The neurobiological malfunction and damage of the brain also contributes to the emerging of schizophrenia (Barlow & Durand, 2012:469). Hadlich et al. (2010:7) and Barlow and

Durand (2012:469) confirm that excessive dopamine functions and an abnormally large ventricle has been observed in individuals with schizophrenia. The vulnerability stress model of schizophrenia on the other hand indicates that life's stressful events such as poverty, death of a relative, exposure to war, natural disasters, homelessness, abuse, urbanisation, unemployment, childhood experiences of social adversity and traumatic life events are likely to cause or trigger psychotic episodes in people with schizophrenia (Hadlich et al., 2010:9). The next session focuses on the symptoms and treatment for mental health users with schizophrenia.

2.2.2 Diagnostic symptoms and clinical description of schizophrenia

According to the APA (2013:100) and Khamker (2012:112), schizophrenia is characterized by five main symptoms including delusion, hallucination, disorganized thinking (speech), grossly disorganised/ abnormal motor behaviour (including catatonia) and negative symptoms. These symptoms are elaborated below.

- **Delusion** - The fifth edition of the Diagnostic Statistical Manual for Mental Disorders [DSM 5] asserts that individuals with schizophrenia experience delusions which are fixed beliefs that are not amenable to change in the light of conflict evidence (APA, 2013:87). Khamker (2012:112) and APA, (2013:87) state that about 80% of individuals with schizophrenia experience delusions as positive symptoms with fixed beliefs that can be bizarre or non-bizarre. Furthermore, there are five types of delusion and these include: **1) persecutory delusion** which is very common amongst mental health users (the individual is paranoid and believes that he/she will be harmed or harassed by another person); **2) grandiose delusion** (individual believes to have exceptional abilities, power, wealth or fame); **3) Erotomaniac delusion** (the individual believes another person is in love with them); **4) Nihilistic delusion** (involves a belief that a huge disaster/catastrophic event will happen); and **5) Somatic delusion** (focusses on the preoccupation of health and organ functions) (APA, 2013:87).
- **Hallucination** - Khamker (2012:112) and APA (2013:87) state that the individual experiences, perceptions, occurrences and the symptoms can be visual, auditory, tactile or olfactory without external stimulus. Furthermore, these experiences are so vivid and clear with a full force that distorts normal perceptions and the individual will not be under voluntary control. The hallucinations can either be sensory modality or auditory but auditory is the most common in schizophrenia with experiences of hearing voices (APA, 2013:87).

- **Disorganised thinking (speech)** - According to the DSM-5, the symptom causes an interference with speech and the individual may switch from one topic to another and answering to questions may be unrelated. Furthermore, severe speech distraction can be incomprehensible and resembles receptive aphasia while less severe disorganisation occurs during the prodromal and residual phase (APA, 2013:88).
- **Gross disorganisation/ abnormal motor behaviour (including catatonia)** - This symptom manifests in different ways ranging from childlike behaviour to unpredictable agitation (APA, 2013:88). The symptoms also cause difficulties for the individual to perform daily activities. For instance, catatonic behaviour decreases activities as the individual resists' instruction, maintains a rigid and bizarre posture, and complete lack of verbal and motor responses. The other features include staring, grimacing, mutism and echoing of speech (APA, 2013:88; Khamker, 2012:112). Lastly, these symptoms are common in persons with schizophrenia but also occur in persons suffering from other mental illnesses (APA, 2013:88).
- **Negative symptoms** - According to the DSM-5, negative symptoms cause most morbidities associated with schizophrenia and this is less common in other psychotic disorders. The main features of these symptoms include diminished negative expression, avolition, alogia, affective blunting anhedonia and social withdrawal (APA, 2013:112; Khamker (2012:113).

In order to make a diagnosis for schizophrenia, APA (2013:100) and Khamker (2012:112) indicate that the following should be identified during the assessment:

- At least two symptoms of delusion, hallucination and disorganized speech should be present for a significant period of 1 month or longer. Furthermore, the grossly disorganised and negative symptoms may also be present during the same time.
- The diagnostic features should indicate Criterion B where schizophrenia involves impairment in one or more major areas of functioning due to the link between the cognitive impairment and the social dysfunction.
- Criterion C indicates that the signs of the disturbance should be persistent for a continuous period of at least 6 months. Furthermore, the prodromal symptoms are present during the active phase of the episode and the residual symptoms may follow and it is characterised with mild forms of hallucination, delusion, negative symptoms, speech problem and grossly disorganised effects.
- Lastly, mood symptoms and full mood episodes are common in schizophrenia

It was important to understand the symptoms of schizophrenia because the disabling symptoms increase the dependability of the mental health users and consequently increase the burden for the family caregivers. Furthermore, an insight into the diagnostic symptoms of schizophrenia was relevant because it enabled the researcher to relate to some of the mental health users' symptoms that were identified by the caregivers as most prominent during the interviews. After the diagnosis of schizophrenia, the mental health user is prescribed treatment for a life time in order to manage the chronic condition. The prescribed treatment is discussed in the next session.

2.2.3 The treatment of schizophrenia

Khamker (2012:113) asserts that schizophrenia is a chronic psychiatric condition with a relapsing and remitting course and the nature of the condition impairs the cognitive, social and occupational functions causing the individual to have a disability. Khamker (2012:113) and APA (2010:9) concur that managing a person with schizophrenia can be challenging due to its complex nature in terms of diagnosis and treatment. Furthermore, the authors agree that a comprehensive treatment approach can be beneficial to the mental health user's care (APA, 2010:9; Khamker, 2012:113). Khamker (2012:113) defines comprehensive treatment as a method entailing a multimodal approach, including medication and psychosocial interventions. In addition, the comprehensive and individualised treatment approach for schizophrenia aims to reduce the symptoms, to improve the quality of life and enable adaptive functioning, and lastly to promote and maintain recovery from the debilitating effects of illness to the possible maximum extent (APA, 2010:9). The authors further agree on the importance of establishing an accurate diagnosis in order to come up with an individualised treatment plan for the mental health user targeting specific aspects of the symptoms, other psychiatric conditions such as posttraumatic stress disorder and depression, medical co-morbidities, suicide ideations and behaviour, past therapeutic responses, medical side effects, and mental health user's choice and expectations (APA, 2010:9; Khamker, 2012:113).

Regarding the pharmacological interventions, the APA (2010:9), Khamker (2012:113) and the National Institute of Mental Health [NIMH] ([Sa]:7) indicate that the antipsychotic medication used to treat schizophrenia is classified into groups of first and second generation of treatment. The first generation of anti-psychotic treatment such as Haloperidol, Trifluoperazine and Chlorpromazine are effective in reducing positive and negative symptoms of hallucination and delusion (Khamker, 2012:113). The second generation of treatment such as Risperidone, Olanzapine, Quetiapine, Aripiprazole and Ziprasidone are administered when there is resistant /

intolerant to the first-generation antipsychotics and they are effective in reducing the symptoms and stabilizing the mental health user (Khamker, 2012:113).

The NIMH ([Sa:7-10]) indicates that anti-psychotic medication may be effective in treating symptoms such as hallucination and delusion; however, the drug may not help with symptoms such as reduced motivation and emotional expressiveness. Furthermore, the medication has side effects, for instance, haloperidol and chlorpromazine may produce side effects that are hard to treat, although lowering the dose and switching the medicine can counteract the side effects. In as much as the medication reduces the risk of future relapse after a recovery from the acute episode, there are chances of relapse. The authors have noted that the discontinuation of treatment has a high rate of relapse; therefore, good adherence that involves taking medication correctly, attending clinical appointments and carefully following the treatment plan should be emphasized. It has been noted that treatment adherence is difficult with persons with schizophrenia due to their denial of the illness, disorganized thinking which leads to forgetting to take medication, inappropriate advice to discontinue treatment, side effects and substance abuse. Fortunately for the mental health user, the doctors and family members can use different strategies to ensure adherence and prevent the worsening of the illness. The treatment can be administered in injectable form and caregivers can use medication calendars and pill boxes to ensure that mental health users not to forget their treatment. The engagement of the family members in observing oral medication intake may also help to ensure adherence (NIMH, Sa:7-10).

The psychosocial intervention is also a significant part of treatment and substantial evidence indicates that it yields positive treatment outcomes when paired with medication. The approach prevents relapse, improves coping skills, and enhances the social, occupational, vocational functioning and the ability to function independently (APA, 2010:104). The psychosocial programmes include the programme for assertive community treatment, family interventions, support employment, cognitive and behavioural therapy, rehabilitation and self-help groups and social skills training (APA, 2010:104). The APA (2010:11) and Khamker (2012:114) indicate that the comprehensive treatment of schizophrenia should be integrated into the acute, stabilisation and stable phase in order to attain the overall goal of treatment and the section below elaborates the three phases of treatment.

Acute phase - According to the APA (2010:11), the goal for the acute phase is defined by the acute psychotic episode. The aim for this phase is to prevent harm, control disturbed behaviour, reduce psychotic symptoms, identify and address factors leading to acute episodes, facilitate

the process of returning the person with mental illness to the level of functioning, developing an alliance with the mental health user and family, formulating short term and long term treatment plans and connecting them with appropriate services in the community (APA, 2010:11). The APA (2010:12) recommends that the caregivers should be engaged and that they collaborate in the process to provide support to the mental health users and to assist them with a crisis that might arise due to the acute psychotic episodes. The psychosocial intervention is initiated at this stage in order to reduce stimulating and stressful relationships and life events while promoting relaxation, low performance, clear communication and structured predictable environments for the patient. Psycho education is conducted to provide mental health users and family members with information that can be beneficial regarding the nature and management of schizophrenia (APA, 2010:12). The educational sessions help the caregivers to cope with the condition as they are overwhelmed about the disorder, disability and prognosis (APA, 2010:12).

Stabilization phase - The APA (2010:12) states that the treatment goal during this phase is to reduce stress on the mental health user, provide support to limit the risk of relapse, improve their adaptation of life in the community, facilitate the reduction of negative symptoms, work towards remission and promote progress of recovery. APA (2010:12) emphasizes that the regimen should be maintained and continuously monitored for a period of 6 months due to risk of relapse. Psychosocial intervention is recommended during this phase. APA (2010:12) notes that mental health users and family members should be provided with psychoeducation on the course of illness, the possible outcomes and treatment adherence. Mental health users are still vulnerable and prone to relapse at this stage; therefore, it is important to ensure effective service delivery.

Stable phase - Khamker (2012:114) indicates that mental health users that recover from the acute psychosis phase eventually reach the stable or maintenance phase. The goal of the phase is to maintain the remission and controlled symptoms, improve the mentally ill's level of functioning and quality of life, treat relapses effectively, and continuous monitoring of the treatment effects (APA, 2010:12). Khamker (2012:114) and APA (2010:12) both emphasize that treatment is continued indefinitely even if the mental health user reaches the remission stage after the first psychotic episode in order to reduce the risk of relapse and maintain stability.

The APA (2010:13) recommends routine specialist care to monitor and evaluate side effects associated with schizophrenia, residual negative symptoms, cognitive deficits and limited social functioning so that specific intervention for the effects can be administered or incorporated in the treatment plan. Adjunctive medications are still prescribed for comorbid conditions during the

stable phase (APA, 2010:13). Individualized psychosocial intervention is recommended during this phase; family intervention, support employment, assertive community, skills training and cognitive behavioural oriented psychotherapy have demonstrated effectiveness depending on the needs of the person with mental illness (APA, 2010:13).

In conclusion, there is an emphasis on the importance of an individualised and comprehensive treatment plan for individuals with schizophrenia because it yields positive treatment outcomes. Furthermore, the use of both medication and psychosocial intervention confirms the importance of managing schizophrenia from a holistic approach as noted by the general systems theory and the biopsychosocial approach. The holistic nature of the treatment further discusses the importance of featuring family caregivers in the acute, stabilization and stable phase to assist them to cope with the nature and management of the illness. Based on the literature, psycho educational intervention with family members proves to be effective and section 2.8 about intervention and support for caregivers sheds more information on the matter. Engaging family members into the treatment plan also equips them with skills on how they can support and assist mental health users in order to prevent relapse, improve functionality and promote recovery (APA, 2010:9). The treatment plan of schizophrenia already highlights the important role of the caregivers and the acquired skills can help family caregivers to cope better with the mental health users, hence reducing the burden. The next section focuses on traditional and complementary medicine as other forms of treatment for mental illness.

2.3 Traditional medicine and mental illness

The WHO (2001:1) and Gureje, Nortje, Makanjuola, Oladeji, Seedat and Jenkins (2015:1) assert that the traditional and complementary system of medicine is a long history of traditional medicine that sums up a diversity of health practices, approaches, knowledge, skills, theories and beliefs incorporating plant, animal, or material-based medicine, spiritual therapies, manual techniques, and exercises that are either applied singly or in combination to maintain the well-being, as well as to treat, diagnose or prevent illnesses. As much as traditional healing is emphasized, the healing approach also encompasses faith healing which has some influence from the indigenous religion such as Christianity or Islam (Gureje et al., 2015:1). Furthermore, the WHO has identified other widespread systems of traditional and complementary/alternative medicine such as Ayurveda, Chinese traditional medicine, chiropractic, homeopathy and Unani (WHO, 2001:2,3).

Terms such as “complementary medicine” or “alternative medicine” are interchangeably used with “traditional medicine” in some countries and it often refers to health care that is provided to

supplement western or allopathic medication (WHO, 2001:2). Gureje et al. (2015:2) note that in an African context, this medicine emphasises on the spiritual world, supernatural forces and religion. Additionally, this understanding derives from the fact that health is not just about the functioning of the body organism but rather about the mental, physical, spiritual and emotional stability of the person, the family members, the community members and also the ancestors who are believed to be protecting the living (Gureje et al., 2015:2). Western medicine has also advanced towards the biomedical model and mental health has expanded from a physiological to a biopsychosocial understanding of the causation, manifestation and consequences of mental illness (Gureje et al., 2015:2). Whether rational or not, Gureje et al. (2015:2) and the WHO (2001:3) agree that traditional medicine is used in the maintenance of health, prevention, diagnosis improvement or treatment of physical and mental illness.

The WHO (2001:3) estimates that about one-third of the world's population and over half of the population of the poorest parts of Asia and Africa do not have access to essential treatment hence the use of traditional and complementary medicine. Recent literature from Van der Watt, Van de Water, Nortje, Oladeji, Seedat and Gureje (2018:555) also adds that traditional and faith healers constitute a key part of the mental health system and it is true to the low and middle income countries where mental health users with severe mental illnesses either do not receive formal psychiatric treatment or receive sub-optimal care due to the incapability of the medical and psychiatric care systems. The scarcity and uneven distribution of formal health care systems and fewer health care personnel in the rural areas has resulted in traditional and contemporary medicine being the first alternative to mental health care (Van der Watt et al., 2018:555). Furthermore, the communities perceive this alternative medicine as accessible and affordable compared to the formal health care provider. The WHO (2001:3) and Van der Watt et al. (2018:555) further concur that the traditional and complementary medicine closely correspond to the mental health user's ideology as it provides culturally relevant information on the causation of mental illness and this belief influences the diagnosis and treatment practice and it further provides explanatory causes of illness to the mental health users and their caregivers and possibly their perception of the suitability and effectiveness of treatment.

Although the DSM 5 is not utilised for the purpose of diagnosis in the traditional and complementary medicine, Gureje et al. (2015:4) identify diagnostic approaches that are used which include a combination of history taking, examination or observation of the mental health user or divination (which is a process of revelation of knowledge from supernatural sources such as spirits or ancestors, using methods of tossing of shells or bones, mirrors, animal

sacrifices, drumming and trance of prayer). Furthermore, the authors note that although traditional medicine attributes the illness to physical causes, there is typically an accompanying of supernatural causation to the person's illness which can be spirits, earthly sorcerers or neglected spirits (Gureje et al., 2015:4). In terms of the treatment methods used by the traditional practitioners, Gureje et al. (2015:5) emphasize that the traditional beliefs of the causation of the mental disorder determines the treatment approach and it aims to reduce or eliminate the causes of the illness rather than the symptoms. Both pharmacological and non-pharmacological treatment approaches are utilised for treatment (Gureje et al., 2015:4).

Gureje et al. (2015:5) note that the pharmacological methods involve different types and preparations of herbs with varying routes of administration. Every part of the plant for instance may be used for herbal remedies, and this is prepared and administered in numerous ways, such as drinking, burning and softening, followed by drinking, inhaling, sniffing, rubbing, smearing and even parenteral application through skin incisions (Gureje et al., 2015:5). Shirungu and Cheikhuyoussef (2018:129) conducted a study in the two Kavango regions in Namibia, on the therapeutic powers of medicine used by traditional healers for the treatment of mental illness and discovered that there is a total number of 37 species belonging to 24 families which are used. Furthermore, these plants that were used to treat mental illness have shown psychoactive effect like sedatives, euphoriants, stimulants and soporifics (Coleta et al., 2008 in Shirungu and Cheikhuyoussef, 2018:129). The traditional healers note that the medicine requires being seduced or enticed for the therapeutic power to be activated to the desired effect on the person with mental illness. The healers also revealed that the medicinal plants have both healing and spiritual powers (Shirungu & Cheikhuyoussef, 2018:130).

The non-pharmacological on the other hand may include a combination of physical restraints including the use of irons and chains, restrictions of food, isolation, recitations from holy books, chants or spells, rituals, sacrificial offerings, exorcism and prayers (Gureje et al., 2015:5).

With regards to the effectiveness of the traditional medicine, Van der Watt et al. (2018:555) conducted a qualitative study by reviewing 16 articles on the perceived effectiveness of traditional and faith healing of mental disorders. Despite the limitation of the methodological aspect, there was evidence that was extracted from the articles indicating the effectiveness of traditional medicine in treating mental illness, especially when used with biomedical treatment (Van der Watt et al., 2018:564). The WHO (2001:4) has also acknowledged that traditional and complementary medicine has demonstrated efficacy in areas such as mental health and it has shown a great potential to meet a broad spectrum of health care needs; however, further

research, clinical trials and evaluations are required in order to ensure standards of safety, reliability, quality control of traditional medicine and that the practitioners have qualifications and that they can prove the validity of their products and practices; the WHO sees the development of national policies as a way to address these concerns (WHO, 2001:). Van der Watt et al. (2018:564) also concluded that the mental health user will continue to seek traditional and faith healing for mental illness if they perceive its effectiveness regardless of alternative biomedical evidence, hence they agree with collaboration to address resource scarcity especially in low- and middle-income countries.

Gureje et al. (2015:7,8) argue that the treatment gap for mental health in low-and-middle income countries imposes an urgent scaling up of delivery of core mental health services. The authors are of the opinion that the collaboration between traditional medicine and the conventional mental health services could yield a potential advantage for the mental health user and the caregiver. Some potential advantages might be cultural acceptability, accessibility, perceived holistic approach to care and less stigma that may lead to a better utilisation of a collaborative service by the mental health users and their caregivers. The availability of numerous treatment options might make it easier for mental health users and caregivers to find therapies that best meet their needs. Other advantages might include the involvement of family, community and the mental health user, manipulation of the environment to achieve therapeutic goals and cost effectiveness. The traditional practitioner could also adopt supportive roles towards the promotion of mental health services such as preventing, detecting and assessing as well as treating mental illnesses. Lastly, the traditional practitioners could refer mental health users to the Primary Health Care Facility or directly to the hospital as well as support the family members and educate them on early warning signs and possible relapse (Gureje et al., 2015:9)

The literature discusses the significant role of traditional medicine in the mental health sector and it further describes the reasons why people access such services which could assist in closing the gap in the mental health system especially in the low- and middle-income countries that face challenges with the provision of mental health services. Just like western medicine, traditional medicine also provides a variety of treatment modalities that are inclusive of both pharmacology and non-pharmacology approaches. Furthermore, traditional medicine appears to value the need to holistically treat the person with mental illness by addressing the mental, physical, spiritual and emotional stability of the person, the family members, the community members and the ancestors; which is similar to the biopsychosocial approach used by western medicine when treating mental illness (Gureje et al., 2015:2). The highlighted benefits of

integrating traditional medicine and western medicine in order to achieve positive goals in the mental health user's care could assist the family caregivers of mental health users in communities and in terms of reducing the burden of care. Traditional medicine and the state of policy development in Namibia is discussed in the next section.

2.3.1 Traditional medicine and policies in Namibia

As noted earlier, Meincke (2018:1) concurs with the international and regional public health policy that have been promoting an integration and regulation of traditional medicine with the aims to provide safe traditional healing to the mental health users and to improve the health care services in the rural areas by using the traditional practitioners as auxiliary health personnel. Differing from other African countries, the author notes that Namibia has not officially recognised traditional medicine and practitioners as part of the contemporary health care system although it is acknowledged in the National Health Policy Framework and the community-based health care policy. The policies reflect on the international and regional conceptualisation of traditional medicine as well as acknowledge the role of traditional healers in the Namibian PHC which is based in their standing in the community and they are seen as health promoters and outreach personnel. Namibia's 2005 Mental Health Policy on the other hand is silent on the issue of traditional healing (Shirungu & Cheikyoussef, 2018:134).

Despite the lack of legislatives, policies and guidelines, the traditional healers in Namibia continue to provide services to the Namibian population (Meincke, 2018:1). The WHO (2001:26) notes that traditional healers have been practicing their craft to citizens and the statistics by Limpkin's report in 1994 indicated a ratio of at least one traditional practitioner per 500 people in Kavango and Owambo regions, while in Caprivi (Zambezi region), the ratio is one traditional practitioner per 300 people. In Windhoek (Katutura), there is one traditional medicine practitioner per 1000 people. There were also three chiropractor practitioners identified in Namibia (WHO, 2001:26). The interventions offered by the traditional practitioners in Namibia are classified into herbalist, faith herbalist, diviner herbalist, diviners, faith healers and traditional birth attendant (WHO, 2001:26).

With regards to the legislation on traditional medicine, Meincke (2018:4) and the WHO (2001:26) note that the Ministry of Health and Social Services and the WHO developed a separate traditional health practitioner's bill in 1997 after they had conducted a research. The bill was revised in 2010 and tabled in parliament in 2014; however, the bill has not yet been objectified (Meincke, 2018:5). If the legislation is in place, the government intends to include traditional medicine in community-based health care programmes and to incorporate the

traditional medical system into the country's official health services referral system (WHO, 2001:26). Furthermore, it will establish a national traditional health practitioners' council under the auspices of the MoHSS to clarify the roles and responsibilities of traditional healers, oversee the registration and regulation of traditional medicine, and provide supervision and control mechanisms to the traditional medicine practitioners in Namibia (Meincke, 2018:4).

Shirungu and Cheikhoussef (2018:134) reveal that people in Namibia draw on both allopathic and traditional medicine to treat mental illness, and as much as half or 61% of mental health users who attend state health facilities for mental illness also consult traditional healers. Furthermore, the increased medical costs, side effects and lack of medicine especially in the rural areas prompt people to seek for traditional medicine to manage their health problems. Due to the highlighted, the authors are of the opinion that traditional medicine can be a potential source of safe and affordable alternative medication. Despite the early stages and limited effort from the government in terms of the collaboration of traditional healing and the allopathic framework, the authors still advocate for the collaborative services of mental health care as it can be beneficial to a country like Namibia with its limited resources (Shirungu & Cheikhoussef, 2018:134).

The trend in the reviewed articles discusses the lack of a legislative framework in the guidance of the provision of traditional medicine in Namibia. There are limited resources with regards to the provision of mental health care; however, the collaboration of the biomedical and traditional medicine as well as the development and implementation of a policy on traditional medicine could yield potential benefits especially to mental health users and caregivers in the rural areas with limited resources. The evolution of mental health care through the process of deinstitutionalisation and how it has left family members as primary caregivers of mental health users is discussed in the next segment.

2.4 Deinstitutionalisation in mental health care

Addo, Agyeman, Tozan and Nonvignon (2018:2) note that over the past two decades, the deinstitutionalisation of mental health care has shifted the focus of the management of people with mental illness from the state institutions to homes, implying that the family members who are often unremunerated take on the increased role of caring for the person with mental illness instead of the health professionals. Furthermore, Chan (2011:339) and Lippi (2016:1), agree that the global shift of deinstitutionalisation of persons with mental illness has increased the responsibility of persons with schizophrenia to be that of their family members. In the western countries, 25%-50% of persons with schizophrenia stay with family caregivers after they are

discharged from the hospitals while in Asia, about 70% of the mental health users live with their families (Chan, 2011:339).

Manyaluoe, Mvandaba, Plessis and Koen (2014:1) reviewed a study in Ireland which highlighted the important role of family members in the treatment, care and the rehabilitation of the mentally ill family members. Although there is evidence on the benefits of the process of deinstitutionalisation, other studies have reported on the enormous social and economic burden experienced by the primary family caregivers (Addo et al., 2018:2). Manyaluoe et al. (2014:1) agree and note that contrary to the supposed care expected from the family members, they might also experience that they are forced to fulfil the role of the caregiver. Furthermore, the authors refer to a study in Malaysia where many families reported not being ready to accept, or where they are not properly prepared to undertake the role. Lastly, although they accepted to provide the care towards their mentally ill family members, they seemed to have been faced with challenges such as the lack of understanding and the lack of skills related to mental illness management (Manyaluoe et al., 2014:1-2).

Addo et al. (2018:2) refer to studies that have shown that caring for a mentally ill person affects the caregiver's life, their quality of life and their socio-economic status. Furthermore, the family caregivers are required to provide financial, physical and emotional support to the mental health user while bearing emotional and physical distress as a result of their disturbing behaviour that subsequently affects caregiver's daily routine and ability to partake in social activities (Addo et al., 2018:2). Lippi (2016:1) adds that the care of persons with schizophrenia in developing countries with insufficient financing restricts the development of community resources that can benefit the mental health users and caregivers. Due to the scarcity of resources, the government places the provision of care on family members; however, they lack knowledge about mental illness and they are not well equipped to handle the individuals suffering from schizophrenia (Lippi, 2016:1).

In South Africa, Manyaluoe et al. (2014:1) clarify that the process of deinstitutionalisation of mental health services has been ongoing for a period of two decades as a result of overcrowding in mental hospitals which has led to families becoming the main providers of individuals with mental illness. The authors state that this process was implemented by the North West Province in South Africa and many psychiatric mental health users were discharged from long term hospitals for them to be under the care of their family members. In addition to the deinstitutionalisation, the adoption of the Primary Health Care (PHC) approach by the South African health care system heightened the importance of understanding the role of caregivers

living with a mentally ill person (Manyaluoe et al., 2014:1). The adoption of the PHC and the overcrowding of the mental hospital appear to have been the main cause of deinstitutionalisation hence shifting the caring role towards the family members.

Similarly, to South Africa, the care for persons with mental illness also lies primarily with the family members in Namibia and it is a result of the lack of mental health institutions (MoHSS, 2005:5). The adoption of the PHC approach by the health care system in Namibia acknowledges the significant role of community and family involvement as an extension of the mental health system; however, limited resources remain a global barrier in enhancing mental health care (MoHSS, 2005:5).

The analysis of the literature reveals that the family members in South Africa adopted the caring role due to deinstitutionalisation and the adoption of the PHC. In Namibia, the literature is silent about deinstitutionalisation but highlights that there is a lack of mental health institutions and resources in the country, therefore, family members have taken the responsibility towards the mentally ill persons. In as much as deinstitutionalisation has placed the important role towards the care, treatment and the rehabilitation of the mental health users on their family members, it also has a devastating impact on their quality of life. Chan (2011:339) and Lippi (2016:1) note that the chronic and disabling nature of schizophrenia leaves the person requiring assistance and care for an extended period hence turning the care into a burden for the caregivers. The following section therefore explores the experiences, burden and perceived impact of caregiving, the factors contributing to the concept of burden, the tasks and roles of caregivers, the coping strategies, the stigma towards the family members and lastly the intervention and support that can be a coping mechanism to the caregivers.

2.5 The concept of burden and experiences of mental illness (schizophrenia) on the caregivers

The concept of caregiver's burden is defined by Kim, Chang, Rose and Kim (2011:846) as "a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual". The caregiver's burden has been in existence from the 1970s to the 1980s and it simply describes the adverse consequences of mental disorders for the family members (Chan, 2011:340). Aswini, Sreedhar, Poulouse and Kumar (2015:7), note that the concept of family burden is an unavoidable component of schizophrenia because it is an important social unit providing primary care to the mental health user with schizophrenia. Even though caring for a family member with mental illness is frequently linked to burden with negative consequences, Awad and Voruganti (2008:154) highlight that there are studies that

have highlighted positive experiences hence the aspect of “burden of care” has been replaced with a neutral term such as “experiences of caregiving”. The authors further emphasise that regardless of the distinction in the terms, literature intensively uses the concept “burden of care” to emphasise the extensive negative impact on the caregivers (Awad & Voruganti, 2008:154). Lastly, Chan (2011:340), Awad and Voruganti (2008:151) agree that the concept “burden of care” is further distinguished as an objective and subjective burden as proposed in 1966 by Hoenig and Hamalton. The concepts are broadly defined later in the literature review.

The World Federation of Mental Health [WFMH] (2010:2), ascertains that the burden of caregivers of persons with chronic illness is a global concern and the caregivers require tireless effort, energy and empathy and this undeniably has an excessive impact on their daily lives. Many countries’ policies do not recognize the role of the family caregivers hence they do not provide them with financial support for the care provided to the mentally ill (WFMH, 2010:16). Furthermore, the caregivers struggle to get stability between their work, family and caregiving role and as a result, they compromise on their quality of life thus affecting their physical, emotional, social and financial wellbeing (WFMH, 2010:2; Chan, 2011:340). As a result of the compromised wellbeing of the caregivers, which leads to their inability to manage daily challenges of providing care to the mentally ill and their deficiency of personal, financial and emotional resources, they tend to face tremendous stress, depression and anxiety (Chan, 2011:340).

Marimbe, Cowan, Kajawu, Muchirahondo and Lund (2016:1) concur that caring for mentally ill family members places an enormous burden on family caregivers and this has shown to have a significant impact on the family’s quality of life. The authors note that the care of people with severe mental disorder falls on the family whether it’s a result of the history of deinstitutionalisation or limited mental health services. Marimbe et al. (2016:3-5) conducted a study on the perceived impact of caring for a family member with a mental disorder, the coping strategies and the needs for the family caregivers in Zimbabwe. A total number of six broad themes emerged from the study which characterised the impact of mental illness on the family. The study revealed that the caregivers suffered from physical harm/illness, psychological and emotional impact, financial burden, material burden, social factors and stigma (Marimbe et al., 2016:3-5).

In South Africa, Monyaluo, Mvandaba, Plessis and Koen also conducted a similar research in 2014 on the experiences of the families living with mentally ill family members in the Thabo-Mofutsanyana district of the Free State province. Three categories emerged from the data

analysis and the noted that caregivers experienced: positive and strength experience, negative experience, and support of families living with a mentally ill family member (Monyauloe et al., 2014:4). In comparison with the research that was conducted by Marimbe et al. in Zimbabwe, the research highlighted positive experiences from the family caregivers such as: accepting living with the mentally ill family member, assistance from the community members, education by nurses, families desiring the best treatment for their mentally ill family member and lastly, families obtained formal support for themselves and their mentally ill family member (Monyauloe et al., 2014:4). In as much as the research highlighted the positive experiences of caring for a person with mental illness, they still expressed negative experiences which appear to have engulfed the positive experiences and as a result, family members still experienced the burden of caregiving.

Looking at the negative experiences, Monyaluoe et al. (2014:4-5) noted that family members still found it difficult and painful to live with a mentally ill family member. In addition, they also blamed themselves for having a mentally ill family member. The families further revealed the risk of being injured or killed by their violent and aggressive mentally ill family member. One participant for instance shared that: “she is destroying things; she is destructive and she destroys anything she touches”. Marimbe et al. (2016) had similar findings as the participants expressed the challenging experience they had as the family members living with mental illness became both physically and verbally aggressive to the caregivers (Marimbe et al., 2016:3). Manyaluoe et al. (2014:5) further reported a negative experience similarly to Marimbe et al. (2016:3) about the families experiencing health problems as a result of living with a mentally ill family member. Confusion, stress, depression and high blood pressure were some of the conditions that were highlighted by the caregivers (Manyaluoe et al., 2014:5). Lastly, the families expressed a concern in terms of the mentally ill family member’s behaviour of aggression, violence, verbal abuse, substance abuse, heavy smoking, damage to property, disputing other people and poor hygiene (Manyaluoe et al., 2014:5).

Linking the reviewed studies, Lippi’s (2016:2) article on “Schizophrenia in a member of the family ...” confirms that caring for a family member with schizophrenia subjects’ caregivers to mostly negative experiences which turn out to negatively impact the caregivers. Furthermore, the negative aspects experienced are a consequence of their daily caregiving role (Lippi, 2016:2). Awad and Voruganti (2008:154) add that the roles such as the increased visits to the doctor, emergency room, and hospitalisation constitute the negative impacts on the physical and emotional state of caregivers. Furthermore, Aswini et al. (2016:7) also indicate that the

unpredictable, continuous, relapsing and frightening nature of schizophrenia requires the caregivers to acquire different adaptive skills for caring. The positive and negative symptoms of schizophrenia also interrupt family dynamics and interaction; while the low functioning, chronic nature and the lack of insight of schizophrenia makes the lives of caregivers even more miserable (Aswini et al., 2016:7).

As a result, Lippi (2016:2) and Chan (2011:340), note that the caregivers experience both an objective and subjective burden associated with the consequences of caring and reaction towards the caring process, which having a direct influence on each other. The objective burden is defined as “the burden that is experienced due to patient’s symptoms, behaviour and sociodemographic characteristics and factors such as change in the household routine, family and social relationships, leisure time and physical health” (Chan, 2011:340). The noted burden occurs due to the practical problems, difficulties and observable negative effects of schizophrenia on the caregivers resulting in the significant change in the lives of caregivers (Lippi, 2016:2). Lippi (2016:2) highlights the objective burden experienced by caregivers such as: the neglect of other family members and disruption of family life, deterioration in social and family relationships and matrimonial problems; disruption in daily social, work and leisure activities; isolation and lack of family support; increased medical expenses and financial problems; changes in house roles and routines; neglect of hobbies; difficulties inviting people to the house; chaotic lifestyle and poor quality of life; experiencing stigma related to the illness and the need for care services.

The subjective burden on the other hand is the extent to which the caregivers feel burdened because of the situation, resulting in emotional and psychological reactions affecting the wellbeing of the caregivers (Lippi, 2016:2). The subjective burden includes different psychological and emotional reactions by the caregivers such as: feelings of guilt, shame, self-blame, anger, feeling of loss, apathy and denial of illness, depression, anxiety, tension, worry, fear, emotional cost/wellbeing, helplessness and hopelessness, exhaustion from increased activity, lack of sleep, low self-esteem, feeling of being incapable of caring for the mental health user and embarrassment in social situations (Lippi, 2016:2).

The trend in the literature indicates that the concept of “burden of care” is mostly utilised to focus the attention on the negative experiences of the family caregivers of mentally ill individuals while the concept of “experiences of caregiver” seeks to investigate both negative and positive experiences. Due to the highlighted aspects, the present study focuses on the concept of “experiences of caregivers” instead of exclusively “caregivers’ burden” in order to elicit

information on both the negative and positive experiences of caregivers of mental health users with schizophrenia in the Nankudu district. It is also evident from the literature that the caregivers are subjected to biological, psychological and social consequences due to their caring role hence it is important to explore their experiences from a biopsychosocial perspective. The section below discusses the impact of mental illness (schizophrenia) on caregivers with emphasis on the emotional, physical, social and financial impacts.

2.5.1 Impact of mental illness (schizophrenia) on the caregivers

As noted earlier, Hatala (2012:51) emphasises that in order to understand the impact of mental illness on the care givers, the biological, psychological and social aspects should be assessed as per the biopsychosocial approach. Furthermore, the trend in literature already indicates that family caregivers experience emotional/psychological, physical, social, and financial impact as a result of the implications of schizophrenia and their role towards the persons with schizophrenia (WFMH, 2010:2; Chan, 2011:340). Due to the above noted, this section focuses on describing the biological / physical, social and psychological/emotional and financial impact of schizophrenia on the family caregivers.

Emotional/psychological impact

Mark (2013:12) notes that “acting as a primary caregiver of a relative suffering from severe and chronic mental illness is taxing in many ways as caregivers struggle to emotionally handle the stress of supporting their relative”. The caregivers are likely to suffer from stress, depression, anxiety and other illnesses (World Federation of Mental Health [WFMH], 2010:22). Compared to the general population of non-caregivers, the caregivers of persons with mental illnesses exhibit harmful behaviour and increased use of alcohol and other substances (WFMH, 2010:22).

Mark (2013:40) conducted a study in 2013 on the experiences of the family caregivers for mental health users with chronic severe mental illness including schizophrenia and findings revealed that caregivers experienced “incredible stress” which was overwhelming and devastating (Mark, 2013:40). WFMH (2010:22) also highlight that with regards to stress, it causes the physical and mental health state to deteriorate causing damaging effects to the well-being of both the mental health user and the caregiver. Furthermore, if there is no stress management then it could further result into depression and anxiety as a result of the demanding and emotional work of caring for someone with a neurological disorder. The WFMH (2010:22) further reveals that many caregivers don’t seek for interventions as they do not realise that they are emotionally drained and physically ill.

Gater, Rofail, Tolley, Marshall, Abetz-Webb, Zarit and Berardo (2014:4) conducted a qualitative study to investigate the subjective experience of caregivers of people with schizophrenia in order to understand the “caregivers’ burden”. The findings confirm that people with schizophrenia rely on the caregivers for care and support; as a result, caregivers subsequently reported lacking time for themselves and their responsibilities. Furthermore, the findings from the study noted six dimensions (emotional well-being, caregiver’s concern, physical impact, impact on daily activities, financial demands and impact on relationships) of the caregiver’s life which are affected by schizophrenia. Regarding emotional well-being, Gater et al. (2014:4) noted that about 74% of caregivers felt emotional about caring for a person with schizophrenia. In addition, caregivers reported specific emotions that were experienced due to their roles. Similar to the research findings of Mark (2013:40) on the stress being experienced by caregivers; the participants in Gater et al.’s (2014:4) research expressed similar impacts of stress and described caring for a person with schizophrenia as very demanding and leading them to feeling overwhelmed. Other emotions identified include sadness related to the caregivers themselves and the mental health users, and feelings of helplessness in terms of assisting the person with schizophrenia. The authors noted that the other emotions experienced were a result of the person with schizophrenia’s behaviour causing frustration, embarrassment and anger (Gater et al., 2012:4). The emotions experienced by the caregivers were often described as changeable and unpredictable in nature and one participant described the experience by stating that “emotionally, it’s a roller coaster”. Lastly, other emotions emerging from the caregivers were their concerns relating to their role, fear of the future of the person with schizophrenia and constant worry about the psychotic episodes and symptoms of schizophrenia worsening (Gater et al., 2014:5).

Physical/ biological impact

Mark (2013:15) established that as much as the caregivers experience emotional impact, they may also experience physical impact. The author further notes that research focus mostly on the emotional and psychological impact of chronic conditions and overlook the physical impact. Furthermore, the majority of research on the physical impact of caregiving focuses on challenges presented by caregivers on chronic conditions such as cancer and Alzheimer instead of the challenges of caregivers of persons with mental conditions such as schizophrenia (Mark, 2013:15). Despite the physical impact being overlooked, literature by the WFMI (2010:22) note that the caregivers are physically less healthy than the non-caregiver population and they have more chronic illnesses like high blood pressure, heart disease, diabetes and

arthritis. Furthermore, they may suffer from poor immune functioning and exhaustion as a result of neglecting their own health. A study by Gater et al. (2014:6) confirms that caregivers of persons with schizophrenia indeed experience an impact on their physical health as participants reported feeling tired, worn out, drained and stressed. In addition, some of the participants reported disturbed sleep due to the person with schizophrenia's behaviour and having to continue with their caregiving role at night (Gater et al., 2014:6). Furthermore, the caregivers reported feeling that the emotional impact of stress, anxiety and worry affected their physical wellbeing. Marimbe et al. (2016:4) concur with the above findings and note that persons with mental illnesses become physically and verbally aggressive towards their caregivers particularly when experiencing a psychotic episode. Furthermore, due to the demand of the caring process, they become stressed to an extent that they develop some of physical illness. The caregivers complained of pain, weight loss and injuries sustained as a result of physical assault from the mental health users (Marimbe et al., 2016:4).

Social impact

The WFMI (2010:18) asserts that the caregivers often experience lack of social support and social networks; therefore, they become isolated from family and friends as they provide care to their loved ones. This social isolation increases as the disease progresses and caring demands intensify. In addition, the insufficient support and family conflict worsen the isolation and loneliness thereby resulting in stress (WFMI, 2010:18). A study by Marimbe et al. (2016:5) revealed that caregivers experience rejection by relatives due to the illness. One participant for instance reported rejection from her own mother and sibling due to her son's illness and disruptive behaviour. Furthermore, other participants reported that they were not able to attend events because no one could care for their relative with mental illness, and the other relatives were not willing to help (Marimbe et al., 2016:5).

Lastly, Gater et al. (2014:4,5) add that caring for a person with schizophrenia impacts the daily activities of the caregiver and they lack time for themselves and other social responsibilities. During the study, some caregivers reported cancelling plans and not being able to attend to other events, an indication that the caregiver's social life is impacted. Furthermore, some caregivers felt that they were not able to control their lives as it was centred on the person with schizophrenia.

Financial/ economic impact

The WHO (2003:5), notes that the mental illness prevalence has an enormous economic and financial burden on the individual, their family and society as a whole. In addition, the economic impacts of the mental illness affect the personal income, ability of ill persons and often their caregivers to go to work, the level of work productivity and general contributions to the national economy and utilisation of treatment and support (WHO. 2003:5). Furthermore, the WHO (2003:12) adds that the family caregivers bear the financial expenditure associated with mental health treatment and care because they are not generally covered by the state insurance. Furthermore, family members set a significant amount of time to care for the person with the mental disorder. Due to the dedication in caring, they find it difficult to gain employment, holding on to existing jobs and or they may suffer a loss of earnings due to days taken off from work.

The research by Marimbe (2016:4) confirms that the caregiver indeed suffers from a financial burden because caregivers expressed that they had to leave jobs in order to take on their caregiving roles. Other caregivers also noted that although medication is free at government psychiatric hospitals, some had to buy medication as it was frequently unavailable at the hospital (Marimbe et al., 2016:4). Some caregivers' financial expenditures identified by Awad and Voruganti (2008:156) towards the care of the person with schizophrenia include time loss, medical care, transportation, food, clothing, housing, recreation, insurance and debt. The conducted study used the biopsychosocial approach to explore and understand the emotional/psychological, physical/biological, social and financial impact of schizophrenia on the caregivers. The next session focusses on some factors that contribute to the concept of burden for the caregivers.

2.5.2 Factors contributing to the concept of burden for the caregivers

Adeosun (2013:1) agrees with the notion that the burden of caregiving is a complex and multifaceted construct that derives from a combination of physical, emotional and social pressure of caring for the mentally ill. The author, further makes reference to various studies from Europe, America, Australia, Asia and Africa that have shown that informal caregivers of mental health users with schizophrenia experience moderate to high levels of burden; however, sociodemographic and clinical factors associated with the burden of caring may vary. The severity of the mental health users' symptoms, low level of education attainment and poor social support are some factors constantly associated with the higher levels of caregiving burden (Adeosun, 2013:2). Due to the differences in the sociocultural aspect and the parities in the formal support services available to mental health users and their caregivers, Adeosun (2013:2)

is of the opinion that the findings from the studies conducted in the western world are limited in terms of being generalised within the low income sub-Saharan African countries.

Adeosun (2013:5) conducted a research to determine the correlates of caregiver burden among family members of persons with schizophrenia in Lagos, Nigeria and various dimensions were associated with the burden experienced by the caregivers. According to the findings, the female caregivers had significantly higher burdens of the emotional and financial strains domain; the attainment of their role reflects on the sociocultural expectations that are placed on females to adapt the caregiving role when a family member falls ill (Adeosun, 2013:5). Aswini et al. (2016:7) also add that gender has a significant influence on the family burden. Male mental health users for example require more supervision than the female while female caregivers suffer high burden of care in all areas of support and the mental health user's behaviour (Aswini et al., 2016:7). Furthermore, unemployment and poor social support also reported high levels of burden especially on the financial/physical domain (Adeosun, 2013:5). Unemployed caregivers are likely to spend more time at home with loaded caregiving tasks compared to the employed. Moreover, the burden is greater as they do not have a consistent source of income. Chan (2011:344) agrees and further indicates that the socio-economic status, for example, is an important aspect to be examined because research indicates that the poor socioeconomic status of caregivers increases the burden of care. On the other hand, poor social support in a country like Nigeria constitutes to high levels of burden due to the nonexistence of social support and welfare. Lastly, older caregivers and caregivers who are parents or the spouse to the mental health users experienced high burden of caregiving. With regards to the older caregivers, the realisation that their role is a lifetime made them worried about who was to step in when they are gone, while for the spouses, they felt trapped about their choice of staying with their relative with mental illness (Adeosun, 2013:6).

Kim, Chang, Rose and Kim (2011:847) and Chan (2011:344) concur with Adeosun (2013) on the aspect that the degree of burden experienced by caregivers may vary depending on several contextual factors such as caregiving-related factors, the sociodemographic status of caregiver and disease related factors. In 2011, Kim et al. (2011:852) conducted a study on the predictors of the caregiver's burden of individuals with dementia and the results indicated that 16% of the caregiver's burden derives from the disease related factors such as progression and symptoms; followed by socio-demographical factors such as age and gender with 15% and lastly caregiving-related factors accounting for 11% of the burden. The findings of the study also revealed that the more impaired the multidimensional aspect of caring, the more the burden the

caregivers experience (Kim et al., 2011:855). Lastly, the role of the caregiver, the social support system, inadequacy of resources and ability to cope with the demands of caregiving also defined the extent of burden experienced by caregivers (Kim et al., 2011:847).

In South Africa for instance, there is a lack of community resources catering for mental health services and it contributes to the burden experienced by caregivers (Lippi, 2016:3). Furthermore, the caregivers hardly talk about the burden they experience and as a result, the health professionals are not fully aware of the negative impacts they encounter whilst caring for the mentally ill and how they can be assisted to lessen the burden (Lippi, 2016:2).

Lastly, Awad and Vorunganti (2008:115) reviewed a community survey that included 697 caregivers and 439 mental health users with schizophrenia and they identified the following critical factors that contribute to the perception of the burden of caregiving:

- Noncompliance and treatment adherence issues,
- Lack of motivation and poor self-care,
- Co-morbid substance abuse amongst mental health users,
- Disrupted family dynamics and collective coping styles,
- Inadequate social and economic support,
- Access to crisis psychiatric care and hospitalization when required, and
- Access to information and support network

The reviewed literature reveals a lot of aspects that contribute to the concept of the caregiver's burden and the level of impact on the caregiver's well-being. Although it was not the focus of the research, this study also highlighted certain factors that might contribute to caregiver's burden by looking at the biological, psychological and social pressures that caregivers face. The next section discusses the daily roles and tasks of caregivers of mental health care users with schizophrenia as an element that also contributes to the negative experiences or caregiver's burden.

2.5.3 Roles and tasks of the caregivers

Aswini et al. (2016:7), indicate that the family is the most important social unit providing the most support and primary care to persons with schizophrenia and the role of caregiving is usually taken by the spouse, parents and siblings. Goldberg and Rickler (2011:41), also note

that the people living with chronic illnesses such as mental illness cannot live independently without the family caregivers. As highlighted earlier, schizophrenia is a disabling condition which implies that the individual needs support from the caregivers in order to improve their quality of life. The authors outline that despite the lack of knowledge and skills to care for the individual, the caregivers acquire roles of advocacy on behalf of the mental health users; they also provide physical, emotional and financial support due to the disabling nature of the illness. The authors add that the other's form of tasks for caregivers includes making medical decisions, negotiating with the insurance company or medical care, paying bills, legal work, personal care and providing support during hospitalisation and rehabilitation. The long-term care includes overall medication management for the mental health user (Goldberg & Rickler, 2011:41). The family member's role is important because Goldberg and Rickler (2011:41) ascertain that they influence the mental health user's psychological adjustment and management of the illness, adaptation of the behaviour that influences recovery, functioning and adherence to medication.

The World Federation for Mental Health (2010:7) adds that caregivers should establish and maintain a routine of meals and activities as a way to attain security for the mental health user. The other roles and tasks of caregivers can be supporting the person with mental illness to be independent in aspects such as managing finances or maintaining health and hygiene to lessen the burden for the caregivers. Other important aspects noted include improving safety at home (locking up medication, harmful chemical and objects), providing love and support, treatment monitoring and adherence and ensuring proper nutrition intake (World Federation for Mental Health, 2010:7-8)

The noted earlier tasks and roles of caregivers result into psychological, physical, emotional and financial impact on the caregivers and it was explored by this study. The next session is about the stigma and its impact on the family members of mental health users.

2.5.4 The family and stigma

Stigma is one of the experiences encountered by the caregivers of mental health users with schizophrenia. Banfine (2015) as cited by Nxumalo and Mchunu (2017:203), state that stigma in mental illness is a serious problem that is exhibited by the community due to fear, lack of respect and refusal to accept the person with mental illness. Kadri, Manoudi, Berrada and Moussaoui (2004:626) therefore define stigma as "the social devaluation of a person because of a personal attribute which leads to shame, disgrace, and social isolation". Stigma does not only affect the individual but the family members as well by virtue of their association with the mentally ill person (Kadri et al., 2004:626). Furthermore, it remains a concern in mental illness

because it perpetuates a cycle of disability on the mental health users and family members and reversing such behaviour is difficult (Nxumalo & Mchunu, 2017:203).

Nxumalo and Mchunu (2017) conducted a study in the Ilembe district of Kwazulu Natal in South Africa in 2017 on the stigma related experiences of family members of persons with mental illnesses. The results of the study indicated that the stigma experienced by the families contain stereotypes of isolation, blame and exploitation, community neglect, labelling and stereotyping (Nxumalo & Mchunu, 2017:206-207). One participant was quoted saying:

“The community has an attitude of distancing us from them and all the happenings of the area. They often want us to be alone, away from every one.....”

The above quote illustrates the isolation experienced by the caregivers from the community. Nxumalo and Mchunu (2017:206) established that the community keeps the caregivers away from events due to the fear that they will bring the family member with the mental illness to the event thus causing destruction in their homes. Consequently, the stigma experienced leads to the lack of motivation to help the person with a mental illness during the recovery, hence prolonging the recovery process or the illness which also has financial and emotional consequences for the family members (Nxumalo & Mchunu, 2017:203). Furthermore, when the family members are discriminated and stigmatised, they may stop playing a vital role in the community as a result of being linked to the person with a mental illness (Nxumalo & Mchunu, 2017:203). Lastly, Kadri et al. (2004:627) add that stigma obliges the mental health users and family members to remain isolated, which leads to the mental health user not recognising the illness, which leads to treatment noncompliance.

Kadri et al. (2004:625) also conducted a study to determine if family members of persons with schizophrenia suffer from stigma and if they do, which areas in their lives are affected. Secondly, the researchers wanted to determine if the family members had knowledge about the illness and their attitude towards the mental health user. The findings of the study proved the hypothesis that family caregivers of mental health users with schizophrenia experience stigma because of the illness. About 86.7% reported to having difficult lives because of the illness, 72% reported suffering from psychological, sleep and relationship disturbances and poor quality of life. About 15% reported being harmed in many situations and experiencing distrust, mockery (21%) and maltreatment (41%) (Kadri et al., 2004:627). With regards to neglect, about 34% reported to have experienced neglect from neighbours and relatives and 21% indicated that people were afraid of them. In addition to rejection, 7% of family members got divorced, 2%

were ejected from rent houses and 6% of the fathers left the family, leaving the mother to care for the mental health user (Kadri et al., 2004:627).

In order to curb stigma amongst the family, Nxumalo and Mchunu (2017:210,211) propose a holistic approach of dealing with stigma. Firstly, the authors propose the collaboration of the government and the private sector in supporting the development of the community-based support group to educate and assist the families to cope with stigma. Secondly, they propose a combination of both emotional focused and problem focused coping skills (elaborated under section 2.6, coping strategies) to the family caregivers. Thirdly, on-going research on family related stigma is encouraged. Lastly, the nurses should be equipped with skills to diagnose family related stigma, and to equip the family caregivers accordingly (Nxumalo & Mchunu, 2017:210,211).

The literature indicates that family members are indeed subjected to stigma by virtue of their association with persons with schizophrenia and they experience several negative impacts that can hamper the treatment and recovery process. The reviewed studies all proved the hypothesis that family members are indeed affected by stigma and there are means to curb the stigma experienced by family members. In the context of this study, the family members of mental health users with schizophrenia were explored to determine the stigma that is subjected to them by the society and how it affects them.

2.5.5 Needs of the family caregivers

As mentioned before, schizophrenia is a chronic mental illness and sufferers depend on the caregivers for support. Yen, Hwu, Chen, Chen and Wu (2007) conducted a study in 2007 in Taiwan to assess the perceived need of caregivers so that adequate services can be provided for them in the community as psychiatry does not respond to all their needs. A total of 177 primary caregivers were interviewed and 14 perceived needs were identified and classified into four different clusters using the general association plots. The findings revealed that 77.7% of caregivers needed assistance with the care of their relatives. The caregivers, under the cluster of needing assistance with the care of their mental health users noted the need for assistance in terms of comforting and assisting the aggravating mental health user, transporting them to service settings, financial aid and lastly general psychological or practical support (Yeh et al., 2008:648). About 66.1 % of the caregivers were in need of access to relevant information. The caregivers were in need of knowledge to understand the medical terms, the diagnosis and treatment as well as the identification of early signs of relapse (Yeh et al., 2008:648). Furthermore, 68.2% of caregivers revealed that they were in need of societal support. According

to the authors, the research findings revealed that the caregivers needed continuous campaigns against the stigma of schizophrenia as it was demonstrated by high prevalence of the perceived need to understand the mental law and the need for acceptance in the society. As a result, they also needed occupational therapy and sheltered workshop facilities (Yeh et al., 2008:650). Additionally, only 27.2% of the caregivers needed burden release through advice on intimate relationships for the mental health user as well as their long-life custodial care (Yen et al., 2008:648). Lastly, Yen et al. (2008:649) noted that variables such as admission, duration of illness, caregiver and mental health user's relationship and the educational level of the caregiver were the significant factors related to the perceived needs of the caregivers.

Chen, Zhao, Tang, Jin, Liu, Zhao, Chen and Lu (2019) conducted a similar study in 2019 and identified that caregivers were in need of more financial support, being respected and rehabilitation institutions (Chen et al., 2019:7). The authors assert that the caregivers hoped for more types of free supply of medication and expanded health insurance coverage for people with schizophrenia. Furthermore, the caregivers of persons with schizophrenia experienced vulnerability as a result of discrimination; therefore, they hoped for a non-discriminatory environment in the society. Although less attention was focused on being respected, the caregivers want to maintain the reputation, status, rights and health of mental health users and themselves. To conclude, more affordable rehabilitation institutions were needed by the caregivers for their schizophrenic family members (Chen et al., 2019:7).

Similar to Chen et al. (2019), the study by Marimbe et al. (2016:5) also identified financial assistance from the government or donors as one of the needs of caregivers in Zimbabwe. Furthermore, the caregivers expressed the need for support groups that are similar to those for in HIV/AIDS programme, for both caregivers and mental health users as they believed that it could assist them to cope with the challenges of caregiving. The authors also added that the caregivers required training in order for them to deal with psychological problems encountered as a result of caregiving. They needed written materials consisting of knowledge on mental illness so that they can know of the signs and symptoms of the mental condition. Another need identified was that the caregivers needed to spend more time with the health professionals to explain to them the mental disorders and to explore the challenges faced in their role in order for them to be assisted accordingly. Finally, the study also revealed that the caregivers wished to be given hope by the health professionals; they needed someone to talk to them and re-assure them as it could assist them with their anxieties (Marimbe et al., 2016:5).

It appears that different factors or variables of the caregivers determine their perceived needs in the provision of care towards their family member with a mental illness. The literature noted the different perceived caregivers' needs that could assist them to cope better with their role as caregivers. According to Yen et al. (2008:651), if the perceived need of caregivers is addressed, it may prevent caregivers from experiencing physical and emotional exhaustion and upsurge their possibility of caring for the mental health user. Henceforth, the perceived needs assessment could establish effective psychiatric service program and offer guide towards the setting clear goal for mental health policy (Yen et al., 2008:651). This study also explored the needs of caregivers of mental health users with schizophrenia in the Nankudu district. The coping strategies of the caregivers of mental health users are discussed in the next section.

2.6 Coping strategies for caregivers

Urizar, Maldonado, Garcia and Castillo (2012:497), state that the burden of taking care of a person with schizophrenia is associated with the reduction in the quality of life and an impact on the health and behaviour of the family caregiver. Moreover, Walke, Chandrasekara and Mayya (2018:184) concur and add that due to the increased challenges that emerge from caring for a person with schizophrenia, there is a concern about the caregivers being unable to manage and cope with the demands and responsibilities. Due to such experiences, Urizar et al. (2012:497) indicate that caregivers adopt different coping strategies to reduce the burden of care.

The coping strategies are defined as the constant changes of cognitive and behavioural efforts to control or manage specific external and internal demands that are perceived by individuals as taxing or exceeding their resources (Urizar et al., 2012:497; Walke et al., 2018:181). Urizar et al. (2012:498) further state that the coping strategies are further summarised into two broad concepts of problem and emotional centred coping strategies. The problem focused coping strategy attempts to manage or alter the problem while the emotional focused coping strategy aims to regulate emotional responses to the problem, to change the way the stressful situation is viewed or to change the personal meaning of a situation resulting in separating events, escape, avoidance or seeking social approval (Lazarus & Folkama 1984 as cited by Marimbe et al., 2016:2). Furthermore, Urizar et al. (2012:498) refer to further studies related to the coping strategies used by caregivers of persons with schizophrenia, and differentiate three types of coping strategies as cognitive, behavioural and emotional. The studies identify the cognitive coping strategy as the most frequently utilised, followed by the behavioural and the emotional reaction being the least effective as it generates more despair amongst caregivers (Urizar et al., 2012:498). Marimbe et al. (2016:2) further classifies the coping strategies experienced by the

caregivers into either positive or negative. The utilisation of appropriate social support from family, friends and church constitutes positive coping strategies whilst negative thinking, substance abuse and avoidance are regarded as negative coping strategies (Marimbe, 2016:2).

Urizar et al. (2012:498) note that variables such as personal and situational types which include dysfunction, burden, personal appraisals, available support, personal traits, socio cultural and ethnic types, and educational level among others influence the coping strategies adopted by the caregivers. Furthermore, these factors play a role by determining which aspect is considered stressful and consequently what type of coping mechanism to apply to deal with it (Urizar et al., 2012:498). For instance, seeking for spiritual help or the religious approach is a way to cope in some culture while searching for social and professional support styles of social coping can be used in another (Urizar et al., 2012:498).

Urizar et al. (2012) conducted a qualitative research in 2012 on the coping strategies of caregivers of persons with schizophrenia in the Aymara ethnic group. The following emerged as coping strategies for the caregivers: Collusive reaction towards the mental health user, social participation, resignation, constraints, maintenance of social interest, positive communication, information, use of alcohol and drugs, talking with friends about the mental health user and seeking spiritual help (Urizar et al., 2012:500). The caregivers from the study were likely to use spiritual intervention as the coping strategy because they believe that the causes of the disease are attributed to either a rage of gods as a reaction to failed rituals and offerings or to wizards' actions (Urizar et al., 2012:500)

In a different quantitative study conducted in India by Walke et al. (2018:184), the caregivers showed that the frequently used coping styles were drawing strength from religious activities, active coping in terms of doing something about the situation, planning, acceptance of the situation, instrumental support (getting advice from others), and positive reframing practice (seeing the good in what is happening). Furthermore, the least utilised coping strategies were denial or refusal to believe what is happening, behavioural disengagement such a giving up on trying to deal with the situation, self-blame over the situation, humour and substance abuse (Walke et al., 2018).

In Zimbabwe, Marimbe et al. (2016) also found seeking for spiritual assistance from both traditional and faith-based healers as the most frequently used coping strategy due to the belief that the problem is linked to witchcraft. Other caregivers used coping strategies such as shouting, ignoring, and avoiding the person with mental illness (Marimbe et al., 2016:5).

All the reviewed research had “seeking for spiritual or religious intervention” as the most frequently used coping strategy. Furthermore, the coping strategies that were used by the caregivers could be identified whether it was centred on problem solving or emotional focused form of coping strategies. Lastly, their caregivers displayed both negative and positive form of coping strategies. This study also identified forms of coping strategies by the family caregiver of mental health users in the context of the Nankudu district, Namibia. The intervention and support for the caregivers is discussed in the next section.

2.7 The intervention and support for the caregivers

Chan (2011:344) and Lippi (2016:1) both acknowledge that the family is the primary long-term care and a significant resource for individuals with schizophrenia, hence, family intervention and programmes have to be implemented to improve the quality of care for individuals with schizophrenia and the quality of life for the caregivers. Lippi (2016:5), asserts that family psychoeducation programmes and interventions is an evidence-based practice that proves to reduce relapse rates and facilitates recovery and it further assists caregivers of mental health users with schizophrenia. A study by Manyaluae et al. (2014:1) confirms that education is indeed one of the important needs of the caregivers of mental health users. During their research on the experiences of caregivers of family members with a mentally ill family member, it was noted by participants that they needed education from the health professionals on the signs and symptoms of relapse, how to handle a relapse with aggression, and how and when they need to seek assistance (Manyaluae et al., 2014:1).

Thorning and Dixon (2016:180) also refer to the schizophrenia Patient Outcome Research Team (PORT) that was funded by the health care policy and research and the National Institute for Mental Health to review scientific evidence and to develop and disseminate recommendations for the treatment of schizophrenia. Based on the reviewed studies, the PORT made recommendations for family interventions to be integrated in the treatment due its positive impact on the treatment outcome. The research highlights that family psychoeducation offered at least 6 to 9 months proves to be effective in reducing the rate of relapse and hospitalisation, increase medication adherence, improve functioning, reduces the level of perceived stress for mental health users, hence, lowering the burden and stress and improving the family relationships and functioning (Thorning & Dixon, 2016:196; APA, 2010:104). The PORT study provides evidence that family intervention consists of key elements such as educational and therapeutic theory, and a process to address the burden of care by increasing awareness of risk and preventative factors, building on formal and natural support and enhancing resilience

among all family members. Thorning and Dixon (2016:196) add that the mental health professionals such as the social worker, psychiatrists and psychiatric nurses provide information about serious mental illness and how it affects the individuals and family; they also provide information about the diagnosis, medication, wellness management, and crisis management through anticipatory planning, stigma busting, care coordination, community resources and steps towards community reintegration.

Lippi (2016:5) states that the psychoeducation and support groups are beneficial and should be developed based on psychoeducation, cognitive behavioural therapy, problem solving and coping mechanism perspectives. The author adds that it is important to engage the family members in different intervention programmes to decrease family burden and disruptions of social lives of caregivers. One of the highlighted coping strategies common in South Africa is religious and it can be implemented in interventions to decrease the burden of care. Early implementation of the interventions is encouraged in order to change relatives' views, decrease levels of burden/distress and increase their coping mechanisms (Lippi, 2016:6).

The next segment discusses the mental health system in Namibia as well as the barriers in the provision of the mental health services that could possibly contribute to the burden experienced by the caregivers of mental health users with schizophrenia.

2.8 Mental health in Namibia

Namibia adopted the Primary Health Care (PHC) approach after independence in 1990 which emphasises the need of developing and integrating mental health care into health services that are provided to the community (MoHSS, 2005:2). The country has since established a mental health policy that addresses major mental health issues and defines approaches that direct interventions for mental health services to the communities and families and lastly the protection of the rights of people with mental illnesses. The management for mental health services lies primarily with the Ministry of Health and Social Services, other multi sectoral ministries, non-governmental organisations, private, and traditional sectors.

According to the MoHSS (2005:6), the specialised mental health services are only provided at Windhoek Mental Health Care Centre and at the Oshakati Intermediate Hospital's psychiatric unit. Furthermore, the mental services are also provided in all district hospitals country wide as part of the general ward. The private sector also provides mental health services; however, it is limited to those who can afford it and their mental health users are referred to the mental health care unit in Windhoek for hospitalisation (MoHSS, 2005:6). Lastly, although the number is unknown, there are individuals who seek services from the traditional healers and as noted

earlier, their interventions are being offered by the herbalist, faith herbalists, diviner herbalists, diviners and faith healers in Namibia (MoHSS, 2005:6; WHO, 2001:22).

Batholomew (2016:106) developed a body of literature based on various researches that explored the psychological well-being and mental health in order to understand the psychological need across Namibia. Feinstein (2002, as cited in Batholomew, 2016:106) revealed potential psychological areas of concern such as the rate of alcohol abuse, prevalence of post-traumatic stress disorder, domestic violence related psychological distress and psychological symptoms and behaviour related to HIV/AIDS. The high occurrence of post traumatic symptoms among the Namibian people is linked to the endured civil strife throughout the apartheid and colonisation regime (Bartholomew, 2016:106). Furthermore, many years of the liberation struggle together with the major psychological stressors appear to have implicated the state of mental health in the country (MoHSS, 2005:4). An analytic study by Dhaka, Musese, Kaxuxuena, Bakare and Janik (2017:10) yielded similar psychological concerns but again, the high incidents of road accidents seems to have a direct influence on mental health and wellbeing. In 2015 for instance, Namibia was ranked number one by the WHO in terms of the number of road deaths per 100 000 people. For survival, it implies that a number of mental disorders may arise due to untreated trauma and head injuries (Dhaka et al., 2017:10). Furthermore, the researchers also identified symptoms of depression amongst the orphaned children and women navigating stressful interpersonal relationships and other life events while the high prevalence of substance abuse and psychological distress such as suicide have been observed amongst Namibian adolescents (Batholomew, 2016:106). The high prevalence of substance abuse is linked to substance abuse related mental disorders (Dhaka et al., 2013:13). Lastly, although there are no clear statistics reflecting the reality of the mental illness in the country, the MoHSS' statistics reveal that schizophrenia is the leading mental health diagnosis at the outpatient setting and it's associated with disability (MoHSS, 2010:13).

As noted earlier, the mental health service in Namibia lags behind other health services like in other African countries and it receives low priority due to the limited resources directed towards communicable and life-threatening diseases (MoHSS, 2005:2). Nevertheless, the MoHSS (2005:2) refers to the study by the WHO and other studies that made recommendations to consider both disability and mortality in assessing health priorities. The findings reveal that mental disorders cause significant levels of disability and mortality combined, posing enormous economic, social and psychological burdens on the family members. It therefore prompts the government to take mental health as a serious public health issue (MoHSS, 2005:2).

This section briefly discusses the status of mental health services in Namibia and the next section is a review on some of the barriers that affect the effective service delivery of mental health in the country.

2.8.1 Barriers in the delivery of mental health service

For a long time now, the mental health services in Namibia are still provided under the Mental Health Act, Act no. 18 of 1973 which is outdated in many regards hence hampering service delivery (MoHSS, 2005:7). Furthermore, the mental health policy is available although it is not fully implemented and Dhakar et al. (2017:14) argue that the lack of implementation of the policy is not due to limited resources, rather, the lack of consideration because Namibia is now classified as an upper middle-income country. Ashipala (2013:95) on the other hand conducted a study on the mental health implementation as an integral part of PHC in the Oshana region and the findings highlighted some challenges hindering implementation. The conflicting policies and the lack of guidelines for identifying and managing mental health disorders were some of the hindering factors (Ashipala, 2013:95). The study further revealed other factors that hinder implementation of the policy in the Oshana Region such as:

- The lack of supervisory support in terms of mental health by the general health service manager from the national level cascading to the district level,
- Nurses prohibited from prescribing common psychotropic medication at some health facilities,
- 94% of the health facility lacks basic mental health services such as counselling, follow up and after care of the discharged mental health users at most of the facilities,
- The lack of confidence by trained health professionals in delivering mental health service to the clients, and
- Unavailability of mental health services in most of the health facilities in the region.

The results from the study can be replicated to the regions because the MoHSS (2005:7,8) also highlighted similar findings as factors that hinder the provision of mental health services in the country. Based on the available data, the MoHSS (2005:7.8) indicates that a small percentage of individuals receive appropriate evidence based mental health services due to the following attributes:

- The lack of skilled health care professionals
- Inability to accurately diagnose mental disorders,

- Inaccessibility of available mental health services as they are only provided at the district hospital,
- Lack of follow up and aftercare services at health facilities,
- Ill-informed belief systems about the causes and treatment of mental disorders,
- Lack of knowledge about mental health amongst the key decision makers,
- The lack of regional representatives for mental health care, and
- The outdated legislation.

The above noted challenges prove that the barriers in mental health care and the lack of policy implementation go beyond resources; it also has to do with the lack of guidance in the management of the mental illness and many more factors.

In terms of mental institutions, the Windhoek Mental Health Centre and the Oshakati psychiatric unit are the only institutions providing specialized inpatient and outpatient mental health services countrywide (MoHSS, 2010:13). There are no specialists rendering mental health care at the district level and the services are not integrated into the PHC programmes in the communities, which implies that the mental health users still travel long distances to access mental health services at the district hospital (MoHSS, 2005:6).

Dhaka et al. (2017:14) also identified the disproportionateness in terms of the patient-staff ratio. The country has a population of about 1.5 million people; however, there are only 3 psychologists, 2 psychiatrists, 43 psychiatric nurses and 3 social workers at the two institutions providing specialised mental health care services. At the private sector with costly services, there are 10 psychologists and three psychiatrists (Dhaka et al., 2017:14; MoHSS, 2005:6). Furthermore, the private sector still refers mental health users to the Windhoek Mental Health Care Centre for hospitalisation and further intervention. As a result, the number of mental health hospitals, mental health professionals and mental health problems remains highly disproportional (Dhaka et al., 2017:11).

The highlighted challenges indeed hamper the provision of mental health service in Namibia and as a result, the family caregivers can be affected. One of the objectives of the mental health policy is to develop a comprehensive and decentralised community based mental health policy for the population of Namibia, and to integrate it into the existing social welfare and community systems (MoHSS, 2005:9). The next section therefore discusses the role of social workers in the provision of mental health services as they also strive to improve the social welfare of those affected by mental illness in the community.

2.9 Social work role in assisting people experiencing mental disorders and their caregivers

The Canadian Social Work Association (CSWA) [Sa], claims that social workers work with individuals and families as they are concerned with improving their physical, mental, and spiritual wellbeing. In a mental health setting, Farley, Smith and Boyle (2009:153) and CSWA [Sa] indicate that the social worker operates on three levels: prevention, treatment and rehabilitation with the aim to respond to the needs of the individual, family and community. At the prevention level, Farley et al. (2009:152) state that the task is to seek the causes of mental illness and to eradicate them. The social worker involves families in educational programmes regarding emotional care; health relationships with persons suffering from mental illness; building knowledge and skills amongst caregivers to be acquainted with the handling of the mental health user, and advocating for social justice as a way to deal with stigmatisation (CSWA, [Sa]). During the treatment phase, social worker conducts counselling sessions with families during admission and discharge (Farley et al., 2009:159). The authors add that the intervention is significant in order to strengthen support during hospitalisation as well as compliance with the treatment plan and strengthen psychosocial support after the mental health user is discharged. Treatment is effective in ensuring that the incidents of relapse are reduced (CSWA, [Sa]). The last level of operation, known as rehabilitation, enables the reduction of the after effects of the mental disorder and the restoration of normal activities. Farley et al. (2009:160) indicate that it is important to involve family members in rehabilitation due to the distress and burden they encounter. The CSWA [Sa] adds that the social worker can offer direct counselling to the families, assist them in crisis intervention during relapse, advocate and link them to resources that will be responsive to their needs; coordinate multi-disciplinary services to the caregivers, work with communities to identify mental health issues and develop programmes from the communities' perspective (CSWA, [Sa]). Lippi (2016:6) also adds that the rehabilitation programme for the mental health users will lessen health and economic problems, hence, decreasing family burden and a disruption of the social lives of the caregivers.

Social workers play a significant role in the care of mental ill persons and the present research explored some of the social work interventions that are provided to the caregivers of mental health users with schizophrenia and the findings enabled the researcher to make recommendations to the social workers in order for them to render effective services and thus lessen the burden for the caregivers.

2.10 Summary

This chapter firstly explored the overview of mental health with emphasis on schizophrenia. The literature further explored national and international deliberations on the allopathic and traditional medicine and the benefits of possible collaboration especially towards the caregivers of mentally ill persons. Secondly, the concept of burden and the experiences of the caregivers of mental health users with schizophrenia was reviewed, with emphasis on the impact of schizophrenia on the caregivers, the contributing factors towards the concept of burden, the family and stigma, the roles and task of the caregivers as well as the needs of the caregiver. Thirdly, the coping mechanisms employed by the family caregivers on persons with schizophrenia were explored. Evidence based intervention and support for the caregivers were also highlighted in the literature. Finally, the mental health state in Namibia, the barriers in the provision of the mental health services and the role of the social worker in assisting people experiencing mental disorders and their caregivers were explored.

The next chapter discusses the research methodology and empirical findings.

CHAPTER THREE

RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS

3.1 Introduction

In Namibia, schizophrenia is the common mental health diagnosis and due to the limited resources for mental health care, family members remain the primary caregivers of mentally ill persons (MoHSS, 2005:5). The study aimed to understand the experiences of caregivers of mental health users with schizophrenia in Nankudu district, Namibia. In order to understand the caregivers' experience, the research was guided by the core question: What are the experiences amongst caregivers of mental health care users with schizophrenia in the Nankudu district, Namibia?

The chapter firstly elaborates on the research approach, research type, research design, and the research methodology that was utilised during the actual study. The pilot study and the ethical considerations that were followed are also presented. Secondly, the chapter focuses on the empirical findings. The biographical information of participants is noted and later, the themes and sub themes that emerged from the interviews are highlighted with supporting literature.

3.1.1 Goals and objectives

The below noted were the goal and objectives of the research:

3.1.1.1 Goal

The goal of the research was to explore the experiences amongst caregiver of mental health users with schizophrenia in the Nankudu District, Namibia.

3.1.1.2 Objective

In order to attain the goal, the study focused on the following objectives:

- To describe the phenomenon of schizophrenia in Namibia, Nankudu district from a systems theory perspective.
- To explore the biopsychosocial experiences of caregivers for a person living with schizophrenia.
- To ascertain the tasks and roles of caregivers in caring for a person living with schizophrenia.
- To explore the interventions and support provided to the caregivers of a person living with schizophrenia.

- To suggest strategies for social workers on intervening with caregivers of mental health care users with schizophrenia in the Nankudu district, Namibia.

3.2 Research approach

The researcher used the qualitative research approach because the purpose of the study was to explore the experiences amongst caregiver of mental health users with schizophrenia in the Nankudu district, Namibia. The explorative nature of the research paved the way for the researcher to gain more insights of the livelihood of the caregivers through open and unstructured interactions (Fouché & Delport, 2011:65; Padgett, 2008:13). Open ended questions were used during the semi structured interviews in order to obtain more information on the issues and to broaden the aim of the study. The researcher was seeking to understand the experiences of the caregivers; therefore, the paradigm of the study was based on a phenomenological approach. This approach enabled the researcher to understand the experiences of the caregivers as well as rationalise their daily functions when caring for mental health users with schizophrenia (Babbie & Mouton, 2001:28, in De Vos, Strydom & Patel, 2011:8). The study was the first to be conducted in Namibia, therefore, exploring the phenomena based on the phenomenological approach enabled the researcher to gain in-depth information concerning the experience of caregivers and bridging knowledge gap in mental health (Fouché & Delport, 2011:95). Lastly, the qualitative approach is an emerging design and it gave the researcher an opportunity to be flexible to make changes when it was necessary to achieve the aim of the study throughout the research process (Creswell, 2014:186; Fouché & Delport, 2011:65).

3.3 Research type

An applied research type was used during the study because it aims to resolve problems in practice; resolve policy related problems and assist practitioners to achieve tasks (Fouché & De Vos, 2011: 95). This applied research was explorative in nature and it enabled the researcher to gain in-depth information as well as understand the experiences of the caregivers of persons with schizophrenia in Nankudu district. Henceforth, the study findings sought to give recommendations to the Ministry of Health and Social Services that will assist to address problems that caregivers are experiencing. Moreover, recommendations can inform the policy makers and suggest strategies to social workers on ways to intervene with the caregivers to ease their burden of care and integrate caregivers in treatment plan for mental health users with schizophrenia.

3.4 Research design

The case study design was used for the research and it enabled the researcher to explore real life cases of caregivers of mental health care users with schizophrenia; in a contemporary bounded system, through detailed, in-depth data collection involving interviews that produced rich data and an understanding of the phenomenon (Fouché & Schurink, 2011:321). The case study for the research was 10 caregivers of mental health care users in the Nankudu district, Namibia (Creswell, 2013:97). Utilising the case study design enabled the researcher to holistically understand the caregiver's relation, interaction and how they give meaning towards caring for their relatives with schizophrenia (Maree, 2007:75). The instrumental case study design was the focus of the study. In order to answer the research question, caregivers of mental health users as one bounded case were used to illustrate and provide in-depth information through interviews (Creswell, 2013:101). The instrumental case study was suitable as it allied with the applied goal of the research. New knowledge was developed from the perspective of the caregivers regarding their experiences caring for persons with schizophrenia. Hopefully, the findings of the study can be used by policy developers and social workers in Namibia to come up with strategies to intervene and lessen the burden experienced by the caregivers of mental health users with schizophrenia (Fouché & Schurink, 2011:321).

3.5 Research methodology

The section discusses the practical activities undertaken during the research such as the sampling, data collection, data analysis, data quality and the pilot study (Carter & Little, 2008:1318).

3.5.1 Study population and sampling

The study population consisted of caregivers of mental health users with schizophrenia in the Nankudu District, Namibia. The Health Centres and clinics in the district refer all mental health cases to the Nankudu District Hospital for further treatment and management. Therefore, selecting such a study population addressed the issue of representation as mental health users and their caregivers in the district access mental health services at the hospital. The total number of caregivers of persons with schizophrenia was unknown to the researcher hence the non-probability sampling approach was used to obtain participant for the study (Rubin & Babbie, 2016:220). To be precise, the purposive or judgmental sampling method was used to select the caregivers to participate in the research (Strydom, 2011:232). The selection process was based entirely on the researcher's judgment of the unit which presented the most characteristics or

useful criteria to generate information that was needed for the research (Rubin & Babbie, 2016: 221). The participants for this study were selected based on the following inclusion criteria:

- Primary caregiver staying in the same household with persons with schizophrenia for a period of one year
- Caregiver residing in Nankudu district for over a year and speaking Rukwangali or English
- Male or female caregiver above the age of 18 years.

Prior to data collection, the researcher firstly met with the nurses and doctors working at the inpatient and outpatient department to identify caregivers who met the above inclusion criteria to participate in the study. They managed to identify a list of mental health users with schizophrenia from their records and they also gave their physical address for the purpose of tracing. The researcher telephonically made arrangements as well as seeking for the caregiver's consent to participate in the study and thereafter, an appointment to carry out the actual interview was scheduled. The researcher managed to conduct in-depth interviews with ten caregivers until data saturation was reached (Maree, 2007:76; Padgett, 2008:56).

3.5.2 Data collection

The researcher used a semi-structured, one-on-one interview schedule as a data collection technique during the study (see appendix for the interview schedule). The study was explorative in nature, hence, interviews as a two-way conversation allowed the researcher to ask open ended questions to elicit rich and in-depth information from the caregivers regarding their world view in caring for mental health care users with schizophrenia (Maree, 2007:87). The advantage of using the semi structured interviews was that the researcher managed to get a lot of in-depth data in an effective manner from participants. Furthermore, the semi structured interview had pre-determined questions that guided the flow of the interview and participants shared information that was appropriate and responsive to the posed questions without diverting the interview into a therapeutic session as the questions evoked emotional consequences on the caregivers (Greeff, 2011: 351,360).

During the actual interviews, the researcher firstly took the participants systematically through the informed consent form for them to understand and be acquainted with the purpose of the study prior to the interviews (see appendix for the informed consent form). The participants that gave consent were expected to sign the consent forms before the researcher conducted the

interviews. Subsequently, the researcher used a digital audio recorder to record the interviews with the permission of participants to capture the entire interview; and it gave time for the researcher to concentrate on the procedures as well as the flow of the interview process (Greeff, 2011:359). The recording device further assisted the researcher to write the verbatim transcription after the interviews (Smith et al., 1995 in Greeff, 2011:359). Additionally, the researcher wrote field notes during the interview to capture empirical observations, interpretations and other experiences that were not captured by the digital recording device (Babbie, 2007 in Greeff, 2011:359). To commence with the interview, the researcher and the participant firstly read the semi-structured interview questions together to ensure that the questions were clear to the participants (Greeff, 2011:359). Furthermore, the researcher followed a logical sequence of asking questions by firstly focusing on questions about the caregiver and mental health user's biographic information which were less sensitive; then moved on to ask seven main open-ended questions that were appropriate to elicit information on the experiences amongst the caregivers (Greeff, 2011:352). Moreover, the researcher also applied probing skills to elicit additional information where necessary (Greeff, 2011:351). The interview schedule was translated in the Rukwangali version which made it easy for the researcher to collect data because the participants were not very fluent in English. Two participants were interviewed in the comfort of their households while the other eight participants were interviewed at Nankudu district hospital in an office at the administration block. The participants who were interviewed at the hospital were provided with transport money after the interviews were conducted.

3.5.3 Data analysis

Cresswell (2013:179) indicates that the process of data analysis involves organizing the data, conducting preliminary read through of the data, coding and organizing themes, presenting the data and forming an interpretation of the data. During the analysis phase, the researcher used the five steps of data analysis as prescribed by Cresswell (2009) to give order, structure and meaning to the data that was collected from the caregivers (Schurink, Fouché & De Vos, 2011:397). Although the five stems were not followed in a rigid approach, it gave guidance to the researcher during the process (Schurink, Fouché & De Vos, 2011:397). Below is the data analysis process that was followed by the researcher:

- **Planning**

The planning process was the initial stage of the analysis process where the researcher organised items to be used for the data analysis process (Creswell, 2014:197). Items such as the audio recorder, colouring pens for the coding process, earphones for listening to the audios that were recorded, a laptop and memory stick to store the data that was collected during the interview were arranged (Schurink et al., 2011:404). Furthermore, field notes that were written to capture observations and experiences during the research process that could not be captured during the recording were also put in place for the purpose of incorporating them in the analysis (Schurink et al., 2011:405).

- **Managing the data**

During the stage of managing the data, the researcher read thoroughly through the field notes and listened attentively to the audio recordings to have a general sense of the information and an opportunity to reflect on its overall meaning; and afterwards the researcher began the process of writing the interview transcripts (Schurink et al., 2011:408; Creswell, 2014:197). The interviews were conducted in Rukwangali vernacular language as the participants that were interviewed were not very conversant with English; therefore, the researcher and an assistant facilitator translated the interviews into English during the transcribing process. After the transcripts were typed into word documents, the researcher created a folder on the laptop in order to save the transcripts and the audio recordings. Furthermore, the audio recordings and the typed transcripts were saved on a memory stick for backup purposes.

- **Reading field notes, transcripts and writing memos**

During this stage, the researcher explored the data by spending time reading the transcripts and the field notes while writing memos in order to be acquainted and making sense out of the data that was collected from the participants regarding their experiences. The researcher wrote the memos at the margin of the transcripts and the memos were considered during the coding process (Schurink et al., 2011:409).

- **Describing, drawing patterns, themes and coding**

The researcher achieved this process by reading all the transcripts in order to identify the main themes and descriptions that were shared by the participants. As highlighted by Schurink et al. (2011:410), the researcher was able to identify themes by the frequency of common ideas shared by the participants during the data collection process. Furthermore, the semi-structured

interview schedule had guiding questions, which implies that the responses from the questions enabled the researcher to easily identify commonality in the language, ideas and patterns of beliefs that linked participants within the collected data. After identifying the themes, the researcher assigned different colour codes to the themes and the codes were interpreted into categories in order to reduce the data into small manageable themes for final reporting (Creswell, 2014:197; Schurink et al., 2011:410).

- **Presenting and visualising the data**

Creswell (2014:200) notes that presentation and visualising the data is the final stage of data analysis as it involves the interpretation of the findings or results. The researcher presented the findings by means of a table format, pie charts and other graphical presentations of the generated themes. Furthermore, as noted by Schurink et al. (2011:410-419), the researcher also presented the participants' experiences that were narrated during the data collection process through verbatim quotations in the report writing.

3.5.4 Data quality

In order to attain data quality, the researcher applied two concepts of credibility and conformability as proposed by Lincoln and Guba (1985). Lietz and Zaya (2010:191) state that the data quality of a study can be achieved by closely presenting the perspectives of the participants into the research findings.

3.5.4.1 Credibility

This concept refers to "the degree in which the research findings represent the meanings of the research participants (Lincoln & Guba, 1985 in Lietz & Zayas, 2010:191). Furthermore, it is done to demonstrate that inquiry was conducted in a manner that ensures that participants' input is accurately identified and described (Schurink et al, 2011:420). The researcher used the concept of credibility to ensure that the participants' inputs were reflected in the findings and not necessarily the researcher's pre-assumptions. Furthermore, this process enhanced the data quality as it was able to minimise bias from the researcher.

The researcher used member checking and peer debriefing strategies to increase credibility. With regards to member checking, the researcher managed to telephonically conduct interviews with the participants before the final report was written to discuss the major findings, themes and descriptions and to also determine if participants' perceptions were accurately represented.

Furthermore, peer debriefing was done with a social worker from the Ministry of Health and Social Services through the research process. The social worker assisted the researcher in terms of reviewing and asking questions about the research to resonate with the researcher about the study findings. The interaction with the social worker and her experience in medical social work helped to increase the credibility of the study (Creswell, 2014:201).

3.5.4.2 Conformability

Conformability refers to the ability of others to confirm or corroborate the findings of the research; it captures the traditional concept of objectivity of the research (Schurink, 2011:421). Furthermore, conformability is achieved by ensuring that the data can be linked to the findings. The researcher ensured conformability by forwarding the findings of the research to the supervisors to evaluate and confirm if research procedures were followed and whether the data collected can be linked to the findings and by doing so, conformability was increased (Lietz & Zayas, 2010:197).

3.6 Pilot study

Strydom and Delpont (2011:394) assert that a pilot study is informal and participants having similar characteristics as those to be investigated are involved in piloting prior to the study in order to identify trends that might affect the main study in the future. The researcher conducted the pilot study prior to the actual research in order to test the feasibility of the study in practice and to test if the proposed design was able to answer the research question. The researcher managed to identify two caregivers of mental health users with schizophrenia in Rundu who met the inclusion criteria of the study and the researcher managed to interview them. By conducting a pilot study, the researcher was able to test the semi-structured interview schedule and took notes of the shortcomings. The semi-structured interview for instance did not capture the relationship between the caregiver and the mental health user as well as the employment status; therefore, the researcher captured such information as part of the field notes. Furthermore, the pilot study also gave the researcher an estimation of the total cost of transportation money for the caregivers and time of the main study and it helped to minimise unforeseen problems during the actual study. Finally, it helped to improve the researcher's interviewing and communication skills (Strydom & Delpont, 2011:394). The participants used for piloting were excluded from the main study.

3.7 Ethical considerations

De Vos and Strydom (2011:42) state that social science research studies human behaviour, attitudes and beliefs, interactions, and institutions in order to test hypothesis, get information

and resolve problems. The research was studying human behaviour; therefore, the researcher had to abide by certain ethical principles to ensure that the participants were not subjected to harm. Prior to the commencement of the study, the researcher got ethical clearance from the research panel of the Department of Social Work and Criminology and the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria. The researcher also got authorisation to conduct the research from the MoHSS in Windhoek, Namibia (see appendices for the ethical clearance and permission from the MoHSS).

3.7.1 Avoidance of harm

In social science research, researchers explore participants' personal life, making them prone to emotional harm, although physical harm cannot be ruled out (Strydom, 2011:115). Caregivers of mental health users may be subjected to emotional and psychological impact; therefore, the researcher had to make sure that the emotional distress evoked during interviews was addressed. To avoid harm to participants, the researcher made sure to inform them about possible discomfort that was likely to arise during the interviews. Furthermore, the researcher did debrief sessions with participants after every interview to ensure that they asked questions, talked about their experiences and raised any discomfort experienced. Finally, the researcher made arrangements with a social worker from the MoHSS to render counselling and other psychosocial interventions to participants in need (Strydom, 2011:115).

3.7.2 Informed consent

The researcher compiled a detailed consent form which was thoroughly read and explained individually to the participants before the interview was conducted so that they were acquainted with the purpose of the study, the duration of being involved in the study, procedures to be followed during the research, the possible advantage and risk/discomfort that participants could experience, the credibility of the researcher, voluntary participation aspects and issues of confidentiality and privacy. After the informed consent was explained, those who gave consent were required to sign forms as an indication of informed consent. Furthermore, the researcher informed the participants about their right to withdraw from the study despite giving consent at any given time without facing any negative impact. The research also obtained consent from the participants to audio record the interview sessions for the purpose of transcribing. Lastly, the participants were informed that the collected data was going to be stored for a period of 15 years in the Department of Social Work and Criminology (Babbie, 2014:67; Strydom, 2011:117). (see appendix for the informed consent form).

3.7.3 Voluntary participation

The researcher did not force or deceive the participants to take part in the research. The identified participants were informed of their right to take part in the study as being entirely voluntary, and that opting out of the study when they were no longer interested was permissible and that it was not going to have any negative impact on them or their mental health users. Furthermore, the researcher informed the participants that there was no monetary compensation or incentives to be given as a result of taking part in the study; therefore, it was entirely their decision to take part in the study (Babbie, 2014:65; Strydom, 2011:116).

3.7.4 Violation of privacy, anonymity and confidentiality

The researcher ensured privacy by only using the collected data for the purpose of the study and the caregiver's responses were not linked to them as pseudonyms were used to identify the participants during report writing and not their names in order avoid harm. The researcher identified the caregivers by using false pseudonyms such as P1-P10 to identify the ten caregivers that were interviewed. The researcher also ensured that the information shared during the interviews was kept confidential and did not identify the participants' responses publicly (Babbie, 2014:68). Furthermore, the assistant facilitator also signed a confidentiality form prior to the interviews to ensure that confidentiality was not compromised. The recorded interviews, field notes, and consent forms were stored by the researcher so that people would not have access to the data (Babbie, 2014:68-69; Strydom, 2011:119). Lastly, the transcripts were only saved on the researcher's personal computer and memory stick for back up purposes.

3.7.5 Publication of findings

Researcher had an ethical obligation to ensure that investigation proceedings were correctly followed and findings were not deceiving to the public. Furthermore, the findings were not manipulated to prove the researcher's point of view but rather the participant's perspectives (Strydom, 2011:126). Throughout the study, the researcher focused attention on accuracy and objectivity during report writing and also avoided language bias and plagiarism as they are some of the main forms of ethical misconduct in research. The researcher also made sure that the findings were revealed to the participants, the public and the MoHSS in an objective manner that did not impair confidentiality (Strydom, 2011:126).

The next section focuses on the empirical findings of the research.

3.8 Empirical findings

This section discusses the findings of the research by firstly presenting the biographic information of the caregivers and the mental health users, followed by the themes and sub-themes that emerged from the data that was collected. Furthermore, verbatim quotations from the caregivers are presented with the support of the literature that was reviewed by the researcher.

3.8.1 Biographic information of the caregivers and mental health users with schizophrenia

Table 3.1: Biographical information of the caregiver

Participant pseudonyms	Age	Gender	Marital status	# of children	Religion/ Church	Home language	Highest qualification	Employment status	Relationship with MHCUs
P1	48	Female	Single	1	Lutheran	Oshiwambo	Grade 9	Business woman	Aunt
P2	36	Male	Married	3	Catholic	Rukwangali	Grade 10	Casual job	Sibling
P3	48	Male	Married	6	Catholic	Rukwangali	Grade 6	Unemployed	Sibling
P4	62	Male	Widow	9	Lutheran	Rukwangali	Grade 12	Pensioner	Uncle
P5	58	Female	Married	6	Catholic	Rukwangali	Grade 8	Unemployed	Parent
P6	45	Female	Cohabiting	9	Catholic	Rukwangali	Grade 7	Unemployed	Sibling
P7	63	Female	Married	6	Lutheran	Rukwangali	Grade 6	Pensioner	Parent
P8	49	Female	Cohabiting	0	Lutheran	Rukwangali	Grade 9	Unemployed	Sibling
P9	49	Female	Widow	2	Lutheran	Rukwangali	Grade 8	Unemployed	Parent
P10	29	Female	Single	2	Lutheran	Rukwangali	Grade 10	Kindergarten teacher	Sibling

Table 3.1 gives an overview of the biographical information of the ten caregivers that participated in the study. The caregivers are identified by pseudonyms with “P1” representing “participant 1” up to “P10” representing “participant 10”. The variables outlined in the table include the participant’s age, gender, marital status, number of children, religion/ church, home language, highest qualification, employment status and the relationship with the mental health user. The oldest participant was 63 years old while the youngest participant was 29 years old. The study was dominated by female participants (7) as supposed to males. Furthermore, four (4) participants indicated that they were married, while the rest were single, widowed or cohabiting. Nine (9) participants out of ten indicated that they had children and only one (1) participant did not have a child. The majority of the participants (9) spoke Rukwangali as a

home language. All the participants noted that they have attended school and grade 12 was the highest level of education obtained. All the participants were Christians belonging to the Lutheran and Roman Catholic Church respectively. Moreover, the majority of the participants (5) were unemployed and only one had a stable job as a kindergarten teacher. With regards to the relationship with the mental health user with schizophrenia, all the caregivers were blood relatives with the mental health users. Below is the table on the biographic information of the mental health users.

Table 3.2: Biographical information of the mental health users with schizophrenia

Participant	MHCUs	Age	Gender	Marital status	Number of children	Religion/ Church	Home language	Highest qualification
P1	1	37	Male	Single	0	Lutheran	Oshiwambo	Grade 4
P2	2	36	Male	Single	0	Catholic	Rukwangali	Grade 9
P3	3	35	Female	Single	2	Catholic	Rukwangali	Grade 4
P4	4	37	Male	Single	3	Lutheran	Rukwangali	Grade 10
P5	5	26	Female	Cohabiting	2	Catholic	Rukwangali	Grade 10
P6	6	-	Male	Single	3	Catholic	Rukwangali	Grade 10
P7	7	25	Female	Cohabiting	2	Lutheran	Rukwangali	Grade 10
P8	8	53	Male	Single	3	Lutheran	Rukwangali	Bachelor's degree
P9	9	23	Male	Single	1	Lutheran	Rukwangali	Grade 10
P10	10	41	Female	Single	0	Catholic	Rukwangali	Grade 10

Table 3.2 gives an overview of the biographical information of the mental health users with schizophrenia. The oldest mental health user with schizophrenia was 53 years old while the youngest was 23 years. Six (6) mental health users were male while only four were females. Furthermore, three mental health users did not have children while the other seven (7) were reported to have 1 to 3 children. Furthermore, five (5) mental health users were from the Catholic Church while the other five (5) were from the Lutheran church. Lastly, the educational level indicated that the majority of mental health users made it to their secondary education with the highest qualification being a Bachelor's Degree. The next section (3.8.1.1) gives more explanations on the individual variables of the participants (caregivers) as they were the focus of the study.

3.8.1.1 : Variation of participants by age

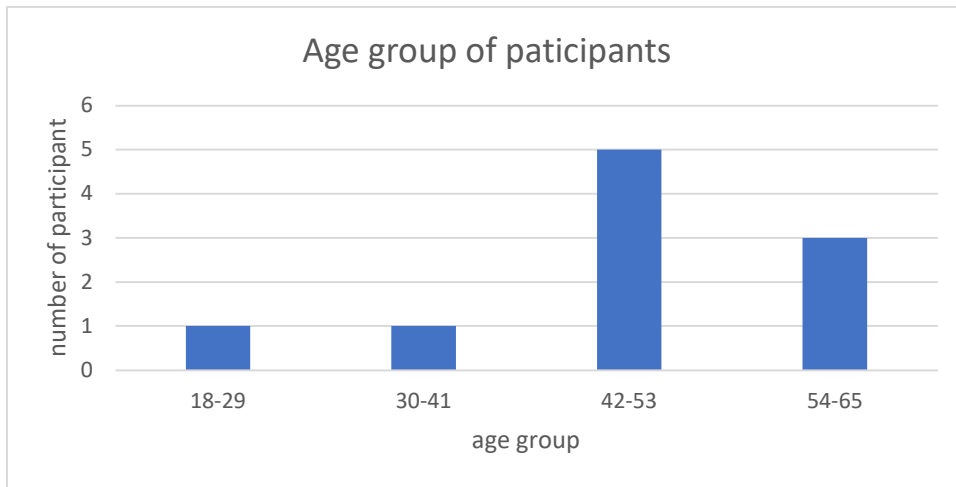


Figure 3.1: Variation by age of participants

The column cluster chart indicates that one (1) participant was between the age group of 18-29 years and one (1) was between the ages of 30 and 41 years. The majority of participants (5) were in the age group of 42-53 and only three (3) participants were between the age group of 54-65 years. All the participants who took part in the study were above the age of 18 as per the inclusion criteria of the study outlined under section 3.5.1. Eight participants who took part in the study were above 42 years and these findings can be linked to Adeosun's (2013:1) research where the mean age of the participants was 44.8 years. Based on the findings of this study, it appears that the role of caregivers of mentally ill persons is mostly done by people above the age of 42 years old.

3.8.1.2 Variation of participants by gender

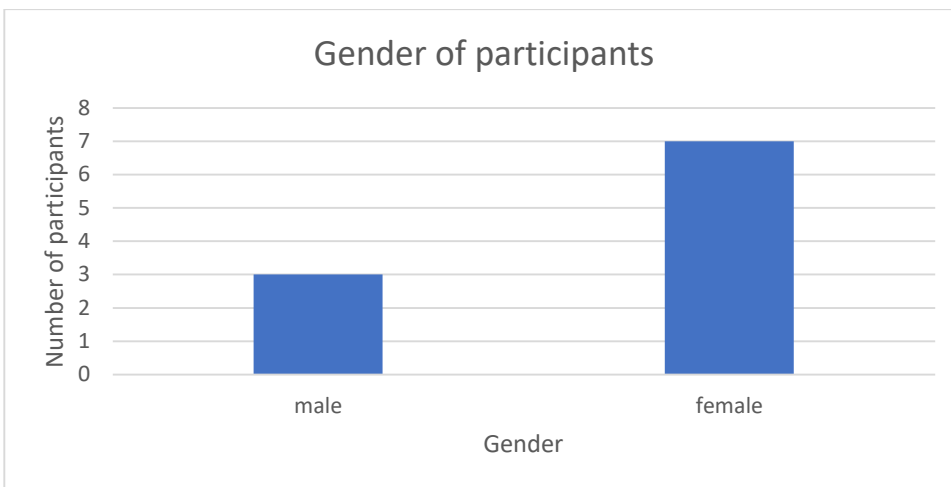


Figure 3.2: Variation of participants by gender

The graph shows that the study was predominantly conducted with seven (7) female participants and only three (3) male participants. The World Federation for Mental Illness (2010:1) and Adeosun (2013:5) validates this finding by indicating that about 80% of females are responsible for the caregiving role due to sociocultural expectations when a family member falls ill and as such, female caregivers had a significantly higher burden of emotional and financial strains domain in their role of caregiving.

3.8.1.3 : Variation of participants by marital status

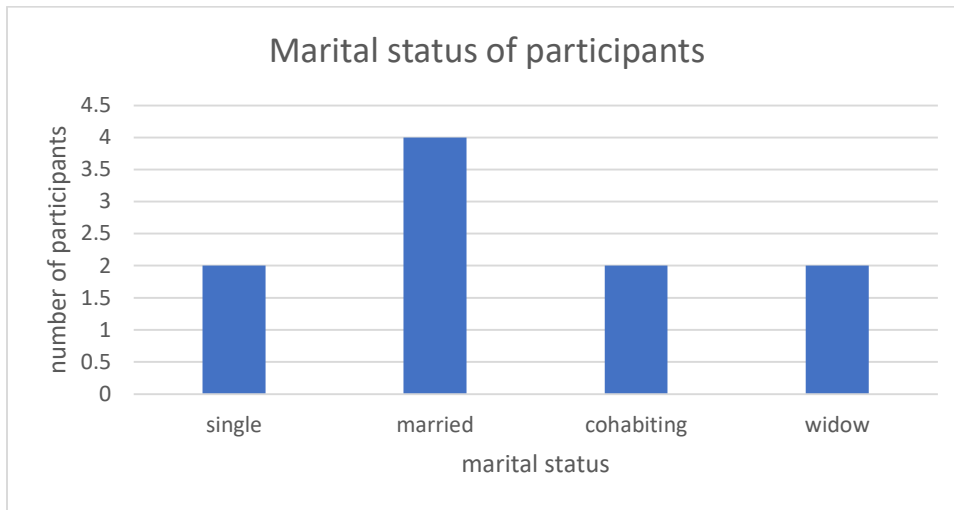


Figure 3.3: Variation by marital status of participants

The graph illustrates that the majority (4) of the participants were married while two (2) were single, two (2) were cohabiting and lastly two (2) were widowed.

3.8.1.4 : Variation of participants by the number of children

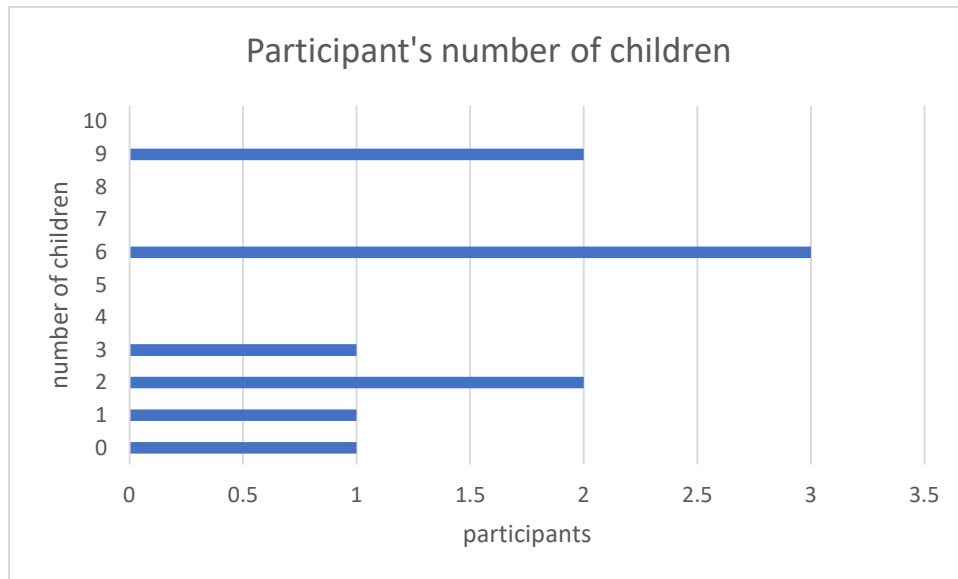


Figure 3.4: Variation by number of children of participants

The graph indicates that three (3) participants had 6 children each, while two (2) participants had nine children and the other two (2) participants had two (2) children each. Furthermore, one participant had three (3) children and another one (1) only had one (1) child. Only one participant indicated that s/he did not have children. Although not related to the caregiver's number of children, Adeosun's (2013:4) research highlights that a bigger number of people in a household can be a protective factor in terms of multigenerational family systems in Africa as tasks of caring for the mentally ill can be shared by the people unlike the typical nuclear family (Adeosun, 2013:4).

3.8.1.5 : Variation of participants by religion/ church

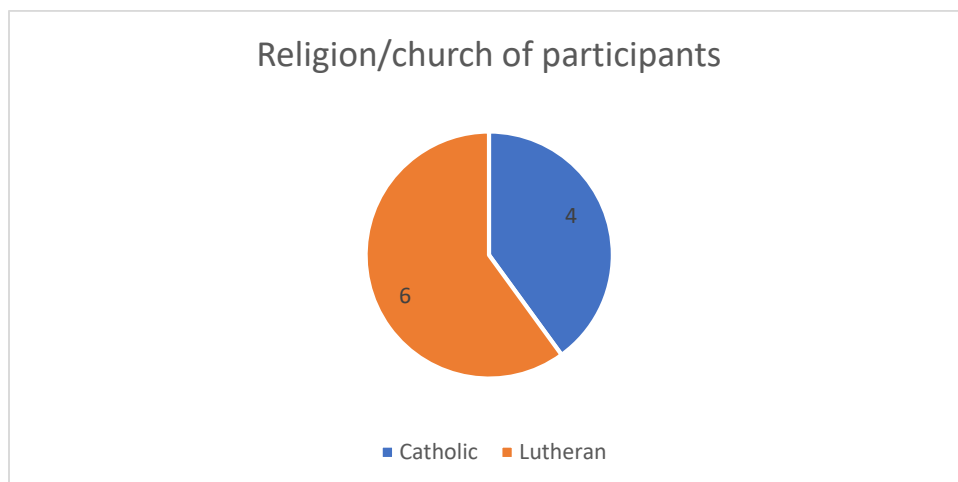


Figure 3.5: Variation by religion / church of participants

The pie chart indicates that all the participants were Christians, with six (6) participants belonging to the Lutheran church and four (4) participants belonging to the Roman catholic church. Studies by Marimbe et al. (2016:5) and Urizar et al. (2012:498) have found spiritual, faith healing and religious seeking as one of the coping strategies for the caregivers of mentally ill persons.

3.8.1.6 : Variation of participants by home language

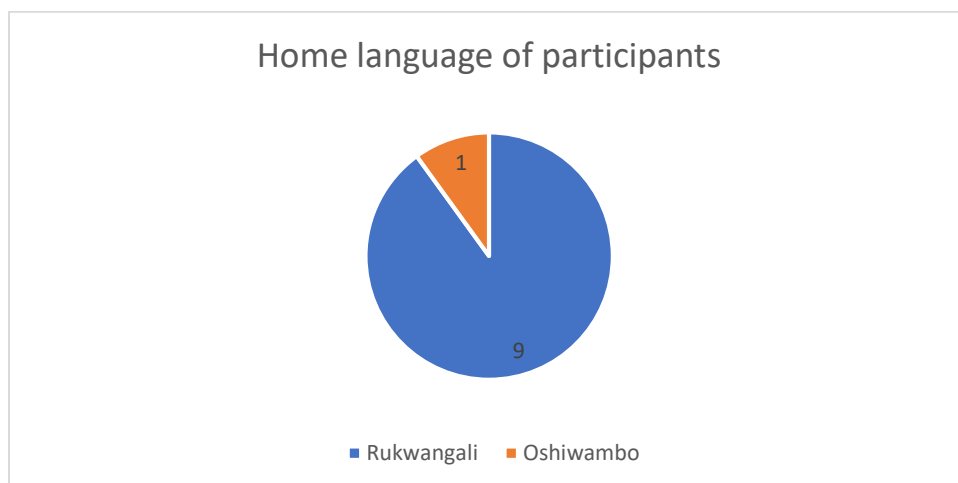


Figure 3.6: Variation by participants' home language

The pie chart indicates that the majority of the participants as shown by nine (9) out of ten (10), spoke Rukwangali as their home language and only one (1) participant spoke Oshiwambo as

the home language. Such findings are due to the fact that the Nankudu district is highly populated by the Vakwangali speaking tribe.

3.8.1.7 : Variation of participants by highest qualification

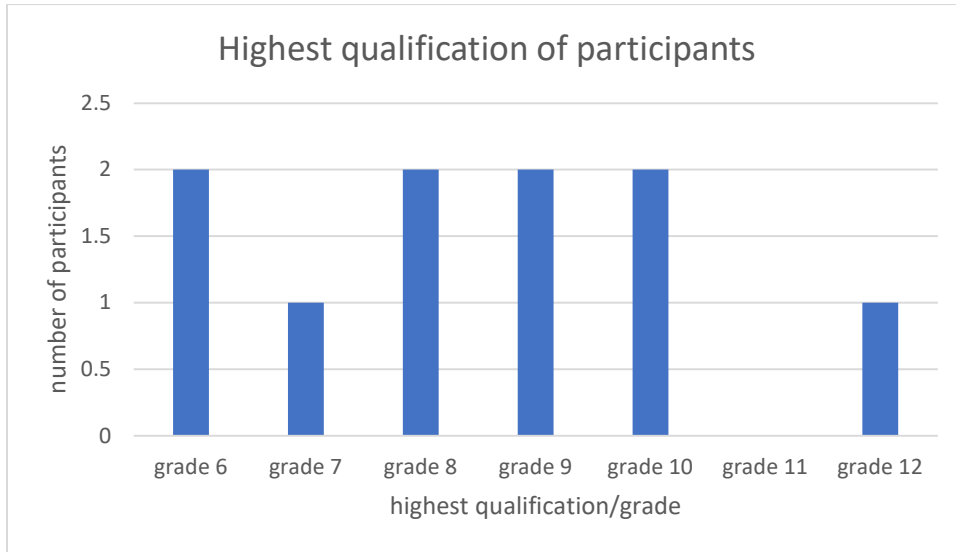


Figure 3.7: Variation of participants by their highest qualification

The cluster column graph shows that all the participants attended school and the highest qualification attained was grade 12 while the lowest is grade 6. Adeosun (2013:5) notes that low levels of educational attainment can constitute higher levels of caregiver burden due to the lack of understanding of the mental condition and the difficulty in attaining employment.

3.8.1.8 : Variation of participants by relationship with the mental health user

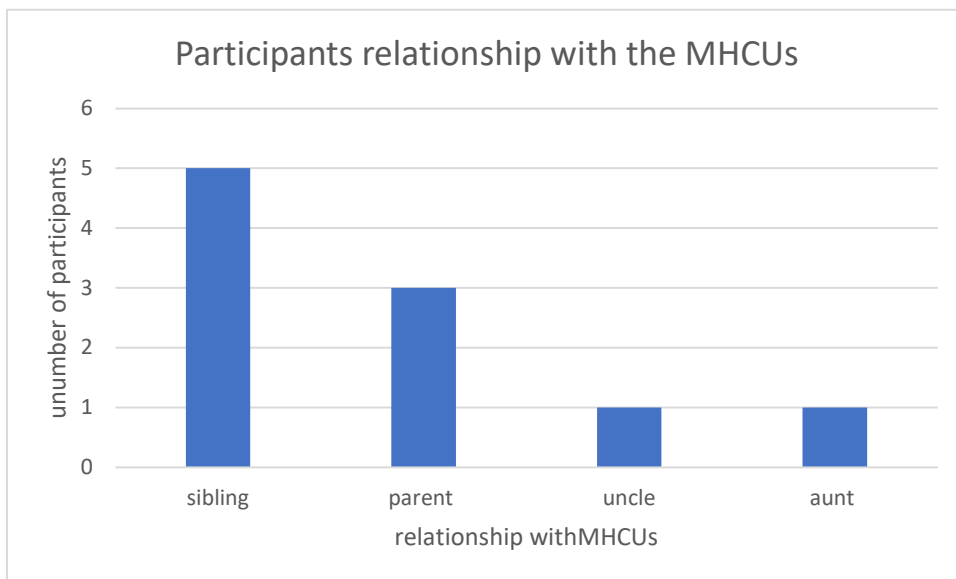


Figure 3.8: Variation of participants by relationship with the mental health users

Aswini et al. (2016:7) indicate that the family is the most important social unit providing care to mental health users and the role of caregiving is usually taken by spouse, parents and siblings. The above cluster column graph indicates that the majority of participants (5) were siblings to the mental health users, followed by three (3) participants who were parents, and one (1) participant being the uncle and then another one (1) as an aunt to the mental health user. Remarkably, there was no literature found on the caregiving role being a responsibility of uncles and aunts as primary caregivers, and just as noted by Adeosun (2013:4), it shows how family systems in Africa are beyond the typical nuclear family relations. It therefore appears that other extended family members are likely to take on the role of being a primary caregiver and not necessarily just within the nuclear family.

3.8.1.9 : Variation of participants by employment status

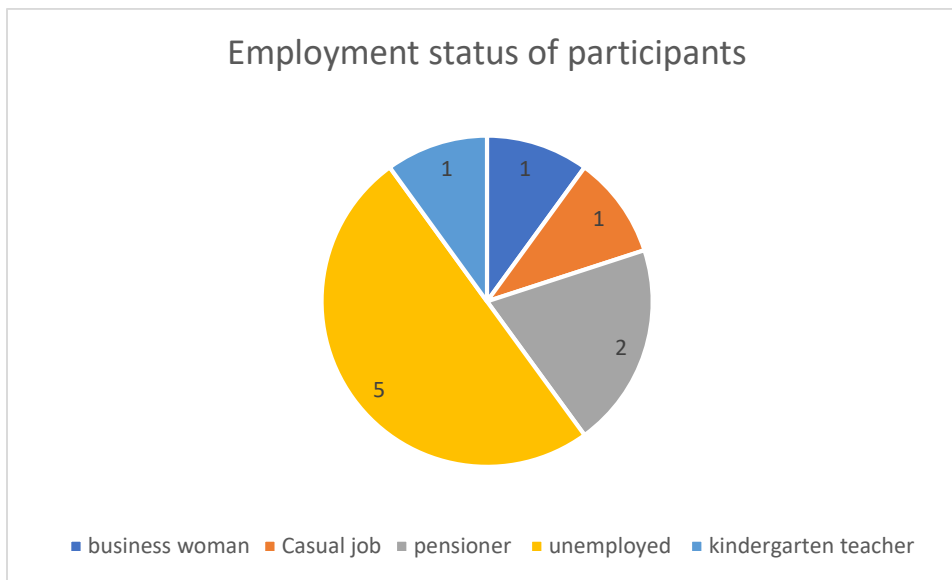


Figure 3.9: Variation by employment status of participants

The pie chart illustrates that the majority of the participants (5) were unemployed, followed by two (2) participants who were old pensioners, and then one (1) kindergarten teacher, one (1) casual worker and one (1) business woman. Adeosun (2013:6) identifies unemployment of caregivers as a contributing factor towards high levels of caregiving burden due to the inconsistency in the source of income and the work overload as the caregivers are regularly at home.

3.8.2 Presentation of themes and sub-themes

The following section discusses the themes and sub-themes that emanated from the responses of the caregivers regarding their experiences of caring for a person with schizophrenia. Additionally, direct verbatim quotations from the participants and the supporting literature that validates or confirms the findings are presented.

THEMES	SUB-THEMES
Caregiver's perception of schizophrenia	Caregiver's understanding of schizophrenia Identified symptoms of schizophrenia Medication
Physical implications	Physical harm towards caregiver Mental health users' disturbing behaviour
Caregivers' roles and responsibilities	Involvement in the treatment plan Seeking alternative traditional medicine Daily functioning support
Psychological and emotional impact	Difficult, negative emotions and helplessness Feeling of grief Overthinking, stress and worries
Social implications	Rejection and conflict Lack of family support Lack of community based mental health services Stigma: blaming, mockery and labelling
Financial and economic burden	Poverty Unemployment
Positive experiences	Acceptance towards caregiving Caregiver's support system Mental health user's medication adherence and recovery
Supportive services required by the caregivers	Social grant for mental health users and other material assistance Educational programmes Social work intervention

3.8.2.1 Theme 1: Caregiver's perception of schizophrenia / mental illness

The researcher was able to identify three sub-themes that highlighted the participant's understanding of schizophrenia. The three sub-themes were based on caregivers' understanding of schizophrenia, the symptoms observed by the caregivers and lastly their understanding of the medication. These three sub-themes are discussed below.

- **Sub theme 1.1: Caregiver's understanding of schizophrenia**

The participants were not acquainted with the term "schizophrenia"; however, they had an insight regarding the perception of the condition their family members were suffering from. The cited quotes give an example of the participants' perception of schizophrenia and how it affects the mental health users. They stated:

P6: *"the way I know it, I only know that it is an illness of the mind. But I don't know what it does to him"*

P10: *"what I know is that, how should I say it, if the condition starts, the person becomes mindless and they do whatever they feel like doing... even fighting, they can start a fight at home."*

P3: *"Madness." [Researcher: what type of condition is madness], "it is a condition that causes confusion, it brings about this and that, sometimes it can lead to anger... That is a symptom now...We brought her to the hospital and the doctors told us that the condition she was having is this one [mental illness]."*

P5: *it is a kind of sickness, whereby a person will just do anything that is out of control, everything is just bad. Like it happened to mine [mental health user], you just notice that the words that are coming out of the mouth is in appropriate. The things she is doing, she has not done it before, and at first, it gives you a shock, it will really make you think that, no, her brain is not functioning.*

Barlow and Durand (2012: 455,456), define schizophrenia as "a severe mental illness that is characterized by broad spectrum of cognitive and emotional dysfunction". Furthermore, the authors assert that the condition is severe, disabling and affects the individual's daily functions. Based on the participants' responses, the researcher could link their perception of schizophrenia to the above definition. The participants' understanding of schizophrenia seemed to be from a holistic and biopsychosocial point of view because although they did not know the term "schizophrenia", it seemed like they were aware that it was a condition that affected their relative's mind (biological) and it further caused psychosocial dysfunction (mental health user's

anger, confusion, violence and odd behaviours constitute the psychosocial aspect in the biopsychosocial model).

- **Sub theme 1.2: Identified symptoms of schizophrenia**

All the participants were able to identify some of the symptoms associated with schizophrenia which also reflected on their understanding of the mental illness. The following quotes are examples of some of the symptoms that the participants identified especially when the mental health user was having a psychotic episode:

P4: *“because you can see, sometimes he talks alone, sometimes he will say that there is a person following him [paranoia] and telling him to do something”*

P7: *“ she says that people are coming for her and they want to kill her... she sees people coming to her and that they want to kill her... and then we ask her about those people because we do not see them, she is the only one that sees them.”*

P8: *“... he won't come out of the room, he will just be there very quiet, you might think that he is not there, like he has gone out somewhere, while he is in the room, he will keep quiet in his room... and that means he does not want.”*

P9: *he just started talking irrelevant things, saying he had a camera in his stomach, and he was walking around, doing nonsense, he was walking around, going to the road, goes to the gate and comes back, just walking around wherever, he goes and starts fighting people, yes, he will fight people and beat them. Even if he wants something, if you don't give him then he would want to beat you.*

Schizophrenia has characterised clinical symptoms such as delusion, hallucination, disorganised thinking (speech), being grossly disorganised / abnormal motor behaviour (including catatonia) and negative symptoms (Khamker, 2012:112). In the present study and based on the participants' responses, the researcher was able to link the participants' responses to the symptoms of schizophrenia such as hallucination, social withdrawal and delusion. The participants were relating to the clinical symptoms of schizophrenia in their responses. Several participants mentioned that their persons with schizophrenia were seeing things and based on the clinical symptoms of schizophrenia, it implies that they were hallucinating. Furthermore, one participant identified that his mental health user with schizophrenia had a belief that someone wanted to kill him and that can be linked to persecutory delusion whereby a person is paranoid and believes that someone is about to harm

them (APA, 2013:87). Such a link gives an impression that the participants had some knowledge on the symptoms that are presented by mental health care users with schizophrenia.

- **Sub theme 1.3: Medication**

Seven out of ten participants cited that their mental health users were receiving medications such as pills and injections from the hospital; however, due to their level of education, they could not give the medical terms of the medication. Only one participant identified the medication that her mental ill person was receiving. She stated:

P1: "the medication, I know that in the morning he takes one Biperiden and the other type written CPZ (chlorpromazine) he takes two...in the evening, he also takes the same medication."

Other participants were only able to describe the medication they were given. These is what they cited regarding the medication:

P7: "They give her pills and injections"

P2: "The medicine. He is just given tablets... sometimes he is given tablets in small packages, small pills like this, that is what he started taking until up to date."

P4: "The medicine he takes is very strong, it is supposed to sedate him, so that he does not roam around a lot, he is supposed to just stay home. That is what I give him often."

The NIMH ([Sa]:7) asserts that antipsychotic medication, be it in the form of pills or injection as identified by the participants, is used for the treatment of schizophrenia and it assists the mental health users to function more effectively and appropriately. Furthermore, the dose of treatment is individualised for each mentally ill person as they may differ in the amount of medication required to reduce the symptoms (such as hallucination and delusion) of schizophrenia (NIMH, [Sa]:7). Chlorpromazine, the medication identified by one caregiver is regarded as a first-generation antipsychotic medication that is used to reduce positive and negative symptoms of hallucination and delusion (NIMH, [Sa]:8). The NIMH ([Sa]:8) suggests the importance of family involvement into the administering of oral medication because it can help to improve adherence. It is evident from the research that although the participants could describe the medication given to their participants, they did not know the medical terms, which implies that they need more insights on the aspect of medication that is taken by their family members. Furthermore, it was apparent to the researcher that the common treatment for the mental health user was

pharmacological and none received any psychosocial treatment which helps to deal with behavioural symptoms of the disorder (NIMH, [Sa]:9).

The manifestation of schizophrenia, the cause, symptoms and medication can be regarded as the biological aspects in the biopsychosocial model and it is important for the caregivers to have an insight so that it can improve treatment outcomes and reduce their burden. Chan (2011:340) asserts that if caregivers lack adequate knowledge of the mental condition, they may not be able to care for the MHCUs, thus leading to relapse and readmission which can increase the burden for the caregivers.

3.8.2.2 Theme 2: Physical implications

NIMH (2002:5) clarifies that people with schizophrenia are not violent; however, schizophrenic individuals with paranoia and psychotic symptoms, which worsens with medicine discontinuation may be at a higher risk of violent behaviour. Furthermore, this violent behaviour occurs at home, targeting the family members and friends (2002:5). Based on the participants' responses, it appeared that caregivers were vulnerable to physical harm and other problematic behaviours as a result of the caregiving and especially when the persons with schizophrenia were experiencing psychotic episodes. Additionally, two sub-themes associated with the physical implication that the participants encountered were: physical/biological harm and other disturbing behaviour. These sub-themes are broadly discussed below:

- **Sub theme 2.1: Physical/biological harm**

Nine out of ten participants narrated that they experienced aggressive behaviour during psychotic episodes of their mental health users and it resulted to physical/biological harm. The following quotes are recounts of some of the participants' experiences:

P5: *"...the things I go through is that she shows anger, it's anger, she gets very angry... you will see her talking too much and it will make you realize that you need to respond to her in a good way because if you have any misunderstanding then she will fight with you..."*

P9: *"...there was a time that he beat me up. It happened in his grandmother's house. He went there to ask for money, and when he was not given, he wanted to beat his grandmother but some younger boys were stopping him. So, I also went in and told him not to beat his grandmother. He just started kicking me, yes, he kicked me badly..."*

One participant expressed how her health was affected, while the other participant felt heartache due to the burden. These are the participants' words:

P6: *"...yes, it gives me so much worries, and as a result, I have been diagnosed with high blood pressure... I now take medication for it..."*

P7: *"...my heart feels pain... it really pains my heart...there really isn't anything I can do..."*

All the participants experienced some sort of physical/biological harm but most of them expressed the assault that they endured from the mental health users and only a few participants identified the non-physical impacts of high blood pressure, stress and heartache. A study by Marimbe et al. (2016:4) supports the reality of physical harm subjected to the caregivers because in their study, the participants reported that their persons with mental illness were physically and verbally aggressive particularly when they had psychotic episodes. Due to such aggression, the participants became stressed; developed medical conditions such as high blood pressure and some reported injuries that were as a result of physical assault (Marimbe et al., 2016:4). The highlighted confirms the findings of this study that caregivers of mental health users become prone to physical/biological harm. Lastly and based on the biopsychosocial model, this finding further confirms that the biological aspect of the caregivers is affected when providing care to MHCUs.

- **Sub theme 2.2: Mental health users' disturbing behaviour**

The participants shared other disturbing behaviour that they experienced from their persons with mental illness. The participants identified destructive behaviour such as aggression towards community members, roaming around, destroying properties and burning of houses as behaviour that contributed to their burden of care. The following views were narrated by the participants:

P1: *"what we go through is a lot, especially if he is having an episode... he roams around a lot at night... he roams around at night.... He goes to other people's houses and sometimes he just wanders around the roads.... you will also notice that he widens his eyes and he talk too much, you can't just ask him anything, he will attack you. if I ask him something, he already gets angry... At other houses, he takes their things elsewhere and throws it or sometimes he puts it on the fire [burns it]."*

P7: *“she sings and runs... we have to hold her down, she runs into the bush, unless we chase after her...yes, sometimes we tie her, you need to tie her so that she can be restrained... if you leave her like that then she will just go... yes, she also destroy things, she will enter there [house], she can destroy and scatter everything in the house.”*

P10: *“if the condition worsens, she gets mad and want to fight with everyone be it at other people’s houses or not, and she might be throwing children on the ground, and say things like, ‘I need a child’ since she does not have one...In the house, there was a time that she burned the rooms”*

Another participant narrated how her person with schizophrenia always threatens to commit suicide:

P 5: *“...she wants to destroy or kill herself... if you try talking to her, she says, no, I will just destroy myself [commit suicide], that is what she is likely to say and then you beg her...”*

A study by Manyaluoe et al. (2014:5) revealed how caregivers were concerned about the behaviour of their mentally ill family member. Their concerns were about the mental health users’ disturbing behaviour such as aggression towards other people, violence, substance abuse, damage to property and disturbing people. In addition, Gater et al. (2014:) reported similar findings, where participants talked about disturbed sleep as a result of a person with schizophrenia’s behaviour and having to continue with the caregiving role throughout the night. Such revelations can be linked to this study, which implies that caregivers are also exposed to certain disturbing behaviour displayed by their family members with mental illness and it affects them physically.

Mark (2013:5) mentioned that research focuses on the psychological and emotional impact of chronic conditions on caregivers and that physical impact is overlooked. The findings of this study validate that caregivers also experience the physical burden of care; therefore, it was important to use the biopsychosocial approach to holistically understand the experiences of caregivers of mental health users with schizophrenia.

3.8.2.3 Theme 3: Caregivers roles and responsibilities

It appeared that all participants adopted a range of roles and responsibilities towards their relatives with schizophrenia. The next paragraphs discuss the three sub-themes that emerged as roles and responsibilities of the caregivers including: involvement in the treatment plan,

seeking alternative traditional medicine and daily functioning support by noting the precise quotes of the participants.

- **Sub Theme 3.1: Involvement in the treatment plan**

The theme emerged because all participants indicated that they were involved in their family member's treatment plan to certain extent. Below are participants' quotes describing their involvement in the treatment plan:

P1: *"...Yes... I am the one who usually take him to the hospital. Whether he goes [referred] to Windhoek or Nankudu Hospital, he is under my care. my understanding of the treatment is that I have to take care of it [medicine]. If it's time to go to the hospital for follow up date, then I take him to the hospital. And, when it's time to take medication, I have to be concerned and also make sure that before he drinks his medication, I first have to give him food to eat..."*

P9: *"every morning when I wake up, I check on him to see if he is fine or not. And I have to give him his medication in the evening. That is my work. And if he is going to the hospital for his follow up, I encourage him to go to the hospital."*

As much as the participants were involved in the treatment, three of them revealed that their persons with schizophrenia were not complying with their treatment plan and they were not stable. One participant noted:

P8: *"...I am involved, but this person, no, he does not agree. You might bring him to the hospital and they give him medicine but after that, he will say that he won't come back to the hospital again because they might kill him, like they wanted to kill him in Windhoek... so one can't really manage to bring him to the hospital to come get his medication, you won't manage. He just stays like that..."*

Based on the participants' responses, it can be deduced that participants were involved in the treatment plan and their roles ranged from monitoring daily administering of medicine, support during hospitalisation, escorting mental health users for follow up visits and accompanying them when referred for further treatment at Rundu or Windhoek psychiatric unit. Literature by Goldberg and Ricklers (2011:41) confirms that one of the caregivers' long-term care functions involve the overall medication management for the mental health users. Furthermore, they also make medical decisions, negotiate with medical care providers, paying bills, providing support during hospitalisation and rehabilitation. Due to the important role of caregivers' involvement in

the treatment, the NIMH (2002:8) sees the relevance of educating the family members about schizophrenia, its symptoms and the prescribed medication as it remains an important part of the treatment process.

- **Sub theme 3.2: Seeking alternative traditional medication**

Three participants disclosed that their involvement into the treatment went as far as seeking for alternative traditional medicine for the management of the mental condition. The following quotes are participants' own words:

P7: " *...they decided to send her to Windhoek and she was referred back here [Nankudu hospital] ... there was still not much improvement... then we decided to go back to the blacks [traditional healers] at the same old man... That is when we got assistance, it became better....*"

P2: " *...with regards to taking him at the traditional healers, my grandmother tried, she tried to take him there but it did not help until we brought him back here [at the hospital] that is when we could see that he is like becoming better*".

P3: " *At first, it was at the hospital but then later on we tried taking her to the blacks [traditional doctors].*"

By analysing the responses, it appeared that the participants were taking their mentally ill family members to both the hospital and the traditional healers due to their cultural beliefs and also the hope to find effective treatment. Literature has shown that users of traditional medicines believe that physical illnesses are accompanied by supernatural causes to the person's illness which can be spirits, earthly sorcerers or neglected spirits (Gureje et al., 2015:4). Van der Watt et al. (2018:556) further confirms that traditional healers are consulted subsequent to mental health users going to the hospital because they provide culturally relevant information regarding the causation of illness, diagnosis and treatment to the mentally ill and their caregivers. Shirungu and Cheikhoussef (2018:134) also reveal that people in Namibia draw on both allopathic and traditional medicine to treat mental illness; and about half to 61% of mental health users accessing mental services at state hospitals also consult traditional healers. The general systems theory seeks to understand human behaviour by looking at the interrelations that exist between a person and their social environment (Beder, 2001:41). In the context of this study, it is evident that participants interrelated with other sub-systems such as traditional healers in their environment who in return influence their role as caregivers.

- **Sub theme 3.3: Daily functioning support**

This sub theme emerged as the participants related to the different daily functioning support provided to their family members with schizophrenia. Despite their involvement in the overall management of treatment discussed in sub theme 3.1, the participants also reported other daily functions that they adopted while providing care. The quotes below highlight some of those daily functions:

P1: *“on a daily basis, I make sure that before drinking his medicine, he eats then I give him medicine, and I make sure he baths, I make sure I wash his clothes, I sweep in his room, makes his bed and I also started teaching him to tidy his room.”*

P2: *“my roles are, to make sure that I encourage him to take his medication and I tell him to be in the house not to go anywhere, that is all and he listens.... with regards to clothes, like I indicated, he now gets his benefits [social grant] so that is up to him, he gives me money himself to buy for him. He does not have a problem.”*

P10: *“what I do for her; I cook for her always. She can’t cook because she is always sweating when she goes near the fire. So, I have to cook for her all the time. I also wash her clothes. When it comes to bathing, she baths herself. Mine[responsibility] is just to cook and clean her clothes.”*

One participant highlighted that her responsibilities included taking care of the mental health users’ children. Here is what she said:

P5: *“With regards to taking care of her, in the morning, when the sun raises, it is my responsibility... I have to think about what I need to do first before she drinks medicine, she has to get something to eat first, together with her little ones [her children], same goes in the afternoon, I need to be concerned all the time, every day, I need to do such things...and I also need to be besides her all the time and not be like someone who roams around, no, I have to be besides her and talk to her... even when she goes roaming around, I have to be like that with her children... when she comes back, I am just with the children, that is my responsibility and I have to do it..”*

Another participant narrated how she goes as far as giving money to her son when he goes for his follow ups at the hospital. She noted:

P9: *“...his problem is that unless you take money and give him. You need to give him N\$20,00 so that he can hike to the hospital. He says, if you don't give me money then I am not going, I won't go. That is the problem. Unless I look for the money to give him.”*

Goldberg and Rickler (2011:41), assert that people living with a mental illness cannot live independently without the family caregivers. The dependability of the persons with schizophrenia is evident in the participants' responses. It appeared that participants had to adopt roles such as promoting personal hygiene, providing basic needs (soap, food and clothes), emotional and financial support, giving instructions and supervising the movement, and managing finances for their mental health users. The World Federation for Mental Health (2010:7), confirms these findings by stating that the caregivers should manage finances or maintain a health hygiene for mental health users to lessen their burden. Furthermore, they should ensure safety at home, monitor treatment and adherence, provide love and support, and ensure the provision of proper nutrition intake (WFMI, 2010:7). The caregivers' roles and responsibilities can be regarded as a social factor in the biopsychosocial model that can have an influence on their wellbeing.

3.8.2.4 Theme 4: Psychological and emotional impact

Participants expressed the negative psychological and emotional impact of caring for a mental health care user with schizophrenia. The associated sub-themes under psychological and emotional impact were categorised into three. Firstly, participants defined their feelings towards caring for a person with schizophrenia as a difficult feeling which caused them negative emotions and the feeling of helplessness. Secondly, the participant expressed the feeling of loss/grief after their family member was diagnosed with schizophrenia, and lastly, caring for a person with schizophrenia gave them a lot of thoughts, worries and stress. The noted sub-themes are discussed in the next paragraphs.

- **Sub-theme 4.1: Difficult, negative emotions, and helplessness**

The participants cited that their role was difficult and devastating hence their experience of negative emotions such as sadness, fear and hurt. Furthermore, some participants felt helpless in their role, it appeared like they did not have a choice but to be caregivers to their family member with a mental illness. Manyaluae (2014:1) refers to a study where similar observations were made; in that study, the participants noted that contrary to the support they were supposed to give, they experienced that they were forced to fulfil their role of being caregivers to their family members with mental illness. Below are examples of the quotes expressing the participants' feelings towards the care for a mental health user with schizophrenia:

P2: *"...it is a difficult feeling because it gives you that fear that the person might go do something bad again like what happened previously, it does not look good to other people and to us who are taking care of him. Like in my case I am also young, just like him, I really don't know what to do...I lost all my parents long ago and the people that we are living with are not really that good. I just don't have a choice"*

P9: *"it feels difficult. I really feel difficult because you will see that in other people's house, they are all normal but, in our house, all three people have gone mad. It really feels difficult. I feel bad"*

P7: *"...my heart feels pain... it really pains my heart...there really isn't anything I can do... sometimes I think to myself that she was supposed to be removed from this phase of earth so that I can just be and not face this suffering... just wondering around, tired of going here and there without getting any real help..."*

Some of the negative emotions like helplessness emerged from the stigma that participants were facing in the community. One participant stated:

P8: *"It really pains my heart, I always think to myself, "for them, it's because it has never occurred to them, that is why they do that... if it happens to them, in their family, they will understand what type of an illness this is." it is difficult, it is not what he wants... it pains my heart.."*

Lippi (2016:2) asserts that caregivers experience subjective burden which is the extent to which the caregivers feel burdened because of their situation, resulting in the negative emotional and psychological effect. Subjective burden includes different negative emotional and psychological reactions similar to the emotions that were expressed by participants in the above quotes. Guilt, feeling of loss, helplessness, blame, stress, fear, self-blame, and embarrassment are other emotional and psychological reactions that caregivers of mental health users are likely to experience (Lippi, 2016:1). Additionally, a study by Gater et al. (2014:3) also confirms these findings because in their study, participants reported that their role was demanding and it led to the feeling of being overwhelmed which impacted their psychological and emotional wellbeing. The next sub-theme focuses on the feeling of loss or grief, which is one of the emotional and psychological reactions of caregivers of mental health users as identified by Lippi (2016).

- **Sub-theme 4.2: Feeling of grief/loss**

Four participants expressed that they felt grief after their beloved ones were diagnosed with mental illness. Below are the quotes from participants, narrating their feeling of loss and grief:

P2: *“... we thought he could become an intellect in our family, but now we can see that we have lost very much”*

P8: *“... well I just have to accept and take care of him but I feel so much pain in my heart, he was an important person in the family, someone who used to provide for people... for this thing[mental illness] go get him and he is now like this, my heart feels so much pain, we have lost our caregiver”*

P9: *“...I have lost my child. I don't know if he will manage with his school very well, because his brain is not really fine.”*

P6: *“he was very fine, used to live with his wife and their children. He had a good life. He was fine and he was the one who even paid for my school fee at the missionary school when I was younger.*

It appears that the participants felt the grief after their family members were diagnosed with schizophrenia because they were no longer the same people they used to know. Moreover, the participants might have felt that way as they had lost out on potential breadwinners and the people that they expected to be their caretakers in the future. One participant plainly expressed how she felt pain because she had lost an important caregiver who was supporting their family; and another participant also expressed that they had lost out on their son, and they were worried about the future of his education. Mark (2013:59) concurs with these findings as in his research; the common themes identified by the participants which are similar to the findings in this study were grief, mourning and loss of a predictable future for themselves and their mentally ill persons. Furthermore, grief was related to the loss of the person they knew before they became ill and the loss of their own future (Mark, 2013:59).

- **Sub-theme 4.3: Overthinking, stress and worries**

The participants highlighted that caring for a person with schizophrenia was difficult and it triggered a lot of thoughts, worries and stress. Here are some of the participants' expressions that cited their thoughts, worries and stress as a result of the burden of caring for their family member with schizophrenia:

P9: *"I am living a difficult life, it is difficult, my mother's head is not working [mentally ill] and now my son. I am having a problem... I ask myself a lot of things, I question myself so much, because, I don't know why it has to happen like this... and my son, last year, he made it, he passed very well and got the second-best position in his class. And now, when the school was about to open, it started. I am having a problem because of this condition. I do not know whether this condition is in the blood or what."*

P1: *"The way I used to feel, I used to think a lot to myself, why has God given me this type of a problem, both mother and son to have a problem like this one..."*

P4: *"There are times that I go at the crawl, in the inland, at the farm. So, it worries me so much, what if he experiences an episode and it just young girls with him at home, what will happen... that is my worry."*

P10: *"...when I go to school sometimes, I really get very worried and stressed. Even working, I won't really manage to work... sometimes you will find her, sometimes you might not know when it [psychotic episode] will start. She chases the babysitter that I leave my child with, you will find that she has been chased from the house. she grabs my child and chases her from the house. That is the concern I have. Nothing really, even working, you can't work well"*

Some of the participants' thoughts and stress emerged from the stigma that they encountered from the community members. Here is what one participant said:

P6: *"...such mockery of people saying that he fakes it, has brought me an illness because I think a lot and stress, he was not like this before and now he is like that ... that is why I am now having an illness [high blood pressure]"*

Based on the participants' responses, it appears that their negative emotions might have been a result of overthinking about their circumstances with the mental health users as well as the fear and worry about what they might do in their absence due to the possibilities of psychotic episodes. Interestingly, two participants indicated that they were caring for more than one family member with mental illness and it might have triggered them to overthink and question God about their fate; hence it impacted their emotional and psychological wellbeing. Lippi (2016:1) highlights self-blame as one of the subjective burdens experienced by caregivers and it was also observed in this research. One participant questioned whether the mental condition was in their blood [inherited] which gives an impression that she was blaming herself for her child's

condition. The caregivers blame themselves for having a mentally ill family member (Monyaluoe et al., 2014,4-5). Furthermore, Marimbe et al. (2016:6), concur with these findings because they had similar observations of participants “thinking too much”. In their study, the participants frequently used the Shona phrase *kufungisisa* which is translated as “thinking too much” to describe the emotional and psychological impact of living with a relative with a mental disorder (Marimbe et al., 2016:6).

Theme 5: Social implications

The findings on the participants’ emotional and psychological status during the care of MHCUs can be considered as a psychological factor in the biopsychosocial model which informed the study and it helped the researcher to understand the participants’ psychological experience.

With regards to social implications, some participants cited their experience of rejection and conflict with their family and community members and such implications were as a result of the behaviour of the mental health users especially during psychotic episodes. The participant also noted that there was a lack of educational and supportive services for them in their communities. Furthermore, the participants experienced stigma and it was mostly from the community members.

The sub-themes relating to the social implications encountered by the participants are: rejection and conflict, lack of family support, lack of educational and supportive programmes for caregivers, lack of social work intervention and external stigma which consists of blaming, labelling and mockery.

- **Sub-theme 5.1: Rejection and conflict**

The participants noted that they were challenged with rejection and conflict from the family and community members and it appeared to have been a result of their mentally ill person’s behaviour. Here is what some participants said concerning the rejection that they encountered:

P3: “...they will bring her back and tell me that I should take my mad person to the hospital. That is what they say. But they do not show anger, or show that they want to fight, they just tell me that I should take my mad person to the hospital for injections. I can notice that it frustrates them, so I just take her to the hospital.”

P4: “sometimes even if he goes and walk around, you will hear people calling you, telling you that you should go and get your crazy person roaming around, then I just go and fetch him... the problem I have noticed in the family is that there is no person that you

expect to care for him because they have all distanced themselves from him [abandoned him].”

As a result of rejection, some participants encountered problems/conflict with the community members. Here is what the participants narrated regarding the problems they encounter with the community members:

P1: *“...we encountered a problem in the community when we chained him. The same people who were complaining that he eats and destroys their things were the same people who reported us to the police, that we tied a person [mental health user] and the police should come and arrest us because we tied him up.”*

P9: *“when he used to beat, they used to tell me to go and get him, because he can't mistreat them and do bad things to them. Unless he does it to me, yes, he should be beating me.”*

P10: *“they come to me and tell me that I should tell my person not to hurt their children because she [mental health user] goes to other people's house and want to fight them, even their children. Those that she goes to, are the ones who come to me. tell your mad person not to come to our house and beat our children.”*

The above quotes illustrate the rejection and conflict that the participants encountered as a result of their mental health users' behaviour during psychotic episodes and it appears to have negatively impacted on their social relationships with family and community members. The study by Gater et al. (2014:7) had similar findings where caregivers' relationships with family members and friends were affected in a negative way. Participants reported not paying attention to other social relationships and also isolating themselves in their houses because they did not want other people to witness the behaviour of the person with schizophrenia. In the context of this study, the social relationships were negatively impacted in a way that led to rejection and conflict. Marimbe et al. (2016:5) reported similar findings where participants experienced rejection and one participant reported being rejected by her own mother and sibling due to her son's illness and disruptive behaviour.

- **Sub-theme 5.2: Lack of family support**

Out of ten participants, four narrated that they did not get any support from other family members. This is what they had to say when they were asked if they got any support from other family members:

P1: *“uhm-uhm, I don’t get help from anyone...”*

P7: *“...her life is not really good. it is difficult living with her... even the family members do not really assist, it is just me that is struggling with her... hmm... unless it is my husband and her husband... yes, there really isn’t much help...”*

P4: *“there is no one who brings anything here, not even food. They just abandoned him...”*

P9: *“From my side, in terms of support, no one supports me. If they assisted me, unless it’s just by calling the police to come and take him [to the hospital]. Nothing really.”*

The participants’ quotes illustrate that there was a lack of support from other family members and it might have contributed to their burden of care. Furthermore, Chan (2011:341) reviewed different research studies where he confirms that poor support from other family members and friends contributes to high level of burden. For example, he reviewed a study in the U.S by Biegel, Shafran and Johnsen (2004) where high levels of burden of caregivers’ burden was observed due to mental health users’ frequent behavioural symptoms and low amount of support from other family members (Chan, 2011:341). Due to such findings, he recommends the strengthening of the families’ social network as it may be a useful strategy to alleviate family care burden (Chan, 2011:341). This study was informed by the biopsychosocial approach; therefore, their family support was assessed in order to holistically understand their experience towards the care for a family member with schizophrenia. Hatala (2012:51) affirms that social aspects such as the family relations and support should be assessed because it is implicated in the various stages of the well-being of the caregivers.

- **Sub-theme 5.3: Lack of community-based educational and support services**

Eight out of ten participants reported the lack of community based educational and support services relating to them as caregivers of persons with schizophrenia. The only service they were relating to was the mental health services that were provided to their mental health users during follow up visits. The following quotes are some participants’ quotes regarding the lack of community based educational and support services:

P9: *"...I have never come across any type of education in the community, nothing...we don't get any assistance; we only get service concerning his treatment from the hospital. He gets his treatment at Nankudu [hospital]."*

P8: *"no, there isn't such programs in our community."*

P7: *"no, there is nothing in the community. It is just ourselves... There are only those that can encourage you. they just encourage you to keep calm and not stress."*

The researcher discovered that out of ten participants, only two received community based educational and support services. One participant received continuous support from the community health assistant while the other one was educated on how to care for the mentally ill person during a once-off awareness campaign at their village. This is what they said:

P4: *"I got education from the Ministry of Health, there was a programme which took place near the school, they taught us about how to live, treat and speak to a person with mentally illness."*

P2: *"I get help, especially from the nurse in the community [health assistant], we even live close by and we are related. That nurse [Health assistance] always come to our house to check on our patient's condition, and his health passport and also tells us the date for his follow up."*

In Namibia, mental health care services are only provided at the district level and they are poorly integrated into the PHC programmes in the communities, which imply that the mental health users still travel long distance to access mental health services at the district hospital (MoHSS, 2005:6). Furthermore, there are no community based mental health services targeting family members of persons with mental illness, hence it clarifies the participants' report on the lack of community based educational and supportive services (MoHSS, 2005:10). In South Africa, Lippi (2016:3) highlights similar experiences of lack of community based mental health centres and perceived support from the mental health care department, which increases the level of burden experienced by families of persons with schizophrenia. Due to the lack of community-based services rendering support to the family members, the participants identified these services as a required need to lessen their burden and their views are discussed under theme 8 which focuses on the supportive services required by the caregivers. Community based mental health services is a social factor in the biopsychosocial model that can improve the wellbeing of caregivers of MHCUs.

- **Sub theme 5.4: Stigma (blaming, labelling and mockery)**

All the participants narrated that they experienced stigma and it had a psychological and emotional impact on them as it was highlighted in Theme 3 which discusses the participants' psychological and emotional impact. Below are the words of the participants expressing the stigma that they encountered:

P10: *"People in the community, says, especially when it starts [psychotic episode], you will hear them say that, this crazy person of theirs, why do they leave it like that and not take it to Windhoek where the mad people are staying. Just like that...why do they even live here, when their parents died a long time ago, so that it can injure our children ... just like that."*

P6: *"...it has affected me because people say I am not taking care of him or supporting him, and that is why he goes out roaming around... and that one day he might not come back home from where he usually goes."*

P7: *"...they think that she is faking it [her mental condition] and they say that she mentions other people bewitching her while it is ourselves who are bewitching each other."*

P8: *"...they just stare and say, agh, we are tired of them.... they say, what is this that has gotten to them, all of them, their heads do not function well."*

P5: *"...they say that poverty also causes madness... that some just get mad because of poverty... that is what they say...hmmm... and when you hear about it, you just accept it... because, I am poor, yes maybe it is indeed poverty. Maybe when poverty affects you so much, your thoughts divert, even your brain..."*

Kadri et al. (2004:626) assert that stigma does not only affect the individual mentally ill person but also their family members by virtue of their association. The above quotes prove that the participants in this study encountered stigmatisation due to their association with the family member with schizophrenia. One participant was accused of bewitching her daughter simply because, during her daughter's psychotic episodes, she used to mention that other community members were bewitching her. The other participant was also blamed for not taking care of her brother because he was roaming around the community. Such findings prove that participants encountered stigma from the community members and it appeared that they were subjected to blame, labelling and mockery. These findings can be linked to Nxumalo and Mchunu's (2017:206) research on the stigma related experiences of family members of persons with

mental illness where participants in that study also expressed stereotypes of isolation, blame and exploitation, community neglect and labelling stereotyping. Nxumalo and Mchunu (2017:203) add that stigma might lead to the lack of motivation to help the person with mental illness during the recovery; hereafter it prolongs the recovery process or the illness which also has financial and emotional consequences for the family members.

Social implication is part of the objective of burden that the caregivers encounter and Lippi (2016:2) affirms that both objective and subjective burden results in high levels of burden for the caregivers. It was therefore important to explore the social implication of caregivers as a social factor in the biopsychosocial approach to understand their experience towards the care of persons with schizophrenia comprehensively.

3.8.2.5 Theme 6: Financial and economic burden

The participants revealed that they were challenged with financial and economic burden. The biographic information of the participants, under sub section 3.8.1.9 which is about the variation of participants by employment status highlights that 5 of them were unemployed while two relied on their old age pension grant for survival. Furthermore, one participant was a business woman, the other one was a kindergarten teacher, and lastly, one was only doing casual work. It appeared that the majority of the participants were unemployed and those that had other employment status did not have a stable financial standing hence the impact on their socioeconomic well-being.

Unemployment and poverty emerged as sub themes associated with the financial and economic burden experienced by the caregivers. One participant narrated that she was not able to work because of her relative with schizophrenia. Here are her words:

P1: "...The area of my life that is affected is my work. I usually do work with my hands, but if I have to leave home and go to the fields, I need to take him with. And if I don't have money for transport for both of us then it means that we have to stay... Because if I leave him, people at home won't be able to take care of him properly. He will just be roaming around at other people's houses, eat their food, grab their things and they will usually call me to pay for their things because he destroys them."

The above quote can be related to the WHO (2003:12) literature asserting that family members set a significant amount of time to care for the person with a mental disorder and as a result of such dedication, they find it hard to gain employment, hold on to existing jobs or they may suffer a loss of earnings due to days taken off from work. The quote further illustrates how the

participants had to pay for the damage caused by the mental health user and such can add on to their financial expenditure resulting into financial burden.

The identified sub-themes are discussed below:

- **Sub-theme 6.1: Unemployment**

This sub-theme developed because the majority of the participants were unemployment and it appeared that they did not have a reliable income to care for their family members with schizophrenia. During the interview, some participants cited that they were in need of financial and material assistance because they were not working. Below are their narratives demonstrating how unemployment affected them:

P1: *"...he should also be assisted so that I am able to go through the problem with them. So that he can buy his own food and bathing soap because I also do not work"*

P8: *"...in terms of assistance, like I said, he was my provider and I am not working. now, he is just like that... so the only assistance unless they should assist the caregiver in providing for the patient."*

P5: *"if you are just at home and unemployed it's really hard to survive with this type of a person... we need these people [social workers] and also assistance, especially with food..."*

P6: *"...like myself, I do not work anywhere, I do not do casual jobs anywhere, I can't also work in the sun because of this heat, it affects my condition[high blood pressure], I am just sitting at home... so, if there is any assistance we should be assisted so that we can see how to survive."*

A study conducted in Nigeria by Adeosun (2013:5) on the correlate of caregiver burden among family members of persons with schizophrenia had similar findings; in that study unemployment and poor social support led to high levels of burden especially on the financial and physical domain of the caregiver's life. As a result of unemployment, caregivers noted that they had to spend more time at home loaded with caregiving responsibilities. Furthermore, the burden was greater because they did not have a consistent source of income (Adeosun, 2013,5). It this study, it can also be noted that the majority of participants were unemployed and even those who were having a different employment status did not have a consistent source of income, and it appeared that they also faced financial and economic burden. Participant number one for

instance was a business woman; however, she still highlighted that she was unemployed and needed assistance with her mentally ill family member. Based on the findings, it can be noted in this study that unemployment as a social factor in the biopsychosocial model had a negative impact on caregivers of mental health users with schizophrenia.

- **Sub-theme 6.2: Poverty (lack of money and food)**

Poverty emerged as a sub theme because most of the participants narrated that life was difficult because they had to struggle to get money and food to provide to their persons with schizophrenia. The researcher observed that as a result of unemployment, some participants were living in poverty and when paired with caring for their mental health user with schizophrenia, it became a burden. Below are the quotes from the participants citing how poverty affected them:

P5: *"it has affected me a lot due to poverty... one might say there is no poverty but no, there are different types of poverty... there is poverty whereby one gets food with difficulties, another type of poverty is that you just sit there without getting anything unless your friend assists you. for instance, I have not yet reached old age [to qualify for social grant] therefore life becomes difficult... in other words that is all poverty... yes, that is what I encounter in my life with my person... let me say my people because she is now having children. as I speak now, the children [grandchildren] are staying with me... "*

P7: *"life is difficult, we have to struggle for food and look for relish... sometimes there is no relish, there is no money and food... that is how we just try, until I get paid, then I can go and look for something to eat..."*

P3: *"...we sometimes go to the police to ask for help, and they bring her to the hospital... but other times the police will refuse and say we should call the hospital... the hospital, we called them but they sometimes say that to use the ambulance, you need to have money to pay for transport... But we do not have money..."*

P9: *"...the life we are living at home, no, it is not a good life, it is poverty. We survive with difficulties. And this child of mine is living with difficulties. He wants to eat, but I really don't have enough food, he has to eat every time, four times a day and it is a problem."*

Chan (2011:344) noted that the poor socioeconomic status of the caregivers increases the burden of care. The above quoted illustrates that some participants were living in poverty and it was more of a burden caring for their family members with schizophrenia because they had to

struggle to get money and food. Aswini et al. (2015:6) concur that the socioeconomic status of the family contributes to the burden of care. The authors refer to the psychiatric epidemiology survey that shows a significant association between mental illnesses like schizophrenia and low economic communities. Furthermore, psychiatric diagnosis can lead to poverty. A research by Yazici et al. (2016:99) found poverty as a related factor to the burden for the caregivers of persons with schizophrenia. The study highlighted that poverty may involve restrictions for the caregivers due to the increased perceived burden in areas of accessing health services and other social facilities, meeting the basic needs of mental health users and unification with the society and all that restriction increases the caregiver's burden. In the context of this study, poverty restricted caregivers from meeting the basic needs of the participants as well as accessing health services for their mentally ill relatives. One participant for instance narrated that he was not able to pay for the ambulance to take his family member to the hospital during psychotic episodes due to lack of money. Poverty is a social factor in the biopsychosocial model which contributed to the burden of caregivers in this study.

3.8.2.6 Theme 7: Caregiver's positive experiences

In as much as the caregivers were experiencing the negative burden of caregiving, they also highlighted some positive experiences. The sub-themes that emerged include their acceptance towards the caregiving role, community support, family support and the mental health user's adherence to treatment and recovery. These sub-themes are discussed below:

- **Sub-theme 7.1: Acceptance towards caregiving**

It appeared that all participants accepted their role as caregivers of mental health users with schizophrenia to a certain degree. Below are some participants' quotes concerning how they have accepted caring for their mental health users:

P1: *"At first, it caused me difficulties, it caused me difficulties but then later on, I just accepted that there is nothing I can do about it, because God's will, is just like that."*

P7: *"there is nothing else I can do, she is my daughter, I just have to be strong, be in prayers with God, and encourage her to take her medication and not default... I also tell her to do this and that, encourage her to also have faith and pray... yes, so that God can have mercy on her"*

P8: *"a person has to just deal with it... because it has affected my friend [brother] and even if I neglect him, where will he go, he might die of hunger... so I have to handle it..."*

whatever I get, I should also give him...whatever I do, I need to assist him... even if I neglect him, it won't really help"

P9: *"...he is my child, he is my child, there isn't any place I can take him. He is my son. I can't take him anywhere. Who should I say should take and be with him? no one. Unless, me as the mother should be responsible. Yes, I have accepted that it is from God. There isn't anything I can do; I should just be responsible."*

Some participants who experienced stigma also showed some level of acceptance and resilience from the stigma that they encountered. One participant had this to say:

P4: *"Eer, I feel okay, because you tell yourself that things that comes or happen to you, it won't just happen to you alone, because if there is an illness, an illness happens in your family, then the same illness might also happen to another person 's family. so, you just accept it, those who talk can talk... you just focus on motivating the patient to be serious and take their medication and go to the hospital... and not allow it[stigma] to affect you."*

Based on their responses, it appeared that participants did not have much choice but to accept their caring role towards their family member with schizophrenia. One participant narrated that the person with schizophrenia was their child; therefore, they could not chase them anywhere or entrust their responsibility with anyone else but themselves. Such expressions indicate that some participants did not have a choice but to take on the responsibility of caring for their person with schizophrenia (Chan (2011)). Furthermore, it appeared that some participants separated themselves from the situations with their mentally ill family member by surrendering it all to God. Urizar et al. (2012:498) distinguishes coping strategies as either problem focused or emotional focused coping mechanisms, and based on the participants' responses, it appeared that their coping mechanism was more emotional orientated as opposed to problem solving. With the emotional focused coping mechanism, Urizar et al. (2012:498) note that individuals manage to regulate their emotional response to their situation and also change the way they view the stressful situations, or they change the personal meanings of a situation. The last quote for participant 4 for instance shows how the participant diverts his focus from the stigma that he encountered towards the care of his mental health user. These findings were further observed in a study by Manyaluoe et al. (2014:4) where participants also stressed that they learnt to accept and live with their family member although they felt that they were incompetent. A different study conducted in India by Walke et al. (2018:184), had similar findings as

participants in that study displayed different coping mechanisms such as acceptance of their situation and seeking for religious interventions. Acceptance as a coping mechanism that was displayed by the participants while caring for MHUCs can be considered as a psychological factor in the biopsychosocial model.

- **Sub-theme 7.2: Caregivers support system**

The participants shared that within the community, they got support from their family members, neighbours, friends and the police. In as much as some participants reported the lack of family support in sub theme 4.2, the others highlighted a good family support system. Below are some of their words regarding the support that they received:

P2: *“our family members, especially the ones living nearby, even the time he was not getting benefits [social grant] ...when you go to them for help, they can assist you with money and you give him to go get his medication... We really get a lot of help from our family members”*

P5: *“the family members assist me; I do not do anything [unemployed], they give me bathing soap even without asking, when they get paid, this one buy you soap, this one gives you money... they assist and encourage me, they give me strength and I feel at peace.”*

P6: *“...my family, myself and my sister are the ones who stay and take care of his... his three children are all working, two of them are teachers and the other one is a secretary.... So together, we all assist in caring for him... his children buy for him a lot of food and they bring it over to me so that I can cook and give him...”*

P8: *“support, we just get from the family members... there is a younger brother who assists him... he is like the head of the household now, but he does not stay there... he buys food and I just cook... and everything else”*

The following quote captured the view of participants who received support from their friends and neighbours:

P3: *“hmm mmm I reach out. Sometimes I go to my friends to see if they can help me...if they help, I have to come and give her...yes... I give her....and then she uses it...”*

P2: *“they treat us very well, especially our neighbours they give us anything that we may ask for, it can be food or money they can assist, that, I have seen.”*

P5: *“... sometimes when it starts[psychotic episode], she will just run and when they see her, they follow her and ask her where she is going... so they even hike a car to bring her home... that is how I usually get help from the others, they would even escort her home, then I just beg her to calm down, that is how I get support.”*

Interestingly, other participants narrated that they got support from the police, especially when their family members were behaving violently during psychotic episodes. The following were the participants' own words regarding police support.

P3: *“... we sometimes go to the police to ask for help, and they bring her to the hospital...”*

P9: *“if he is having an episode, he just fights people and roam around...unless we call the police to come and pick him and take him to the hospital... an ordinary person won't manage to take him...”*

It can be deduced from the above quotes that participants received physical, emotional, financial and material support from their support system which consisted of family members, friends and neighbours and the police officers. Mark's (2013:43,44) research on the experiences of caregivers for relatives with chronic severe mental illness confirms these findings; in his research, the participants' support system consisted of family members, friends and neighbours, therapists, the church and the National Alliance on Mental Illness organisation. In South Africa, Manyauloe et al. (2014:4) reported that caregivers received support from the community to look after the mentally ill person, reprimanding them when misbehaving or taking them to the clinic for treatment in their absence. Participants in this study reported similar support. One participant reported that her neighbours assisted by bringing her mentally ill person back home when she was wandering around. Interestingly, the researcher did not come across literature where police officers were regarded as a support system for the caregivers of persons with schizophrenia. Despite the lack of evidence to support the finding, the participant in this study regarded the police officers as part of their support system in the community. It appeared that strong support systems can be a protective factor to reduce the burden of caregivers.

The biopsychosocial approach unlike the biomedical model enabled the researcher to assess the caregiver's support system as a social factor and it is evident from the findings that social factors influenced the lives of caregivers of mental health users with schizophrenia (Hatala, 2012, 51).

- **Sub-theme 7.3: Mental health users medication adherence and recovery**

This sub theme emerged as a positive experience because seven out of ten participants noted that their mental health users were adhering to medication and their conditions were stable. Participants narrated the following:

P1: *“Yes, he complies because everything is in my care. I am the one who gives...that medication, I am the one who gives it.”*

P2: *“yes, he does take his pills always. He takes four, he takes it in the evening, mostly in the evening.”*

P9: *“he only takes his medication in the evening because if he drinks it in the afternoon, it is a problem, it makes him to sleep so much... he takes it and comply with the treatment.”*

As a result of treatment adherence, some participants shared that their mentally ill family members were recovering well. Below are quotes from the participants:

P4: *“recently he has become a person [normal]... He is taking his medication seriously and I can see that the medication is working properly...but back then, he would just sit there and talk to himself while we are together... but currently, we talk well together and sometimes he will even go work and bring something...”*

P5: *“I can say my patient is better, her mind is functioning and she is continuing with her studies and she is still taking her medication.”*

P10: *“the treatment that she gets really assists her”*

The WHO defines adherence as “the extent to which a person’s behaviour-taking medication, following diet and/or executing lifestyle changes corresponds with agreed recommendations from a health care provider” (Aswini et al., 2015:7). In the context of the study, and in terms of medicine adherence, at least seven participants noted that their family members with schizophrenia were taking their prescribed medicine hence the improvement in their mental condition. The NIMH (2002:7) confirms that the anti-psychotic medication is currently the best treatment available although it does not cure and prevent relapse. Furthermore, the medication reduces symptoms of schizophrenia and usually allows the mental health user to function more effectively and appropriately (NIMH, 2002:7). The above noted quotes illustrate that treatment adherence truly improves the functioning of the persons with schizophrenia and that can reduce the burden for the caregivers. Aswini et al. (2015:7) associate poor adherence of anti-psychotic

medication to rehospitalisation and relapse; however, it was not considered a challenge by the participants of mental health users who were adhering to their medication. The aspect of the mental health users' medication adherence and recovery is a biological factor in the biopsychosocial model which can be used to build on assumptions that relate to illness and healing in addition to the psychological and social factors (Hatala, 2012:52).

3.8.2.7 Theme 8: Supportive services required by the caregivers

All the participants cited that they accessed mental health services of their mental health users from Nankudu district hospital; however, as noted in sub theme 5.2 and 5.3, there was a lack of educational and supportive services and social work intervention for them in their communities. Due to such findings, the researcher also identified three sub-themes associated with the supportive services that were required by the caregivers to lessen their burden of care. These sub-themes were: social grant for mental health users and other material assistance, educational programmes and social work services.

- **Sub theme 8.1: Social grant for mental health users and other material assistance**

Based on the majority of responses by the participants, it was apparent to the researcher that the caregiver required that their family members with schizophrenia be registered for the social grant so that they can get money to cater for their mental health users' needs. Furthermore, the caregivers highlighted the need for material assistance such as food, money, clothes and bathing soap for their mental health users. Below are some of the quotes from the participants:

P1: *"There are opportunities were I also want to go and do something. I have not gotten a job in the government before and I am just surviving on my own, so we want the government to assist by giving us something [money] so that we can use it for our survival and also give people like this [mental health user]."*

P3: *"From my side, there are others who are getting assistance [social grant], they are getting paid, they are getting paid so they can provide for themselves... but for her, we do know how we will do it... she has not received a letter from the hospital stating that at her level [of mental illness] she should get assistance like the others."*

P7: *"yes, I need assistance with the food, we just need food"*

P9: *"we are having a problem, like myself, I have a problem, like my son, he is not getting anything [social grant] now. he is someone who wants to eat, I have a problem, he is always asking for food. I want them to assist me, the government to assist me,*

even with what they register [social grant], even if they register him to get [money] for a few months, so that I can buy for him food.”[Researcher: besides the assistance with food, what other programmes do you need as caregivers] “ even those who have even clothes can give him, even soap because I live with difficulties, even clothes, they can give him... or those with soap, they can also give him, even lotion, they can give him.”

The above quotes illustrate that the participants were in need of financial support through the registration of their family members with schizophrenia for a social grant. They also highlighted other material assistance such as food, clothes and bathing soap for their mental health users. Similar findings were observed in the study by Marimbe et al. (2016:5) in Zimbabwe. The participants in that study identified financial assistance from the government or donors as their need. Furthermore, the identified needs further confirm that some of the participants in this study were living in poverty as alluded in sub theme 6.2 and this can be a target area of intervention by the social workers as a way to lessen the burden for the caregivers.

- **Sub theme 8.2: Educational Programs**

In this study, the participants indicated the need for educational programmes. It appeared like the caregivers did not have any formal educational programmes that taught them to care for their mental health users; hence, they identified educational programmes as one of the required support services. The following quotes describe the participants’ need for educational programmes:

P8: “in terms of assistance, unless we are told that this type of a person, unless you handle him in this way and that way... and a person like this has to be spoken to in this way, depending on who he wants to talk to... just like that”

P9: “it is a good thing if they can give us knowledge, to teach us on how to be with the patient.”

P10: “food maybe, and I also need to be educated to increase my knowledge on how I should care for her.”

The above quotes highlight the participants’ need for educational programmes and similar findings were observed in the study conducted by Marimbe et al. (2016) and Manyaluoe et al. (2014) in Zimbabwe and South Africa respectively. Manyaluoe et al. (2014:6) recommended the implementation of educational programmes at clinics for both mental health users and their family members on causes of mental illness, personal hygiene and treatment. Participants in the

study for Marimbe et al. (2016:5) required training on how to deal with psychosocial problems and they also needed reading materials on the signs and symptoms of schizophrenia. Thorning and Dixon (2016:81) mention that if psychoeducational programme is offered effectively, it can reduce relapse and hospitalisation, increase medical adherence, improve functioning, reduce levels of perceived stress and in return lower the burden of care and improve functioning of the caregivers.

- **Sub theme 8.3 Social work services**

It was apparent to the researcher that most of the participants did not access social work services. Out of ten participants, only two of them accessed social work services. Here is what one participant cited regarding the social work intervention she encountered:

P5: "there is help, especially from the social workers, it is where I got good education... they called me and asked me questions. I told them all my problems... they tell me that if you get problems, you should come to the hospital so that the patient can get medication... and with the treatment, you should still take care of her and not abandon her because, their thinking is not right and cannot take medication properly and needs assistance from me... I got all that [information], from the social worker."

As a result of the lack of social work interventions, some participants highlighted it as a required need. Here are some of the words of the participants regarding social work intervention:

P1: "me as an individual, I am requesting that the government should create programmes and give us counselling. And they should assist us in our problem that we are having with people with illness like this."

P4: "ah-ah, the programmes, we want the hospital and social workers to move and come and visit patients with this mental illness. Because there is danger... in communities, not just this community...even if it's in this community, they [mental health users] are a lot... some are just sitting home, without taking medication like this and they are really making people suffer... hmmm"

P5: "We need programmes to strengthen us, to strengthen us... those who can bring us such is the social worker because you do not know who to take you problems too... its only when it happened to me that I have realized that these people are important [social workers]"

It can be assumed from the above noted remarks that participants required social work intervention such as creating supportive programmes, counselling and home visits for continuous psychosocial support. Thorning and Dixon (2016:196) note that the mental health professionals such as the social worker can provide information about serious mental illness and how it affects the individuals and family; furthermore, they also provide information about the diagnosis, medication, wellness management, crisis management through anticipatory planning, stigma busting, care coordination, community resources and steps towards community reintegration. Farley et al. (2009:153) and the CSWA [Sa] add that the social worker operates on three levels including the prevention, treatment and rehabilitation with the aim to respond to the needs of the individual, family and community. Due to the significant role of social workers identified, recommendations to social workers for effective services towards the advancement of caregivers of mental health users with schizophrenia are noted in the next chapter.

The social grant and material assistance, educational programme and social work interventions that were identified as needs for the participants can be considered as social factors in the biopsychosocial model and they can have a positive influence on the caregiver's well-being.

3.9 Summary

Firstly, this chapter started with an overview of the research; presenting the research methodology that was used, the pilot study and the ethical considerations that gave guidance to the researcher. Secondly, the chapter outlined the presentation of findings by focusing on the biographic information of the participants and then the presentation of themes and sub-themes that emerged from the interviews. The biographic information of the participants was discussed and presented in tables, pie charts and graphs. Then the eight themes and sub-themes that emerged from the interviews of the research were presented by highlighting the participants' quotes about the experiences with mental health users with schizophrenia and then literature was used to support the findings of this study.

The next chapter presents key findings, conclusion and recommendations.

CHAPTER FOUR

KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

This chapter gives an overview of how the goal and objectives of this study were met by presenting the key findings of the study. Furthermore, the conclusions are made from the study and the recommendations are presented based on the findings that emerged from the study.

4.2 Goals and objectives

The goal and objectives of the study were met to a certain degree as presented through the following paragraphs.

4.2.1.1 Goal

The goal of the research was to explore the experiences amongst caregiver of mental health care users with schizophrenia in the Nankudu District, Namibia.

4.2.1.2 Objective

The following sub-section presents the individual objectives and also highlights how they were met during the study. The following objectives were followed in order to attain the goal of the study:

- **Objective 1:** To describe the phenomenon of schizophrenia in Namibia, Nankudu district from a systems theory perspective.

The objective was realised in chapter 1 (sub-section 1.1), where it was noted that schizophrenia affects an estimated 2.6 million people worldwide and in Namibia, schizophrenia is a leading mental health diagnosis which is associated with disability (WHO, 2008:43; MoHSS, 2010:3). Despite the lack of statistics on the prevalence of schizophrenia in Nankudu district, the national prevalence can be generalised to the context of the district. In subsection 1.2, Barlow and Durand (2012:455,456) define schizophrenia as the severe mental illness characterised by a broad spectrum of cognitive and emotional dysfunction. The phenomenon of schizophrenia was further explored in chapter 2 (subsection 2.2, 2.2.1, 2.2.2 and 2.2.3), whereby an overview of schizophrenia was discussed, focusing on the prevalence, causes, and the diagnostic symptoms of schizophrenia including: hallucination, delusion, disorganised thinking, gross disorganisation and negative symptoms (Khamker, 2012:133). The pharmacological and psychosocial treatment for schizophrenia were highlighted and it was indicated that a comprehensive and individualised treatment plan is beneficial to the mental health user and it should be incorporated in the acute, stabilisation and stable phase to attain the treatment goal

(APA, 2010:9; Khamker, 2012:133;). Due to the disabling nature of schizophrenia, the family members adopt the caregivers' role and the next objectives focus on the biopsychosocial experiences of those caregivers.

- **Objective 2:** To explore the biopsychosocial experiences of caregivers for persons living with schizophrenia

The researcher used the biopsychosocial approach to explore the experiences of caregivers of mental health users with schizophrenia in chapter 2, sub sections 2.5, 2.5.1, 2.5.2, 2.5.4 and 2.5.5. The concept of burden encountered by the caregivers was distinguished by several authors as objective and subjective burden. Several authors concur that as a result of caregiving burden, the quality of the caregiver's life is compromised and it affects their physical, psychological and emotional, social and economic well-being (Chan 2011:340; Manyaluoe et al., 2014:4; Marimbe et al., 2016; Lippi, 2015:2). The researcher further discussed the factors that contribute to the burden of care. Adeosun (2013:2) conducted a study in Nigeria where he identified various factors that contribute moderately to high levels of burden of care such as sociodemographic and clinical factors, although these may vary in different circumstances. Mental health users' symptoms, social support system, gender, unemployment, socioeconomic status, inadequate resources and inability to cope with demands of caregiving also define the extent of burden experienced by the caregivers (Kim et al., 2011:847; Adeosun, 2013:5). Stigma was also identified as a factor that affects the caregiver and Kadri et al. (2004:622) asserts that it affects the family giver by virtue of their association with the mentally ill person.

The researcher used the biopsychosocial approach to explore the caregiver's experiences and chapter 3 highlights the participants' experiences in caring for a person with schizophrenia.

In chapter 3, sub theme 2.1 on physical/biological harm and sub theme 2.2 on the mental health users disturbing behaviour; the participants narrated some of the physical and biological harm as well as the mental health users' disturbing behaviour which they experienced during psychotic episodes. One participant reported that she was physically assaulted by her son while the other participant noted that she was diagnosed with high blood pressure due to the stress of caregiving.

In the same chapter, sub theme 4.1 presented difficult, negative emotions and helplessness, sub theme 4.2 presented feelings of grief/loss and subtheme 4.3 presented overthinking, stress and worries; the participants reported about the psychological and emotional impact they

encountered. Some participants narrated that they experienced feelings of loss because they had “lost” people whom they considered as bread winners in the family. These findings were linked to a study by Mark (2013:59) whereby participants experienced grief, mourning and loss of a predictable future for themselves and their mental health users. There was also evidence of emotional and psychological impact; the participants described their experience with the mentally ill persons as a difficult feeling that is packed with negative emotions such as sadness, pain, heartache, grief, fear, worries and stress. Gater et al. (2014:3) also confirm from their study that the role of caregiving was overwhelming and it led to a psychological and emotional burden.

The participants also experienced social, financial and economic burden and their experiences were discussed in chapter 3, under sub theme 5.1 as rejection and conflict, sub theme 5.2 as lack of family support, sub theme 5.3 as lack of community based educational and support services, sub theme 5.4 as stigma, sub theme 6.1 as unemployment and sub theme 6.2 as poverty.

Interestingly, the researcher also noted some positive experiences from the participants’ responses and they are outlined in chapter 3, under sub theme 7.1 as acceptance towards caregiving role, sub theme 7.2 as caregivers’ support systems and lastly sub theme 7.3 as mental health users’ medication adherence and recovery. Similar positive experiences of caregiving were reported in a study conducted by Manyaluoe et al. (2014:4) where participants also stressed that they learnt to accept and live with their family member although they felt that they were incompetent.

All the above noted aspects were identified as the experiences of the caregivers of mental health users with schizophrenia in this study. As a result of caregiving, certain caregiving roles are adopted by family member; they were identified and these are discussed in the next objective.

- **Objective 3:** To ascertain the tasks and roles of caregivers in caring for a person living with schizophrenia

This objective was met in chapter 2, sub section 2.5.3 and also in chapter 3, sub theme 3, which discussed the roles and responsibilities of the caregivers. Family was regarded as an important unit that provides the most support and care to the person with schizophrenia and the primary caregiver’s role is usually taken by the spouses, parents and siblings (Aswini et al., 2016:7). Interestingly, in this study, the researcher discovered that an uncle and aunt were the primary

caregivers of persons with schizophrenia. In sub theme 3, participants identified their overall involvement in the treatment plan (which ranged from monitoring daily administering of medicine, support during hospitalisation, escorting the mental health user for follow up visits and referral to other hospitals), seeking for alternative traditional medicine and lastly providing daily functioning support to the mental health user (in terms of promoting personal hygiene, providing basic needs, emotional and financial support, instructing, supervising and managing their finances) as their roles and responsibilities towards their family member with schizophrenia. WFMH (2010:7) and Goldberg and Ricklers (2011:41) confirm similar roles and responsibilities of caregivers of persons with chronic conditions such as schizophrenia and they are highlighted in chapter 2, sub-section 2.5.3.

Objective 4: To explore the intervention and support provided to the caregivers of a person living with schizophrenia

This objective was met in chapter 2, sub section 2.7 where the required intervention and support for the caregivers was discussed. Lippi (2016:5) notes that a family psychoeducational programme and intervention was an evidence-based practice that proves to reduce relapse and facilitate recovery. If provided effectively, Thorning and Dixon (2016) attest that family psycho education can also lower the burden for caregivers and improve their functioning.

In chapter 2, sub-section 2.9, the role of social workers in assisting people experiencing mental disorders and their caregiver were discussed. In this study, the participants identified social work services in chapter 3 (sub theme 8.3) as a required support service to offer them strength through counselling, creating supportive programmes, and conducting home visit for continuous psycho-social support. In the same chapter, sub-section 7.2, the participants reported getting physical, emotional, financial and material support from their support systems consisting of other family members, neighbours, friends and police officers. Additionally, in sub-theme 8.1 and 8.2, the participants reported social grants for mental health users and material assistance as well as educational programmes as the supportive services they require as caregivers of persons with schizophrenia. Marimbe et al. (2016:5) confirm these findings as participants in that research also required training and financial support from the government and donors for them to lessen the burden of care.

Objective 5: To suggest strategies for social workers on intervening with caregivers of mental health care users with schizophrenia in the Nankudu district, Namibia

This objective was realised in chapter 1, sub section 1.3.2 where it was mentioned that the findings of this study would be used to make appropriate recommendations on intervention strategies that can be used by social workers when providing mental health services to the caregivers of mental health user with schizophrenia.

In chapter 2, sub section 2.9, the social worker's roles in supporting caregivers and mentally ill persons were discussed. The CSWC [SA] highlight that social workers can provide supportive interventions to the families through counselling services, crisis interventions during relapse, advocacy and linking them to services that can be responsive to their needs, engaging with communities to identify mental issues, and developing programmes based on the community's perspectives.

In chapter 3, sub-theme 8.3, the majority of the participants reported that they did not receive any social work interventions; therefore, they identified it as a required service. The recommendations on strategies to social work during their intervention with the caregivers are outlined in this chapter.

4.3 Key findings, conclusion and recommendations of the empirical study

This section presents the key findings, conclusions and recommendations according to each theme that emerged from the study in chapter 3 sub-section 3.8.2.

4.3.1 Theme 1: Caregivers perception of schizophrenia

This theme related to the participants' understanding of the mental condition of schizophrenia. The three sub themes that developed under the caregiver's perceptions or understanding were: Caregivers' understanding of schizophrenia, identified symptoms of schizophrenia, and medication.

- **Key findings**

All the participants were not acquainted with the term schizophrenia; however, they related to it as a condition that causes madness, affects the mind and makes a person to lose control or to be mindless and that it affects the behaviour of the person. The participants identified anger, confusion and aggression and other odd behaviours as displayed by their mental health users when they were describing their understanding of schizophrenia. The researcher was able to identify some of the clinical symptoms of schizophrenia in the participants' responses; symptoms such as hallucination, delusion and social withdrawal were highlighted. Identifying the symptoms of schizophrenia gave an impression that they had a fair understanding of the mental condition. One participant for instance mentioned that her family member with the mental condition always mentions that there were people coming to her and wanting to kill her; and

based on the clinical symptoms of schizophrenia this is delusion (paranoia). The majority of the participants did not know the medical terms of their family member's treatment and it might have been as a result of their level of education. Only one participant mentioned the medical term of the treatment given to their family members. The rest of the participants were only describing the treatment as either pills or injection and the effect it had on the mental health users.

- **Conclusions**

It can be concluded that although the participants were not acquainted with the medical term "schizophrenia", they had a fair perception of the mental condition and they were able to identify the symptoms of schizophrenia that were displayed by mental health users. In terms of mental health users' prescribed medication, the majority of the participants lacked insights because they did not know the medical term of the medicine that was prescribed to their mentally ill family member.

- **Recommendations**

There is a need to educate the caregivers of mental health users with schizophrenia on the causes, symptoms, signs of relapse and the treatment administered to their mentally ill family members in order to increase their perception of the mental condition and in return improve treatment outcomes.

The Ministry of Health and Social Services should establish and implement psycho educational programmes for the caregivers of mentally ill persons.

4.3.2 Theme 2: Physical implications

This theme focused on the physical implications that were encountered by the participants and the associated sub-themes which include: physical/biological harm and mental health users' disturbing behaviour.

- **Key findings**

The participants in the conducted study reported the experience of physical harm especially when their mental health users were having psychotic episodes. The majority of the participants narrated that they were physically assaulted by their mental health users, and one reported that she developed high blood pressure as a result of the psychological and emotional effect of caring for a person with a mental illness. Additionally, participants narrated that their mental health users had disturbing behaviour that resulted in aggressive behaviour towards other people, destroying and burning of property, and wondering around at night. It appeared that all the forms of disturbing behaviour contributed to the subjective and objective burden of care.

- **Conclusions**

It can be concluded that caregivers of MHCUs with schizophrenia experience physical assault especially when there is a psychotic episode; and they are likely to develop medical conditions such as high blood pressure due to the psychological and emotional burden. Furthermore, it can be concluded that the caregivers of persons with schizophrenia seem to encounter more burden due to the mental health user's disturbing behaviour that results in more physical harm towards other people and property.

- **Recommendation**

It is recommended that the caregivers of mental health users with schizophrenia should have a crisis response plan and liaise with the police officers to assist them when their mental health users become aggressive in order to avoid physical implications.

The caregivers should ensure the mental health users' adherence to medication in order to minimize the experiences of psychotic episodes.

The health professionals should hospitalise the mentally ill during the psychotic episodes until they are stable in order to prevent harm towards the caregivers and other society members.

4.3.3 Theme 3: Caregivers' roles and responsibilities

This theme concentrated on the roles and responsibilities that the participants adopted while caring for their family members with schizophrenia. The three sub-themes associated with the roles and responsibilities of the participants were: involvement in the treatment plan, seeking for alternative traditional medicine and other daily functioning support.

- **Key findings**

All the participants adopted various roles and responsibilities towards the care of their family members with schizophrenia. The participants narrated their overall involvement in the treatment plan and it ranged from daily administering of treatment, support during hospitalisation, escorting the mental health user for follow up visits and any referral to other hospitals. Some participants revealed that their role included seeking for alternative traditional medicine for their persons with schizophrenia. It seemed that they relied on both western and traditional medicine for the management of their family members with schizophrenia. Moreover, the participants provided daily functioning support to their mentally ill persons because they

could not function independently. The support ranged from: promoting the personal hygiene, providing basic needs such as food, soap and clothes, emotional and financial support, giving instructions, supervising movement and managing mental health users' finances.

- **Conclusion**

It can be concluded that caregivers of persons with schizophrenia adopt certain caregiving roles which range from treatment management to daily functioning support. Furthermore, caregivers rely on both western and alternative traditional medicine to manage their family member's mental illness.

- **Recommendation**

It is recommended that the caregivers of mental health users with schizophrenia should be recognised as treatment supporters and they should be included in the treatment plan from the point of diagnosis and throughout the treatment of the mental health users.

The Ministry of Health and Social Services should engage and collaborate with the traditional healers to ensure safe and effective management of the mental health users.

The social workers should provide psychosocial support to the caregivers of persons with schizophrenia to minimise the burden that results from their roles and responsibilities.

4.3.4 Theme 4: Psychological and emotional impact

This theme concentrated on the psychological and emotional challenges that the caregivers of persons with schizophrenia were encountering. The associated themes include: difficult, negative emotions and helplessness, feeling of loss/grief and overthinking, stress and worries.

- **Key findings**

All the participants experienced the psychological and emotional impact as a result of caregiving. They narrated that caring for a person with schizophrenia was a difficult and devastating role. The participants reported a range of negative emotions that they experienced such as sadness, fear, hurt, self-blame and pain. Furthermore, some participants expressed the feeling of helplessness. For example, one participant noted that he was still young, just like his brother who was mentally ill and he did not know what to do. It was also identified that stigma affected the psychological and emotional wellbeing of the participants. Some of the participants reported that they experienced the feeling of loss and grief after their family members were diagnosed with schizophrenia. One participant narrated that she felt like had she lost her son while the other one was experiencing grief because he had lost a brother who was the bread

winner in the family. Lastly, some participants narrated that they experienced difficulties in their role, and it triggered too many thoughts, stress and worries. One participant noted that she was constantly worried and stressed about leaving her mentally ill sister with the baby sitter because of the unpredictable psychotic episodes.

- **Conclusion**

It can be concluded that the role of caring for a person with schizophrenia is difficult and devastating; hence, the participants experience a lot of psychological and emotional impact. Furthermore, it can be concluded that the caregivers experience sadness, pain/hurt, self-blame, stress, worries, fear, grief and helplessness due to their circumstances with their mentally ill family members. Lastly, factors such as stigma can also contribute to caregivers' psychological and emotional harm.

- **Recommendation**

It is recommended that social workers and psychologists should provide counselling services to the caregivers of mentally ill persons to help them deal with their psychological issues.

Social workers should create and facilitate support groups for caregivers of persons with schizophrenia to encourage them as well as link them to other caregivers with similar experiences and also as a way for more external support.

It is also recommended that caregivers of persons with schizophrenia should also seek for counselling services when the need arises in order to help them deal with the psychological and emotional burden of care.

4.3.5 Theme 5: Social implications

This theme concentrated on the social implications that the participants encountered when providing care to persons with schizophrenia. The sub themes were rejection and conflict, lack of family support, lack of community based educational and support services and stigma.

- **Key findings**

The participants reported that they were subjected to social implications and it was mostly due to their mental health users' behaviour during psychotic episodes. Some participants noted that they experienced rejection and conflict with the other community members. One participant reflected on an incident where she was confronted by a community member because of her mentally ill family member who was beating up their children. As a result of rejection and conflict, social relationships with other community members were affected. Four out of ten

participants stated the lack of family support which contributed to poor social networks. Participants also reported lack of community based educational and support services, only two participants in this study were exposed to community-based education and support services. Lastly, the participants experienced stigma from the community members which ranged from blaming, mockery and labelling.

- **Conclusion**

It can be concluded that participants encounter various social implications because they are associated with a person suffering from schizophrenia. Due to the impact on social relationships, it can be concluded that social relationships also get affected. It can be concluded that the lack of community based educational and support services, as well as lack of family support can result in poor social support systems which result in burden of care. Additionally, the participants experience stigma in the community and it results into psychological and emotional impact.

- **Recommendation**

There is a need for social workers to conduct community-based awareness campaigns to sensitize the community members on issues pertaining to mental illness such as stigma and other educative programmes that can enhance their knowledge and in return strengthen the support system for the caregivers.

The Ministry of Health and Social Services should integrate PHC programmes through community health assistants so that they can provide continuous support to the mental health users and their caregivers.

4.3.6 Theme 6: Financial and economic burden

The focus of the theme was on the financial and economic burden experienced by the caregivers of persons with schizophrenia and the associated sub-themes were: unemployment and poverty.

- **Key findings**

The majority of the participants were unemployed and those that were having a different employment status did not have a reliable and sufficient income; therefore, all the participants experienced some sort of financial and economic burden. One participant reported that she was

a business woman; however, she still maintained that she was unemployed and needed assistance with her relative with schizophrenia. Furthermore, participants narrated that they were living in poverty and it appeared that they had a poor socio-economic status due to unemployment. The participants reported that they struggled to get money and food for their mental health users. Poverty restricted the participants from fulfilling their roles in the care of their persons with schizophrenia. One participant narrated that her son was eating four times a day and she did not have enough food. Another participant narrated that he was not able to pay for the ambulance to take his relative with schizophrenia to the hospital. Such disclosure confirms that the participants were experiencing financial and economic burdens.

- **Conclusion**

It can be concluded that caregivers of persons with schizophrenia experience financial and economic burdens due to unemployment and poverty. Furthermore, it can be concluded that when caregiving for a person with schizophrenia is coupled with poverty and unemployment, the caregivers experience more financial and economic burdens and they cannot fulfil their roles and responsibilities towards their family members with mental illness. For instance, they cannot meet the basic needs of mental health users such as providing them with food and paying for ambulance fees.

- **Recommendation**

It is recommended that all the persons diagnosed with schizophrenia are registered for disability social grants in order to relieve their caregiver with the financial and economic burden.

The social workers should assist the needy caregivers of persons with schizophrenia with the registration process for social grants.

The social workers should link caregivers to ministries and organisations such as the Constituency Counsellor's offices that provide material and food aid to the disadvantaged people.

4.3.7 Theme 7: Positive experiences

The theme focused on areas that seemed as positive experiences for the caregivers. The sub-themes that were apparent include acceptance towards caregiving, the caregiver's support system and the mental health users medication adherence and recovery.

- **Key findings**

The majority of the participants narrated that they accepted their caregiving responsibilities and it appeared that for some, they did not have a choice but to accept it; while for the others, they believed that it was God's will. Based on their responses, it appeared that acceptance and entrusting their situation to God was their coping mechanism. The participants further reported good support systems from other family members, friends, neighbours and police officers. Although the researcher did not come across literature supporting police officers as the caregiver's support system, participants in this study identified them as their support system. The participants narrated that their support system provided them with physical, emotional and psychological, financial and material assistance. The police officers for instance were assisting the participants to take the persons with schizophrenia to the hospital, especially when they had a psychotic episode. Additionally, the majority of the participants reported that their mental health users were adhering to their treatment plan and they were responding well to treatment. One participant indicated that his mentally ill relative seemed like a person [normal] to him and they were having relevant conversations.

- **Conclusion**

It can be concluded that in as much as the participants experienced the burden of care, there were other experiences that were positive. It can also be concluded that other family members, friends, neighbours and police officers can be a support system that can lessen the burden of care for the caregivers of persons with schizophrenia. Lastly, the mental health user's medication adherence can yield positive results that can improve their functioning hence lessening the burden for the caregivers.

- **Recommendation**

The social worker should work from a biopsychosocial approach to ensure that the participants' support system is strengthened because that can be a protective factor in relieving the participants from the burden of care.

Police officers play a significant role in terms of handling a person with schizophrenia during their relapse; therefore, the caregivers of relatives with schizophrenia should devise an emergency response plan that involves police intervention in order to avoid physical harm.

Social workers provide support to the caregivers and emphasize the need for their involvement in the relative's treatment plan as it can result in reduced psychotic episodes and effective functioning of the mental health user thus limiting the caregiver's burden of care.

Social workers should provide counselling and support to the caregivers of persons with schizophrenia from the point of diagnosis, and throughout the treatment circle to help caregivers cope and accept their caregiving role.

4.3.8 Theme 8: Supportive services required by the caregivers

This theme focused on the supportive services that the caregivers of persons with schizophrenia identified. The associated sub-themes were: social grants for mental health users and material support, educational programmes and social work services.

- **Key findings**

As a result of unemployment and poor socioeconomic status, some participants narrated that their MHCUs should be registered for disability social grants in order for them to get money that can cater for their needs such as food, bathing soap and clothes. Furthermore, the majority of the participants noted that they needed educational programmes for them to better the handling and caring of the persons with schizophrenia. If applied effectively, it can improve the lives of the caregivers and their MHCUs. Lastly, participants narrated the lack of social work interventions; therefore, they cited the need for social work services to give them strengths through counselling, conducting home visits, and providing support and education.

- **Conclusion**

It can be concluded that there is lack of mental health services at the community level; hence, caregivers of mental health users with schizophrenia require financial and material support, education programmes and social work interventions in order to minimise the burden of care. The financial and material support could relieve the participants' financial and economic burden. Additionally, the educational programmes could also increase the participants' perceptions of schizophrenia in terms of the causes, symptoms, treatment and how to handle the person with schizophrenia and in return it can address the physical and biological aspects of caregiving. Lastly, the social work services could address the highlighted biopsychosocial experiences of caregivers such as social implications, stigma, financial and economic burden, psychological and emotional impact.

- **Recommendation**

The Ministry of Health and Social Services should establish educational programmes that can improve the caregivers' perception about schizophrenia. All persons diagnosed with schizophrenia should be registered for a disability grant.

The Ministry of Health and Services should employ social workers at district hospitals in order for them to provide psychosocial support to address the biopsychosocial experiences of the caregivers of mental health users with schizophrenia.

The Ministry of Health and Social Services should also incorporate mental health services in the PHC programmes in order to render support to the caregivers and their mental health users in the communities.

4.4 Future research

Future research can focus on exploring the caregivers of mental health users with schizophrenia in urban areas to compare the findings with this study that was conducted in rural areas. Furthermore, the study can be conducted in various cultural settings to minimise cultural bias and to get different perspectives of caregivers of people with mental illness in other ethnic groups. Additionally, future researchers can further explore the experiences of children living with parents with chronic mental health illnesses like schizophrenia.

4.5 Summary

This chapter firstly presented the goals and objectives of the study. Furthermore, the individual objectives were discussed in-depth to understand how they were realised and met throughout the study, in order to answer the research question. Secondly, the findings, conclusions and recommendations of the study were presented by looking at the themes that emerged in chapter 3. Lastly, guidance for future researcher was also presented.

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Research Ethics Committee

APPENDICES

Appendix A: Ethical clearance

13 June 2019

Dear Ms VL Mudumbi

Project Title: The experiences amongst caregiver of mental health users with schizophrenia in the Nankudu District, Namibia.

Researcher: Ms VL Mudumbi

Supervisor: Dr NJ Bila

Department: Social Work and Criminology

Reference number: 17276919 (HUM005/0319)

Degree: Masters

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 13 June 2019. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely



Prof Maxi Schoeman

Deputy Dean: Postgraduate and Research Ethics

Faculty of Humanities

UNIVERSITY OF PRETORIA

e-mail: PGHumanities@up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomo

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Mr A Bizos; Dr L Blokland; Dr K Booyens; Dr A-M de Beer; Ms A dos Santos; Dr R Fasselt; Ms KT Govinder; Andrew; Dr E Johnson; Dr W Kelleher; Mr A Mohamed; Dr C Puttergill; Dr D Reyburn; Dr M Soer; Prof E Taliard; Prof V Thebe; Ms B Tsebe; Ms D Mokalao

Appendix B: Permission from the organization



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: 061 - 203 2562
Fax: 061 - 222558
E-mail: hnangombe@mhss.gov.na

OFFICE OF THE EXECUTIVE DIRECTOR

Ref: 17/3/3 VM
Enquiries: Dr. H. Nangombe

Date: 27 May 2019

Ms. Veronika Mudumbi
PO Box 2318
Rundu

Dear Ms. Mudumbi

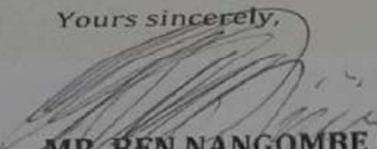
Re: The experiences amongst caregivers of mental health care users with Schizophrenia in the Nankudu District, Namibia

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
 - 3.1 The data to be collected must only be used for academic purpose;
 - 3.2 No other data should be collected other than the data stated in the proposal;
 - 3.3 *Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;*

BNL

- 3.4 A quarterly report to be submitted to the Ministry's Research Unit;
- 3.5 Preliminary findings to be submitted upon completion of the study;
- 3.6 Final report to be submitted upon completion of the study;
- 3.7 Separate permission should be sought from the Ministry for the publication of the findings.
4. All the cost implications that will result from this study will be the responsibility of the applicant and **not** of the MoHSS.

Yours sincerely,


MR. BEN NANGOMBE
EXECUTIVE DIRECTOR



Appendix C: Interview Schedule

Interview schedule

1. Biographic information

1.1 Biographic information (Caregiver)

Age :
Gender :
Marital status :
Number of children :
Religion :
Home language :
Highest qualification :

1.2 Biographic information (mental health user)

Age :
Gender :
Marital status :
Number of children :
Religion :
Home language :
Highest qualification :

2. Knowledge of mental health condition (schizophrenia)

- What do you understand by schizophrenia?
- First place visited for assistance for condition?
- Involvement in treatment plan and understanding of treatment?
- Does family member always take treatment?

3. Mental health and the family

- Tell me about your family member who is living with schizophrenia.
- When and how did you find out that your family member had schizophrenia?
- Can you tell me about your experiences within the family home, living with a person with schizophrenia?
- How was person prior to diagnosis?

4. Caregiver burden and coping

- What are your feelings about caring for a person with schizophrenia?
- What impact has caring for your family member had on the different areas of your life?
- Describe your daily role as caregiver.
- Family support to you as caregiver?
- What do you do to cope with your role as caregiver?

5. Stigma

- How do you think the community views persons with mental health condition such as schizophrenia?
- How do people treat you and your family member in your community?
- How does this make you feel?

6. Services

- What resources and services are there in community for psychiatric treatment or care?

- What services are there in your community that provide support and care for people living with schizophrenia?
- What services are there in your community that provides support and education to caregivers?
- How do you get to these services?

7. Social work intervention

- Any interaction with/referral to a social worker regarding the person living with schizophrenia?
- What kind of assistance did they give?
- Your experience of their intervention?

8. Recommendations

- Do you have any recommendations for programmes for caregivers in your community?

Appendix D: Informed consent



Date: 05/03/2019

Name: Veronika Mudumbi

Email: veronicalisha@gmail.com

Cell phone No: +264 81 855 0838

Dear Participants

INFORMED CONSENT FORM FOR CAREGIVERS OF MENTAL HEALTH CARE USERS WITH SCHIZOPHRENIA

Research Information

This letter serves to invite you to participate in a study on the experiences amongst caregivers of mental health care users with schizophrenia in the Nankudu District, Namibia. The informed consent gives a brief explanation of the purpose and procedure of the research and the rights of participation. Please go through the form before you make an informed decision regarding your participation.

Title of the study

The experiences amongst caregivers of mental health care users with schizophrenia in the Nankudu District, Namibia.

Purpose of the study

The purpose of the study is to explore the experiences amongst caregivers of mental health care users with schizophrenia the Nankudu District, Namibia.

Procedures

You have been informed of the study and provided your contact details for researcher to contact you to partake in the study. The researcher will be responsible for conducting a face to face interview in order to collect data on your experiences as the caregiver of a person living with schizophrenia. Once you sign this letter, you agree to take part in the study. The researcher will arrange to conduct an individual interview with you when it suits you best. The interview will be recorded, with your permission, to ensure that all the information you are sharing is captured for research purposes. A semi-structured interview schedule will be used during the interview to guide the interviewing process. Please note that the recording will only be used for the purpose of data analysis of the research and will be kept confidential. Lastly, the interview might take longer than 60 minutes depending on your responds to questions that will be asked.

Risks and discomforts

Please note that the researcher does not intend to put you or the mental health care user under any risk or discomfort with the information you will share. There is a possibility of emotional harm related to the sharing and exploration of your experiences of caring for a person with schizophrenia. The researcher will debrief you after the interview is concluded and should you experience a need for counselling, you will be referred to a professional counsellor for intervention. You are free not to answer any question that will make you feel uncomfortable during the interview.

Benefits

You will not receive any form of remuneration/ compensation/ incentives for participating in the study. The study is however about improving mental health services and lessening the burden of care for the caregivers of mental health care users, by formulating intervention strategies aimed at aiding caregivers in their caring role. The findings of this study can also help professionals to better understand the experiences of caregivers.

Participants' rights

Your participation in the study is entirely voluntary and you may withdraw from participation at any time and without negative consequences to you or your family members. Should you wish to withdraw from the study, all data gathered in respect of your interview will be destroyed.

Confidentiality

The information shared during the interview will be kept confidential and will be used for the purpose of the study only. The researcher will also not identify you by name during the report, using only pseudonyms to protect your identity. The only people who will have access to the data, will be the researcher and the supervisor.

Data usage and storage

Please note that the data collected might be used in the future for further research purposes, a journal publication or conference paper. The data collected will be stored in the Department of Social Work and Criminology, University of Pretoria for the period of 15 years as required.

Access to the researcher

You may contact the researcher using the contact details provided above for the duration of the study, should you want to access your data, or there be any questions or uncertainties regarding the study and your participation. It must be clearly stated, that the role of the researcher is to do research and not to provide counseling or therapeutic services.

Please ask any questions about the proposed research before signing the following section on the next page if you agree to participate voluntarily in the study.

Yours sincerely,

.....

Researcher

SECTION B: INFORMED CONSENT OF PARTICIPANT

I (*Full Name of participant*) declare that I have read and understood the above information. I was given adequate time to consider my participation in the study. I was also given the opportunity to ask questions and all of them were answered to my satisfaction. I hereby give consent to participate voluntarily in this study.

Participant: -----

Date: -----

Signature: -----

I.....hereby declare that I have explained the information in Section A: Research Information to the participant and he/she indicated understanding the contents and was satisfied with the answers to questions asked.

Researcher: -----

Date: -----

Signature: -----

Appendix E: Confirmation letter from editor

ACET Consultancy
Anenyasha Communication, Editing and Training
Box 50453 Bachbrecht, Windhoek, Namibia
Cell: +264814218613
Email: mlambons@yahoo.co.uk / nelsonmlambo@icloud.com

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To whom it may concern

LANGUAGE EDITING – VERONIKA MUDUMBI

This letter serves to confirm that a Masters of Social Work in Health Care thesis entitled *The experiences amongst caregivers of mental health users with schizophrenia in the Nankudu district, Namibia* by Veronika Mudumbi was submitted to me for language editing.

The thesis was professionally edited and track changes and suggestions were made in the document. The research content or the author's intentions were not altered during the editing process and the author has the authority to accept or reject my suggestions.

Yours faithfully



DR NELSON MLAMBO
PhD in English
M.A. in Intercultural Communication
M.A. in English
B. A. Special Honours in English – First class
B. A. English & Linguistics

