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THE EXPERIENCES OF CAREGIVERS OF MENTAL HEALTH CARE USERS WITH SCHIZOPHRENIA IN UPINGTON, NORTHERN CAPE

A mini-dissertation

by

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Submitted in partial fulfilment of the requirements for the degree

MASTER OF SOCIAL WORK
in
HEALTH CARE

in the
Department of Social Work and Criminology
FACULTY OF HUMANITIES

UNIVERSITY OF PRETORIA

Supervisor: Dr. C.L Carbonatto

NOVEMBER 2019

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ACKNOWLEDGEMENTS

- First of all, I would like to thank God for blessing me with the opportunity to pursue my studies in this field of Social work health care and for guiding me and giving me the strength to take on and complete this task.
- I would like to thank my partner, Elreeve Titus, for all his love and support throughout this process. Thank you for listening. Thank you for encouraging and motivating me to stay strong and overcome the challenges I experienced during the course of my studies. Thank you for believing in me when at times I didn’t believe in myself and for always being there to help me when I needed it. Your belief in me strengthened and motivated me to see this through. Thank you. I love you.
- To my supervisor, Dr C.L Carbonatto. This has been quite a journey. Thank you for everything that you have taught me over the course of this degree. Thank you for your support and direction throughout my year of coursework and research. I have learned so much. Your guidance and support have gotten me to where I am today. I am eternally grateful. Thank you.
- To my parents, Ebdy and Sophia Selborne, thank you for your encouragement and belief in me. Thank you for always supporting me in everything I do and for granting me the opportunity to graduate with a BSW degree. I would not be where I am today if it was not for everything that you have taught me. I love you very much. Thank you.
- To my cousin and best friend Ingrid, thank you for all the messages and words of encouragement. Your support has greatly contributed to my accomplishment. To my friends, Rushni, Jonine - thank you for always asking how I am doing and sending me messages of support. It meant so much. To everyone who encouraged me to stay strong and wished me well in my endeavour to finish this degree. Thank you.
- Thank you to all the participants in the Upington community who took part in this research study. Without you, none of this would have been possible! Also thank you to all the clinics who participated and the nurses who took time out of their busy schedules to assist me. Your efforts are greatly appreciated. I wish you the best of luck and thank you for the services you provide to our community.

- Last but certainly not least. Thank you to my classmates, Veronika, Malebane, Lee-Ann and Fanuel. We have supported each other throughout this process. We have shared challenges and encouraged one another to keep moving forward and succeed. We have made it! Thank you so much!

ABSTRACT

THE EXPERIENCES OF CAREGIVERS OF MENTAL HEALTH CARE USERS WITH SCHIZOPHRENIA IN UPINGTON, NORTHERN CAPE

CANDIDATE:	**SHARIKA RAYLENE VERONIQUE SELBORNE**
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DEGREE:	**MSW (HEALTH CARE)**

The process of deinstitutionalization in South Africa after 1994 have resulted in mental health services being decentralized to community level in an effort to integrate psychiatric care into primary health care services at community level, thus moving away from institutionalised and pharmacological treatment alone, to include environmental resources such as community-based clinics and hospitals as care providers for mental illness such as schizophrenia, which is at the centre of this study. Primary health care services alone were not affected by this shift, but the families of psychiatric patients, as well as the families were required to assume responsibility of care for psychiatric patients. A major concern with regards to deinstitutionalisation was the preparedness of families to resume this responsibility of care.

Public health care in South Africa is characterised by a great divide between public –and private health care services with the minority of the country being served by the majority of health care professionals employed in the private health care system, thus contributing to disparities in health care and contributing to a lack of specialised human resources in the public health care system. Challenges such as lack of public awareness on mental health; stigma against mental health care users and families, and inequity between the provinces in the country with regards to the distribution of resources and services amongst others, are external factors contributing to the functioning of the family system and the burden experienced by those caring for family members diagnosed with mental illness. In addition to these environmental factors, families are also affected by mental illness as they have to adapt, learn new skills and coping mechanisms to deal with schizophrenia and care for their family member.

The aim of the study was to explore the experiences of the caregivers of mental health care users with schizophrenia in the town of Upington in the Northern Cape. Research was qualitative in nature with a sample of eight participants – all of whom were responsible for caring for family members diagnosed with schizophrenia – drawn from different primary health care clinics in Upington.

The findings of the study indicate that caregivers are experiencing challenges mainly related to factors external to the family system. These challenges cannot be attributed to a single factor, but to different environmental factors related to treatment, availability of support services and lack of awareness amongst others. The experiences of the caregivers with regards to their role are influenced more by external factors as previously mentioned, than by the patients they care for and their behaviour.

The study concludes that caregivers are influenced and affected by different systems within their environment in which they function. It is also concluded that there is a lack of basic support, education and training services aimed at creating awareness on schizophrenia and developing caregiver skills to cope with the role of caregiver. The recommendation is made that community-based mental health care services are implemented to provide support to families living with mental illness, that community awareness is raised on schizophrenia to enable caregivers to cope in a more effective manner, resulting in improvement of family functioning and reducing caregiver burden.

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1. CHAPTER 1: GENERAL INTRODUCTION AND STUDY BACKGROUND

1.1 Introduction

Schizophrenia is a worldwide phenomenon affecting approximately 1% of the population (World Health Organisation, 2017). According to the South African Depression and Anxiety Group [sa], many people can maintain a healthy and productive lifestyle should they receive treatment. Statistics by the South African Depression and Anxiety Group [sa] on schizophrenia outcomes, indicate that 25% of people diagnosed with schizophrenia (after 10 years of treatment) are much improved and able to live independently. These statistics, however, also indicate that 25% (after 10 years of treatment) have improved conditions, but still require constant support.

In the late 1950s, with the development of psychotropic medications, a phenomena namely deinstitutionalisation started taking place in the United States of America. The latter resulted in psychiatric patients being moved out of State Psychiatric facilities and into community-based care structures. This shift in mental health care had implications requiring community clinics and hospitals to provide primary psychiatric treatment to patients suffering from mental illness (Allen & Spitzer, 2016:358). The shift to out-patient treatment can be assumed to have an effect on the family of the individual suffering from mental illness. The family play a crucial supporting role with regards to mental illness, as they are often the main source of support upon whom the individual can rely on for consistent and long-term support (Allen & Spitzer, 2016:119). Given the complexity of schizophrenic disorder and the presence of cognitive and behavioural symptoms of schizophrenia, the family can be adversely affected by the burden of caring for the individual suffering from schizophrenia. With regards to the latter, questions arise on how the family is equipped to deal with the individual suffering from mental illness, specifically schizophrenia and how taking care of an individual suffering from schizophrenia affects the family holistically. In South Africa, the new democratic government after 1994 emphasised national health care with a shift to universal primary health care. Consequently, mental health care service provision shifted from institutionalisation to decentralisation of mental health care services at district level (Petersen, Bhana, Campbell-Hall, Mjadu, Lund, Kleintjies, Hosegood & Flisher, 2009:140). With this shift in health care, the family caregivers became the primary source of care for the mentally ill patient receiving out-patient treatment. In the research study, the researcher plans to explore the psycho-social experiences, challenges and needs of caregivers, focused on their caring role, to gain a better understanding of the caregiver's experience. This, in turn, can be used to recommend future studies for the development and implementation of programmes to assist the family caregiver in preventing caregiver burden. The study will also focus on exploring and describing the experiences of caregivers of mental health care users with schizophrenia, whilst also exploring the influence of caregiving on the biopsychosocial functioning of the caregiver within the family systems, as well as looking at how the caregiver is influenced by different systems and subsystems within their environment.

1.2 Definition of the key concepts

1.2.1 Experience

Experience is a word that describes the knowledge or skills that are gained by means of practically doing something for a period of time, thus gaining experience of that to which the person was exposed to or practically took part in (*English Oxford Living Dictionary*, 2017). In this study, experience refers to the knowledge and skills that the caregivers of persons with schizophrenia have gained, by practically providing physical and/or emotional care to persons living with schizophrenia over a period of time (*English Oxford Living Dictionary*, 2017).

1.2.2 Caregiver

A caregiver is a person who provides direct care (physical, emotional and/or financial) to another person who is, for example, not able to function independently (*Merriam-Webster Dictionary*, 2017). For the purpose of this study, caregiver refers to a person – family member or non-related person – who provides care (whether physical and/or emotional care) to another person with schizophrenia, for example, where said person may not be able to function independently (*Merriam-Webster Dictionary, 2017).*

1.2.3 Mental illness

The word mental illness refers to a range of disorders that have an effect on a person's mood, behaviour and thinking. It not only affects the individual's cognitive functioning and behaviour, but is also associated with psychological distress and interference with aspects of daily living (Harris & White, 2013:100; Mayo Clinic, 2015). In this study, mental illness refers to a severe mental disorder namely schizophrenia. The latter not only affects a person's mood, behaviour and thinking, but is also associated with psychological distress and behaviour that interferes with aspects of daily living related to functioning.

1.2.4 Mental health care user

A mental health care user refers to "…a person receiving care, treatment and rehabilitation services or using health service at a health establishment, aimed at enhancing the mental health status of a user…and in certain circumstances may include: (i) prospective user; (ii) the person's next of kin…" (Mental Health Care Act 17 of 2002). In the context of this study, mental health care user refers to a person with schizophrenia, who receives either care, treatment and/or rehabilitation services at a health establishment specialising in mental health services or aimed at providing health care services to enhance the mental health status of the said person.

1.2.5 Schizophrenia

"Schizophrenia is a severe mental disorder, characterised by profound disruptions in thinking affecting language, perception, and the sense of self. It often includes psychotic experiences, such as hearing voices or delusions" (WHO, 2017). For the purpose of this study, schizophrenia refers to a severe mental disorder that is characterised by profound disruptions in thinking that affects not only the persons cognitive functioning, but also their behaviour and thus their daily functioning. Schizophrenia is a mental illness that impacts different spheres of the individual's life and functioning, as well as that of their caregivers. The following section will focus on the motivation for the study and research methodology used in the study.

1.3 Motivation for the study

The need for the intended study arose from the observation of caregiver burden in caring for family members suffering from mental illness in Upington, where the researcher practised as a social worker. The designated research area – Upington – is characterised by a lack of services and resources focussing specifically on mental health care. The researcher's interest in the topic of the study is thus related to practice. Working in an NGO, delivering community-based services to substance abusers, the researcher came into contact with some clients with a dual diagnosis of substance abuse and mental illness. It was observed that many family members do not understand the client's behaviour and find it difficult to effectively communicate with the client and handle the demands associated with the role of caregiver, especially because this role is associated with enormous tasks, as the patient may require long-term support and care, which can place a burden on the caregiver (Adeosum, 2013:1). The researcher realised that there was a gap in the education of caregivers on what mental illness is and what caring for a person with a mental illness entails. This prompted the researcher to investigate the experiences of the caregivers with the aim of creating awareness on caregiver burden and challenges, so that her research may be used to influence future research on intervention strategies and programmes.

1.4 Theoretical framework

The theoretical framework were selected according to the topics identified by the researcher and through a literature study on the experiences of caregivers of persons with schizophrenia, the caregiving burden and expressed emotions (Maree, 2016:32). The general systems theory and the biopsychosocial approach was selected, as the research study intends to explore the experiences of the caregiver related to their psychosocial functioning within different systems in their environment, taking a look at different factors that may influence wellbeing, for example, psychological, emotional and social factors.

1.4.1 The Biopsychosocial approach

George Engel formulated the biopsychosocial model as a "dynamic, interactional, but dualistic view of human experience in which there is mutual influence of mind and body" - thus aiming to understand the patient and identifying the patient's needs on different levels other than only in the medical domain (Borrel-Carrió, Suchman & Epstein, 2004:581). The biopsychosocial approach consists of three components, that is, biological, psychological and social components and the approach considers how these components interact with one another in understanding the experiences of the caregiver in relation to biological, psychological and social factors relating to schizophrenia (The Biopsychosocial Approach, [sa]). The model was the beginning of a movement away from the Biomedical model and towards the integration of psychosocial elements into the treatment and view of illness or disease (Smith, 2002:309). George Engel did not agree with the medical model and argued that medicine was in a crisis stemming from adherence to a medical model of disease that was in his opinion, inappropriate for the scientific tasks and social responsibilities of both medicine and psychiatry (Engel, 1977:129). Genetics play some role in the aetiology of schizophrenia, but sociological factors that may contribute to the development of the illness or continuity of the characteristic symptoms of schizophrenia cannot be ignored (Borrel-Carrió et al., 2004:578). Engel believed that clinicians had to take a broader look at the patient – taking different factors into account and that they should not only focus on the biological symptoms. He was of the belief that clinicians needed to understand the patient's experience of suffering and that they needed to provide adequate care which he believed could only be done by attending to three dimensions of illness namely: the biological, psychological and social (Borrel-Carrió et al., 2004:576). Biological, psychosocial and social factors have an influence on illness and interact with each other on a constant basis, making up the state of the patient which is referred to as illness (Dogar, 2007:1). The premise of the biopsychosocial model is that the patient, their illness and/or condition cannot be viewed in isolation (Ghaemi, 2009:1). Other factors need to be taken into account, for example, psychosocial factors which refer to aspects related to the patient's personal life, family, emotions and influences by their community (Smith, 2002:309). This means that one cannot simply focus on the illness or condition of the person which might be presented by visible symptoms, but that one also needs to take a more holistic view at the patient, their environment and focus on aspects within that environment that not only affects them biologically but also psychologically and socially. This is why the researcher chose this approach, as not only the visible symptoms experienced by the caregivers want to be explored, for example, the biological/physical symptoms as reported by the caregivers, but also their experiences related to their psychological functioning, their functioning within their social environment and their social interaction with others.

The biopsychosocial approach can be used to understand how a mental illness such as schizophrenia affects the caregiver's subjective experience of the illness while caring for the person suffering from schizophrenia and how these experiences can contribute to health outcomes and humane care (Borrel-Carrió et al., 2004:576). It was developed in response to the Biomedical model and has a broader and more inclusive focus on the patient and the illness, taking on an integrated approach in order to understand illness and the impact of biological, psychological and social factors and the disease itself; management of the disease and care of the patient; the cause of illness and in general, the prevention of disease or illness. This approach can be used to look at and understand how physical, psychological and social factors within the caregiver's environment influence each other (Cowles, 2000:12), thus giving the researcher a clearer understanding with regards to caring for a person with schizophrenia and also giving the researcher insight into the caregiver's functioning within these three areas and how their functioning is affected by the caregiving role.

Taking into account the subject of experiences of caregivers, the biopsychosocial approach outlines the caregivers' biological state (the effect of caring on the biological wellbeing of the caregiver); psychological well-being (emotional wellbeing and mental wellbeing, referring to the impact of the caregiving function on the psychological functioning and wellbeing of the caregiver); and the social component, which focuses on the social aspects related to the functioning of the caregiver (social interaction with people outside of the home, social activities and so forth and how these three components interact with one another) (Gilbert, 1994:137).

The researcher thus chose to use the biopsychosocial approach, as this model aims to give a holistic view of the caregiver, because other than the medical model, it seeks to look at the person as a whole, taking into account psychological factors, as well as social factors while looking at the person in their environment and the effect that the biological aspect (in this case, the physical effects of caring) has on the health of the caregiver (Cowles, 2000:12).

1.4.2 The General Systems Theory

The systems theory is focused on the person in their environment, influenced by different systems in that same environment, which has an effect on the individual as a whole. According to the systems theory, a system is made up of different parts that interact with each other; each of these parts having its own purpose. Systems may be either individual elements or subsystems of other systems. The premise of the systems theory is that each system contains elements that influence each other. Systems do not operate individually or on their own, but rather in an enveloping environment. Due to the manner in which systems operate within their environment, they affect their environment and vice versa (Nash, Munford & O'Donoghue, 2005:52, 53 & 59), for example, the manner in which the family member diagnosed with schizophrenia functions, affects the family system and vice versa.

A system thus consists of different parts that are connected to and relate to each other. Different parts of a system interact with one another resulting in changes in one part of a system affecting change in another part. The latter thus referring to interconnectedness between systems (Visser, 2009:23). Therefore, in order for the researcher to understand one part of a system, for example, the caregiver and their experiences, the researcher needs to look at this specific part of the system in context of the whole system (thus not excluding other parts), for example, looking at experiences of the caregiver in relation to the caregiving role and functions, as well as the behaviour of the person with schizophrenia, family support and functioning within the community.

A system also consists of boundaries that are responsible for differentiating one part of a system from the other. A system can be either open or closed. The system, with regards to the research study, may be an open system as there may be continuous interaction between different parts of the system, for example, interaction between the caregiver and patient; the family system and the community referring the clinic or hospital where treatment and services are provided. Change in one part of this system can affect change in another, for example, lack of education resources to help the caregiver cope with the role of caring and understanding the diagnosis can result in the deterioration of the relationship between the caregiver and patient or a lack of proper care or caregiver burden (Visser, 2009:24).

The biopsychosocial approach was derived from the systems theory, in the sense that it takes on a holistic approach to understanding the person in their environment, looking at different factors, namely the biological, the psychological and the social that influences behaviour. Thus the relationship between the different parts of the caregiver's system ultimately affects health, behaviour, emotional wellbeing and coping mechanisms of the caregiver in relation to the family member with schizophrenia for whom they are caring, the role of caregiving, community resources and even external family systems.

1.5 Rationale and problem statement

Statistics on mental health services in South Africa indicates that a small proportion of doctors and nurses are trained in mental health and also identify the lack of medical and allied healthcare workers in the country, working in mental health facilities (WHO, 2007:5-6). Based on the latter, it can be concluded that there is a gap in service delivery and support to family and non-familial caregivers. Due to this need identified, it can be deduced that the caregiver is not properly educated and this, in turn, can be a contributing factor to not only the mental well-being of the patient, but also to the biological and psychological well-being of the caregiver.

The researcher's interest in the topic of the study is related to practice. The need for the study arose from the observation of caregiver burden in families with members suffering from mental illness in Upington, where the researcher practised as a social worker. In this municipal area, there are currently no designated mental health care structures or facilities specialising in mental illness, no psychiatrists, or NGO's specialising in mental health care that can provide specialised care to the patient, nor educate the family or caregiver on the process of caring for the patient. There is a need for service delivery and support to family and non-familial caregivers in this region.

Working in an NGO, delivering community-based services to substance abusers, the researcher came into contact with and provided interventions to service users with actual diagnosis with mental illness as well as substance abuse. It was observed that many family members do not understand the family member's behaviour and find it difficult to effectively communicate with them and handle the demands associated with the role of the caregiver, especially because this role is associated with enormous tasks, as the patient may require long-term support and care, which can place a burden on the caregiver (Adeosum, 2013:1). The researcher realised that there was a need for education of caregivers on what mental illness is and what caring for a person with a mental illness entails. Stigmatisation and lack of education posed contributing factors to the caregiving burden experienced by family members, as well as a lack of mental health care services in the area of the study. The latter contributed to the choice of research topic, as the researcher concluded that in order to provide efficient care to the patient with the aim of contributing to their mental wellbeing, it is necessary to understand the experiences of the caregiver and how caring for a person with schizophrenia can influence the wellbeing of the caregiver. The latter can be built on by the development of future programmes and strategies to equip families or private caregivers with the necessary skills to take care of a person with schizophrenia.

The research question for the study is: what are the experiences of caregivers of mental health care users with schizophrenia in Upington, Northern Cape?

1.6 Goal and objectives

The goal of the study was to explore the experiences of caregivers of mental health care users diagnosed with schizophrenia in Upington. In order for the researcher to achieve the overall "dream" (Fouché & De Vos, 2011:94) of the intended study, the following objectives were identified:

- To describe and contextualise schizophrenia using the biopsychosocial approach;
- To explore and describe the biopsychosocial experiences and challenges of caregivers of mental health care users with schizophrenia;
- To ascertain the tasks, roles and challenges of caregivers in caring for a person living with schizophrenia;

- To explore the intervention and support provided by professionals to the caregivers of a person living with schizophrenia; and
- To suggest strategies for social workers on intervening with caregivers of mental health care users with schizophrenia.

1.7 Research methodology

In this section the researcher will give a brief account of the research methodology. The latter will be described in more detail in the third chapter of the research report. A qualitative research approach was used, as the researcher’s aim was to explore the experiences of caregivers of mental health users with schizophrenia in an attempt to become familiar with their experiences and how these experiences influence them in different spheres of their lives, thus gaining a more comprehensive understanding of certain issues experienced by caregivers using specific methodology to explore complex phenomena (Fouché & Delport, 2011:64; Fouché & De Vos, 2011:90). The study is thus being applied in nature. By means of descriptive research, the findings with regards to the experiences of caregivers will be laid out in more detail. An interpretive approach was being applied to explore the experiences of caregivers and how their experiences influence their physical, psychological and social functioning within their environment while simultaneously fulfilling the role of caregiver (Nieuwenhuis, 2016:60).

An instrumental case study design was chosen for this research study, in order to focus on specific cases related to the experiences of caregivers of mental health care users with schizophrenia to gain a better understanding of their experiences and the influence thereof on the caregiver (Nieuwenhuis, 2016:82, 83).

The study population for this study consisted of family and one non-familial caregiver of mental health care users diagnosed with schizophrenia who are responsible for caring for their family member within the community setting. A non-probability purposive sampling method as well as snowball sampling was applied to identify caregivers within the community, with inclusion criteria of above 18 years, caring for a family member diagnosed with schizophrenia and the family member being on treatment for the illness.

Data for the study was collected through the process of face-to-face interviews making use of a semi-structured interview schedule with the aim of collecting as much data as possible in an effective manner by recording data both manually and electronically with the use of voice recordings. This allowed the researcher to focus on the interview without spending too much time taking down notes, thus, also giving the researcher the opportunity to observe the participant's behaviour and body language.

1.8 Chapter outline

Besides this chapter, the research report consists of another three chapters, which are outlined as follows:

Chapter two

This chapter consists of a literature study. A thorough discussion is provided on the theoretical frameworks as well as on the topic of schizophrenia and the caregiver, taking a look at the impact of schizophrenia on different aspects of caregiver's live as well as shedding light on caregiver burden related to the function of providing care to a family member diagnosed with schizophrenia.

Chapter three

In this chapter, a description is provided on the research methodology, ethical considerations, empirical findings and themes.

Chapter four

This is the final chapter in the research report and provides a discussion on the key findings of the research study as well as recommendations for future studies and possible programmes to assist caregivers of mental health care users diagnosed with schizophrenia. Limitations of the research will also be discussed in this chapter.

In the chapter to follow, a discussion will be provided on literature relevant to the research study, focussing on mental health and schizophrenia as well as schizophrenia and the family, taking a look at the impact of the caregiving function on the caregiver and caregiver burden.

The following chapter will focus on the literature study.

2. CHAPTER 2: SCHIZOPHRENIA, THE FAMILY AND THE CAREGIVER

2.1 Introduction

This chapter consists of a review of the literature that is relevant to the topic of this research study. The literature review forms an important part of an applied research study as its aim is to consult different sources of information, mainly literature that is relevant to the study in order to answer the question that the researcher is posing. By conducting a literature study, the researcher aims to connect the research study to existing theory on the topic of schizophrenia and the experience of caregivers, thus also identifying previous literature on said topic and using this literature to guide the researcher in navigating her research project (Marlow, 2011:53). The main focus of this chapter is on schizophrenia and relevant factors related to the nature of the illness as well as the impact of this mental illness on the caregiver from a biopsychosocial view point taking into account the person in their environment.

Schizophrenia is a form of severe mental illness that is characterised by the presentation of psychotic symptoms which affects the patient’s behaviour. It is one of the four most pervasive psychiatric disorders in the world (Incayawar, Wintrob & Bouchard, 2009:252). Recovery after diagnosis and treatment differs from person to person and while some people may recover in a fairly short period of time, others experience the illness as chronic, over a long period of time, with the illness deteriorating throughout its course (Oltmanns & Emery, 2014:364-365). Schizophrenia is equally prevalent in men and women, but there is a difference between the two genders with regards to the age of onset and the course of the illness. The age of onset in men is earlier than that of women and more men are admitted for treatment before the age of 25 than women are. While age of onset in men is generally quite early, between the ages of 10 and 25, onset in women tend to present at a later stage in life, between the ages of 25 and 35. Persons diagnosed with schizophrenia have a higher mortality rate than the general population as they may face more challenges with regards to clinical treatment related to their diagnosis (Sadock, Sadock & Ruiz, 2015:301). People with mental illness are often ostracized and stigmatized by society. This does not only affect the patients themselves, but also the family. Having a family member diagnosed with a mental illness can be a very traumatic experience for a family as this affects different aspects of functioning with the family –and external systems. With research on schizophrenia expanding over the years, more interest has been directed towards the family and how certain factors within the family system may have contributed to the development or maintenance of schizophrenia (Goldenberg & Goldenberg, 2014:416-417).

In the chapter to follow, the literature study will focus on and provide insight into mental illness and the shift from institutionalised care to community and family-based care through the process of deinstitutionalisation, both internationally and nationally. Literature will further continue to focus on the nature of schizophrenia, looking at aetiology, symptoms, diagnosis and treatment options, as well as the impact of schizophrenia on the family and caregiver burden. This will improve understanding the experiences of caregivers in their role as caregiver for a person with schizophrenia.

2.2 Key terms

Mental illness, mental health, schizophrenia, caregiver burden, stigma, patient.

2.3 Nature of mental illness and historical background

2.3.1 Nature of mental illness

The terms “mental illness” and “mental disorder” are often used interchangeably or synonymous (Morgan, 1961:160) and can be viewed as an umbrella term for a wide range of mental health conditions of which schizophrenia is one of these conditions (Mayo Clinic, 2015). There is no explicit operational definition for the term mental disorder due to the wide range of mental health conditions and concepts being covered by the term. The latter is supported by the DSM-5 which states that “…no definition can capture all aspects of all disorders in the range contained in DSM-5…”. The DSM-5 does however indicate the elements necessary to identify mental disorders and classifies these disorders as “…a syndrome characterized by clinically significant disturbance in an individual’s cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning” (American Psychiatric Association, 2013:20). This is supported by the National Mental Health Association (2018) who defines mental illness as a condition that affects an individual cognitively, emotionally and psychologically. It is important to keep in mind that the term mental disorder is used to classify the disorder that a person has and not the person themselves (American Psychiatric Association, 2013:xxi, xxii). For a person to be diagnosed with a mental illness or disorder, the person must meet certain criteria as set out in the DSM-5 which identifies criteria for diagnoses. The diagnostic criteria indicate symptoms that must be present for a person to be diagnosed with schizophrenia. In the National Mental Health Policy Framework and Strategic Plan (Department of Health, 2013:11), mental illness is explained to present itself through symptoms which may cause distress and impairment in the individual’s functioning in one or more different domains related to behaviour, cognition and emotional functioning. It can thus be deduced that mental illness or disorder is abnormal behaviour that is characterized by changing patterns or disturbance in an individual’s psychological functioning and behaviour (Nevid, Rathus & Greene, 2003:3).

2.3.2 Historical background

Historically people with mental illnesses were referred to as insane. These people were kept in prisons and/or monasteries while others lived within the community. The “problem” of care for these individuals was addressed by establishing asylums in the 16th century, thus creating institutionalisation. This became more common in countries like the United States of America and abroad in the 18th century. Patients were “looked after” in harsh circumstances which were based on a lack of understanding of mental illness and set beliefs that mental illness was a result of demon possession (Morgan, 1961:165, 185). In 1972, a French physician named Phillipe Pinel began to transform institutional care of mentally ill patients, by invoking more humane treatment of people who were mentally ill within asylums. He did this by expelling traditionally known ways of treating patients in asylums, for example, patients were unchained and moved from dark crowded cells to sunny rooms and were treated with more kindness. Hence the start of a modern mental health movement based on humaneness, understanding of mental illness and caring for mentally ill individuals (Morgan, 1961:165, 185). The understanding of mental illness and treatment of mentally ill patients have greatly evolved over time. In earlier times, for example, 5000 BC, it was believed that mental illness was the result of demon possession or possession by supernatural forces. This idea shifted to a more naturalistic view during the ancient era with Hippocrates being of the belief that mental illness was the result of the imbalance of blood, phlegm, yellow and black bile within the body. The Middle-Ages followed with religious doctrines explaining mental illness as a punishment of sins and reverting back to demon possession as a reason for this. It can be deduced that this public view and doctrine affected the progression of science and treatment, as punishment and death were seen as ways to handle these “possessed” individuals. The latter continued into the Renaissance era to the development of asylums and to more scientific research into the aetiology of mental illness. This period was also characterised by the more humane treatment of patients as the understanding of mental illness started to develop, but despite this change, asylums and in-patient treatment were still at the order of the day. It was only towards the end of the 19th century that awareness began to increase with an increase in scientific discovery based on the aetiology, treatment and nature of mental illness (Cartwright, 2008:454-456).

2.3.3 Prevalence

Statistics show that in 2008, schizophrenia was prevalent amongst 1% of the global population (Asmal, Mall, Kritzinger, Chiliza, Emsley & Swartz, 2011:367). This statistic is supported by Turner (2009:44) who states that schizophrenia has a lifetime prevalence of about 1% with an annual incidence of 10-15 people out of a 100,000 being affected by the illness. The onset of schizophrenia, in most cases, is in late adolescence or early adulthood with statistics indicating that more than 21 million people worldwide are affected by schizophrenia, describing the latter as a treatable disease at the community level, emphasising the importance of family and community involvement (WHO, 2017). The South African Depression and Anxiety Group [sa] identifies the onset of schizophrenia between adolescence and early adulthood, referring to onset age between late teenage years and mid-30s. The mean onset can thus be identified as early adulthood (Lippi, 2016:1). More recent statistics indicate that more than 23 million people worldwide are affected by schizophrenia, with mental illness being more prevalent amongst men than women. Despite this high number of affected individuals, schizophrenia is still less prevalent than other mental illnesses (WHO, 2018). An individual diagnosed with schizophrenia has a life expectancy which is less than average, because of the prevalence of a higher rate of suicide and accidents amongst people diagnosed with schizophrenia (Durand & Barlow, 2010:483). Due to the nature of the illness, different aspects of the individual’s life related to behaviour and functioning are affected, for example, difficulty with normal day to day functioning due to functional deterioration; decline in physical and home conditions due to inability to work and possible poverty; and continuing care and assistance due to the impact of the illness on cognitive, emotional and physical functioning (Lippi, 2016:1). The course of illness or even recovery is further influenced by the prevalence of relapses accommodated by psychotic symptoms (Lippi, 2016:1) which poses a remaining challenge for the treatment of schizophrenia (Asmal et al., 2001:367). Statistics from the National Mental Health Policy Framework and Strategic Plan 2013-2020, identifies the 12-month prevalence of schizophrenia among adults at 1% and 0.5% amongst children while also placing emphasis of the impact of comorbidity, environmental factors like poverty and violence as well as lack of support services as contributing factors to the development of mental health issues and decline in mental health amongst the South African population (Department of Health, 2013:11-13). About 10% of patients diagnosed with schizophrenia (Robertson, 2017), will have one psychotic episode, while about 30% of diagnosed patients will go into full remission between psychotic episodes. She indicates that another 50% of patients diagnosed may experience a progressive decline in functioning over the course of the illness or that each psychotic episode in this statistical group may be followed by a decline in functioning and only partial remission.

2.4 The State of Mental Health in South Africa

The World Health Organisation (WHO, 2019), defines health as “…A state of complete physical, mental and social wellbeing”. In South Africa however, this statement does not always ring true as many are denied physical, social and mental wellbeing due to vulnerability to communicable and non-communicable diseases; lack of access to health care services and basic human needs; and subjection to poverty, crime, sexual abuse and victimization, making them all the more vulnerable and ultimately affecting their mental wellbeing as social, physical and mental wellbeing are factors influencing and affecting each other on different levels within the individual’s environment (Hassim, Heywood & Berger, 2007:4). Mental health in South Africa is a neglected topic and up to date only a single large population-based health epidemiological study – The South African Stress and Health (SASH, 2003

–2004) study – has been conducted in the country. The SASH study focused on common mental health disorders in South Africa, including: anxiety disorders, mood disorders, impulse control disorders and substance use disorders (Herman, Stein, Seedat, Heeringa, Moomal & Williams, 2009:339, 340). The study did however not include psychotic disorders like schizophrenia for example. Statistics show that neuropsychiatric diseases such as schizophrenia, account for 2.19% of years lost to disability amongst women and 1.95% amongst men, compared to other mental illnesses such as bipolar disorder, other neuropsychiatric disorders, panic disorder and compulsive-obsessive disorder which are all notably lower than that of schizophrenia (Moultrie & Kleintjies, 2006:347-349).

In the ANC National Health Plan (1994), the two major functions of the state with regards to health are stipulated. The first function of the state is to create, monitor and make amendments to the National Health System within which healthcare is promoted and services are provided within South African communities and secondly, to be a major provider of health care services. The plan also clearly stipulates that it is the function of government to ensure access to quality health care (ANC, 1994:59). The latter is supported by the National Health Act 61 of 2003, which stipulates that it is the aim of the National Health Act to establish a health system which is able to provide the best possible health care services that available resources can provide. Despite the objectives of the National Health Act and other legislation, it can be concluded that health care in the country is not up to par based on the challenges that are faced by the health care system on national, provincial and district level. Looking at our society, it is often more evident than not, that our health system is struggling to provide much needed physical and mental health services within our communities. The bridge between the public and private health care system in South Africa is described by the World Health Organisation as a stark public-private divide with the decline in public health services being contributed to a shortage of human resources, mismanagement of resources, underfunding and the deterioration of infrastructure in the country. The public health system serves more than 80% of the population, whereas 16% of the population make use of private health care services funded by their private health insurance. Despite the majority of the population being served by the public health system, the majority of doctors and specialist are working within the private health system, thus contributing to the disparity in quality service delivery between the public and private health care system (Keaton, 2010:803). In South Africa, the public health system aims to provide free health care to all, especially the most vulnerable of people. Due to certain challenges as indicated above, many people who are able to, make use of private health systems as services provided by these systems, for example, medical aid schemes and private clinics –and hospitals, are characterised by more timely and high-quality services than the public sector. Despite the quality and range of medical –and health care service availability, the majority of South Africans do not access these health care services due to the costs associated (Young, 2016:4, 9). The latter is not in line with legislation as the National Health Amendment Act 12 of 2013, explicitly states that all health establishments in the country must comply with the quality requirements and standards that are set out by the Minister of Health. Statistics from the South African Depression and Anxiety Group (SADAG) indicate that less than 16% of South Africans suffering from mental illness actually receives treatment. This number is substantially low due to the burden on the mental health care system in the country which is characterised by a lack of specialised mental health care services, stigma associated with mental illness, and lack of human and financial resources to address and treat mental illness (The South African College of Applied Psychology, 2018). Discrepancies between the nine provinces in the country with regards to budgets and resources allocated to mental health care; availability of assessment and treatment protocols for key mental health conditions; and the availability of psychotropic medication for the treatment of mental illness/mental health issues, further affects access, quality and outcome of mental health services. A lack of mental health care services was further exacerbated by the absence of a national mental health policy. As a result of this, provinces like the North West and Free State resorted to developing their own mental health policy, using the Mental Health Act, 17 of 2002, as a guideline (Ministry of Health, 2007:5).

According to statistics on key findings in the South Africa Demographic and Health Survey (2016), government clinics and community health centres account for 55% of overall health care providing resources, providing health care services to South African residents. Statistics also show that 38% of South African women aged 15 years and older indicated experiencing at least one problem related to accessing community health care services with the most commonly reported challenges being distance and access to health care services (National Department of Health, 2018:16). In South Africa, neuropsychiatric disorders are ranked third in their contribution to the overall burden of disease in the country (Department of Health, 2013:11). Yet, looking at policies and legislation under the department of health, neuropsychiatric disorders and mental health do not receive nearly as much focus nor attention as HIV and AIDS and other communicable diseases. This statement can be supported by looking at health outcomes in the National Development Plan 2030, where there is no indication of mental health as a priority area. The plan does however make provision for the development and implementation of quality health care at primary level, focussing on aspects relevant to mental health like education and disease management, planning to reform the current public health system in such a manner that current challenges as identified in the National Mental Health Policy Framework and Strategic Plan, be addressed to promote all inclusive, quality healthcare by well trained and functioning professionals (National Development Plan 2030, 2012:41).

In a message from the president of the Republic of South Africa, President Cyril Ramaphosa – in the Presidential Health Summit Report (2018:4) he communicates that amongst numerous complaints he has received about poor quality of health care, one of these included poor delivery of mental health services and delays in accessing health care. At present the South African health system is negatively affected by a range of factors not only affecting the functioning of health care institutions, but also the quality and availability of health care services, for example, lack of infrastructure, funding constraints, lack of human resources (doctors, nurses, allied health professionals etc.), corruption and political interference in operations. With most of the health care services being provided by hospitals, hence the term hospi-centric (as termed in the report) many people find it difficult to access these services due to them residing in rural areas (Presidential Health Summit Report, 2018:43). The latter is supported by the National Mental Health Policy Framework and Strategic Plan (Department of Health, 2013:9) stating that mental health in the country is experiencing challenges with regards to a lack of functioning; lack of public awareness on mental health and mental health issues; stigma against mental health care users; inequity between the provinces in the country with regards to the distribution of resources and services; and the fact that until the development of the National Mental Health Policy Framework and Strategic Plan, there was no officially endorsed mental health policy in the country. This is a clear indication of the need for a well-constructed, sound and strategically planned mental health policy with objectives aimed at addressing the needs, challenges and inequalities in the current mental health care systems.

2.5 Deinstitutionalisation

Deinstitutionalisation can be defined as the discharging of patients from mental health institutions into the community. After 1994, the focus of mental health shifted from institutionalized care and pharmacological treatment only, to decentralisation and the provision of primary health care at community level, as part of the restructuring of mental health and health services in South Africa with the aim of integrating mental health services into primary health care (Petersen, Bhana, Campbell-Hall, Mjadu, Lund, Kleintjies, Hosegood, Flisher & the Mental Health & Poverty Research Programme Consortium, 2009:40-41). With the development of psychotropic medications in the late 1950s, the phenomena of deinstitutionalisation in the United States started taking place where psychiatric patients were moved out of State Psychiatric facilities into community-based care. This shift in mental health care had implications requiring community clinics and hospitals to provide primary psychiatric treatment to patients suffering from mental illness (Allen & Spitzer, 2016:358). One of the approaches of deinstitutionalisation, according to Du Plessis, Greeff and Koen (2004:4), was to discharge psychiatric patients into the community, with the expectation that their families must take on the responsibility for their care within the community setting. Payne (1995:13) states that deinstitutionalisation emerged from the aim of community care policy to shift care to the community and away from institutions, as well as to prevent people from being required to only receive mental health services within institutions. The shift to out-patient treatment can be assumed to have had an effect on the family of the individual suffering from mental illness, as the family plays a crucial supporting role with regards to mental illness and because they are often the main source of support upon whom the individual can rely on for consistent and long-term support (Allen & Spitzer, 2016:119). Patients are often dependent on others for assistance across an array of domains related to their everyday care and functioning outside of the inpatient setting, as many of them may be unable to maintain full-time employment (to care for themselves financially), successful interpersonal relationship or stable family relationships (Bowie & Harvey, 2006:531). Payne (1995:13) states that the policy of deinstitutionalisation is as controversial as that of long-term institutional care. This statement can be derived from evaluating the process of deinstitutionalisation and the effect on the patient and the caregiver in the community setting. For example, deinstitutionalisation resulted in care being provided by family members at community level, making use of primary health care and community-based services. The aim of the process was for individuals to function more independently. This can be applicable to individuals with less debilitating mental illness who have access to needed resources, family support and the means to function more productively in their community setting. The question however arises: what about the individual who needs long-term specialised care and who is not able to merely function with family support and care within their community? Should they not be able to function in a different system than that of institutionalised care due to relapse for example, they would have to be moved back to an institutionalised care setting, thus making the phenomenon of deinstitutionalisation controversial as there is still a need for long-term institutionalised care with regards to certain cases. The researcher is of the opinion that the latter can be linked to the South African context when we look at resources specifically. In many rural areas and even urban areas, there is a lack of mental health resources including physical resources, structural resources, support services, health care services and so forth. Moving patients from institutionalised care to community-based care may have seemed like a functional move, but specific services needed to be in place to assure that the patient receives all the necessary services within their community setting. Lack of relative resources results in negative consequences starting a chain reaction that ultimately trickles down to the family system, affecting the caregiver and family and ultimately the patient.

In South Africa, deinstitutionalisation came about with the transformation of the national health care system that included the integration of primary health care services at community level, resulting in the shift of care from institutionalised care to family care at the community level (Mavundla et al., 2009:358). Due to deinstitutionalisation from government institutions to the community, the inpatient population were reduced considerably (Chamberlin & Rogers, 1990:1214) consequently resulting in the need and expectation for community-based services to render support to the patient and family (Du Plessis et al., 2004:4).

The question resulting from the whole process of deinstitutionalisation is this: Are families equipped with knowledge and do they have access to the necessary resources to support and provide care to their family member? North, Pollio, Sachar, Hong, Isenberg and Bufe (1998:39) provides some insight into this question by arguing that deinstitutionalisation was linked to a decrease in sources of funding in the mental health sector, resulting in care responsibility being shifted from the state to the family, even though the latter may not necessarily be equipped to care for the patient, due to possible lack of resources within the community; lack of knowledge regarding the illness and needed care and the lack of support services to the family to successfully take on the caregiving role. This is supported by findings of Du Plessis et al. (2004:3), where the researcher reflects on their own experience as a psychiatric nurse in rural SA, stating that families were often not empowered to support and thus care for their schizophrenic family member in the community setting, resulting in readmissions and families becoming discouraged. Thus, even though deinstitutionalisation may represent progress for the patient referring to discharge into community care – as argued by Jungbauer, Wittmund, Dietrich and Angermeyer (2004:665) – this progress can be halted and even result in regression of patient wellbeing, due to certain prominent factors, for example, lack of community resources and support to families and a lack of knowledge of the illness and care needed. Despite the family gaining more importance in the process of care and treatment (Jungbauer et al., 2004:665), it can be deduced that contributing societal factors relating to funding, resources, psychosocial support and care, may result in families experiencing certain burdens affecting their mental, physical, psychosocial wellbeing. The researcher is of the opinion that deinstitutionalisation is based on the idea that the individual is integrated back into society, receiving necessary mental health care services, enabling that person to function optimally in their environment. In South Africa however, the development of community-based health care services to support the initiative, was not fast or effective enough, resulting in a number of new challenges, mostly negative, affecting mental health care users (National Department of Health, 2018:16).

2.6 Schizophrenia

The mental disorder schizophrenia was initially described as a medical syndrome by Emil Kraepelin in 1893, who believed the disease to be caused by unknown pathology in the human body, presenting with positive symptoms such as delusions, hallucinations and strange motor behaviours. Kraepelin named the disease dementia praecox which was later renamed in 1911 by Eugen Bleuler (Swiss psychiatrist) as schizophrenia, which literally means split brain. Bleuler was in agreement with Kraepelin on the symptoms of schizophrenia but disagreed with the age of onset and future prognosis. Kraepelin was of the belief that the onset of schizophrenia was in early life and bound to deteriorate with age, whereas Bleuler was of the view that the course of schizophrenia may vary with regards to the age of onset, prognosis and deterioration. Bleuler was of the opinion that schizophrenia could be recognized based on four symptoms, that is, association, affect, ambivalence and autism. Other symptoms like hallucinations and delusions were considered by him as secondary symptoms. Others, however, disagreed with Blueler. Kurt Schneider, a German psychiatrist was of the opinion that the four primary symptoms suggested by Blueler were too vague and that they did not adequately distinguish schizophrenia from other mental disorders. He proposed first rank and second rank symptoms. First rank symptoms, being unique to schizophrenia, whereas second rank symptoms, were those characteristic to other mental disorders as well. Delusions and hallucinations were identified by Schneider as first rank symptoms, while disorganised thinking and mood disturbances were considered second rank symptoms. Research, however, has since found that first rank symptoms are present in other disorders like bipolar disorder (Nevid et al., 2003:402).

Schizophrenia is a severe mental illness (Saunders, 2003:175) that is characterised by structural and functional abnormalities in the cerebral cortical and subcortical areas of the brain as well as the abnormal transmission of dopamine and glutamate in the brain (McGuire, Howes, Stone & Fusar-Poli, 2007:91). It is a disorder that interferes with the pathways in the brain (Osborne, Esterline & Perkins et al., 2016:13) and as stated by Nevid et al. (2003:401), it is a disabling clinical syndrome that interferes with intimate connections between the affected person’s thoughts and emotions, by filling the mind with what is referred to as positive symptoms, that is, hallucinations, delusions and illogical thoughts. The onset of schizophrenia is usually between the age of 15 – 25 years in males and 20 – 30 years in females and is preceded by the presentation of a prodromal phase that is characterised by odd behaviour and decline in functioning (Robertson, 2017). Some authors identify it as falling under the category of chronic conditions, as it is an illness which requires on-going management throughout the lifespan of the individual (Whitehead, Jacob, Towell, Abu-qamar & Cole-Heath, 2017:22). Schizophrenia, Turner (2009:44) states, is a syndrome in that it is a common form of a psychotic disorder that can present itself in various ways with relapses often occurring after long-term treatment. In the DSM-5, schizophrenia is classified as a prototypical psychotic disorder, being complex in nature and not only affecting the individual, but also having a devastating effect on the lives of family members (Barlow & Durand, 2005:455). These findings/views by the above authors show that schizophrenia, is indeed a long-term illness – thus chronic – with relapses occurring during the course of the illness.

2.6.1 Aetiology

The cause of schizophrenia and the way in which it develops is unknown (Tandon, Keshavan & Nasrallah, 2008:1). Due to similarities in the symptoms and prevalence of schizophrenia across different cultures, biological factors are considered to play an active role, influencing the development of schizophrenia. Genetics are also thought to be a determining factor in the development of schizophrenia, as the disease can be genetically transmitted. This does however not explain who will get the disease or whether it will be genetically transmitted (Green, 2000).

2.6.1.1 Neurobiological influences

Researchers are in agreement that there is no one single gene responsible for the development of schizophrenia, but rather multiple genes (Getzfeld, 2004:99). A study by Turner (2009:44) focuses on genetic factors as being a contributor to the development of the disease. Even though not proved as the reason for the development of schizophrenia, genetic predisposition is believed to be a precipitating factor in the development of the illness, as it leaves an individual vulnerable to develop the disease (Cartwright, 2008:467). Genetic predisposition has been studied through twin studies, where research investigated the possibility of monozygotic and dizygotic twins of schizophrenic parents developing the disease (Cartwright, 2008:267). In the case of dizygotic twins, there is a 10-15% chance of both twins developing schizophrenia if one twin has the disease, as they share 50% of their genetic material. With monozygotic twins, the risk of both twins developing schizophrenia is substantially higher with a 40-50% risk of one twin developing the disease, when the other one already has schizophrenia (Tandon et al., 2008:6). Schizophrenia has been found to run in families, with the number of cases developing over a certain period of time amongst at-risk groups being related to certain external factors associated with the development of the disease, for example, a meta-analysis of all published studies between 1965 through 2001 found an association between gender, migration and urbanicity and high risk for developing schizophrenia (Tandon et al., 2008:2). The risk of children developing mental illness is also considerably higher when a parent is diagnosed with severe mental illness (Rasic, Hajek, Alda & Uher, 2014:28).

Another theory for the development of schizophrenia is related to elevated levels of dopamine at receptor sites in the brain, causing symptoms characteristic to schizophrenia due to excess secretion of the neurotransmitter. The cause of schizophrenia as mentioned before is unknown and not entirely understood, but does involve the abnormal transmission of the neurotransmitters, dopamine and glutamate in the brain, as well as abnormalities in brain structure and function in the cerebral cortical and subcortical areas of the brain (McGuire et al., 2007:91). Studies have shown that prenatal and perinatal influence may have a contributing impact to the development of schizophrenia, identifying environmental factors such as exposure to infections and complications during pregnancy and birth as factors affecting the development of the syndrome (Durand & Barlow, 2010:490).

2.6.1.2 Psychosocial and environmental influences

Besides biological theories on the aetiology, there are also psychological theories that have been developed to better understand schizophrenia. These theories were developed by psychoanalytical theorists, learning -and cognitive-behaviour theorists, identifying abnormalities of speech and abnormalities in behaviour during childhood as being precipitating factors contributing to the development of the disease. Life events are also identified as a possible trigger for schizophrenia (Jorm, 2000:397). Other causes of schizophrenia are theorised to be contributed to environmental factors, for example, infections or incidents during birth or in early childhood, as well as substance abuse (Smit, 2018). Although substance abuse cannot be identified as a cause of schizophrenia, there is evidence identifying the link between substance abuse and psychoses based on the high prevalence of substance abuse amongst patients with schizophrenia. The most commonly used substances amongst patients suffering from psychoses include nicotine, alcohol, cannabis and cocaine (Winklbaur, Ebner, Sachs, Thau & Fischer, 2006:37). The notion that psychological and social influences are contributing factors to the development of schizophrenia, can be supported by evidence of twin studies where it was found that one identical twin did not develop schizophrenia whereas another did, thus indicating that genetic processes cannot be solely responsible for the development of the disease (Durand & Barlow, 2010:491). The authors go on to identify stress prior to onset as a possible contributing factor, indicating that research has studied the impact of stress on schizophrenia as stress is most often present before patients start to show symptoms of the syndrome. Studies have however not definitively proved stress to be a causal factor, but rather a stressor influencing behaviour. Environmental influences cannot be identified as sole contributing factors to the development of schizophrenia. There are however, suggestions that environmental stressors may precede onset and development of schizophrenia, thus indicating that genetic factors, along with other environmental stressors in combination, can be a causal factor in the development of schizophrenia (Austrian, 2000:103).

2.6.2 Features associated with schizophrenia

Eugene Bleuler believed that the diverse symptoms displayed by persons with schizophrenia could be contributed to the difficulty they experienced in keeping a consistent train of thought (Barlow & Durand, 2005:456). Schizophrenia is generally viewed as a complex syndrome with the causes of the disease still unknown. A person suffering from the disease is affected in the sense that their normal functioning is interrupted. Episodes of schizophrenia may consist of different phases which include: pre-onset/prodromal phase, where changes in the person’s behaviour start to occur impacting their physical and mental functioning; onset/active phase which is characterised by the presence of hallucinations and/or delusions; and residual phase which is similar to the pre-onset phase with regards to psychotic features, but less intense (Golightley, 2011:29-30). Schizophrenia has been classified as consisting of four subtypes. Weiten (2007:574-575) identifies the subtypes and characteristics as follows: paranoid type which includes delusions of persecution as well as delusions of grandeur either causing the person to believe that they are being harassed (paranoia) or that they are a highly important person (grandeur); catatonic type which is recognised by motor disturbances that range from withdrawal or catatonic stupor to a state of catatonic excitement; disorganised type which is characterised by the deterioration of the individual's adaptive behaviour, for example, changes in speech, withdrawal, incoherence etc.; and undifferentiated type, which includes those persons who do not fit into the three previously mentioned schizophrenic types, but suffer from the disease. There has, however, been critique on dividing disorders of schizophrenia into the above-mentioned subtypes and debates have ensued about the classification of the subtypes. Five subtypes of schizophrenic disorders are identified in the DSM-4: paranoid, disorganised, catatonic, undifferentiated and residual. A person is, however, not definitely categorised into one specific subtype, because symptoms may change over time causing the diagnosis of a subtype to change accordingly. The DSM-5, does not differentiate any longer between types, but only between symptoms which are categorised into five domains, with schizophrenic disorders being defined by abnormalities in either one or more of these domains, which are identified as delusions, hallucinations, disorganised thinking or speech, negative symptoms and grossly disorganised or abnormal motor behaviour (American Psychiatric Association, 2013:87).

Ho et al. (2003), cited in Weiten (2007:574) supports the concept of the four different subtypes of schizophrenic disorders and also identifies the previously mentioned four subtypes. These subtypes, as stated, have been removed from the DSM-5. Critics have pointed out a lack of meaningful differences between the subtypes with regards to aetiology, prognosis and the patients' response to treatment (Weiten, 207:575). Authors like Nancy Andreason (1990), Carpenter (1992) and McGlashan and Fenton (1992) as cited in Weiten (2007:575) have proposed and developed a new scheme dividing schizophrenic disorders into only two categories which are based on the predominance of positive and negative symptoms (Weiten, 2007:575).

Negative symptoms refer to behavioural deficits, for example, "…flattened emotions, social withdrawal, apathy, impaired attention and poverty of speech" (Weiten, 200:575). The latter is supported by Walker et al. (1993), as cited in the research of Martens (1998:2), who states that "…negative symptoms include deficits in behaviour" and further states that positive symptoms are a subtype that "…includes the most positive signs of psychosis: delusions and hallucinations". Negative symptoms are thus symptoms displaying deficits in behaviour, as well as psychological deficits (Turner, 2009:44), indicating the absence of something, for example, the absence of feeling, speech, social interaction or attention. Positive symptoms, on the other hand, are identified by add-ons in behaviour, for example, delusions.

Delusions refer to a distorted reality or misinterpretation of reality, while hallucinations refer to perceptual disturbances (Zunker, 2008:126). Many authors agree on the classification of the subtypes of schizophrenia, as well as on the impact of schizophrenia on the functioning of an individual. There is, however, not a specific cause for schizophrenia as already indicated above.

2.6.3 Symptoms

As a psychotic disorder, schizophrenia is defined by certain key features including delusions, hallucinations, disorganised thinking, grossly disorganised or abnormal motor behaviour (including catatonia) and negative symptoms (American Psychiatric Association, 2013:87, 88). Symptoms experienced by a person with schizophrenia include delusions, hallucinations, disorganised speech and the deterioration of adaptive behaviour (Weiten, 2007:573) and because of this, it can be argued that schizophrenia can be a debilitating disorder, leaving the individual cognitively and emotionally weak and infirm, as it not only affects their cognitive functioning, but impacts on their emotional state. The latter is supported by Lippi (2016:1) who argues that schizophrenia is a psychiatric disorder characterised by a slow deterioration of an individual's functional abilities, episodes of relapse or the "…acute exacerbation of psychotic symptoms". Symptoms of schizophrenia can be both extreme and diverse contributing to the absence of a specific set of standards or criteria to define and diagnose the condition resulting in clinicians having to rule out other causes for behaviour before being able to diagnose a person with schizophrenia based only on symptoms (Osborne et al., 2016:3). The presence of excessive symptoms and absence of or deterioration of behaviour can be referred to as positive and negative symptoms respectively. The symptoms associated with schizophrenia can be divided into three categories, namely: positive symptoms, negative symptoms and cognitive symptoms (National Institute of Mental Health, 2016).

2.6.3.1 Positive symptoms

Positive symptoms refer to changes in normal brain functioning and senses, with the impact of the disease resulting in normal functions becoming disordered or false, for example, the person may experience false perceptions relating to their senses by hearing, seeing, feeling or smelling things that are not there – this can also be referred to as olfactory and tactile hallucinations (Turner, 2009:44, 45). Positive symptoms are identified by behaviour that can be described as being in excess (Osborne et al., 2016:3), for example, experiencing auditory hallucinations. These symptoms occur when the person exhibits behaviour that was not previously present (Cartwright, 2008:465). The National Institute of Mental Health (2016), describe positive symptoms as psychotic behaviour that is not present in people not suffering from schizophrenia. These symptoms include:

- **Delusions**

These are fixed beliefs that a person maintains despite evidence that contradicts these beliefs. Delusions can be subcategorised into persecutory delusions (the belief a person holds that his/her wellbeing or safety is threatened by another person, group or organisation); referential delusions (when an individual personalises everything, for example, comments or gestures, to themselves, thus making everything about themselves or applicable to themselves); somatic delusions (when an individual becomes preoccupied with their health and functioning or their organs/internal bodily system); and grandiose delusions (when a person believes that they have exceptional abilities, for example, extraordinary abilities or powers, wealth or fame).

- **Hallucinations**

Hallucinations are experiences that are involuntary and not brought on by external stimuli, for example, hearing voices that are not one’s own. Hallucinations can be either sensory or auditory, but with regards to schizophrenia, auditory hallucinations are more common.

- **Disorganised thinking**

Disorganised thinking becomes evident through speech and in severe cases a person’s communication may become incomprehensible.

- **Grossly disorganised or abnormal motor behaviour**

This involves changes in goal-directed behaviour and includes catatonia (where there is a decrease in the individual’s reaction to environmental stimuli), negativism (characterised by the individual’s resistance to follow instructions), mutism (complete lack of verbal response), stupor (complete lack of motor response) and catatonic excitement (overreacting to environmental stimuli without obvious reason with reactions being characterised by excessive motor activity) (American Psychiatric Association, 2013:87, 88).

2.6.3.2 Negative symptoms

Negative symptoms are the absence of behaviour that is characteristic of the person, for example, the absence of feelings or behaviour that are normally exhibited (Cartwright, 2008:465). Negative symptoms refer to the absence of abilities or attributes own to the person. These symptoms are not as obvious as positive symptoms, as it is characterised by subtle changes in the person’s behaviour and personality with normal characteristics becoming absent. This does however not mean that negative symptoms are less severe than positive symptoms (Osborne et al., 2016:3). The person may undergo a change in personality as certain characteristics start to become absent in their behaviour or personality and they start to lose interest in things that were once important to them or that they enjoyed, for example, poverty of speech and flat effect relating to emotions and changes, resulting in the person spending their time not doing anything. These deficits in cognition may continue or deteriorate throughout the course of the illness even though the person is on treatment for schizophrenia (Turner, 2009:45). Some prominent negative symptoms associated with schizophrenia include:

- Avolition: when the person becomes disinterested or demotivated in initiating meaningful activities and is not able to persist with what can be considered common tasks;
- Alogia: poverty of speech or decrease in speech output resulting in the person being in a state of mutism for a certain period of time;
- Anhedonia: when the person starts to loose pleasure in things they once enjoyed and when their ability to experience pleasure from positive stimuli decreases, resulting in an inability to experience emotion; and
- Affective flattening: when there is a decrease or complete absence in emotional response to environmental stimuli (Nolen-Hoeksema, 2008:388; Turner, 2009:45).

2.6.3.3 Cognitive symptoms

Cognitive symptoms do not present the same in all people suffering from schizophrenia. In some cases these symptoms can be subtle, whereas in other cases it can be severe, resulting in patients observing changes in their cognitive functions like memory or thinking. These symptoms generally include deficits with regards to thinking, memory and execution. For example, the patient may find it difficult to focus and understand information, resulting in poor execution due to decreased ability to comprehend and remember information (National Institute for Mental Health, 2016). Davidson, Reichenberg, Rabinowitz, Weiser, Kaplan and Mark conducted a follow-back study on the behavioural and intellectual markers for schizophrenia in apparently healthy male adolescents. The study found that the best predictors for schizophrenia were lower intellectual functioning, poor organizational ability and deficits in intellectual functioning, indicating that cognitive symptoms such as behavioural and intellectual abnormalities are symptoms preceding first onset of psychosis (Davidson et al., 1999:1328, 1329). The type of cognitive impairments experienced by patients with schizophrenia include general intelligence, working memory, attention, verbal fluency, verbal learning and memory, and executive functioning (Bowie & Harvey, 2006:532, 533).

The outcome and recovery of the patient is not only dependent on controlling positive symptoms of schizophrenia by means of pharmacology, but also on the treatment of negative –and cognitive symptoms which can’t be treated by means of medication, but through psychosocial methods including support to the patient and the caregiver and family; psycho-education to the patient and family on the illness; vocational training and education to the patient; and psychotherapy to treat cognitive and affective symptoms (Smit, 2018).

Of all the symptoms associated with schizophrenia, negative symptoms are more prominent in schizophrenia than in other psychotic disorders and "…account for a substantial portion of the morbidity associated with schizophrenia…". The DSM-5 further identifies avolition and diminished emotional expression as particularly prominent negative symptoms experienced in patients diagnosed with schizophrenia (American Psychiatric Association, 2013:89).

2.6.4 Diagnosis

To diagnose schizophrenia, other mental disorders first have to be ruled out and the physician has to determine whether symptoms are due to other factors, for example, substance abuse, pre-existing medical conditions and/or medication that the patient is using as various symptoms evolve over the course of the illness (Robertson, 2017). Diagnosing schizophrenia can be an on-going process and involves the following:

2.6.4.1 Methods of diagnosis

Diagnosing a patient involves physically examining the patient to rule out other physical –or mental health problem and also to check for possible complications experienced and to evaluate the symptoms experienced by the patient (Mayo Clinic, 2018). Tests and screening are consequently done to rule out conditions presenting with similar symptoms. These tests involve molecular imaging to study chemical changes in the brain and include positron emission tomography (PET) and single-photon emission tomography (SPET) as well as magnetic resonance imaging (MRI) to "…measure the concentration of specific molecules within the brain" (McGuire et al., 2007:91).

2.6.4.2 Diagnostic criteria

When diagnosing a patient, a clinician must take certain factors into consideration, for example: the cultural and socioeconomic background of the patient, especially in cases where the clinician and patient do not share the same background; gender-related issues as the clinical expression of schizophrenic features differ between males and females with regards to age of onset, intensity and nature of symptoms; and social functioning as women generally tend to function better than males (American Psychiatric Association, 2013:103, 104).

Diagnosis may de defined as:

> "…The determination of the cause or nature of an illness by evaluation of the signs, symptoms and supportive tests in an individual patient. Diagnostic criteria are a set of signs, symptoms and tests for use in routine clinical care to guide the care of individual patients…. Diagnostic criteria are generally broad and must reflect the different features of a disease (heterogeneity), with a view to accurately identify as many people with the condition as possible" (Aggarwal, Ringold, Khanna, Neogi, Johnson, Miller, Brunner, Ogawa, Felson, Ogdie, Aletaha & Feldman, 2015:2)

The diagnostic criteria according to the DSM-5 (American Psychiatric Association 2013:100) are as follow:

- A. Two or more of the following symptoms must be present for a significant period of time during a one-month period:
    - Delusions
    - Hallucinations
    - Disorganised speech
    - Grossly disorganised behaviour
    - Negative symptoms

  At least one of the first three symptoms identified above, must be present during the time- frame indicated.
- B. A decrease in an individual's level of functioning in major areas like self-care, personal life (interpersonal relationships) and work example (with regards to adults).
- C. Continuous signs of disturbances in functioning that carries on for at least six months with certain symptoms as identified above, persisting for at least one month. During these periods the individual may experience prodromal or residual symptoms. During periods where the individual is experiencing either prodromal or residual symptoms, the signs of these symptoms may present as

negative symptoms or may be revealed by two or more of the symptoms indicated in point A.

- D. As mentioned earlier, the diagnostic process includes ruling out other conditions that may affect psychosis. With this in mind, schizoaffective disorder, depressive disorder or bipolar disorder with psychotic features, can be ruled out under the following circumstances:
    - When no major depressive or manic episodes have occurred at the same time when experiencing active-phase symptoms which include (list active phase symptoms);
    - When mood episodes occurring during the active-phase symptoms have only been present for a lesser part of time during active and residual periods of the illness;
    - If an individual has a history of autism spectrum disorder or a communication disorder having its onset in childhood, an additional diagnosis of schizophrenia can only be made; and
    - if there is a presence of prominent delusions or hallucinations along with other symptoms of schizophrenia for at least one month. Thus, for a person to be diagnosed with schizophrenia at least two symptoms in criteria A must present over a period on one month or longer.

2.6.4.3 Diagnostic features

As already indicated the diagnosis of schizophrenia involves the process of identifying a group of signs and symptoms associated with impairment in major areas of the individual’s life and functioning. Looking at the nature of schizophrenia, it is a clinical syndrome that is diverse in character and due to this; the features may vary to a significant extent from one individual to another, resulting in impairment in one or more major areas of functioning. Disturbances or dysfunction occurs or continue to occur for a certain period of time and cannot be ascribed or contributed to a single feature. Disturbance or dysfunction usually occurs for a period of six months with active-phase symptoms being present for at least one month of the period of the illness. The illness is characterised by inappropriate affect, dysphoric mood, anxiety and phobias, abnormalities in sensory processing and cognitive deficits and patients diagnosed with schizophrenia may not be aware of their disorder in the sense that they are not aware of the symptoms they are displaying.

This lack of awareness can be seen as a coping strategy as well as a common reason for non-adherence to treatment (American Psychiatric Association, 2013:101).

2.6.5 Treatment

As indicated previously, a person diagnosed with schizophrenia may experiences positive, negative and/or cognitive symptoms. McGuire, Howes, Stone & Fusar-Poli (2007:91), mention pharmacological treatment as more effective in reducing positive symptoms compared to negative –and cognitive symptoms, revealing in their study that one-third of patients diagnosed with schizophrenia pose resistance to first-line antipsychotic medications. They recommended research to focus on finding new drugs for the treatment of schizophrenia as treating patients with antipsychotics results in poor tolerability, which poses a problem as they have to be on treatment for a number of years.

2.6.5.1 Pharmacological treatment

No cure has been found for schizophrenia and treatment involves multiple approaches based on pharmacological and psychological interventions as well as rehabilitative approaches (Nevid et al., 2003:430). In a study by McGuire et al. (2007:92), identified antipsychotic drugs such as Clozapine as a treatment for schizophrenia and that its efficacy is superior to other antipsychotic drugs and haematological monitoring is involved, as the side effects include myocarditis, seizures and cardiomyopathy and can cause a serious blood condition. Due to the latter, blood is monitored before a patient starts treatment, during their treatment and for four weeks after treatment (MedlinePlus, 2019). Antipsychotic medication like chlorpromazine was initially used to treat schizophrenia and revolutionised the field of pharmacological treatment with regards to this severe mental illness. Over time, these medications were used as the main method of pharmacological treatment until 1990 when clozapine was introduced, which is still being used today to treat the illness. It should however be noted that there are more than two dozen types anti-psychotic medications that are used in the treatment of schizophrenia and that these medications are classified according to their level of potency, for example, high, medium and low level potency, each with their own side effects. Newer, safer medication like Risperdal was subsequently used to treat schizophrenia, targeting dopamine and serotonin levels in the brain. These types of medication can be administered to patients in the form of a pill or in the form of injections, especially for patients who are prone to non-adherence. (Austrian, 2000:105).

2.6.5.2 Psychosocial intervention

Psychological treatment involves learning-based and psychosocial rehabilitation approaches as well as family intervention programmes aimed at empowering both the affected person and the family with the necessary skills to adapt to changes and cope with the burdens associated with the disease (Nevid et al., 2003:437). Family support plays a very important role in the treatment of schizophrenia and may improve the patient's functioning over the course of the illness if the support from the family or caregiver/s are characterised by factors such as accepting the person for who they are with the illness and providing a good support system without high levels of expressed emotion (Robertson, 2017).

2.6.5.3 Behavioural approaches to treat cognitive symptoms

Behavioural approaches to treat cognitive symptoms or deficits in schizophrenia have produced positive results (Bowie & Harvey, 2006:534). These approaches mainly include educational strategies focused on teaching patients new learning strategies (as memory impairments and deficits are a result of cognitive symptoms); assisting patients in learning new information and enabling them to perform what is referred to as novel tasks. The author is of the opinion that behavioural approaches, combined with pharmacological treatment, can contribute to an improvement in cognitive functioning in patients with schizophrenia. Hospitalisation is an important part of treatment at the onset of the disorder, as this is the time during which a diagnosis is made based on the presenting symptoms. Through hospitalisation, the patient's behaviour with regards to functioning, behaviour and thoughts are carefully observed as part of the process of diagnosis. Hospitalisation also allows for treatment by allied health professionals like occupational therapists that assesses the patient's functioning and educates the patient on the illness, how to use medication and how to maintain a healthy lifestyle once discharged (Robertson, 2017).

2.6.5.4 Family therapy and psychoeducation

Psychoeducation is used as a therapeutic treatment method aimed at the caregiver and/or family. The major focus of this approach is education. The focus is on educating the caregiver and family members on the disease itself, taking in account different aspects, for example, symptoms or schizophrenia and consequent behaviour. The aim of this approach is to equip the caregiver or family member with the skills to understand the disease as well as to cope with the disease. By providing support to families, these approaches aim to empower caregivers or family members to cope more effectively by improving their personal strengths, coping skills and communication with each other. By doing the latter, the caregiver or family member is equipped and empowered to solve day-to-day stressors by using their skills and strengths, thus giving them the opportunity to take control and gain a sense of accomplishment as they address stressors independently. This method of treatment allows for the improvement in family relationship and strengthening of family bonds. It is not a structured step by step plan, but is based on the needs and expectations of the caregiver or family members and involves different approaches and theories (Goldenberg & Goldenberg, 2013:214, 215, 216). Corwin (2002:166) identifies reduction in expressed emotion (EE) as a desirable outcome of psychoeducation and agrees that psychoeducation is aimed at educating family members on the symptoms, latent content of the patient's communication and related behaviour which may often demonstrate conflicting thoughts and behaviour. By understanding why the patient is behaving the way they do, there may be less feelings of hostility or anger due to the patient's behaviour towards a caregiver for example, and more empathy as they know and understand the cause behind the behaviour. With regards to the patients themselves, psychoeducation helps them to understand the nature of their illness and how to manage it.

It can thus be concluded that the best way to treat schizophrenia is by taking on an approach that combines pharmacological treatment, behavioural, cognitive and family therapy (with psychoeducation as a major approach) as neither one of these treatment methods on its own can effectively treat the symptoms of schizophrenia. Despite using combinations of approaches to treat schizophrenia, there is no cure for the disease, and relapses may still occur (Getzfeld, 2004:101).

2.7 The impact of schizophrenia on the family and caregiver

Living with schizophrenia is not only difficult for the person diagnosed with the illness, but also for the family members who often take on the role of caregiver. Tilbury (1993:99) describes the mental illness of a family member as being a prolonged crisis for the family itself. Caring for a person with schizophrenia requires the family system to adapt to changing circumstances requiring them to obtain new knowledge and learn new coping skills to deal with the positive and negative symptoms of schizophrenia (McFarlane, Dixon, Lukens & Lucksted, 2003:224).

Family functioning, in a manner, becomes disrupted by the consequences of schizophrenia, if we look at the positive and negative symptoms of the syndrome (Goldenberg & Goldenberg, 2013:416). The manner in which the family responds to a member with schizophrenia can be influenced by both external and internal factors. Society’s attitude towards mental illness, popular culture and the impact of schizophrenia on the family members themselves, together with internal factors like their perceptions of schizophrenia and their belief system can ultimately influence their attitudes and behaviour towards a family member with schizophrenia. During the onset and course of the illness, the patient becomes reliant on the family system for support (physical, financial, emotional and with regards to security). Due to the latter, the quality of the relationship between the family and the patient has an influence on the wellbeing of the patient as well as on treatment outcome. Based on the latter, it can be concluded that the nature of the relationship between the patient and the family can contribute to caregiver burden should caregivers be exposed to negative experiences and interactions in these relationships (McFarlane et al., 2000:5). Given the complexity of schizophrenic disorder and the presence of cognitive and behavioural symptoms of schizophrenia, the family can be adversely affected by the burden of caring for the patient suffering from schizophrenia. With regards to the latter, questions arise on how the family is equipped to deal with the patient suffering from mental illness, specifically schizophrenia and how taking care of a patient suffering from schizophrenia affects the family as a whole in different facets of their lives. Schizophrenia can thus be described as a chronic condition resulting in diagnosed individuals experiencing difficulty functioning within society and despite receiving treatment; the individual is likely to experience difficulties throughout their lives (Barlow & Durand, 2005:467). Due to the latter, family support can be considered a significant contributing factor with regards to the care of the patient and their functioning and taking into account the nature of the illness and the lifelong difficulties associated with the illness, it can be deduced that caring for a person with schizophrenia can have a direct impact on family functioning.

Controlled trials have been conducted, with all of these trials providing evidence that intervention by the family, contributes to a reduction in relapse rates and hospitalisation of the patient, thus emphasising the importance of the families' role relating to intervention, especially because of the significant impact of schizophrenia on the functioning of the patient (on different levels). Due of the latter, caring for a person suffering from schizophrenia can also have a significant impact on the caregiver, because schizophrenia is a chronic illness requiring long-term treatment and can result in the person suffering from the illness, being unable to live a fully independent life, thus indicating the need for care. However, this caring role may interfere with their work, daily routines, social activities and affect them financially, thus contributing to the burden of care experienced by the caregiver (Koujalgi & Patil, 2013:251).

The family itself has an impact on the patient as the family plays a role in the development of the patient's value system by modelling acceptable behaviour and setting guidelines for set behaviour (Du Plessis et al., 2004:16). Within the family system, different relationships are affected by schizophrenia and vice versa. From the literature on schizophrenia and the relationship between the illness and family and/or caregiver experience, it is evident that those people closest to the diagnosed individual are affected on different levels. It must, however, be said that family caregivers experience the effects of schizophrenia differently. Parents (caring for a child with schizophrenia) and spouses may have similar experiences during the course of the illness, for example, having to adapt to and deal with changes in the persons personality; constant fear of a possible relapse, as well as alternating between stages of acute and chronic symptoms (Jungbauer et al., 2004:672). Despite there being similarities in experience, there are also differences due to the nature of relationships between the individual with schizophrenia and the family member/s. Spouses experience burdens that are much different from those experienced by parents, as the problems that they experience are central to the relationship in the sense that it directly affects the spousal relationship on different levels, for example, challenges with regards to intimacy and commonality which can be brought on by changes in personality. Roles within the family system have to change as one spouse now has to take over the responsibilities and tasks of the other in cases where the latter is no longer able to. This impacts the family dynamic and results in plans having to be redefined and life readjusted to accommodate both partners (Jungbauer et al., 2004:672). A qualitative study to investigate subjective burden in spouses of patients with schizophrenia found a gap in research with regards to spouses and their experiences versus that of parents. There was a clear difference in experience between spouses who have mental illness and those who do not, as well as between those relationships that are more stable and where the patient has moderate or less severe symptoms and longer periods between relapse/psychotic symptoms compared to those of opposite nature. Relationships were evaluated positively where there was a prevalence of mutual understanding, respect and affection; the cause of illness was more favourable in the sense that the patient was not seriously impaired; and, the patient’s personality was relatively intact, allowing partners to relate to and communicate with each other. From this, it can be concluded that relationships that were more stable, were experienced and perceived as more positive compared to those that weren’t. This statement is supported by findings indicating that partnerships which are experienced more positively are represented by stabilising factors for managing day to day living along with mental illness (Jungbauer et al., 2004:665, 673). The study found that spouses who also suffered from mental illness experienced fewer changes in their partnerships as well as advantages, as there was the presence of mutual understanding and support. These spouses also showed tolerance and a special kind of understanding as they are well aware of the impact of mental illness on the patient. In contrast with the two examples described previously, there are findings that suggest that the presence of schizophrenia and acute episodes contribute to a decisive point where spouses feel the need to re-evaluate the relationship. Despite the negative views often associated with schizophrenia, studies have revealed that spouses of patients with schizophrenia report positive outcomes. Research indicates that many spouses were of the opinion that is it possible to have a satisfying relationship with someone diagnosed with schizophrenia, especially when there is a longer period of time between psychotic episodes; the person is able to function relatively independent and the spouse views the relationship as manageable (Jungbauer et al., 2004:671, 672). It can thus be deduced that relationships are perceived as more manageable when there is more stability and mutual gratification of needs.

2.7.1 Experiences of caregivers

A study by Mavundla et al. (2009), exploring the experiences of informal caregivers, namely, family members in rural areas in South Africa, found that the experiences of these informal caregivers were conceived as negative due to culturally explanatory models of mental illness that is prevalent in the rural areas in South Africa where the study was conducted. The latter is an indication that cultural perception of mental illness affects the caregiver, caregiving functions and caregiver burden. It should however also be noted that conceptualization of experiences can also be influenced by challenges that the caregiver experiences with regards to the availability of health care services specifically aimed at treating the patient, knowledge associated with caregiving and experiences and/or ability to provide in the emotional and physical needs of the patient (Mavundla et al., 2009:360). Experiences of caregivers can be influenced by numerous factors concerning the patient, for example:

- Adherence to treatment;
- Isolation;
- Physical care; and
- Lack of education and support (Mavundla et al., 2009:361)

2.7.1.1 Economic and financial experiences

In a study by Mhaule and Ntswane-Lebang (2009), researchers found that poverty and unemployment greatly contributed to the experiences of caregivers as burdens were intensified by concerns of money related to treatment, such as transport to hospital; expenses related to the behaviour of the person with schizophrenia, namely aggressive behaviour resulting in damaging property, consequently resulting in the family having to take responsibility for costs incurred and; concerns related to the future care of the person with schizophrenia. The latter is supported by Mavundla et al. (2009:361, 362), who found that financial constraints posed a challenge to caregivers with regards to caring for the patient, maintaining the household and assisting the patient in managing finances in cases where the patient receives a grant from the government. The process of deinstitutionalisation can be considered a contributing factor to caregiver burden as the process required the family to restructure the family system to accommodate the mentally ill family member (Mavundla et al., 009:358). It can be concluded that the latter has an impact on the family, as this system is affected by changes in other systems in their environment.

2.7.1.2 Social isolation

Research by Mhaule and Ntswane-Lebang (2009) found that caregivers experienced feelings and changes related to sacrifice, as they had to make the decision to care for their family member when no one else would. Because of this, certain areas of their lives were affected, for example, relationships being sacrificed to care for family members and social isolation accompanied by feelings of entrapment. Social isolation did not only refer to social circles but also to caregivers feeling isolated by extended family members. In this study, family members identified violence and aggression as being the worst part of caring for a family member with schizophrenia. Violent and aggressive outbursts are experienced by caregivers as burdening and catastrophic and are accompanied by feelings of worry/concern of provoking the patient and that the patient may get into trouble with others (Mhaule & Ntswane-Lebang, 2009:129), thus contributing to social isolation. The focus of the caregiver is taken over by the caregiving function and this may result in the caregiver having less time for themselves and engaging less and less in social activities, for example, going to church or being involved in social/community activities. This results in the caregiver neglecting their needs and depriving themselves of social interaction and the possibility of receiving support from systems outside of the family (Mavundla et al., 2009:361).

2.7.1.3 Education

Caregivers in rural areas are often not educated about the illness, methods or mechanisms of coping with the patient and the illness and on how to provide support to the patient, resulting in caregivers experiencing frustration. Caregivers in rural areas are often uncertain about where to find and access resources and there is a need for knowledge regarding the illness and available resources to aid them in their role as caregiver (Mavundla et al., 2009:361, 362). Since the family system or even the non-familial care system (in cases where there are no biological family to provide care and support services) plays such an important part in the functioning of the individual with schizophrenia, it is important that certain needs pertaining to the illness and care aspects be addressed by means of providing information, clinical guidance and support to the family/caregiver (McFarlane et al., 2003:224). The latter can be linked to the experiences of the caregiver (whether a family caregiver or non-familial caregiver) as literature on schizophrenia indicates that families experience coping difficulties relating to the caring aspect and suggests that services should be provided to assist families in dealing with these difficulties and the stigma related to the illness (Fadden, 2007:23, 24). Thus, when looking at suggestions on possible intervention, it can be deduced that the family experiences are influenced by the illness and the availability or accessibility of support services to the family and that services focusing on psychoeducation, support and skills training can help the family to cope better with changing circumstances.

2.7.1.4 Caregiver burden

The impact of schizophrenia on the family is influenced by an array of external and internal factors. These factors may include variable such as family relationships, marital relationships, gender, age, financial income, material assets, family resources, psychological strengths and coping skills of family members. Past research have shown that living with and caring for a person with a severe mental illness can result in what is referred to as caregiver burden. Caregiver burden is a term used to describe features of the caregiving process within the family system, and is divided into objective and subjective burden. Objective burden refers to external factors that are visible and observable such as problems with regards to physical care and finances. Subjective burden refers to internal factors related to the caregiver’s experience of the illness and their role as caregiver. Subjective burden does not follow objective burden and the one can be experienced without the other (Atkinson & Coia, 1995:33).

A lack of information about mental illness can be a contributing factor in the burden experienced by caregivers, as is usually the case at the onset of the illness as well as on where to get support and assistance (Jungbauer et al., 2004:668). A study by Du Plessis et al. (2004:14), found that family members did not understand the patients' behaviour due to a lack of information on mental illness. The latter can be contributed to a lack of community resources to provide services and education – this is characteristic to most areas of South Africa (Lippi, 2016:3). Lippi (2016:6) further argues that families of persons with schizophrenia experience a high level of burden and receive minimal education relating to their members' illness and how they can cope with it. Due to this, families often feel disempowered (Fadden, 2006:26). Apart from inadequate service provision by mental health professionals, families also experience high levels of burden and significant stress (Saunders, 2003:175). Stress can be caused by various factors involved in dealing with the daily care of mentally ill patients as it affects all aspects of family life (Saunders, 2003:176). Du Plessis et al. (2004:4), found that families started to become despondent because of their inability to cope with their responsibilities relating to care and support to the patient. The researcher is of the opinion that this can be linked to a lack of information about schizophrenia and support services to family members.

- **Subjective and objective burden**

In a study on the "Caregiving burden among relatives of patients with schizophrenia in Katsina, Nigeria", the authors identify caregiving burden as being either subjective or objective (Yusuf, Nuhu & Akinbiyi, 2009:43). They found that caring for a person with schizophrenia has a significant effect on the caregiver, because of what they call the "shift of burden" from institutionalised care to family care. This burden of care can be either subjective or objective. Objective burden refers to the tasks that the caregiver must perform in order to care for the patient, whereas subjective burden refers to the "…extent to which the caregivers perceive the burden of care" (Awad & Voruganti, 2008:149). Yusuf et al. (2009:43), on the other hand defines objective burden as "…readily verifiable behavioural phenomena", referring to the negative impact that caring for a patient with schizophrenia has on the caregiver, for example, socially, financially and with regards to employment. This definition relates to Jones's definition of objective burden in the sense that the tasks required can affect the caregiver on different levels of functioning, for example, the caregiver might not be able to sustain full-time or even part-time employment, due to the obligation of caring for the patient. This, in turn, can have an adverse effect on the caregiver with regards to financial income and may be a cause of worry or stress for the caregiver. In contrast with Awad and Voruganti (2008:149), Yusuf et al. (2009:43), define subjective burden as the emotional strain experienced by the caregiver. Emotional strain can be influenced by stigma related to the illness and can include feelings of fear, sadness, anger, guilt, loss, and rejection by the caregiver. In accordance with Awad and Voruganti (2008:149), Yusuf et al. (2009), agree that the shift to community-based treatment has had an impact on caregiving burden, as the day to day responsibility of caring for mentally ill patients have been shifted from institutionalised care to the family. The latter, according to Yusuf et al. (2009:43), has led to a "profound psychosocial, physical and financial burden on patients' families". Based on the latter, it can be concluded that an array of responsibilities is placed on the caregiver with regards to caring and providing in the needs of the patient. Caregiver burden can also be a result of patients not adhering to treatment as it has been found that patients cease to use medication as a result of side-effects experienced, not remembering to take their medication or because of negative attitude towards western medication and belief in cultural medicines or practices to treat and/or cure illness (Mavundla et al., 2009: 359).

2.7.1.5 Stigma

Stigmatizing people sometimes means applying a certain stereotype, for example, that people with schizophrenia are dangerous. Public perceptions influenced by stigma can be detrimental to the patient and the family as it can affect their functioning within different life areas, for example, socialisation, interpersonal relationships, their ability to access employment and health care services (West, Hewstone & Holmes, 2010:132). Stigma is a complex phenomenon and is closely linked to societies' level of education and knowledge of mental disorder, hence what they know about mental illness and their beliefs about people who are suffering from or living with mental illness. Stigma can be divided in three categories:

- **Self-stigma** which refers to the way in which the patient with a mental illness perceives themselves and their own mental illness;
- **Personal stigma** which refers to the manner in which the patient view or perceive mental illness;

- **Public stigma** which describes society's view on and attitude towards mental illness and is the general belief that people who are living with a mental illness are stigmatised by society (Gibson, 2011).

Both self-stigma and public stigma involves stereotyping, prejudice and discrimination. For example, with regards to public stigma, people with mental illness may be perceived as being dangerous. This results in attitude where mental health care users are avoided or not granted the same opportunities as people without mental illness, as they are regarded as dangerous. With regards to self-stigma, people with mental illness may perceive themselves as not being competent compared to others, resulting in them feeling demotivated or not taking hold of opportunities because of their perception of themselves (Corrigan, 2004:617). From this it can be deduced that public stigma influences self-perception, resulting in self-stigma as the individual internalises the negative perceptions from the public resulting in them developing negative feelings about their mental illness and about themselves (Latalova & Prasko, 2014:1399). In South Africa, caregiver burden can be further exacerbated by stigmatisation of mental illness and cultural perception, that may become barriers to mental health care (Kritzinger, Swartz, Mall & Asmal, 2011:140). Stigma can be perceived as an external factor which affects its objects internally, consequently resulting in subjective internalisation of the negative valuations from the external environment (Phillips, Pearson, Li, Xu & Yang, 2002:448). A study by Mhaule and Ntswane-Lebang (2009) found that caregivers experienced fear and embarrassment with regards to their affected member brought on by other family members' fear and embarrassment as well as by gossip. Shame felt because of their situation and about the patient, in some cases, resulted in social isolation to avoid having to answer questions about the patient's behaviour and/or condition. People living with mental illness are often subjected to discrimination and stigma, which can subsequently result in isolation and an increase in suicide rates (Matlala, Maponya, Chigome & Meyer, 2018:46).

In conclusion, it can be deduced that stigma is a phenomenon resulting from society's negative attitudes and behaviour towards mental illness, illustrating the level of social separation between society and those viewed as mentally ill, creating a division resulting in people with mental illness being excluded from society and their rights as citizens. Societal views and attitudes towards mental illness play a fundamental role in how persons with mental illness are perceived and affect the families' behaviour towards the patient. Isolation and alienation due to stigma may result in a poorer prognosis for the patient. It is also very possible that the difference in how the patient views their mental illness and the families' perception of mental illness may result in different degrees of stigma (Atkinson & Coia, 1995:24).

2.8 The role of social worker in mental health

The researcher is of the opinion that the role of the social worker with regards to this research topic, stretches over different areas of specialisation within the field of social work. For the purpose of this research study, community-based social work and mental health social work is regarded as a main area of focus.

2.8.1 Community social work

The role of the social worker is threefold if we look at it with regards to community social work. Social work in general, consists out of practice in different areas of society, whether it is community social work, statutory social work, employee wellness, social work in healthcare or clinical social work. Many focus areas of social work are either directly or indirectly geared towards the community as we have to provide services to individuals, looking at those individuals as a functional part of a larger family system. Thus, looking at an individual holistically, as a person functioning within their community. This links to the phenomena of de-institutionalisation, as the individual, after the process of de-institutionalisation, now needs to function in the family system which in turn, functions in the community system. When providing services at a community-based level, the social worker needs to focus on:

- Case management – where the social worker provides direct services to the client, focussing on the specific needs of the client and how the client can use resources, both personal and community-based, to address and/or fulfil needs;
- Community development – where the focus of the social worker is on developing community-based resources, thus creating or further developing existing resources and linking client to these resources to enable them to meet their

needs as indicated above and to make resources available in areas where there is a lack thereof to provide necessary mental health and supportive services;

- Therapeutic intervention – where the role of the social worker is to provide counselling and support services to individuals, for example, to the caregiver of a mental health care user with schizophrenia, to help them deal with personal emotional or mental health issues affecting their day to day functioning and to help them cope more effectively in order to improve and promote healthy family life and relationships (Payne, 1995:1, 2).

2.8.2 Mental health social work

Tilbury (1993:33) describes the role of social work with regards to mental health to "…reduce pain, relieve stress, offer practical services, bring in resources, restore social functioning, promote growth and development, speak up for the weak and powerless, protect the vulnerable and help people take control of their own lives". The role of the social worker is thus to provide counselling and therapeutic services to affected individuals, but also to provide practical assistance with regards to making decisions by educating individuals and providing them with the necessary and most relevant information pertaining to their situation. The role of the social worker is often the same across different areas of specialisation. For example, if we compare the role of the social worker in community-based services with that of mental health care, some of the roles are the same with regards to linking individuals to resources or even developing resources and providing support and therapeutic services to individuals. Tilbury (1993:34) specifically states that the social worker is not a diagnostician, but as a social worker, one needs to be equipped with the knowledge to identify symptoms and behaviour to identify whether one's client possibly presents with mental illness. Other roles of the social worker include:

- To advocate for the rights of clients and those who are most vulnerable and have multiple needs;
- To empower clients with knowledge and skills so that they are able to make informed decisions and make positive changes in their lives and to link them with relevant resources within their communities;
- Discharge planning;
- Case management;

- To address the psychosocial needs of the patient and family;
- To work in a multidisciplinary healthcare team to provide the most effective of services to the patient;
- To coordinate and plan care as well as support services to families;
- To execute interventions that are ethically and therapeutically appropriate to the needs of the patient and family; and
- To be resourceful and creative to come up with alternatives when no resources are available (Corwin, 2002:166).

2.8.3 Role of the social worker with regards to the patient:

The role of the social worker can be described as follows:

- To explore the patient's reality: how they view their mental illness and what they are experiencing with regards to dealing with their diagnosis, symptoms, and the families' reactions and behaviour towards them etc.;
- To show empathy and measure the patient's boundaries of the illness, for example, what functions of their lives the patient is able to sustain. The social worker should not only make assumptions about what the patient can and cannot do, but should evaluate and measure their abilities in order to empower them and prevent them from becoming dependent when they are able to perform certain functions; and
- To help the patient keep in touch with reality by distinguishing between reality and what the patient perceives as reality; to help the patient develop their own specific strategies to cope with and control the symptoms of mental illness and to identify, promote and strengthen their existing skills as measure to improve their coping mechanisms.

2.8.4 Role of the social worker with regards to the family and caregiver

When a family member takes on the role of caregiver, it is natural that the person will have some sort of response to the new role they have to fulfil. The new caregiver may have a response to the mental illness itself as well as towards their new role as a caregiver. It is important that the social worker who is working with the caregiver distinguish between these two responses (Atkinson & Coia, 1995:31). By distinguishing between these roles, the social worker will be able to more clearly identify the caregivers' responses on different levels as well as their needs, challenges, fears, expectations and so forth, providing a clear indication as to what intervention geared towards the caregiver should be focused on. The social worker in the context of providing services to the caregiver may focus on increasing the caregiver's understanding of their responses and coping mechanisms towards schizophrenia by means of education as this will help them understand why they are responding the way they do, and open up new avenues for exploring positive changes by tapping into their internal strengths and resources (Atkinson & Coia, 1995:31).

2.9 Summary

In conclusion, South Africa has not had a fruitful excursion into deinstitutionalisation. Deinstitutionalisation was very successful in countries like America and in Britain, but this was due to external factors like good support systems, excellent public healthcare, informed and educated caregivers. In South Africa, insufficient and ineffective public healthcare systems have contributed to the burden upon the caregiver of mentally ill patients. Caring for patients diagnosed with mental illness requires a strong support system to the family in the form of education to the patient and family on mental illness, the effects, symptoms etc.; easily accessible support services within communities; continuous external support from professionals; and community-based programs to aid in continuous development and education to caregivers and family members. Our Constitution and the Bill of Rights makes provision for the dignity of each individual and access to basic services of which healthcare is a primary issue. Therefore, mentally ill patients along with their caregivers must be provided with the same dignity and respect as any other resident. As a developing country, we are continuously investing in infrastructure and reviewing systems to better the livelihood of all individuals within South Africa. Although the benefits of deinstitutionalisation are clearly stated in this study, it can only suffice with better infrastructure such as more available funds, education for the caregiver, increase in mental health care hospitals and outpatient facilities within provinces, more specialised personnel that provide support and so forth. It is also critical to mention the role that the Social Worker plays within this environment. Not only does the Social Worker provide assessments of the mentally ill patients but can also provide training and debriefing to caregivers of mentally ill patients.

The following chapter will focus on the methodology and research findings.

3. CHAPTER 3: RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS

3.1 Introduction

In this chapter, the research methodology used during the study is described. The chapter focusses on the research approach, type of research, research design and research methods. It continues to describe the study population and sampling methods used to choose the participants for the study. Data collection and analysis is described in detail, as well as the ethical considerations that guided the study and the implementation and outcome of the pilot study, aimed at testing the research instruments. A description of the methods of data analysis is described, as well as trustworthiness and the ethical considerations. The research findings provide a discussion of the themes and sub-themes identified in the study, supported by relevant literature and quotes from the participants' face-to-face interviews.

3.2 Goal and objectives

3.2.1 Goal

The goal of the study was to explore and describe the experiences of caregivers of mental health care users diagnosed with schizophrenia.

3.2.2 Objectives

The objectives of the study were as follows:

- To describe and contextualise schizophrenia using the biopsychosocial approach;
- To explore and describe the biopsychosocial experiences and challenges of caregivers of mental health care users with schizophrenia;
- To ascertain the tasks, roles and challenges of caregivers in caring for a person living with schizophrenia;
- To explore the intervention and support provided by professionals to the caregivers of a person living with schizophrenia; and
- To suggest strategies for social workers on intervening with caregivers of mental health care users with schizophrenia.

3.3 Research approach

The selected research paradigm for the study is the interpretive approach. Nieuwenhuis (2016:60) states that the "…ontological assumptions of interpretivism are that social reality is typified by a multiplicity, since dissimilar people interpret events differently, leaving multiple perspectives of an incident". To understand how the caregivers of persons with schizophrenia construct the meaning of their world and social reality, the researcher aimed through the use of this research paradigm, to explore the caregiver's experiences and their world to understand their experiences and how it influenced their biopsychosocial functioning (Nieuwenhuis, 2016:60). The study followed a qualitative research approach, as the study intended to become familiar with the experiences of caregivers of mental health care users with schizophrenia in Upington. The study explored the biopsychosocial functioning of the caregiver and the influence that caring for a person with schizophrenia can have on the caregiver. The study also aimed to describe the influence of caregiving on the caregiver, thus painting a picture through explorative and descriptive research (Neuman, 2011:39).

Using a qualitative approach enabled the researcher to use a smaller sample of participants to answer research questions, in a way that offered a more comprehensive understanding of the social problem identified (Fouché & De Vos, 2011:90). The purpose of the research study was "…to study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (Padgett, 2008 as cited in Lietz & Zayas, 2010:189), for example, to describe the experiences of caring for a person with schizophrenia, in order to gain insight into the caregiving experience (Fouché & De Vos, 2011:95); to gather information on and explore the influence of the caregiving burden on the biopsychosocial functioning of the caregiver, thus attempting to identify problems or issues that need to be addressed or solved.

Exploring the experiences of caregivers of persons with schizophrenia was done by collecting data on the participants' accounts of their experiences as caregivers and how this affected them on different levels, that is, physical, mental, social and financial functions (Fouché & Delport, 2011:65). Through descriptive research, the study aimed to describe the experiences of the caregivers, that is, how the caregiver was affected by caring for a person with schizophrenia; how the caregiver was equipped to deal with caregiving; and how the caregiver experienced caring for a person with schizophrenia. The researcher sought to comprehend how the caregiver of a person with schizophrenia constructed how they experienced the task of caring for the patient with schizophrenia in terms that were meaningful to them and that offered the researcher insight into the caregiving experience (Flick, 2007:x). As stated by Fouché and De Vos (2011:95), the need for an exploratory study can arise from the need to get acquainted with a situation, allowing the researcher to formulate a problem or develop a hypothesis. Making use of qualitative research in the study was not to test existing theories, but to explore and understand phenomena through the use of specific methodology with the aim of answering questions of complex phenomena (Fouché & Delport, 2011:64). The selected qualitative approach thus aimed to describe the population consisting of caregivers of mental health care users with schizophrenia by gaining first hand narratives from them to understand their experience.

3.4 Type of research

The study was applied in nature as the study aimed to contextualise the experiences of the caregiver, as well as the influence of caregiving on the biopsychosocial functioning of the caregiver. This occurred through exploration and description in a manner which can be used to address concerns and offer solutions, for example, through recommendations for further studies. Applied research was most suited for the study, as it focuses on understanding the nature of the caregivers’ experience and the source of problems experienced by the caregiver. The results of the study can be used to formulate programmes and intervention strategies to help the caregiver cope with caring for a person with schizophrenia by understanding the experiences and using this knowledge gathered to address the psychosocial influence on the caregiver (Patton, 2015:250).

3.5 Research design

The researcher made use of the instrumental case study design where the experiences of caregivers were the phenomena or cases that were studied within the context of caring for a person with schizophrenia (Nieuwenhuis, 2016:81). The case study on the experiences of the caregivers was bound by place and time

(Creswell, 2003 in Nieuwenhuis, 2016:81) as the researcher conducted the interviews in Upington, Northern Cape Province.

The type of case study design that the researcher used in the study was the instrumental case study design, as the study did not only focus on the case itself, which was the experience of the caregiver but also on understanding underlying meanings of the case being studied, to gain insight and understanding into the experience of the caregiver and the influence of caring on the caregiver (Nieuwenhuis, 2016:82, 83).

3.6 Research methods

In the research method section, the researcher focused on the study population, identifying why the chosen population should be the target of study; sampling approach and methods specifying criteria for selection; data collection and techniques and instruments; how data would be analysed and presented; how trustworthiness of the data would be ensured and the testing of data collection instruments through the pilot study.

3.6.1 Study demarcation, study population, sampling method and sample

3.6.1.1 Study demarcation

The study was demarcated in Upington, Dawid Kruiper Local Municipality, ZF Mgcawu District Municipality, Northern Cape Province. The Northern Cape Province, has the lowest population of all provinces in South Africa, at 1 193780, with Afrikaans spoken by 56.8% of the population according to the Provincial Profile: Northern Cape, Community Survey 2016, (Statistics SA, 2018:7). The ZF Mgcawu District, is one of five districts in the Northern Cape, with a population of 252 692, comprising 21.2% of the population of the province (Statistics SA, 2018:9). The ZF Mgcawu District comprises 67.4% coloureds, 23.2% Black Africans, 9% Whites and 0.4 Indian/Asian (Statistics SA, 2018:17). The Dawid Kruiper Local Municipality, comprises a population of 107 161 (Statistics SA, 2018:9). Based on statistics from the 2011 census, Upington has a population of 75,220 people. The town comprises of 78% coloureds, 7.1% Black Africans, 13.2% Whites and 0.7% Indian/Asian. The most spoken language is Afrikaans which is spoken by 93.4% of the town's population (Statistics SA, [sa]). Thus the reason why most of the interviews in this study were conducted in Afrikaans.

3.6.1.2 Study population

The study population comprised caregivers (familial and non-familial) who were caring for persons with schizophrenia in Upington. The researcher took into account the accessibility of the study population to which she had access (Gliner, Morgan & Leech, 2009:15), as Upington had no designated mental health care facilities (both in-patient and out-patient treatment centres). The District Department of Health was approached for permission and ethics clearance to conduct the study in Upington. The study then commenced by approaching five primary health care clinics in different areas of the town for identification and recruitment of participants.

3.6.1.3 Sampling method and sample

Gliner et al. (2009:115), describe sampling as follows: “Sampling is the process of selecting part of a larger group of participants with the intent of generalising from the sample (the smaller group) to the population (the larger group).”

The above mentioned definition of sampling indicates that inductive reasoning is used to move from the particular to the general, following a bottom-up approach (Delport & De Vos, 2011:49), thus selecting a small sample of caregivers from a larger population, studying the population and generalising the results to the larger population.

The sample for the study was selected according to access to cases that were relevant to the study and these cases were studied against the background of schizophrenia (Strydom & Delport, 2011:390). Non-probability sampling was used, as cases were sought and selected to be studied according to selection criteria. The purpose of using non-probability sampling was to collect a wide range of information, in this case on caregiving people with schizophrenia (Strydom & Delport, 2011:392). The researcher opted for purposive sampling by selecting the most productive sample in order to answer the research question (Marshall, 1996:523).

Initially, due to minimalistic mental health care services and lack of mental health care institutions in the district and local municipality and Upington, the researcher planned to ask psychologists at the Dr Harry Surtie Hospital, the Medi-Clinic private hospital and District Department of Health, to help recruit participants by providing them with an information letter on the details of the study. However, the Dr Harry Surtie Hospital and Medi-Clinic private hospital options did not work out and researcher eventually had to approach the District Department of Health for permission and for participants. She was promised assistance with the recruiting of participants, by being invited to a meeting with all the professional nurses in charge of the local clinics. Here she presented an information letter regarding the research to them and requested their assistance with the study, by asking them to share the information letter with nurses working at each of the clinics identified in Upington. They would then share the information of the study with patients' caregivers as prospective participants in the study. Those who were interested would be asked to provide their contact details, so that it could be shared with the researcher to contact them to partake in the study. These details were collected by researcher from the different clinics. Those who met the selection criteria were contacted by researcher and home visits were conducted to explain the purpose of the research study, explain the letter of informed consent and get their voluntary informed consent to participate.

The inclusion criteria for selecting participants were as follows:

- Participants had to reside in Upington.
- Participants had to be either English or Afrikaans speaking, as this was what the researcher spoke.
- Participants had to be responsible for caring for a family member or non-familial member with schizophrenia who resides with the participant in Upington.
- The mental health user who the participant was taking care of had to be on treatment for schizophrenia.

During the sampling process the researcher experienced some challenges finding a sample of ten participants as initially planned. Two of the five clinics that were approached, could not deliver any participants, providing feedback that there either weren't any patients being treated for schizophrenia in the area or that those possible caregivers who were approached were not interested in taking part in the study. Participants were eventually recruited from the three remaining clinics identified for sampling. The researcher was eventually able to get a sample of only eight voluntary participants. Thus researcher has to suffice with a smaller sample, due to the small population of the district, local municipality and town with limited number of clinics and patient caregivers, time constraints and work obligations and relocation to another town in the province.

3.6.2 Data collection

Data was collected through the process of interviewing which is a "…predominant mode of data or information collection in qualitative research" (Greeff, 2011:342). Through one-to-one interviewing, making use of the semi-structured one-to-one interview with an interview schedule, data was collected by making use of audio recordings and field notes to document data. By making use of voice recording as a data-collection method, the researcher was able to remain focused on the interview and the process at hand (Greeff, 2011:359) and not lose focus concentrating on taking down notes. The consent of participants was sought before starting or recording the interview.

One-to-one interviews allowed the researcher to get as much data as possible, which was thick and rich. The interviewing process can be negatively influenced by the unwillingness of participants to cooperate, especially if they feel uncomfortable being recorded (Greeff, 2011:361). Even though all of the participants took part voluntarily in the study, the interviewing process may have been influenced by the use of recordings, as some participants did not communicate as spontaneously once the session recordings started. Some other disadvantages of interviewing as a data collection method, include untruthfulness by the participants; the participants developing an intimate relationship with the researcher, for example, when the relationship borders on becoming therapeutic. The researcher addressed the disadvantages of one-to-one interviewing, by explaining to participants before the commencement of the study the data collection methods and techniques and including this information in the consent form. Communicating with the participants about the purpose of the study and the role of the researcher in the study was useful in avoiding the risk of changing the interviewing relationship into a therapeutic relationship.

3.6.3 Data analysis

Data was analysed according to the six phases of thematic analysis (TA) by Clarke, Braun and Hayfield (2015), focusing not only on the explicit meaning of the data, but also on the underlying meaning of the data, that is, data obtained through interpretive questioning by the researcher (Clarke et al., 2015:225, 226). After collecting and preparing the data the researcher continued to analyse the collected data through the following steps:

- **Familiarisation**

In this first phase, the researcher became familiar with the data by meticulously studying the data, reading through the data at least twice, making notes on any questions that arose, while also recording observations made during interviews and insights gained while observing behaviour. The researcher questioned the data and identified meaning regarding the caregiver experience that lies under the data surface, for example, how did the caregivers view their world and make sense of their experience? There is a level of interpretation as the researcher tries to make sense of the caregiver experience through the worldview of the caregiver (Clarke et al., 2015:226, 230, 231).

- **Coding**

The second phase in TA required the researcher to reduce data to themes through the process of coding. Coding is a systematic process through which the researcher will identify and label relevant features of the data. These relevant features are related to the research topic. The researcher coded at the latent and semantic level, also identifying and noting the underlying meaning of the information or data communicated by the participant. After reading through specific data items, the researcher coded relevant data by scribbling notes on the transcripts from the interviews. The scribbled notes were collated by creating a Microsoft Word document for each code. During the first round of coding, the researcher will mainly be coding semantic data, going through a second round of coding to identify latent data (Clarke et al., 2015:234.235.236).

- **Searching for themes**

Themes were derived from the data by clustering together similar codes and mapping data to create logical and consistent themes. The themes derived from the data must centre around the experiences of the caregiver in the context of caring for a person with schizophrenia, taking into account the influence of caring on the biopsychosocial functioning of the caregiver, linking the experiences to the observations made, or underlying meaning of data identified through familiarisation (Clarke et al., 2015:235, 236). The researcher makes use of thematic maps to develop individual themes and to explore the relationship between themes (Clarke et al., 2015:238).

- **Reviewing themes**

Clarke et al. (2015:238), suggest reviewing themes in two ways: “in relation to the collated, coded data for each theme; second in relation to the entire data set”. If the themes are in relation to the coded data, the researcher will evaluate if it is in relation to the entire data set, for example, the themes identified must be linked to the research question and the content of the data gathered by means of qualitative research methods (Clarke et al., 2015:238).

- **Defining and naming themes**

During this phase the researcher will define the themes identified by describing themes, explaining their nature and the “…scope and coverage, and boundaries of each theme” (Clarke et al., 2015:240).

- **Writing the report**

In this phase the researcher compiled and wrote down her qualitative research findings, identifying how she chose to implement thematic analysis and why (Clarke et al., 2015:241). It is in this phase that the study is placed in context and the written research should be analytical (Clarke et al., 2015:241). The writing of the report entailed linking data or weaving together the collected data, research methods and literature after which the researcher came to a conclusion on the study and made recommendations for further studies.

3.6.4 Data quality

When conducting a qualitative research study, it is of utmost importance that the perspectives of the caregivers and information on their experiences relating to the theoretical framework are gathered in the most genuine way as communicated by the participants; this information must be accurately represented in the study's findings (Lietz & Zayas, 2010:191). In the study, the quality of data will be measured by determining the trustworthiness of the analysed data, findings and conclusions (Nieuwenhuis, 2016:123). In the process of determining trustworthiness, De Vos (2011), Maree (2016) and Lietz and Zayas (2010) agree on the four specified criteria for evaluating the trustworthiness of a study as coined by Guba (1981, 1999, 1985) as follows:

- **Credibility**

The research study will determine trustworthiness by determining if the study was carried out in such a way that it ensures that the phenomenon being studied e.g. experiences of caregivers of persons with schizophrenia, is accurately identified and described in the study (Schurink, Fouché & De Vos, 2016:419, 420). The research study aimed to increase credibility by:

- Managing the risk of research reactivity by concealing recording devices (with the knowledge of the participants) during semi-structured interviews, being aware of the impact of research procedures on findings as well as researchers' bias on the process (Lietz & Zayas, 2010:192). Researcher noticed some participants felt uncomfortable with the recordings and could explore this through debriefing.
- Triangulation was used, where the researcher compared literature from different sources to support data quotes and to identify themes (Lietz & Zayas, 2010:193).
- Member checking was used to corroborate the findings with a couple of selected participants, which helped to evaluate if the findings accurately portrayed their experiences as caregivers (Lietz & Zayas, 2010:193).
- Thick description was strived for through interviews with the participants using audio-recording instruments and taking notes, as well as making use of probing to obtain more information on the subject of the study (Lietz & Zayas, 2010:194).

- **Transferability**

The experiences of the caregivers were explored in the study and are described in the findings section to follow, thus using an explorative and descriptive qualitative approach as already stated. Triangulation was used by using different sources of literature to substantiate findings. The study is transferable in the sense that the findings can be used to further studies in a similar area of focus where it can be applied to another setting (Lietz & Zayas, 2010:195).

- **Dependability**

The qualitative research study was evaluated through dependability by keeping a thorough audit trail or record of the research methods, data collection such as audio recordings and transcriptions, so that another researcher, for example, can see what processes were followed, how decisions were made and how data was collected and analysed to reach the findings (Nieuwenhuis, 2016:124).

- **Confirmability**

The researcher aimed to clearly link the data gathered during the study with the findings and aimed to increase confirmability by member checking and documentation of data (Lietz & Zayas, 2016:197).

3.6.5 Pilot study

The pilot study commenced with a literature review to become fully acquainted with the existing literature on the experiences of caregivers of mental health care users with schizophrenia. By conducting the literature review the researcher was being able to evaluate whether literature is available and relevant in answering the research question while also collecting relevant information that was necessary to clearly formulate a problem statement and plan for the main investigation into the experiences of caregivers of mental health care users in Upington (Strydom, 2011a:236).

The researcher subsequently approached the District Department of Health, requesting assistance in selecting voluntary participants who met the selection criteria as specified under point 9.1: study population and sampling. The researcher conducted the pilot study in the same manner as the main investigation, by following the same sampling process and by using the same data collection methods that were used in the main investigation (Strydom, 2011a:241). After completing phase two, the researcher focused on the feasibility of the study.

The feasibility of the study was tested by focusing on the research methods, research population, available resources, data gathering -and collection. The same research methodology and procedures in the study proposal were used in the pilot study to determine feasibility, advantages and disadvantages of undertaking the study. The latter allowed the researcher to adjust planning of the study and minimise the possible occurrence of unforeseen problems (Strydom, 2011a:239, 240). In the last phase, the researcher tested the measuring instrument by conducting a semi-structured one-to-one interview using an interview schedule with one selected caregiver of a person with schizophrenia. The participant that was selected met the specified criteria. The researcher evaluated by asking the participant to give feedback on the measurement instrument after implementation in order to address any shortcomings, confusion or any other possible disadvantages (Strydom, 2011a:241). Corrections were then made. Due to certain constraints affecting the ability of the researcher to gain more frequent access to participants, as well a the richness of the data collected during the pilot interview, the researcher incuded the participant of the pilot interview in the main study sample.

3.7 Ethical considerations

To ensure that no participants were harmed as result of the study, the following ethical considerations were taken into account:

3.7.1 Informed consent

Before the onset of the study, all voluntary participants had to sign a consent form. The consent form informed the participants of the following: the goal of the proposed study and the duration of the study; the participants' involvement, for example, semi-structured interviews, dates of interviews, length and purpose and the use of data collection equipment, for example, that a voice recorder or cell phone would be used to record the interview; procedures reporting findings; any possible advantages and disadvantages of the study and publication of findings; that they had the right to withdraw from the study at any time; protection of identity; voluntary participation which was emphasised at the start of the study, as well as before interviews (Strydom, 2011b:117); and that the data obtained will be stored at the University of Pretoria for 15 years and possibly used for future research.

After submission and approval of the research proposal by the review panel of the Department of Social Work and Criminology, University of Pretoria, the researcher submitted the research proposal along with all required documents to the Faculty of Humanities, Research Ethics Committee, for ethical clearance on-line (University of Pretoria, 2017). Permission was also sought for the study to be conducted by District Department of Health, Northern Cape.

3.7.2 Avoidance of harm

This ethical consideration refers to the possibility of participants being physically or emotionally harmed by the research process. Research must not cause harm to any participant and the researcher must avoid it as far as possible (Strydom, 2011b:115). In the study there was a possibility of emotional harm related to the exploration of the participants' experiences of caring for a person with schizophrenia. The researcher aimed to avoid this harm by informing participants before the commencement of the study of the data collection methods which required them to discuss their experiences and which may also require them to explore their feelings and relive experiences. The researcher debriefed the participants after the interview process and only needed to refer one participant who experienced challenges with a family member patient to the District Department of Health for assistance (Strydom, 2011b:115).

3.7.3 Voluntary participation

The researcher, after the sampling process, explained research procedures and other details specific to the study, giving the participants the choice to decide whether they want to take part in the study or not. The researcher also informed participants that they could withdraw from the study at any time.

3.7.4 Confidentiality

Private information regarding participants will only be known to the researcher. Confidentiality was ensured by indicating assurance of keeping information confidential in the informed consent letter and identifying the researcher and her supervisor as the only persons who will have access to this information. Furthermore, code names/pseudonyms were assigned to participants to protect their identity and this was indicated in the consent form, together with their permission for the recording of interviews. The code IM (interview member) followed by a number starting from one (1) was assigned to each member, for example, IM1, IM2 and so forth.

3.7.5 Debriefing of participants

Participants were individually debriefed after the conclusion of the interview. The purpose of debriefing is to help the participants in working through their experience of partaking in the study, in order to minimise harm, clear any misperceptions they may have had and also to terminate the process and provide closure (Strydom, 2011b:122). Debriefing was done by engaging in communication with the participants after concluding the interview and determining whether any emotional harm was caused; providing information of questions that participants had; explaining how the research process is to be continued and terminated the process.

3.7.6 Action and competence of researcher

The researcher has a BSW degree in Social Work from the University of Stellenbosch and a background of practising social work within the South African context. She is registered with the SACSSP and is currently studying towards a Master's Degree, where a postgraduate module in research methodology was completed. During the study the researcher took into account ethical considerations related to the study and participants; provided original work and avoided plagiarism, referencing sources used using the Harvard method; objectively represented finding; was aware and respectful of participant's' values, norms and views on the subject of study; and evaluated all possible risks and advantages in order to conduct an ethical study (Strydom, 2011b:124). The findings of the study are being reported in an accurate, honest, and unbiased and gender-sensitive manner (Strydom, 2011b:126).

The following section will present the research findings.

3.8 Empirical findings

Empirical data collected through interviewing eight participants who were caregivers of mental health care users with schizophrenia were conducted, recorded and thereafter transcribed verbatim. The transcripts were analysed by the researcher whereby data was coded and themes and sub-themes were identified. The biographical data collected from the participants is presented in the column below, followed by a comprehensive analysis of other biographical data by means of pie charts and a summary of the data. Thematic analysis of the research findings is then presented and supported by verbatim quotes of the participants and literature substantiation.

3.8.1 Biographical data

Table 3.1 shows the biographical data of all the participants who were interviewed making use of a semi-structured one-to-one interview using an interview schedule. A pseudonym was allocated to each participant and the patients they were caring for to protect their identity as part of the ethical considerations. The table displays information on the age, gender, relationship status, number of children, highest educational qualification, relationship to the patient and employment status of the participants.

Table 3.1: Biographical information of participants

Participant Pseudonym	Age	Gender	Relationship status	Number of children	Highest qualification	Relation to patient	Employment status
IM1	83	F	Widow	3	Grade 12	Parent	Pensioner
IM2	51	F	Single	3	Grade 12	Child	Employed
IM3	83	F	Widow	10	Grade 4	Parent	Pensioner
IM4	64	M	Divorced	0	Grade 1	Sibling	Pensioner
IM5	60	F	Divorced	3	Grade 9	Parent	Pensioner
IM6	59	F	Married	0	Grade 6	Spouse	Unemployed
IM7	60	F	Married	4	Grade 5	Parent	Pensioner
IM8	62	F	Married	3	Grade 11	Non-familial caregiver	Employed

The table reflects an overall view of the biographical data. This data is presented further in more detail in the figures below.

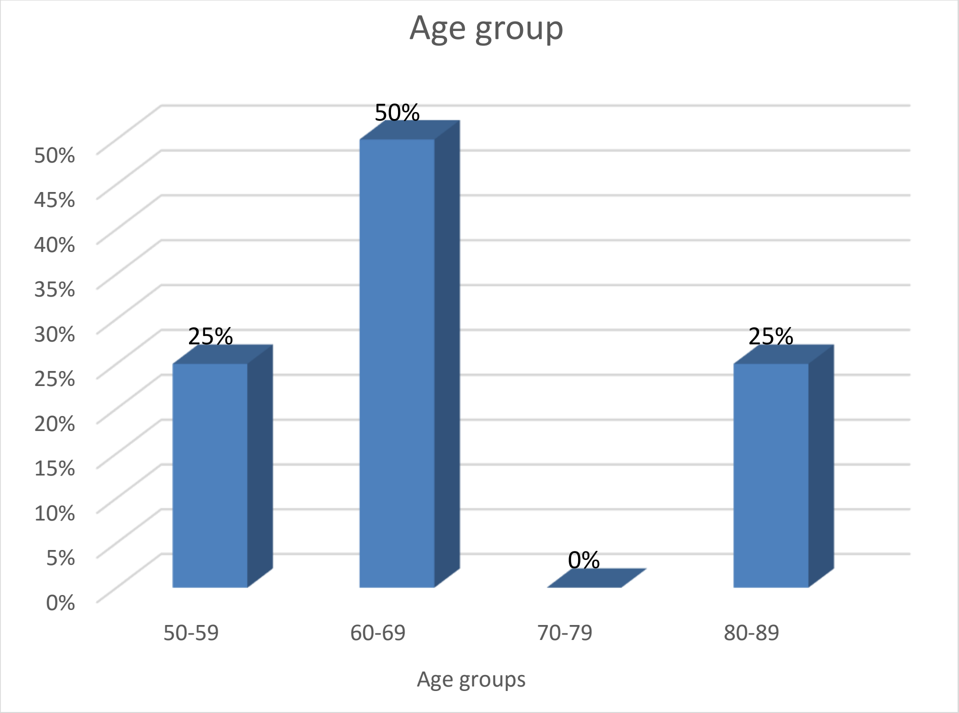

Figure 3-1: **The age of the participants (n=8)**

The figure above, displays all the ages of the participants of the study. Eight caregivers of mental health care users with schizophrenia were interviewed for the study. All participants ranged between the ages of 51 and 83 years. Of the eight participants, only two participants were under the age of 60 (25%). Four participants ranged between the ages of 60 and 64, (50%) and two participants were aged 83, (25%). Two participants thus fall into the category of elderly and six into the category of working age. Statistics show that 5% of the population in the ZF Mgcawu District fall within the age group of 65 and older, with the number of females in this age group in the Northern Cape, being higher than that of males (Statistics SA, 2018:13,15). Of the participants falling into the category of working age, only two were employed.

Figure 3.2 represents the gender of the participants who took part in the study.

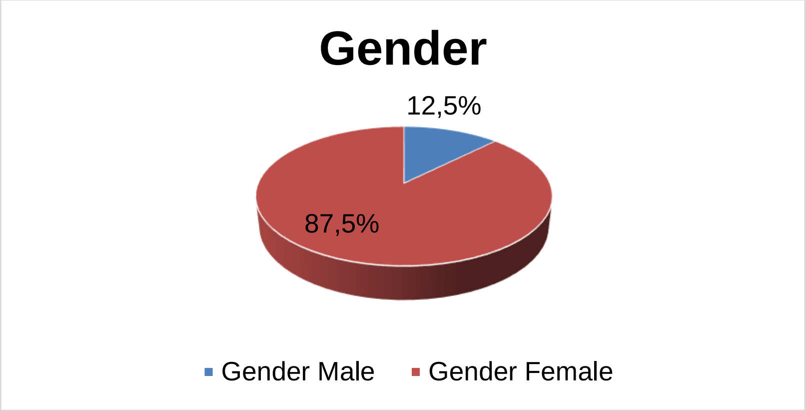

Figure 3-2: **Gender (n=8)**

Of the eight participants, there was one male (12.5%) and seven females (87.5%). This reflects that the gender of most of the caregivers of mental health care users with schizophrenia in the community were female.

The next figure displays information on the relationship status of the family and non-familial caregivers of mental health users with schizophrenia who took part in the research study.

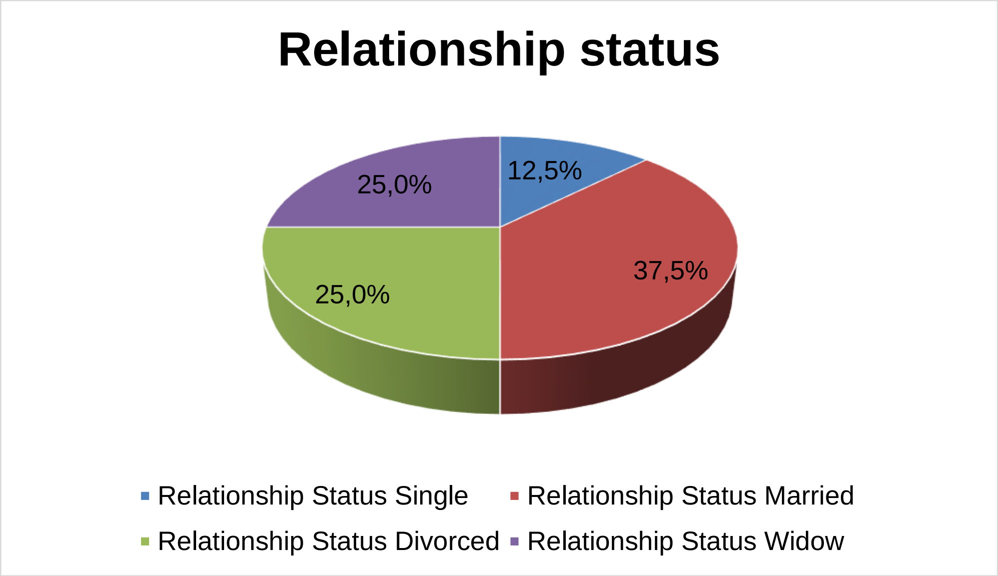

Figure 3-3: **Relationship status of the caregiver (n=8)**

In the figure above, it is indicated that out of the eight participants, two were widowed (25%). One of the participants (12.5%) was single, two (25%) were divorced, and three (37.5%) were married.

This indicates that 25% of participants fall into the category of 4.9% of the population in the ZF Mgcawu District who are widowed; 12.5% into the category of 49.4% who have never been married; 25% into the category of 1.6% who were divorced; and 37.5% into the category of the population of 30.8% who were legally married (Statistics SA, 2018:18).

Figure 3.4 shows the number of children the participants had.

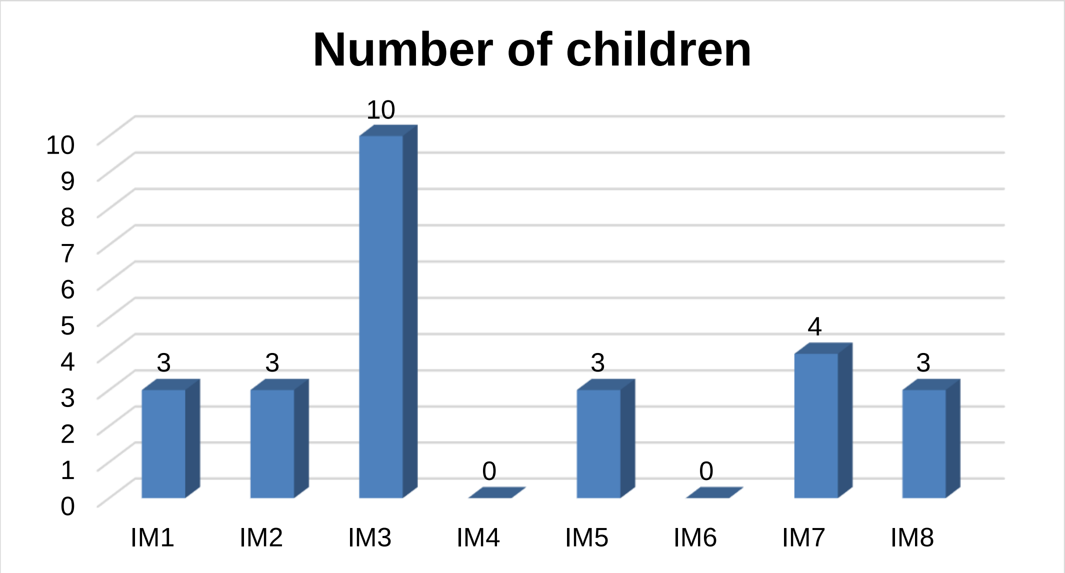

Figure 3-4: **Children of caregivers (n=8)**

Out of the eight participants interviewed, all but two participants had children. Four of the eight participants had three children each. One participant had four children and one participant had 10 children. Thus indicating that four of the participants who were parents to mental health care users with schizophrenia and one non-familial caregiver who portrayed a parental figure role, had the responsibility of caring for other children within their household as well. In the figure 3.5 below, the highest school qualifications of the participants are displayed.

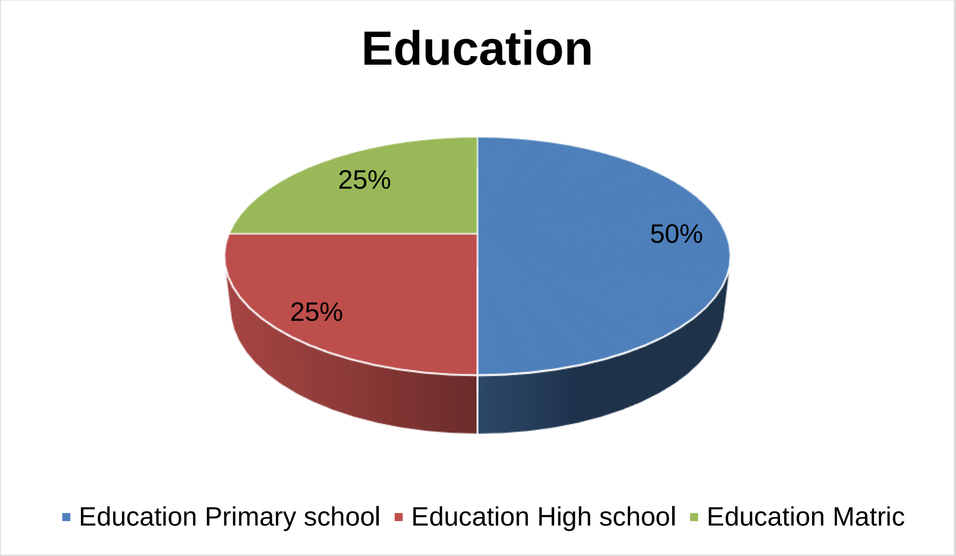

Figure 3-5: **Highest school qualification (n=8)**

The educational qualifications of the participants ranged between grade 1 and grade 12. Out of the eight participants, only four participants (50%) received a high school/secondary level education, with two (25%) completing grade 12. Four of the participants (50%) only received primary level education, ranging between grade 1 and grade 5 before leaving school.

Figure 3.6 represents the relationship of the caregiver to the patient.

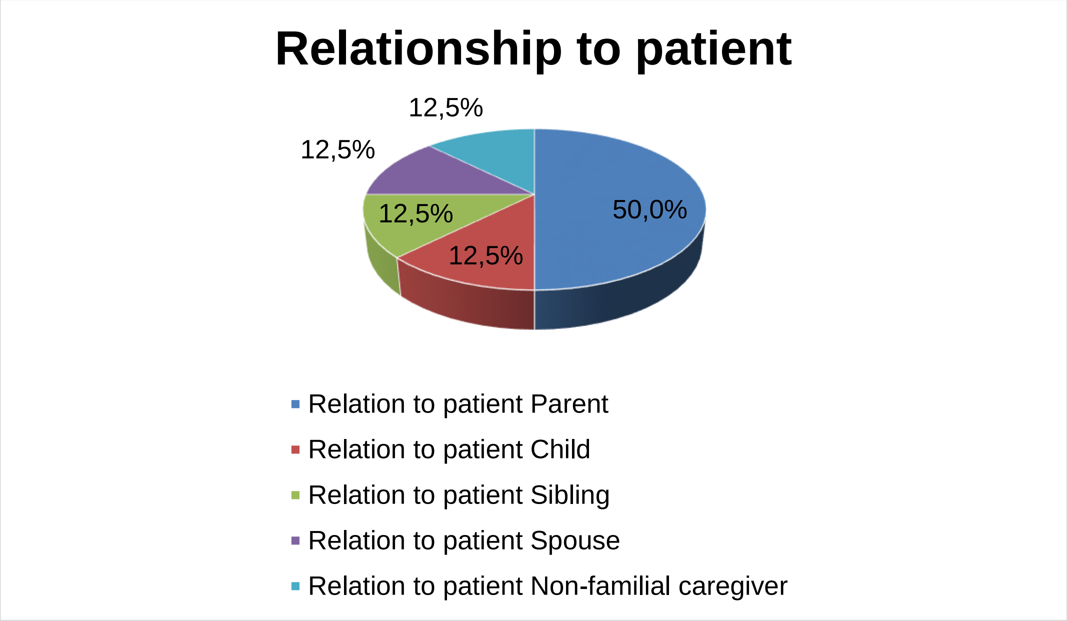

Figure 3-6: **Caregiver's relationship to the patient (n=8)**

Out of the eight participants interviewed for the study, four of the participants (50%), were parents to patients diagnosed with schizophrenia. Only one participant (12.5%) was a child of a parent diagnosed with schizophrenia. One participant (12.5%) was a non-familial caregiver, one participant (12.5%), a spouse and one participant (12.5%) was caring for a sibling diagnosed with schizophrenia.

In the next figure, the employment status of the caregivers of mental health care users with schizophrenia is represented.

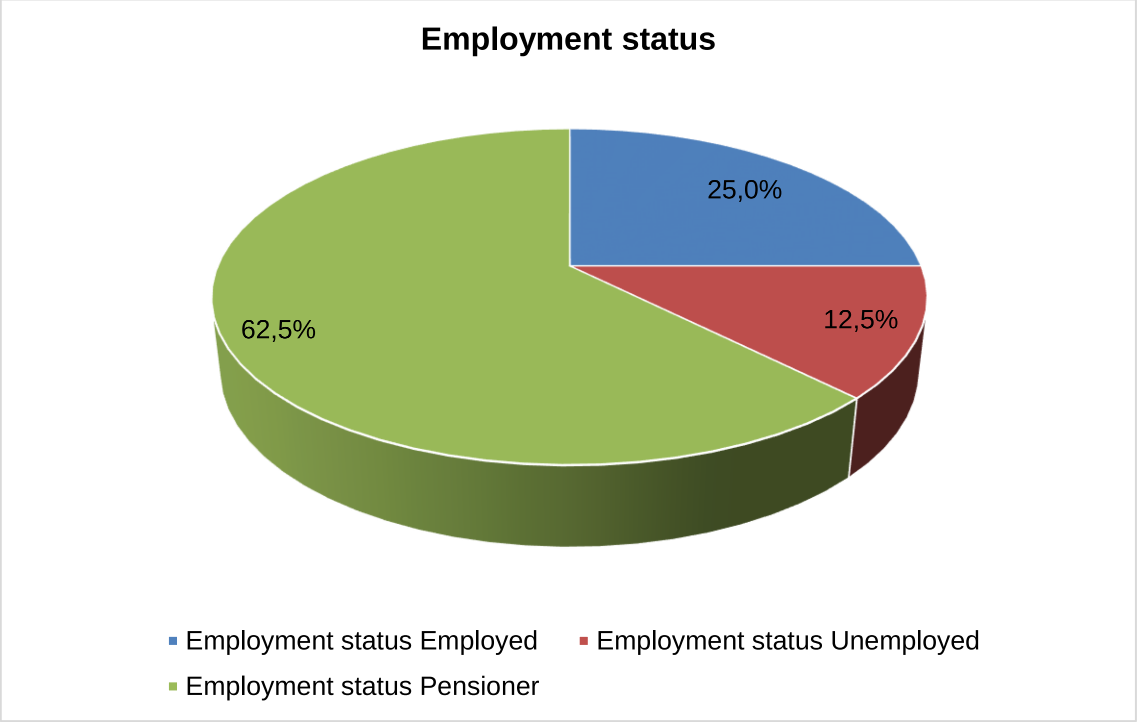

Figure 3-7: Employment status (n=8)

Out of eight participants interviewed, only two participants (25%) were employed. Of the remaining six participants, five (62.5%) were pensioners and one (12.5%) was unemployed. Based on data obtained from the Provincial Profile: Northern Cape, Community Survey 2016 (Statistics SA, 2018:93), lack of employment opportunities is rated third amongst major five challenges that are faced by municipalities in the Northern Cape, thus indicating that employement opportunities are relatively scarce.

3.8.2 Thematic Analysis

In the table below, the themes and sub-themes that were generated during the data analysis are depicted.

Table 3.2: Themes and sub-themes

Themes	Sub-themes
Theme 1 General understanding or concept of mental health and schizophrenia	1.1 Knowledge about mental health 1.2 Knowledge about schizophrenia 1.3 Perceived causes of schizophrenia 1.4 Observed symptoms of schizophrenia
Theme 2 Health care services at community level	2.1 First point of entry into the health system 2.2 Treatment and adherence to medication 2.3 Support services from the health care system to the caregiver
Theme 3 Role of the caregiver	3.1 Feelings about caring for a family member with schizophrenia 3.2 Tasks of the caregiver with regards to caring for a family member
Theme 4 Challenges experienced by caregivers	4.1 Stigma 4.2 Financial implications related to caring 4.3 Family support 4.4 Patient’s behaviour
Theme 5 Support to families living with schizophrenia	5.1 Support and education 5.2 Social work services 5.3 Community awareness 5.4 Caregiver needs

3.8.2.1 Theme 1: General understanding or concept of mental health and Schizophrenia

Most of the participants in the study did not seem to have a general understanding of what mental health or schizophrenia means. This theme was derived from exploration of the participants’ knowledge of mental health and schizophrenia and is described in terms of how they made sense of the illness, what they perceived the causes of the illness to be and what behaviours they have observed which they considered symptoms of schizophrenia.

- **Sub-theme 1.1: Knowledge about mental health**

This sub-theme focussed on the knowledge participants had of mental health:

> "Mmm, weet jy, om ommit 'plain' te sê soos die mense dit sê, sê hulle mos nou mal maar dit is so seer as die mense so sê." *["Mmm, you know, to say it plain as people say, they say crazy but it is so painful if people say that."]*
>
> "Oe ek kan jou nou rerig nie sê nie, want hy issie soos een wat geestesgesondheid had nie." *["Oh I cannot really tell you, because he is not like one who has mental health."]*
>
> "Geestesgesondheid is wanneer 'n mens in jou verstand nou, siek is." *["Mental health is when a person is sick in their mind."]*
>
> "Hoe sê ek tog nou? Dit beteken dat sy… sy sy sy sy, ek weetie hoe moet ek nou sê nie." [*"How do I say now? It means that she, she she she she, I don't know how I must say now."*]
>
> "Geestesgesondheid, is dit nie verstreerd in die, verstreerd in die 'brains'?" *["Mental health, is it not disturbed in the, disturbed in the brains."]*
>
> "Moet jy dan nie gesond wees om, v van van verstandelik gesond wesie, jy moet binnekant gesond wesie." *["Don't you have to be healthy to; of of being mentally healthy, you must be healthy inside."]*

The responses of the participants showed that most of them did not have a clear understanding of what the words mental health meant. Some of the participants understood mental health as a disturbance of the brain or sickness of the mind, with one participant reporting that mental health is what people refer to as crazy. The participants identified their perceptions of what mental health is, based on their understanding of the term; what other people, external to them perceived mental health to be; and some indicated that they were not familiar with the words mental health at all.

The latter is more of a concept of mental illness rather than mental health, as mental illness refers to a disturbance in biological, psychological or developmental processes responsible for an individual's functioning (American Psychiatric Association, 2013:20).

Of all the participants, only one participant perceived mental health as health being related to the state of the mind. This perception is supported by the World Health Organization (2019) who identifies mental health as mental and psychological well-being. Unfamiliarity with the term mental health can be contributed to mental health not receiving enough attention in South Africa (SA) and being a rather neglected topic (Herman et al., 2009:339, 340), as well as to challenges experienced by the SA health system to provide mental health services within communities, thus, possibly resulting in an occurrence of lack of knowledge on mental health –and illness.

- **Sub-theme 1.2: Knowledge about schizophrenia**

This sub-theme focussed on the knowledge participants had of schizophrenia:

> “Mmm… daai is vir my so ‘n lelike woord… Want ek sê, uhm, elke mens het ‘n, soos ons almal kanker selle het, sê ek elke mens het ‘n, as dit dan nou mal genoem moet word, mal, ‘n mal sel. Jy weet jy vang partykeer goed aan wat jy nie kan dink dis jy wat dit gedoen hettie. So dit hang net af hoe dit ontwikkel… dissie laat dit nou ‘n ding is wat uh soos ‘n medisyne of ‘n siekte wat gesond gemaak word of iets soos dit nie.” *[“Mmm… that is such an ugly word to me… Because I say, uhm, every person has a, like we all have cancer cells, I say every person has a, if it should be called crazy, crazy, a crazy cell. You know you sometimes do things that you can’t think it’s you who did it. So it just depends on how it develops… it’s not a thing that uh is like a medicine or a disease that can be healed or something like that.”]*
>
> “Oe ek ken mossie daardie biologiese woorde van julle nie.” *[“Oh I don’t know those biological words of yours.”]*
>
> “Ek weet nou nie wat beteken die woordtie, maar van ek met hulle by die klieniek geloop het, het ek by die klieniek mos nou gehoor is skisofrenie.” *[“I don’t know what the word means, but since I went to the clinic with them, I heard at the clinic that it is schizophrenia.”]*
>
> “Gesplete denke.” [*“Split thoughts.”*]
>
> “Seker gehoor, maar ek verstaan hommie.” [*“Probably heard, but I don’t understand it.”*]
>
> “Nee, ek wetie, wat, wat is skisofrenie nie, maar klink vir my skisofrenie kan wees soos wat *Nash* daar is. ‘Mind nie wat hy sê nie. Hy, hy hy doen daai ding wat hy wil doen wat in sy kop kom doen hy hom…” *[“No, I don’t know, what, what schizophrenia is, but it sounds to me that it can be like what *Nash* is. Doesn’t mind what he says. He, he he does that thing that he wants to do that comes into his head he does…”]*

Two participants were able to express their views on what schizophrenia meant to them, identifying biological and psychological factors as causes for the onset of the disease. The remaining six participants had no knowledge of the term schizophrenia, and could not provide an explanation based on their own thoughts or opinions. One participant was of the opinion that schizophrenia is caused by genetic factors, identifying that schizophrenia is caused by latent cells and that the disease develops based on how these cells develop. Another participant described schizophrenia as split thoughts, providing an indication that her understanding of schizophrenia is that it is a mental disorder.

Schizophrenia is indeed identified as a psychotic disorder in the DSM-5 (Barlow & Durand, 2005:455) and is a severe mental illness (Saunders, 2003:175) that interferes with what Nevid et al. (2003:401), refer to as intimate connections between a person’s thoughts and emotions within the brain. Four out of the seven participants were not able to express their views on what schizophrenia is, indicating that they did not know the word schizophrenia; do not understand it; or have heard it, but do not understand what it means. Another participant was not able to answer the question at all. SA is currently experiencing challenges concerning its state of mental health, as mental health is not a priority area. The latter is substantiated by health outcomes identified in the National Development Plan 2030, which makes no mention of mental health as a priority area to be focused on (National Development Plan 2030, 2012:41). Amongst the challenges experienced in the health system there are two specific factors such as a lack of professional human resources and funding constraints, which can influence education and awareness services at community level. The latter can result in caregivers not being educated on mental health and schizophrenia in particular, due to the lack of professionally employed individuals trained to provide this specific service, as well as funds to run community-based awareness programmes to provide education and training on schizophrenia (Presidential Health Summit Report, 2018:43).

- **Sub-theme 1.3: Perceived causes of schizophrenia**

This sub-theme reflected the views of participants regarding the causes of schizophrenia, based on their experiences of either the onset of the disease, or maternal and psychological factors and possible drug use that could have played a role:

> “Nou destyds toe hy gebore is in die Kaap was [breek] jy weet daar was mos daai, dis mos baie soos in studente wat soos julle nou wat nou kom vir prakties en so by die hospitaal en dan moet hulle nou hierdie klas goed doen nou, ek weet en dat my kraamgeval was baie lank… Nou sien, jy vind nou uit nou se dae, net daai bietjie suurstof wat hy mis, kan vir hom *lewenslank* in ‘n ding sit. Nou dis wat gebeur het. Hulle het ge… daar het gestaan “prolonged labour”. Dit meen die “labour” was dit die dit was te lank, dit het te lank geneem, sien jy.” *[“Now at the time when he was born in the Cape [pause] you know there was that, after all, it is a lot like in students who like you now come for practical and so at the hospital and then they had to do these types of things now, I know that my labour was very long… Now see, you find out these days just that bit of oxygen that he misses can put him in a thing for a* lifetime. *Now that’s what happened. They said… it said prolonged labour.”]*
>
> “Ek kan jou regtig nie sê nie” *[“I really cannot tell you.”]*

> Ek weet rerigie, want uh soos ek sê hulle was 20 jaar en hulle het al gebeginne werk toe word hulle mos nou siek, ek weetie wat is die oorsaak nie. *[“I really don’t know, because uh like I say they were 20 years old and they started to work when they became sick, I don’t know what is the cause.”]*

> “Is haar senuwees.” *[“It’s her nerves.”]*

> Kyk hier hy’t op standerd sewe skool gegaan en toe daar’t hy nou vriend gekry en die vriend het vir hom ‘n, ‘n siggaret gemaak en voor oopgemaak en goeters ingegooi en toe rook hy die siggaret en na die siggaret is hy daar van die skool af is hy hospitaal toe en daar het hulle toe nou die goed loop uitgepomp en lyk my alles hettie uitgekom nie. Van die goed het agter gebly en toe’s dit daar wat hy so is laat hy nou nog so is. *[“Look he went to school in standard seven and there he found a friend and the friend made him, a cigarette and opened it at the front and put stuff in it and then he smoked the cigarette and after the cigarette he went from the school to hospital and they pumped his stomach and seems to me that everything didn’t come out. Some of the things stayed behind and then it was there that he is this way so that he is still this way now.”]*

> Is hy dan nou nie innie innie innie verstand gestrem nie of wat? *[“Isn’t he disabled in the in the in the mind or what?”]*

One participant was of the opinion that complications during birth had an impact on her newly born infant, resulting in a lack of oxygen to the brain that might have resulted in the development of the disease. The latter can be substantiated by studies showing that prenatal and perinatal influences may influence the development of the disease within the brain due to external factors such complications during birth (Durand & Barlow, 2010:490), of which lack of oxygen may be one of those factors. Another participant’s recollection of an event at onset of the disease gives the perception that possible drug use during teenage years may have been a precipitating factor resulting in the development of mental illness. Another participant identifies the patient’s nerves as being the cause for her developing a mental illness, with nerves in this sense referring to stress experienced by the patient. Durand and Barlow (2010:491) consider stress prior to onset of schizophrenia as being a factor which may possibly contribute to the development of schizophrenia. Due to the presence of stress before the onset of symptoms, research has studied the impact of stress on schizophrenia. Studies have however not definitively proved stress to be a causal factor, but rather a stressor influencing behaviour.

Although there is no one single gene responsible for the development of schizophrenia (Getzfeld, 2004:99), genetic influence does play a role in the development of the disease with researchers identifying genetic predisposition as being a precipitating factor in the development of the illness (Cartwright, 2008:467). It is interesting to note that one of the participants in the study is the caregiver of monozygotic twins who were both diagnosed with schizophrenia in early adult years after they started displaying what can be considered, based on the data obtained, positive symptoms. Research in this regard have found that with monozygotic twins, one has a higher risk of developing schizophrenia if the other one already has the disease (Tandon et al., 2008:6). In the case of one of the participants, twin sons developed the illness, one shortly after the other, in their early adult years with age of onset being identified as 20. External environmental factors are theorized to be influencing factors in the development of schizophrenia, with substance abuse being one of these external environmental factors (Smith, 2018). In a study by Winklbauer, Ebner, Sach, Thau and Fischer (2006:37), nicotine was identified as one of the most commonly abused substances amongst patients with psychoses. These researchers continue to identify nicotine as a substance which interacts with dopaminergic and glutamatergic pathways in the mesolimbic area of the brain, linking to findings that the development of the disease involves the abnormal transmission of the neurotransmitters, dopamine and glutamate, in the brain (McGuire et al., 2007:91).

- **Sub-theme 1.4: Observed symptoms of schizophrenia**

This sub-theme specifically focussed on the observations of symptoms by the caregiver:

> “Ja *Noah* het nie gevorder op skoolie… is maar net, jy weet hy kan uh uh, soos enige mens jy weet jy raak kwaad nou hulle raak, aggressief as hulle kwaad raak.” *[“Yes *Noah* didn’t make progress in school… it’s just, you know he can uh uh, like any person you know you get angry now they get aggressive when they become angry.”]*

> “Van daai tyd af, hulle hoor stemmetjies, en hulle word stil dan bly hulle, wil hulle met mense niks te doen weesie. En dan, *James* is nou baie loperig… en hier in die lokasie, hy vloek die mense laat dittie goed gaan nie.” *[“Since that time, they hear voices, and they become quiet then they stay, they want nothing to do with people. And then, *James* wanders… and here in the neighbourhood, he swears at people like it’s nobody’s business.”]*

> “Sy was maar altyd net so gewees, maar altyd, altyd nog geloop vannie huis af, deurmekaar geraak en daai klas goeters.” *[“She has always been like that, always, always walked away from home, became confused and those type of things.”]*

> “Is reeds wanneer sy kwaad word… Dan vind ek uit, nee sy hier is iets nie reggie. En as dit vir so twee drie dae aanhou dan weet ek nee, sy hettie, sy hettie haar

> medikasie ge ge ge gegaan halie." *["It's when she gets angry… Then I find out, no something is not right here. And if it continues for two three days then I know no, she didn't, she didn't go to fetch her medication."]*

> "Om as hy so dom is da will hy nie uit die huis uit gaan nie… Hy is 'n, hy wil 'n ding doen en da wil hy okkie. So is hy. [*"Because if he is so dumb then he doesn't want to leave the house… He is a, he wants to do something and then he doesn't. That's what he is like."*]

> "Hy vattie gou as jy praat nie. As jy praat da, vat hy eers lank voor hy kan vir jou antwoord. Is hy, hy onthou ook nie so lekker nie. Jy jy moet vir hom so twee keer drie keer iets sê, so laat hy kan onthou wat vra jy hom of wat moet hy nou doen, so. Sy sy hele, sy hele houdings, reaksies. En as hy sien jy, hy hy sit nou te lank hier by jou dan staan hy sommer op da loop lê hy." *["He doesn't easily understand when you speak. If you speak, then he takes a while before he can answer you. He is, he doesn't remember so well. You you have to tell him something two three times, so that he can remember what you ask him or what he must do now, like that. His his whole attitude. And if he sees you, he he is sitting here with you too long then he gets up and goes to lie down."]*

> "Soos hy, praat 'n ding, maar is 'n ding wat hy, in sy kop had. Of hy jou seermaak en of hy, hy 'worry' nie wat hy nou daar sê nie." *["Like him, he speaks of something, but it's a thing that he has, in his head. If he hurts you and or he, he doesn't worry what he is saying."]*

All but one participant in the study have been subjected to experiencing symptoms of schizophrenia. This family member citing that his adherence to treatment had resulted in him never having experienced symptoms. The symptoms identified by the participants include cognitive, positive and negative symptoms. It should however be noted that this same participant reported not having any knowledge of mental health or schizophrenia. From this it can be assumed that the participant may not be able to identify symptoms based on lack of knowledge on schizophrenia. Auditory hallucinations such as hearing voices were reported, as well changes in patients' behaviour from what is considered normal to either aggressive or angry, with the latter being signs that participants - through their interaction with the patients - consider being symptoms of schizophrenia. Auditory hallucinations are considered a positive symptom of schizophrenia. It is an involuntary symptom and is quite common with patients suffering from schizophrenia (American Psychiatric Association, 2013:87, 88). Symptoms such as limited intellectual progress in school, confusion with regards to thoughts, difficulties with comprehension and memory, and deficits with regards to execution can be considered cognitive symptoms of schizophrenia. Negative symptoms are more notable in schizophrenia than in any other psychotic disorder (American Psychiatric Association, 2013:89) and can result in changes in behaviour and personality, as well as deterioration of characteristics that are own to the patient. One caregiver described behaviour that can be considered a negative symptom, describing the patient's behaviour as dumb, referring to him wanting to do something, but now being able to execute what he wants to do. This refers to changes in personality that is characteristic of the patient and can possibly be affective flattening (Nolen-Hoeksema, 2008:388; Turner, 2009:45).

Findings from this theme show that the participants did not have much knowledge of mental health, resulting in lack of understanding of schizophrenia. The biopsychosocial approach considers how biological, psychological and social factors interact with each other to influence the individual (The Biopsychosocial Approach, [sa]). Lack of knowledge with regards to the biological factors related to mental illness can be considered to have a psychological and social impact on the participants. This in turn can be considered an influential factor related to caregiving and the participants' ability to cope with their role. The latter will be discussed in subsequent themes. The responses of participants thus identify biological, psychological and social factors as impacting the development of the disease. Genetics does play a role in the development of the disease (Borrel-Carrió et al., 2004:578), and linked to the biopsychosocial approach, the social factors cannot be ruled out as external influences in an individual's environment which can be a contributing influence to the development of the disease and therefore psychological and social factors needs to be taken into account (Borrel-Carrió et al., 2004:576).

3.8.2.2 Theme 2: Health care services at community level

Health care services were a prominent theme throughout the data collection process. All participants and the patients they were caring for had access to health care services at primary level. The health care services accessed by caregivers and patients were primarily local primary health care clinics that provided services with regards to treatment to the patients. No notable services were provided to caregivers themselves in relation to support to help them to cope with mental illness in the family context.

- **Sub-theme 2.1: First point of entry into the health system**

This sub-theme was confirmed throughout the study as all of the participants accessed the primary health care system at one point or another to seek assistance for their loved ones:

> "Kyk, hy't nie gevorder op skool nie. Jy't agtergekom uh uh, hy moes nou al verder gewees het en hy moet nou al, meer, beter gevorder het. Nou dan vat jy hom maar nou weer dokter toe en. *["Look, he didn't advance in school. You realized uh uh, he should have been farther along and he should have, progressed more. Now then you take him to the doctor again and."]*
>
> "By die kliniek." *["At the clinic."]*
>
> "Uh, klaainiek toe." [*"Uh, at the clinic."*]
>
> "Ek het reguit kliniek toe gegaan, na die psigiatriese kliniek." *["I went straight to the clinic, the psychiatric clinic."]*
>
> "Die eerste plek was die kliniek, en toe die dokter." *["The first place was the clinic, and then the doctor."]*

From the quotes from participants, it is evident that the first point of entry into the health care system was a clinic, whether a primary healt care clinic or in one instance a psychiatric clinic that used to operate in the area in the past. Some of the participants were still very much engaged with the health care system with regards to the patients' treatment. The main provider of health care to all of the patients being care for by the participants in this study was their local primary health care clinic.

Of the eight caregivers participating in study, five participants could identify the first place they visited for help with regards to the disease. These participants were all biologically related to the patients, with four of the five caregivers being a parent of a child with schizophrenia. Of the three participants who do not know the first point of entry into the health care system, one participant was a child when her father was diagnosed with schizophrenia and did not know what resources her parents initially accessed to receive treatment for her father; another patient only met her husband after diagnosis and due to this, time and place of diagnosis was unknown to her; and one patient is a non-familial caregiver who took the patient in after his family expressed their inability to care for him. All three of these participant's care for patients who access their local primary health care clinics for treatment. Findings in the South Africa Demographic and Health Survey (2003-2004) indicate that government clinics and community health centres account for 55% of the overall health care providing resources in the country. This explains why the first point of entry at community level is government funded clinics.

- **Sub-theme 2.2: Treatment and adherence to medication**

This sub-theme was quite prominent throughout the study, as all of the participants seeked assistance for their loved ones with regard to their medication and adherence:

> "Uuuhh, net pille. Hy kry maar net pille wat hy soggens drink, en saans. Soggens drink hy maar een want hy het nie rerig nodig, in die dag is hy okay… "Mmm [ja]. Altyd. Ek, baie kere as hy nou soos in die aand partykeer rusteloos, dan vra ek hom of hy sy pille, dan sê hy vir my hy het gedrink. Want ek het nou nie nodig om agter hom te staan vir sy pille nie." *["Uuuhh, only pills. He just get pills that he must drink in the mornings and at night. In the mornings he drinks one, because he doesn't really need to, in the day he is okay… Mmm (yes). Always. I, many times when he is restless sometimes like in the evening, then I ask him if he took his pills, then he says he did drink it. Because I don't need to stand behind him for his pills."]*
>
> "Hy drink elke aand sy pille." ["*He drinks his pills every night*."]
>
> "Hu, *John* loop elke maand, *James* ook, maar van *James* nou van Mei maand af *James* traak nie met die klieniek nie. As jy nog daar kom en hulle kan hom nie help nie, da loop hy… *John* gebruik sy behandeling baie mooi, daarom is hy oraait…*Erica* moet nou vir hom pille gee (*James*). Vamore toe sê hy *Erica* moet nou weer vir hom toor met daai pille… Hy sê hy, sal hulle nie loop drinkie, want *Erica* wil hom nou weer toor met daai pille… en *James* kry nou inspuiting as hy so heeltemal erg raak da gee hulle hom 'n inspuiting ook…" *[They, *John* goes every month, *James* too, but since *James* now since May month *James* doesn't worry with the clinic. If you still get there and they can't help him, then he leaves… *John* uses his treatment very nicely, therefore he is okay… *Erica* must now give him his pills (*James*). This morning he said *Erica* must now bewitch him with those pills… He says he, will not go to drink them, because *Erica* wants to bewitch him with those pills… and *James* gets an injection when he becomes so bad then they also give him an injection"]*
>
> "Hy kry mos nou altyd nou mos net daai spuit… en sy gebruik ook pilletjies…" *["He always gets that injection… and she uses pills too…"]*
>
> "Sy kry die inspuiting, ek kan nou net nie die inspuiting se naam. Sy kry die inspuiting en dan kry sy die pilletjies… Elke maand. Elke maand maar, sy was, sy't geweier later aan dat ek moet saam met haar kliniek toe gaan… Dan gaan sy alleen, en van ver verlede jaar [breek] November, nee nee nie November nie. September, Oktober maand het sy nie haar behandeling gegaan gebruikie toe kom ek agter, toe gaan ek met haar een Maandag vir haar behandeling." *["She gets the injection; I can't remember the name of the injection. She gets the injection and then she gets the pills… Every month. Every month but, she was, she later refused that I go with her to the clinic… Then she goes by herself, and from last last year (pause) November, no no not November. September, October month she did not go to use her medication then I found out, then I went with her one Monday for her treatment."]*

> "Hy't nou verlede week het hy die kliniek geboesoek toe kry hy sy pille, sy medikasie… Hy's baie lief om sy behandeling. Hy glo sy behandeling, en sy pilletjie voor hy eet da drink hy sy pilletjie da eet hy." *["He visited the clinic last week and then got his pills, his medication… He loves his treatment. He believes in his treatment, and his pills before he eats then he drink his pills then he eats."]*
>
> "Hy gaan elke maand. En hy sien al oor drie maande, die, die kop dokter. Hulle laat weet hom ok hy moet nou kom is nou die kop dokter se tyd… Ja nee, en soos, eergister kom hy, Maandag, toe's ek al weer vergeet die pille se datum, toe kom hy alweer trug Maandag namiddag met sy pille [lag]." *["He goes every month. And every three months he sees, the, the head doctor. They let him know that he must come when it is the head doctor's time… Yes, and like, the day before yesterday he comes, Monday, I already forgot the date of the pills, then he already came back with his pills Monday afternoon (laughs)."]*

Treatment for schizophrenia involves different approaches including pharmacological treatment, psychological treatment, behavioural approaches, family therapy and psychoeducation. The main method of treatment is pharmacological treatment (Goldberg, 2018), using anti-psychotic drugs, such as Clozapine, to control the symptoms of schizophrenia (McGuire et al., 2007:91). From the data on the type of medication used, it was found that all patients use medication in the form of pills, while some are also being given injections along with oral medication. Austrian (2000:105) identifies pharmacological medication as being used both orally and by means of injection, with injections being used in cases where non-adherence occurs. Six of the eight caregivers do not experience any challenges with regards to adherence to treatment. Their family members with schizophrenia used their medication daily and generally adhered to treatment. Two caregivers indicated that they were experiencing challenges with patients adhering to treatment with one patient not being honest with her caregiver about using her medication and another not using his medication continuously, resulting in positive symptoms like delusions, where he is under the belief that he is being bewitched. The caregiver in this case had to resort to asking someone else to administer treatment, as the patient refused to take his medication from her. None of the participants identified receiving any other forms of treatment.

- **Sub-theme 2.3: Support services from the health care system to the caregiver**

Support from the health services was a sub-theme experienced negatively by participants:

> “Al ondersteuning is ons sien die dokter by die kliniek, dis seker nou die ondersteuning. Ek weet nie.” *[“The only support is we see the doctor at the clinic, that’s probably the support now. I don’t know.”]*
>
> “Niks. Niks. Ek kry nie ondersteuning nie. As ek gaan da sê hulle net *James* moet sy pille drink.” [*“Nothing. Nothing. I don’t get any support. When I go then they just say *James* must drink his pills.”]*
>
> “Baie! Maar ek kry groot ondersteuning van die kliniek af… *Groot* ondersteuning, want as, wanneer sy so deurmekaar is en ek, en ek gaan en ek gaan *sê* vir hulle, dan help hulle haar *onmiddelik.*” *[“A lot! But I get big support from the clinic… Great support, because if, when she gets so confused and I, and I go and I tell them, then they help her immediately.”]*
>
> “Nee… Is maar net ek wat vir hom kyk en as ek sien iets issie reg nie, da gaan ek terug kliniek toe en da verwys die kliniek my miskien terug hospitaal toe. Is al.” *[“No… It’s just me that looks after him and if I see something is not right, then I go back to the clinic and then the clinic maybe refers me back to the hospital. That’s all.”]*
>
> Hmm mmm [nee], want, hoe sal ek jou sê? Is maar net *Nash* is by my en ek is by home en is klaar.” [“*Hmm mmm (no), because, how can I say? It’s just *Nash* is with me and I am with him and that’s it.”]*

Thus from the above it is evident that there was a somewhat negative connotation, as all but one caregiver directly expressed that they received support from the health services in their area. Seven participants indicated that they received no support as caregivers. It is interesting to note that the type of support that the one participant who expressed receiving support received, was treatment to the patient when the patient’s behaviour became abnormal. Based from the data of all eight participants, no direct support services to the caregiver has been provided that does not include treatment to the patient.

Findings from this theme show that patients were getting treatment, but no other form of support was provided to the patient or caregiver. The focus of treatment and service delivery is thus not on holistic treatment as proposed by the biopsychosocial approach, taking into account psychological and social factors and not just biological factors related to treatment. The aim of the biopsychosocial approach is to move away from the medical model and treat the patient holistically, as well as to understand the individual’s experiences and how certain factors influence overall health (Borrel-Carrió et al., 2004:576; Smith, 2002:309). This is however not the case with regards to treatment. The participant experience was influenced by biological factors related to the patient’s illness. Challenges experienced by some participants with regards to inadequate support and non-adherence were influenced by social factors related to treatment and this in turn affected the participants psychologically, as lack of support services from health care services could be considered a stressor affecting caregiver burden.

3.8.2.3 Theme 3: Role of caregivers

All of the participants in the study were responsible for caring for a family member diagnosed with schizophrenia. From the eight participants, four were parents of the patients they cared for and based on the findings, the diagnosis and function of care had a more diverse effect on them than on those participants who were spouses or children of patients with schizophrenia. Those closest to the patient were affected by the illness on different levels and caregivers' experience over the course of the illness differed as well (Jungbauer et al., 2004:672). The participants who were parents experienced challenges different to those who were siblings or children and have also been subjected to portraying the caregiver role for a longer period of time.

- **Sub-theme 3.1 Feelings about caring for a family member with schizophrenia**

This sub-theme portrays the caregiver's emotions related to their role of caring for a patient with schizophrenia:

> "Jy voel maar baie dae, uh, soos 'n mens sal sê, iemand sal sê, 'Hoekom het dit met my gebeur? Hoekom ek?'… Da besef jy weer jy is eintlik *uitvekore*, want die Here het vir *jou* gekies om daai kind om te sien… Is nou amper soos 'n *babatjie* wat jy moet altyd versorg. Nie versorg versorg nie, maar jy moet altyd vir hom in gedagte hou jy, as jy iewers gaan of wat, altyd vir *Noah* in ag neem…" *["Many days you feel, uh, like you'd say, someone would say, 'Why did this happen to me? Why me?... Then you realise you are actually* chosen*, because God chose you to look after that child… It's almost like a* baby *that you must always take care of. Not take care of, but you must always take him into account when you go somewhere, always take *Noah* into account…"]*

> "Dit het vir my swaar gegaan, maar ek, het maar net gedink *ek* is tog die ma ek moet maar kyk na hulle…Baie dae het ek *bitter* swaar gehad, dat ek maar meer trane gehad." *["It was difficult for me, but I just thought* I *am the mother I have to look after them… Many days it was* terribly *difficult, then I had more tears."]*

> "*Ek voel, ek ek voel, ek voel reg!* Want dit is mos *my kind.* Is mos nie iemand anners se kind nie." *["*I feel, I I feel, I reel right! *Because it is* my *child. It's not someone else's child."]*

> "Ek ek ek sit *baie* in, want ek sit baie in, want ek is lief uh, iemand moenie siek wees rondom my nie. Ek is baie helpsaming, sien. Ek voel *saam* met hom… Werk ek saam met hom en en, ek ervaar baie uh uh, *hartseer* en goed, maar da, as ek as ek nou so 'n ent werk saam met hom saam voel ek nee, maar is nogal nie so swaar om saam met so persoon…" *["An I I put in* a lot*, because I put in a*

> *lot, because I love uh, someone musn't be sick around me. I am very helpful, see. I feel* with *him… Work with him and and, I experience a lot uh uh,* sadness *and things, but then, if I if I work with him then I feel no, but it is actually not that difficult with a person like that…"]*
>
> "Nee dissie vir my 'n, probleem nie. Dis rerig nie vir my 'n probleem nie, want om vir hom te versorg mos nou*…" ["No for me it's not a problem. It's really not a problem for me, to care for him."]*

Transitioning from the role of family member to that of caregiver may elicit some or other response from the caregiver (Atkinson & Coia, 1995:31). From the findings, some participants stated experiencing the role of caregiver as difficult with two participants identifying what can be considered obligation with regards to caring for the patients as they were the parents and had to assume care for their adult children. Two participants conveyed not experiencing their role as caregiver as a challenge as they love taking care op others. All of the responses shared above, were from those caregivers who were parents to the patients they were caring for. As parents, the participants had to deal with changes in personality as well as acute and chronic symptoms presenting over the course of the illness (Jungbauer, Wittmund, Dietrich & Angermeyer, 2004:672)

- **Sub-theme 3.2: Tasks of caregiver with regards to caring for patient family member**

This sub-theme reflected the tasks of caregivers in caring for the family member with schizophrenia:

> "… ons sal vir hom kos maak en sulke goed…" *["… we will make him food and such things…"]*
>
> "Ek moet vir hom sorg. Ek moet, met sy "pay" moet ek vir hom sien laat hy kos, klere als kry*…" ["I have to care for him. I have to, with his pay I have to see that he gets food, clothes, everything…"]*
>
> "Ek moet vir haar kos sorg, vir kos maak en waar sy verkeerd skoonmaak, moet ek weer, half skoonmaak moet ek weer reg skoonmaak." *[I have to see that she has food, making food and where she didn't clean the right way, cleaned half way, I have to clean up again…]*
>
> "Ek doen *alles*... Ek meen, ek gee hom sy kos. Ek was hom partykeer, as hy nie kan nie." *["I do* everything*… I mean, I give him his food. Sometimes I wash him, if he can't."]*
>
> "… as ek nou opstaan uit die slaap uit, da loop kyk ek eers of hy "oraait" is. Da sien ek nee hy lê darem nog, hy's "oraait" en as ek nou sien hy slaap te lank, da loop maak ek 'n bietjie wakker… Soggens as ek hom wakker maak, as hy wakker, da gee ek vir hom sy kos, sy koffie." *["…if I get up, then I first check if he is okay. Then I see he's still in bed, he's okay and if I see he's sleeping too long*

> *then I wake him up… In the mornings if I wake him up, if he's awake, then I'll give him his food, his coffee."]*

> "Ek moet kyk laat hy sy pille drink… Kyk laat hy skoon is. Kyk laat hy geëet het… kyk ek waar of hy veilig is…" *["I have to see that he drinks his pills… See to it that he is clean. See to it that he ate…look for him if he is safe…"]*

From the participants' voices above, the caregiver plays a parental role, as they have to ensure that patients' nutritional needs are met and that they adhere to their medication. The caregiving tasks are not very physical in relation to care as all of the patients are adults and can basically take care of themselves. Apart from the verbatim quotes represented above, all but one of the participants had indicated that they were responsible either presently or at some point in the past, for managing the patient's grants, thus also having the task of managing the patient's finances.

Research has shown that living with a person with severe mental illness can result in what is referred to as caregiver burden. Caregiver burden can be either subject or objective (Atkinson & Coia, 1995:33). Objective burden refers to the tasks that the caregiver must perform in order to take care of the patient (Awad & Voruganti, 2008:149) while other researchers such as Yusuf et al. (2009:43), defines objective burden as "readily verifiable behavioural phenomena" referring to the effect that this burden can have on the caregiver. Findings can be linked to the biopsychosocial approach, with specifically psychosocial factors influencing the caregiving experience. This is with regards to the tasks of the participants related to their role of caregiver and the emotional influences related to caring for their loved ones. These factors influence overall experience of the caregiver and findings show that some caregivers experienced what can be referred to as obligation to care for their loved ones.

3.8.2.4 Theme 4: Challenges experienced by caregiver

Despite the age of the patient, some caregivers caring for patients who are well into adulthood, still perceive the patient as a child who has to be cared for and be under supervision constantly despite their age. It is also noteworthy that all of the participants who were parents – with one participant being regarded as a parental figure, but who is not biologically related to the patient – experienced a sense of obligation with regards to caring for their child. These findings are substantiated by Mhaule and Ntswane-Lebang (2009) who found that caregivers experienced feelings similar to sacrifice as a result of them having to care for their family member when no one else would. In the case of these participants, they were the parents and naturally felt that they had to care for the patients. Some identified emotional struggle related to the role of caring, but felt obligated to care for the patient as it is their child. Caregivers are affected by external influences such lack of support and mental health services, but also by internal factors such as stress resulting from the behaviour of the patients and their daily roles of taking care of their family member (Saunders, 2003:175, 176).

- **Sub-theme 4.1: Stigma**

This sub-theme looked at how the participants experienced stigma.

> “Oe en dis die ergste in hierdie woonbuurt. *Noah* is die gelukkigste as hy by sy skool is of by die kerk. Nou elke dag is hy nou by die skool tot twee uur toe. So hier daai tyd is hy gelukkig, maar sodra hulle by die bus kom afklim dan begin die woonbuurt met mal *Noah*, *Noah*… Jy voel jy wil hom uit die gemeenskap, uit die seerkry uithaal.” *[“Oh and that is the worst in this neighbourhood. *Noah* is the happiest when he is at his school or at church. Now every day he is at school until two o’clock. So that time he is happy, but as soon as they get off the bus then the neighbourhood starts with ‘crazy *Noah*, *Noah*… You feel like you want to take him out of the community, out of the pain.”]*

> “*Baie sleg!* Baie sleg. Baie sleg… Hulle behandel nie, hoe kan ek sê, as hulle jou nie ken nie en hulle weet en jy’s daai sort mense soos *Jacky*, soos eintlik hierie TIK koppe wat mos nou ook geestesverstreurd is. Hulle behandel hulle baie sleg.” *[“Very bad! Very bad. Very bad… They don’t treat, how can I say, if they don’t know you and they know you’re those type of people like *Jacky*, like these TIK addicts who are also mentally disturbed. They treat them very bad.”]*

From the above participant quotes, it is evident that most of the participants were affected by stigma. From the eight participants only two participants did not identify any stigma. In these cases, the patients were older people in the community who adhered to their treatment and did not show any noticeable symptoms of schizophrenia. The other six participants identified the occurrence of positive and in one case negative symptoms. From the comments made by some of the participants in these cases it can be deduced that people external to the family, in their immediate environment, have also witnessed these symptoms, based on either their behaviour towards the patients or verbal comments.

This stigma may be related to a lack of education on mental illness resulting in inability to understand behaviour exhibited by the patients and the type of stigma experienced by the participant can be considered public stigma as it portrays society's views on mental illness (Gibson, 2011). Cultural perception of mental illness in rural areas in SA can affect the caregiver and influence caregiver burden. Ignorance with regards to schizophrenia can be linked to a lack of education and support services and this is a factor that can influence caregiver burden as it relates to stigma (Mavundla et al., 2009:361). The quotes below reflect how stigma caused caregiver burden:

> "Dis erg, dis erg, ek sê jou. Ek voel ek kan baie dae ek kan maar net vir *Noah* vat en daar ver op 'n berg loop bly, want die berge sal hom goed behandel. Niemand sal hom daar woorde sê nie of wat, maar jy kan nie jou, iemand, jy kan nie, daar iewers in 'n hoekie loop sit of wat nie. Jy moet aangaan met jou lewe, jy moet maar net lewe en jy moet maar net elke dag aanvaar soos hy daar kom, party dae is dit beter maar oor die algemeen, nou dis wat wat die, ek dink dis waar die problem lê as ek dit so kan sê. Nie laat ek rerig moet seker weet nie. Maar is dit net die, dis eintlik die oorsaak die die onkunde van die gemeenskap." *["It's bad, it's bad, I tell you. Many days I feel I can just take *Noah* and go and live far away on a mountain, because the mountains will treat him well. No one there will have words for him, but you can, someone, you can't, go sit somewhere in a corner. You have to go on with your life, you just have to live and you must except every day as it comes, some days it is better but in general, now that the, I think that's where the problem is if I can say it like that. Not like I should really know. But is it not the, it's actually the cause of all the ignorance of the community."]*

> "Ek voelie lekker nie. As ek sien mense tree so op da voel ekkie lekkerie… Nou ja, dan sê die mense, 'Die mal ding hy'. Nou da voel jy sleg, want ek het nou daar in Pietoria mos by die hospitaal gehoor jy moenie vir hulle sê mallie, hulle'sie mallie sê liewer siek, hy's siek." [*"I don't feel good. If I see people act like that then I don't feel good… But now, then the people say, 'That crazy thing he'. Now then you feel bad, because I learnt there in Pretroia at the hospital you mustn't call them crazy, they're not crazy rather say sick, he's sick."*]

Caregiver burden is exacerbated by stigma as it resulted in negative emotional impact on the caregiver and it the case of one caregiver, the desire to take her loved one out of the community where he is subjected to the phenomenon, thus indicated the need to isolate oneself from stigma (Matlala, Maponya, Chigome & Meyer, 2018:46).

- **Sub-theme 4.2: Financial implications related to caring**

Financial expenses were identified as a challenge experienced by participants, which also contributed to caregiver burden, as reflected in the quotes below:

> "En ek het mos maar gesorg, daai jare toe ek mos dan nou alleen word, gesorg en, toe later het ek mos dan nou ok vir hom 'n toelaag gekry. Nou dit help in 'n mate. Maar hulle is mos maar rof op alles, ek meen dit vat maar… maar wat finansies, dis net soos wat ek jou daar sê, hy is baie, behoort aan baie verenigings en, is baie uitgawes, maar sukkel maar om by the hou en hy *verstaan nie* as hy nie kan saamgaan nie of, uhm, saam geniet nie." *["And I made sure, those years when I became a single parent, made sure, and then later I got a grant for him. Now that helps in a way. But they are rough on everything, I mean it takes a toll… but in terms of finances, it's just like I tell you, he is very, belongs to a lot of associations and, it's a lot of expenses, struggle to keep up and he doesn't* understand *if he cannot go with or enjoy with others."]*

> "Toe doen ek aansoek vir hulle vir, vir, vir die siek 'pay'. Toe kry hulle, in Pietoria, toe kry hulle die 'pay', maar waar hulle gewerk waar *James* gewees het daar wassie eens 'n uitbetalingie. En daar waar *John* gewees het, ag jaar skool gehou het, ok *niks* gekry nie. Ek het maar so gesukkel en gewerk vir hulle…Nou ek kan nie *byhou* nie, want soos gister ok toe moet ek maar, ek bly leen net by die mense geld om krag te koop…" *["Then I applied for them for the sick pay. Then they got, in Pretoria, then they got the pay, but where they worked where *James* was there was no pay out. And there where *John* was, taught for eight years, also got* nothing. *I struggled and worked for them… Now I can't* keep up, *because like yesterday then I had to, I keep lending money from the people to buy electricity…"]*

> "Dit dit dit, oe dit was 'n uitpunt uitputtende impak gewees, want my finansies het daaronder gelei…My finansies lei nogsteeds daaronder." *["It it it… oh it had an exhausting impact, because my finances suffered… My finances are still suffering."]*

> "Oe baie. Ek het, ek het mos gewerk. Ek werk mos net in die kombuis. Ek het vir hulle so grootgemaak. Toe's hulle nog klein toe moet sy pa maar die werk los en by hulle wees, en ek was mos maarie broodwinner in die huis. As ek haai ou geldjie kry, da bêre ek hulle en da gaan ek so die volgende dag dorp toe. Da loop doen ek my goedjies, en da kom ek trug. En ek het nou vier kêrelkinners gehad, maar al vier moes ek versorg met daai bietjie kombuisgeldjies wat ek het of druiwe geld en meeste van die tyd maak ons mos maar skuld om, om dinge reg te kry vir elke tjeent of innie huis in. Da maak ons so skuldjie vir haai geld en so gaan ons aan met die lewe. So't ek vir hulle grootgemaak." *[Oh, a lot. I did, I worked. I only work in the kitchen. I raised them like that. When they were small, their father had to quit working and stay with them, I was the breadwinner in the home. When I get that money, then I put it away and then I go to town the next day. Then I go to do my things, and then I come back. And I had four sons, but I cared for all four with that kitchen money that I had or money from picking grapes and most of the time we made debt to, to get things in order for every child or in the home. Then we make debt for that money and like that we went on with our lives. That's how I raised them."]*

Of the eight caregivers participating in the study, only two were employed while five participants were aged 60 years or older, receiving a pension grant from the SA government. One participant was unemployed. All of the patients being cared for by the participants were receiving a disability grant from the government. Five participants were single, having no partner who provided financial support to the household. Participants who identified these challenges were those who were not employed and themselves receiving a grant from government. Financial constraints and challenges were linked to the role of caring as well as patient’s behaviour related to money. This data is supported by Mavundla et al. (2009:361, 362) who found that financial constraints posed a challenge to caregivers with regards to caring for the patient, maintaining the household and assisting the patient in managing finances in cases where the patient receives a grant from the government.

- **Sub-theme 4.3: Family support**

This sub-theme showed the role of family support:

> “Hulle’s eintlik, lewe eintlik apart van mekaar… Seker maar nie so goed nie, want ek moet mos nou maar baie keer arm neerlê vir hom en dan werk dit mos nou nie so goed uittie. Anders verstaan nie altydtie.” *[“They’re actually, live seperately from each other…Probably not that good, because I must stand up for him and then it doesn’t work out so well. Others don’t always understand.”]*

> “Familie gee nie ondersteuning nie… Dit is nou so, hulle bly sê mos nou ek bederf, ek het hulle gebederf en ek weet ek het hulle nie gebederfie, want ek was in die werk. Nou en dan, word ek vir hulle ok kwaad as hulle vir my sê ja is mos my ou, my dag dat hulle so is, want hulle, ek bederf hulle. Ek het hulle rerig nie gebederf nie, ek was *in* die werk.” *[“Family don’t give support… It is like that, they keep saying I spoil, I spoilt them and I know I didn’t spoil them, because I was at work. Now and then, I get angry when they say it’s my day that they are like this, because they, I spoil them. I really didn’t spoil, I was* at *work.”]*

> “Is ‘n sware ervaring. Is baie swaar, want ek moet vir *haar* beheer en dies wat normaal is, wattie vir haar verstaan nie, moet ek *ook beheer*. Dan sê hulle ek vat, staan *haar* kant… Ja my ma en my broers ondersteun my baie, want hulle wil nie hê *Jacky* moet weggestuur wordtie. My broers ondersteun my baie. Hulle weier.” *[“It’s a difficult experience. It’s very difficult, because I have to control* her *and those who are normal, who don’t understand her, then I must also* control*. Then they say I choose* her *side… Yes my mother and my brothers support me very much, because they don’t want *Jacky* to be sent away. My brothers support me very much. They refuse.”]*

> “Glad nie. *Ek* is alleen met hom.” *[“Not at all.* I *am alone with him.”]*

> “Ek het net een suster gehad wat altyd vir my so bygestaan het, en die ene kom so *nou* af en toe kom sy. Da kom help sy ok vir my, maar hulle’s gehoorsaam gewees, hulle’t my gehelp, as ek so in die nood is en so.” *[I only had one sister who stood by me, and this one comes* now *and then. Then she also comes to help me, but they were obedient, they helped me if I was in need and so on.”]*

> “…daar’s kinners rondom hom daar. My ousie hulle is altyd rondom hom. Soos hulle, *hou* ook van hom. Hulle’s ok lief vir hom. Sien jy, maar my ousie is ‘n bietjie kwaaier, harder as ek, met hom. Nou hulle’s, die tjeeners is lief vir hom, en almal hou van hom.” *[“…there are children around him there. My older sister and them are always around him. Like them, they* like *him. They also love him. You see, but my older ister is a bit harsher than me, with him. Now they, the children love him and everyone likes him.”]*

Family support that was identified, was generally support in assisting the caregiver with caregiving functions. Four caregivers expressed a lack in family support, identifying conflict in the family system as certain members of the family did not always understand the patient's behaviour. Some participants even identified being accused of spoiling the patients or taking their side. One participant shared that family members blamed her for the patient's uncontrollable behaviour, expressing that her spoiling him led to him displaying such behaviour. These experiences can be considered as a contributing factor to caregiver burden as it affects the caregiver's mental health, physical health and social interactions. Lack of support requires the caregiver to deal with certain stressors on their own and in the case of some caregivers, they have experienced problems in their social environment due to the behaviour of their loved one. This sub-theme can be linked to the sub-theme of patient behaviour and the researcher is of the opinion that the patient's behaviour can have an influence of the level of support that the caregiver receives from their family.

Mental illness is a crisis that not only affects the patient suffering from the illness, but the family as well (Tilbury, 1993:99). Living with a person with schizophrenia requires the family system to adapt and learn skills to cope with the symptoms of mental illness (McFarlane et al., 2003:224). Should the family not be equipped with the necessary skills and coping mechanisms, it can be deduced that family members will not possess the necessary skills to handle and cope with certain behaviour, thus having a direct impact on family members' interaction with each other and their functioning within the family system. The latter, in turn, may also have an impact on the family members' ability to support each other or the caregiver in their role of looking after the patient.

- **Sub-theme 4.4: Patient's behaviour**

This sub-theme looked at the experience of caregivers of the person with schizophrenia's patient's behaviour:

> "Nou ek willie eens hierdie goed sê wat hy partykeer met my opstandig raak en goetie, want dit lyk hulle glo my nie…" *["Now I don't even want to say these things that he sometimes becomes rebellious and things, because it looks like they don't believe me…"]*

> "*James* sit my af ek is 'n bietjie bang vir hom, want dis nou, hy belowe my mos hoe sal hy my doodmaak en hy, daar'sie eens messe in my huis nie, want ek

> kannie nog met messe daar rond nie as hy so aangaan nie [lag, snuif]. Ek is net ‘n bietjie bang, ek is nie meer sterkie. Kan hom, ek kan hom nie hanteer nie. Regtig, kan hom nie meer hanteer nie. Hy stoot my rond, hy vloek my rond [snuif]. _[“*James* puts me down I am a bit scared of him, because it’s now, he promises me how he would kill me and he, there aren’t even knives in my house, because I can’t still with knives when he goes on like that (laughs, sniffs). I am just a bit scared, I am not strong anymore. Cannot, I cannot control him. Really, cannot control him anymore. He pushes me around, he swears at me (sniffs)”]_

> “Vir my uh uh, dis negatief om vir *Jacky* wat ‘n groot vrou is, 42 jaar, mee te _sukkel_, en dis positief om vir my, om vir haar by _my_ te hou. Positief. Ek het ‘n tyd het ek gesê sy moet vir haar ‘n erf gaan soek, want ek kannie meer hou nie, _maar_ sy ge sy *Jacky* *Jacky* ge *Jacky*, uh, ek het niks van *Jacky* se SASSA nie. Ek het niks van *Jacky* se SASSA nie. Die mense wat sy kaart by is, die winkel se mense het die meeste voordele. Want *Jacky* be, *Jacky* loop, die mense wat goed loop en verkoop. *Jacky* los hulle nie laat hulle verbygaan nie en hulle luister my nie. Hulle gee vir *Jacky* alles wat hulle, wat *Jacky* wil hê, want *Jacky* moet vir hulle betaal, as en dan is die haar kos toestand issie, issie geld issie genoegie.” _[“For me it’s negative to_ struggle _with *Jacky* who is a grown woman, 42 years, and it’s positive to keep her with_ me_. Positive. There was a time I told her to go and find a property, because I cannot take it anymore,_ but _she *Jacky*, uh, I have nothing of *Jacky’s* SASSA. I have nothing of *Jacky’s* SASSA. The people with whom the card is, the people from the shop have the most benefits. Because *Jacky* goes, the people who pass by and sell things. *Jacky* doesn’t leave them to pass by and they don’t listen to me. They give *Jacky* everything that they, that *Jacky* wants, because *Jacky* has to pay them, and then her food situation is not, isn’t, money isn’t enough.”]_

> “Omdat hy die, die siek het, die rondloop. Hy loop _verskriklik_ as hy, ‘n anner siek het, die loop.” _[“Because he has, the sick, the wandering. He wanders_ terribly _if he, has another sick, this wandering.”]_

> “Is mos nou net wanneer hy bietjie stres en wanneer hy daai stemmetjies by hom kom en hy stres. Da moet ek mos nou maar stilbly en sag wees, da sê ek vir hom, “Nou *Wyat* wat is dit dan nou weer vamore os was da gister so lekker”. “Neh! Los my uit!”. Nou’s hy sê los my uit da los ek hom maar eers, laat hy alleen aangaan eers met sy koppetjie. Nou _daai_ tyd da kom hy weer trug da sê hy vir my, “Nee mamma ek willie hê os moet so weesie, os moet so weesie en so”. _[“It’s when he has a bit of stress and when he hears those voices and he stresses. Then I must now keep quiet and be gentle, then I tell him, ‘Now *Wyat* what is it now this morning, yesterday we were fine.’ ‘No! Leave me alone!’. Now when he says leave me then I leave him, let him go on with his head. Now_ that _time then he would come back then he tells me, “No mamma I don’t want us to be like this, we musn’t be like this.”]_

> ”Al probleem wat ek had is net, ek moet hom, _druk_ om hom te loop was… As hy so dronk gerook is van die dagga en die pille. Ek hou nie van die pille rookie. Dan is dit vir my _baie_ stresvol. Dan wil ek hom nie sien nie.” _[The only problem that I have is just, I have to_ force _him to wash himself… When he is high from the marijuana and pills. I don’t like this smoking pills. Then it is_ very _stressful. Then I don’t want to see him.”]_

Six participants identified behaviour by patients which caused distress for caregiver. One participant identified behaviour displaying positive symptoms of schizophrenia, but did not find it distressing and indicated a coping mechanism used to deal with behavioural issues. Another participant did not identify any distressing behaviour by the patient she was caring for. Apart from dealing with external factors which may cause burden, the caregiver can also be affected by internal factors such as the behaviour of the patient

As previously mentioned, mental illness can result in the family experiencing prolonged crisis (Tilbury, 1993:99), requiring the family system to adapt to changing circumstances and the impact of schizophrenia brought on by the symptoms experienced by the patient which can disrupt family functioning (Goldenberg & Goldenberg, 2013:416). This can directly impact the caregiver, resulting in caregiver burden. The experiences of caregiver can be influenced by different factors (Mavundla et al., 2009:361) with patient behaviours being one of those factors. From the data displayed above, the caregivers are impacted by behaviours of patients resulting from symptoms related to their illness. The patient's behaviour is influenced by external factors within their environment affecting their behaviour and in turn influencing caregiver burden. Certain aspects within the patient's environment influences them on a biological, psychological and social level, for example, one patient is engaging is substance abuse within his external environment, which in turn has an influence on both his psychological and biological functioning affecting his personal life, behaviour within the family home and the family itself (Smith, 2002:309). Although substance abuse cannot be identified as a cause of schizophrenia, there is evidence identifying the link between substance abuse and psychoses based on the high prevalence of substance abuse amongst patients with schizophrenia. The most commonly used substances amongst patients suffering from psychoses include nicotine, alcohol, cannabis and cocaine (Winklbaur, Ebner, Sachs, Thau & Fischer, 2006:37). In conclusion, body and mind influences health (Borrel-Carrió, Suchman & Epstein, 2004:581) and this relates to the experience of individuals. The biopsychosocial approach views the individual in its entirety, taking into account not only biological influences, but also external influences from the environment in which the individual functions. The caregiver is thus not only influenced by biological factors pertaining to the patient's illness - which in the case of some of the participants results in stress affecting them psychologically - but also by their behaviour, influences from society such as stigma and lack of resources to provide much needed support and other challenges related to care such as financial implications.

3.8.2.5 Theme 5: Support to families living with schizophrenia

All of the participants identified a lack of support services to caregivers at community level. With regards to social work services, all of the participants conveyed that there has been no intervention to either the individual or the family. A lack of information on mental illness and support services can be a contributing factor resulting in caregiver burden (Jungbauer et al., 2004:668). Six of the participants in the study experienced a burden in care related to external support and education services. A lack of these services may be a factor impacting the ability of participants to cope with certain behaviours. Lack of support exacerbates burden as participants have access to no professional services to provide emotional and psychological support. This finding is supported by Lippi (2016:6) who is of the opinion that families who receive minimal support services are at higher risk of experiencing burden.

- **Sub-theme 5.1: Support and Education**

The family system plays a very important role with regards to the functioning of the patient and thus educating and supporting them are crucial. This sub-theme looked at the support they got and whether they were educated on the condition.

> “Geen.” *[“None.”]*
>
> “Ek kan jou regtig nie sê nie, want ek is net daai werk toe mens en trug.” *[“I really can’t tell you, because I just go to work and come back.”]*
>
> “Daar’s niemand nie.” *[“There’s no one.”]*
>
> *“Niks* nie.” [“*Nothing.”*]
>
> “Niks nie.” *[“Nothing.”]*

It is important that family members are educated on the role they have to take on to care for their loved ones in order to encourage understanding of changes in behaviour and personality of the patient as well as to help the family member providing care to cope with their new role of caregiver (McFarlane et al., 2003:224). None of the participant conveyed receiving any valuable information on the illness itself or any services focused on providing support to the caregivers themselves.

A study by Mavundla et al. (2009:361, 362), found that caregivers in rural areas are subjected to a lack of services focussing on providing education on mental illness and manner of coping with patients resulting in caregivers experiencing frustration in this regard and this absence of vital education and support services can result in caregivers experiencing difficulties in coping with the caring aspect (Fadden, 2007:23, 24). The aim of education is to equip the caregivers, through education, with knowledge to improve their coping skills, communication and personal strengths enabling them to better understand and cope with schizophrenia and their role of caregiver. The absence of education and support services to caregivers can be linked to the state and availability of mental health care services in the public sector as the public sector is characterised by a lack of specialised mental health care services, human and financial resources (The South African College of Applied Psychology, 2018).

- **Sub-theme 5.2: Social work services**

The role that social work services played in the lives of these caregivers was reflected in this sub-theme:

> “Hmm mmm [nee]. Ek weetie, ek gaan mos maar self op my eie as ek voel [breek] maar nie rerigie.” *[“Hmm mmm (no). I don’t know, I go on my own when I feel (pause), but not really.”]*
>
> “Nee.” *[“No.”]*
>
> “Ek het met hierie maatskaplike werkers *gepraat*, ek praat die storie… oor en oor, maar kan my nie help nie. Hulle bly sê net vir my hulle sal nog na die toe, uh uh, nog na die toe gaan vra na die toe vra hoe moet dit, hoe, nie een, kyk, “June, July, Augustus” nou, vier maande wat hulle niks, doen nie! Niks! En ek het al, ek kla al hoeka voorrie vier maande.” *[“I* spoke *to these social workers, I talk about this… over and over again, but they can’t help me. They keep telling me that they will, uh uh, go to the and ask what must be done, not one, look, June, July, August now, four months where they haven’t done anything! Nothing! And I have, I have complained long before the four months.”]*
>
> “Ha a. Nee.” *[“Ha a. No.”]*
> “Ek het net by die, by die hospitaal, het ek ‘n maatskaplike werker gekry. Ook nie ‘n, psigiatriese dokter, nog nie ‘n maatskaplike werker nie.” *[“I only got a social worker at the hospital. Also not a, psychiatric doctor, not a social worker.”]*
>
> “Nee.” [“No.”]
>
> “Nee, is net mos net die toelaag wat hulle vir my gesjee het.” *[“No, it’s only the grant that they gave me.”]*
>
> “Hmm mmm. Nee.” *[“Hmm mmm. No.”]*

On the question if any of the participants have been referred to a social worker or have had any interaction with a social worker, only two participants indicated that they have sought assistance. Neither one could identify a positive outcome with regards to seeking help. All participants have indicated that they have never been referred to a social worker and cannot identify any personal or community support services that have been identified by professional to them or in their community.

The role of the social worker is threefold, consisting of case management where direct services are provided to individuals and where they are empowered to use resources to address their needs; community development, where individuals are linked to resources and in the case of absence of certain services, resources are developed; and therapeutic services where support and counselling services are provided to individuals to improve functioning and promote healthy family life. In the study it was however found that none of these vital services had been provided to participants to assist them in coping with the role of caregiver and to encourage a healthy family life through assisting participants to address challenges they experience in their daily lives (Payne, 1995:1, 2). From this information caregiver burden can be linked to lack of social work services as family members are not receiving support or being provided with the resources and skills to cope with mental illness in their family system more effectively.

- **Sub-theme 5.3: Community awareness**

This sub-theme explored to what extent there is focussed on community awareness, which can further be linked to the theme on stigma, as lack of education and information can contribute to ignorance and inability to know how to cope with the illness.

> "Die programme, daar's nie *programme rerig* vir hulle nie, daar's nie rerig deelname nie." *["The programmes, there are not really* programmes *for them, there's not really cooperation."]*
>
> "Nie wat ek, van weetie." *["Not that I know of."]*
>
> "Daar issie." *["There isn't."]*
>
> "Ha a. Nee hiersie sulke goedtie." *[Ha a. No there's no such things."]*
>
> "Mmm. Nee. Dis net jy wat alleen dit doen." *["Mmm. No. It's only you that does that."]*
>
> "Hulle kan liewerster vir hulle, uhm, programme gee te doen laat hy weet hy gaan nou na 'n plek toe en trug weer. Sien jy. Om maar daarnatoe te gaan." *["For them they can rather, uhm, give programmes so that they know they can go to a place and come back again. You see. To go there."]*

All of the participants indicated never having been involved in any community awareness programmes on schizophrenia or receiving any education on the illness. This can be linked to a previous theme 2.3 focussing on support services from health care services to the caregiver. The responses of the caregivers with regards to community awareness identifies a gap in service delivery to both the patient and the caregiver and can be a contributing factor to families experiencing caregiver burden, being subjected to stigma and possibly becoming despondent due to not being able to handle the repsonbilitity of care on their own (Du Plessis et al., 2004:4).

- **Sub-theme 5.4: Caregiver needs**

As already identified through the literature study and the data presented in this chapter thus far, this sub-theme focusses on the needs of caregivers pertaining to their role in caring for the patients and always with regards to themselves.

> “Oe ek voel hulle kan meer doen. Ek voel daar kan meer, uh, uh [breek] *programme* geskep word, meer uh, uh, meer *gedoen* word vir hulle. Ek weetie eintlik wat kan gedoen wordtie maar, ek meen as ‘n mens in, soos in ‘n psigiater is sal jy kan weet, wat, hulle moet meer betrokke wees, behalwe nou net die, by hospitale.” *[“Oh I feel they can do more. I feel more can be done, uh uh (pause) programmes must be created, more uh uh, more must be* done *for them. I don’t actually know what can be done, but I mean if a person is, such as a psychiatrist would know, what, they must be more involved, except now only at the hospitals.”]*

> “Ons het, kyk soos ek ok nou al op die afdraend is, hoe moet ek sê? Mens het mos iemand nodig wat ka vir jou help [breek] en, versorg… Nou as hulle kan vir my ‘n tuisversorgers gee wat darem vir jou kom *lekker* bad en so, en, en, dat jy weer vars en skoon is en, en aantrek [sug]. Is vir ‘n mens ‘n bietjie swaar want jy weet jy’t vir jou mos *als* gedoen en nou kan jy nie.” *[We have, like me who are on the way down, how can I say? You need someone that can help you (pause), and care… Now if they can give me a home-based carer who can come and bathe me and so on and that you are fresh and clean, and dress you (sigh). It’s a bit difficult, because you know you used to do everything and now you can’t.”]*

> “Wat ek nodig had is finansieel. Dis my grootste, finansieel… *Rerig waar,* want soos *Jacky* skuld maak kom ek nie uit met hierie SASSA nie. As hulle kan ook vir ons kospakkies gee, sal dit *baie* goed wees vir my.” *[“What I need is financial. That’s my biggest, financial…* Really, *because *Jacky* makes debts and I don’t come out with this SASSA. If they can also give us food parcels, that would be* very *good for me.”]*

> “Neeee, hulle, “worry” da nie eens nie… Nee maar hulle kan dan nie.” *[“Noooo, they don’t worry… No but they can’t.”]*

> “Ons moet nou eintlik iemand kry wat vir ons kom “uplift” sien jy. Krag gee om saam met die mense te werk, want somskere da, da raak jy ok moedeloos… Hulle moet vir ons ‘n sorg gee. Al issit nie geld nie. Dit hoefie net geld te wesie. Al koop hulle vir ons die goed, en soos met krag. Ons se krag stelsel is baie min.

> Hulle moet vir ons altyd ok so bystaan met die krag ennie water. Ons koop water. Hulle moet vir ons met die water ook bystaan, en dan nou, as kan daai sopkombuis trugbring. Nog te beter." *["We need someone to uplift us. To give us the power to work with the people, because sometimes you get discouraged… They must care for us. Even if it is not financially. It doesn't only have to be money. Even if they buy things for us, such as electricity. Our electricity system is very little. They must assist us with electricity and water. We buy water. They must assist us with water and then if they can bring back that soup kitchen. All the better."]*

> "… sê ek vir die kollega van my as ons af is moet ons by die welsyn gaan aansoek doen om *hierie* mense te versorg. Hierie skisofrenie goed en ou mense en hulpeloses en hierie mense wat so loop... "*["…I tell my colleague when we are retired we must go to welfare and apply to care for* these *people. These schizophrenic and old people and helpless people that wander around…"]*

The responses of the caregivers differed from each other. From all the participants, only one participant couldn't identify caregiver needs, conveying that "they" don't care. "They", referring to professionals who should be responsibe for providing support services to caregivers. Three of the participants indicated the need for community-based services to not only assist the caregiver, but the patient, indicating that the wellbeing of the patient is of great importance. Other participants identified the need for financial assistance and provision of food parcels as grants are not enough. One participant identified the need for assistance with regards to physical care for herself. This participant is not able to care for herself as efficiently as she was used to when she was younger. From the data obtained, it can be concluded that most of the participants need some or other financial support to contribute to household expenses and needs as most of these households are dependent on government grants and based on the information, not able to cover all expenses with this income alone. However, these sub-themes can be linked to each other through one common demoninator, which is the improvement of quality of life. Responses by the participants indicate the needs for a service to improve their lives and help them cope better with the illness. This theme's major focus was on external factors. Social influences have a direct impact on the caregiver experience, as it not only impacts their role and function of caregiver, but also impacts them directly as individuals. This can be linked to the biopsychosocial approach, which aims to view an individual holistically, taking into account different factors in the individual's environment which may influence their experience. Viewing the participants in their environment clearly indicates that they are affected by the disease itself and by the lack of external support and community resources.

All of the latter consequently resulted in the participant’s emotional and mental wellbeing being affected by the burden of care and this is substantiated by the participants’ expression of needs in this theme and well as previous themes.

3.9 Summary

The research methodology applicable to this study was discussed in the first half of the chapter. In the second half of the chapter, the biographical data of participants were displayed, making use of figures and graphs. Eight caregivers of mental health care users with schizophrenia in Upington participated in the study. Data was collected through one-on-one interviews using a semi-structed interview schedule. The researcher analysed transcripsts and developed themes and sub-themes from the data collected. Five themes and seventeen sub-themes emerged from the data. Each theme was discussed; verbatim quotes from participants were provided to support these themes and findings were substantiated with literature from an in-depth literature review in chapter two. The findings revealed that all participants and the patients they were caring for had access to health care services, but that there was a lack of support with regards to services specifically aimed at supporting and educating caregivers. Experiences and challenges encountered by caregivers were described and this provided insight into the experiences of caregivers relating to their role of caregiver; knowledge of schizophrenia; access to and availability of support and intervention services and social influences such as stigma and financial challenges.

The next chapter focusses on the summary, conclusions and recommendations.

4. CHAPTER 4: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

In this chapter, the researcher will discuss the goals and objectives of the study. The focus of the chapter will continue with how each objective, and ultimately the goal of the study was met, followed by key findings and conclusions.

4.2 Summary

The goals and objectives of the research study on the experiences of caregivers of mental health care users with schizophrenia in Upington, Northern Cape will be discussed, followed by key finding and conclusions.

4.2.1 Goal of the study

The goal of the study was to explore and describe the experiences of caregivers of mental health care users diagnosed with schizophrenia.

4.2.2 Objective of the study

The objectives of the study were as follows:

- To describe and contextualise schizophrenia using the biopsychosocial approach;
- To explore and describe the biopsychosocial experiences and challenges of caregivers of mental health care users with schizophrenia;
- To ascertain the tasks, roles and challenges of caregivers in caring for a person living with schizophrenia;
- To explore the intervention and support provided by professionals to the caregivers of a person living with schizophrenia; and
- To suggest strategies for social workers on intervening with caregivers of mental health care users with schizophrenia.

4.2.2.1 Objective 1: To describe and contextualise schizophrenia using the biopsychosocial approach

This objective was achieved by conducting an in-depth literature study on the nature of schizophrenia and the influence of schizophrenia on the family and the caregiver, followed by empirical research on the selected topic. Through the literature review, the researcher studied and described schizophrenia within a biopsychosocial context. The literature study thus provided an in-depth look at schizophrenia taking into account biological, psychological and environmental or social factors with regards to aetiology of the illness, the function of care and the influence of external factors on the caregiver. Empirical results showed that schizophrenia in patients was indeed influenced by external factors such as complications during birth, learning difficulties, possible drug abuse and stress as these were some of the factors identified as possible causes affecting onset of the disease. Through the literature study, biological factors influencing schizophrenia was discussed as well as environmental factors and how these factors can impact a patient suffering from schizophrenia. The experiences of the caregivers were also explained within the context of their external environment. The literature review shed some light on the burden experienced by caregivers, distinguishing between objective and subjective burden. From the findings of the study it can be concluded that caregivers experienced both subjective –and objective burden as caregiver burden was influenced by both external and internal influences related to care as well as the impact of environmental factors such as stigma, lack of support and mental health care services.

4.2.2.2 Objective 2: To explore and describe the biopsychosocial experiences and challenges of caregivers of mental health care users with schizophrenia

The biopsychosocial approach was used with the aim of understanding the experiences of the caregiver in relation to the biological, psychological and the social factors relating to schizophrenia. This objective was reached by investigating the influence of care on the caregiver by means of the empirical research study, taking into account the influences of caring for the patient with schizophrenia as well as influence external of the family system which may affect caregiver burden. Research themes which embarked from the collected data, provided insight into the experiences of the caregivers. One theme in particular focused on the challenges experienced by the caregivers. Through this theme, it was identified that the caregivers were affected on different levels by internal and external influences related to care, their families and the environment. The biological impact of schizophrenia was demonstrated by the exposure of caregivers to symptoms of schizophrenia which were both positive –and negative symptoms. The symptoms displayed by patients had an effect on their behaviour and patient behaviour was identified as one of the challenges experienced by caregivers which had an impact on their emotional wellbeing and caregiver burden. Societal factors such as a lack of support from health care services to the caregiver, lack of social work support services and lack of community awareness were all factors influences caregiver experience and contributing to their ability to cope with mental illness.

4.2.2.3 Objective 3: To ascertain the tasks, roles and challenges of caregivers in caring for a person living with schizophrenia

The findings of the research study indicate that caregivers in this context do not play a very active role in the physical care of their family members as all of the family members being cared for by participants are generally able to look after themselves. Their roles are more of a supervisory role, keeping an eye on the patients and making sure that they eat and adhere to their medication. In some cases, there were caregivers who had to play a more intense supervisory role as they were caring for patients where challenges with adherence and behaviour were experienced. Stigma, financial implications, patient behaviour and family support were sub-themes which emerged in relation to challenges experienced by the participants. All of the participants did however not experience challenges with regards to each of these external factors.

From information obtained through the data collection process, it became evident that a lack of education and support services were a major challenges experienced by caregivers, despite them not explicitly stating that they saw this as a challenge. All of the caregivers indicated that they were not being provided with support services aimed at the caregiver or education on the illness of their family member, which is a necessity in enabling them to cope with caregiver burden more effectively.

From the eight caregivers participating in the study, six participants generally experienced their role of caregiver as a positive one despite certain challenges experienced.

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

All participants indicated that their family members with schizophrenia were receiving health care services from local clinics. None of them identified any kind of support service focused on the caregiver specifically. One caregiver was of the opinion that she received a lot of support from her local clinic. This support was however in relation to treating the patient and not geared toward services for the caregiver herself. All caregivers identified a lack of community-based services and awareness programmes in their communities and none of them have ever attended such programmes. None of the eight participants have received any support services from a social worker with regards to supporting them and or their family in their role of caregiver. Only two out of the eight participants have had contact with a social worker over the course of their family members’ illness.

4.2.2.5 Objective 5: To suggest strategies for social workers on intervening with caregivers of mental health care users with schizophrenia

Strategies with regards to intervention are based on the lack of support services; community awareness on mental health; specialised mental health services; caregiver burden; and the socio-economic environment and employment status of the participants.

The researcher recommends the following strategies for intervention:

- Development and implementation of mental health awareness programmes in Upington and rural areas in the Northern Cape by the Department of Health as mental health is a designated function of this department. The implementation of this strategy should involve social work professionals from all other spheres of specialisation as mental health is an issue that affects people in all spheres of society.
- The inclusion of mental health as a focus area of social work at district level and the prioritisation of support services to caregivers and families of patients living with mental health. These services should be focused on mental health awareness, education and support and should aim not only to educate and equip family members with the necessary skills to cope with the role of caregiving, but also to reduce and eliminate stigma related to mental health.

4.2.3 Research question

The research question that was posed in the study is:

What are the experiences of caregivers of mental health care users with schizophrenia in Upington, Northern Cape?

The research question was answered by conducting a qualitative research study, through which interviews were conducted with the caregivers of mental health users with schizophrenia residing in the town of Upington, Northern Cape. Eight interviews were conducted, after which the data was analysed by the researcher. From the data analysis, themes and sub-themes were identified which were discussed in chapter three of this mini-dissertation. Five themes and seventeen sub-themes emerged from the research study and were utilised to answer the research question.

4.2.4 Limitations

The following limitations in the study were identified:

- **Study time frame**: Due to certain constraints related to each fellow student having to conduct a group research on the same topic in different areas, the approval process of the study took longer and thus the duration of the study was two years instead of one year as planned. The relocation to another town by researcher for a new job, implied that the researcher could not access Upington as frequently as possible to conclude the sampling and data collection within the set time-frame. Thus the empirical study and research report were only completed after a two-year period.
- **Sampling methods and sample**: Non-probability purposive sampling was used to select seven participants using the selection criteria. It was initially planned to sample two participants from five different primary health care clinics in the target area. Only three of the five clinics were able to recruit participants to participate in the study and the sample was thus only drawn from three areas. Sampling was also affected by prospective participants who were contacted, then not agreeing to participate, after sharing the informed consent forms with them.
- **Pilot study**: Due to certain constraints already mentioned, the researcher was unable to consult with experts in the field of mental health in Upington, as no

psychiatrist nor mental health social worker was working in the private nor public sector in this area. One of the participants initially selected and included in the pilot study, was later included as the first participant in the main study, due to the richness of the data collected during the pilot interview. This was of benefit to include in the main sample.

4.3 Key findings, conclusions and recommendations

Key findings and conclusions will be discussed in the following section. The section will be concluded with recommendations to social workers for strategies on intervening with families caring for mental health users with schizophrenia, as well as with recommendations for support services to caregivers within the community context.

4.3.1 Key findings, conclusions and recommendations with regards to the literature study

In the following section, the key findings, conclusions and recommendations with regards to the literature study will be discussed.

- **Key findings**

The biopsychosocial approach underpinned for this study as this approach views the individual holistically, considering biological, psychological and social influences and taking into account how these factors interact with and influence each other. This approach was most suitable for the study, as it was used to explore the experiences of the caregiver relating to both the participant’s and the patients’ biological state, emotional wellbeing of the caregiver and social influences affecting the experience of caregiving. Using this approach resulted in the exploration of different systems in the caregiver’s world and how they viewed and made sense of their world and their role of caregiver.

The literature study provided an in-depth look at mental health in general, as well as mental health in South Africa, pointing out certain challenges faced by the South African health care system based on studies such as the South African Stress and Health Study (2003-2004), statistics from the South Africa Demographic and Health Survey (2016) and the Presidential Health Summit Report (2018). Legislation such at the National Health Act 61 of 2003 and the ANC National Health Plan (1994) stipulate major functioning of the government with regards to health care and provide guidelines for the provision of care. Comparing the latter to the state of health currently, shows that there are major challenges and that mental health needs to be prioritized. The state of health care can be directly linked to the experiences of caregivers as patients with mental illness and their families – especially in rural areas characterised by a lack of structural, human and financial resources – are greatly dependent on government for health care services.

An in-depth look at the nature of schizophrenia, identified the connection between the illness and the experiences of caregivers related to caregiver burden. Another key issue, taking into account the nature of the illness and impact on families as well as caregiver burden, was the role of the social worker related to support services to families. Social work intervention can be considered of utmost importance in educating families and communities and providing them with support. In the literature the role of the social worker is clearly defined, but the execution of social work functions related to mental health is however greatly influenced by the availability of resources.

- **Conclusions**

The biopsychosocial approach was suitable as theoretical approach underpinning this study and the link between the biological, psychological and social was evident. From the key findings it can be concluded that there is a gap in service delivery in the field of mental health. Rural areas are greatly affected by lack of resources needed to effectively create awareness and provide support services to families living with mental illness. It can also be concluded that social work plays a vital role in providing much needed support services to families living with mental illness as the experiences of caregivers are affected by numerous factors related to caring for a mental health care user with schizophrenia as well as by factors external to the caregiver.

- **Recommendations**

Government should place more focus on developing and implementing educational and awareness programmes to raise awareness in communities in rural areas, in an effort to improve caregiver skills and address stigma related to mental health.

The government should place more focus on improving the lack of mental health services in rural areas.
Current practices should be monitored and evaluated as well as gaps identified in mental health service delivery, consequently creating strategies to address mental health issues more effectively.

More social workers should be trained and appointed in the field of mental health care. They should be provided with training on schizophrenia to be more equipped with expertise and knowledge with regards to this mental illness, enabling them to transfer knowledge, create awareness and support families.

Families living with schizophrenia should be assisted through support services by training and employing home-based carers in the communities to provide emotional and practical support services to families living with mental health users.

4.3.2 Key findings, conclusions and recommendations with regards to the research findings

In this section, the key findings, conclusions and recommendations with regards to the research findings will be discussed.

4.3.2.1 Theme 1: General understanding or concept of mental health and schizophrenia

This theme emerged early during the data collection process and focussed on the participants' knowledge of mental health and schizophrenia pertaining to the meaning of terms, nature, causes and symptoms of schizophrenia. Four sub-themes emerged from this theme.

- **Key findings**

The participants did not demonstrate a clear understanding of the concept of mental health nor schizophrenia. Of all the participants, only one identified mental health as being related to the state of the mind. Six participants had no knowledge of the word schizophrenia with some of them directly expressing that they don't know the word. Participants' perceptions of the causes of schizophrenia were based on pre- and perinatal influences and possible substance use. Seven of the eight participants identified having observed symptoms of schizophrenia. The participants' perceptions of what the symptoms of the illness are, were based on behaviour that they experienced throughout the course of the illness. Positive, negative and cognitive symptoms were described. Most of the symptoms identified included behaviour such as auditory hallucinations and delusions, referring to positive and cognitive symptoms such as confused thoughts, difficulty with memory, limited advancement in school and deficits in relation to execution. Lack of knowledge was thus a key finding under this sub-theme.

- **Conclusions**

The participants' general understanding and knowledge of mental health and schizophrenia is limited and can be linked to lack of education at onset and throughout the course of the illness. Most of the participants could identify symptoms of schizophrenia, as they have observed these symptoms throughout the course of the illness and what they perceive as symptoms are based on their experiences of the patient's behaviour. Caregivers were not educated on schizophrenia at a level which could have equipped them with the skills necessary to understand the illness better. This would have made coping with the illness and their role of caregiver more effective.

- **Recommendations**

Primary health care clinics should provide in-depth education and training on schizophrenia to patients and their significant others. More staff may be needed to fulfil this function.

Individuals should be identified and included in support group sessions to be educated and supported by others in the same situation. They are to be trained on the nature of schizophrenia so that they can transfer their knowledge to family members to equip them with the necessary knowledge on the illness.

Home visits to families living with schizophrenia should be arranged.

4.3.2.2 Theme 2: Health care services at community level

This was a very important and prominent theme throughout the study and is linked to all of other themes which emerged from the data collected. This theme was directly linked to the knowledge of schizophrenia, the role of the caregiver with regards to tasks and role transitions, challenges experienced and support services. The reason for the latter is based on the finding that primary health care clinics were basically the only community-based services providing health care and information to patients and caregivers.

- **Key findings**

All of the patients being cared for by participants were receiving treatment from their local primary health care clinics and for most of the participants a clinic was the first point of entry into the health care system. The majority did not experience any challenges related to non-adherence, while two participants identified non-adherence at certain times throughout the course of the illness resulting in behavioural changes in the patients they were caring for. Excluding the two patient's facings challenges with non-adherences, all other patients in the care of the participants were responsible for visiting clinics and collecting medication on their own, without assistance from their caregivers, indicating that treatment is generally adhered to without major challenges. The main method of treatment identified was pharmacological treatment. No participant gave any indication or expressed any form of psychological treatment or psychoeducation being provided to either the patient or themselves. Lack of support from health care services to the caregivers was another key finding. What is considered services to families by some participants were actually pharmacological treatment provided to patients to control the illness.

- **Conclusions**

Participants had limited knowledge on schizophrenia and were subjected to a lack of education and support with regards to their role as caregiver. Apart from knowledge on how to administer medication, participants did not have a broad knowledge base on schizophrenia itself. Their existing knowledge is based on their experiences throughout the course of the illness. This indicates that clinics play a major role in pharmacological treatment of patients suffering from schizophrenia at community level and that these structures are the primary services provider for psychiatric health care services in the area. Support to families as a whole however, seem to be very limited and show that there is a gap in service delivery with regards to vital holistic treatment services to families living with mental illness.

- **Recommendations**

Training should be provided to caregivers and families on the nature of schizophrenia, the effect of the illness on a patient's behaviour and functioning.

Support must be provided to caregivers experiencing challenges with non-adherence to treatment by monitoring cases of non-adherence more intensively and by exploring alternative methods of treatment to complement pharmacological treatment. This is of utmost importance as non-adherence can have a direct impact on caregiver burden and can lead to dysfunction in the family system.

4.3.2.3 Theme 3: Role of the caregiver

The focus of this theme was on the role of the caregiver related to caring for a patient with a mental illness such as schizophrenia. Two sub-themes emerged from this theme. The first identifying the feelings of the caregiver about their role of caring for a person with schizophrenia and the second, the tasks associated with the caregiving function. All of the participants identified physical tasks that they were responsible for in their role as caregiver, but as their loved ones were all adults and most of them were not exhibiting uncontrollable behaviour, most caregivers played a more supervisory role in the sense of keeping an eye on the patient.

- **Key findings**

Of the eight participants, only three did not play a parental role and they also identified the least caregiver burden and stigma experienced in the time that they have cared for their loved ones. The tasks associated with care included providing meals, ensuring adherence to treatment and managing their finances. The patients being cared for were generally able to take care of themselves physically, but needed support with regards to other aspects of care and decision-making.

- **Conclusions**

The caregiver plays a vital role in the everyday functioning of the patients, especially with regards to their mental health, as caregivers identify one of their major tasks as making sure that the patient is fed and uses their medication.

- **Recommendations**

Vocational programmes focussing on skills education and training should be implemented at community level to teach patients vital skills in caring for themselves. Programmes of this nature should focus on engaging patients in stimulating educational activities as a means of giving structure to their day, getting them to interact with others outside of the home and learn valuable skills that can improve cognitive and physical functioning.

4.3.2.4 Theme 4: Challenges experienced by caregivers

This theme focusses on the different challenges that caregivers experience in relation to the caring role, patient behaviour, external environmental and social factors. Four sub-themes emerged from this theme, shedding light on the impact of certain factors on the caregiving function, as well as on the burden experienced by caregivers.

- **Key findings**

Caregiver burden was the key finding that emerged from this theme. In all of the four sub-themes: stigma, financial implications relating to care, family support and patient behaviour, burden experienced by caregivers could be identified. The burden experienced by caregivers was precipitated by internal, external and environmental factors. Caregiver burden was both subjective and objective, affecting the caregiver on different levels, when taking into account their biopsychosocial functioning within their environment.

Emotional difficulties as a result of stigma were identified. All of the participant's who's loved ones experienced positive symptoms of schizophrenia were affected by stigma, as this behaviour was observable by those in the community setting and consequently reacted to. Stigma is an external factor that influences people's behaviour towards that which they don't understand and was a phenomenon that was identified by most participants and that affected them emotionally, as it was difficult for them to see their loved ones being subjected thereto. Stigma can be viewed as a consequence of ignorance, which in turn is caused by a lack of education. Community awareness on schizophrenia was basically non-existent, which was also prominent in theme 5. The only income of the majority of participants was from government grants and it was amongst these participants where the need for either financial assistance or assistance by means of providing food parcels were identified. Most of the participants were dependent on grants. Financial pressure to provide for their families and in the needs of the patients were a factor contributing to caregiver burden.

A sub-theme of family support emerged, which identified half of the participants not receiving support from their closest family and some participants identifying their own family members of accusing them of spoiling the patients and in so doing being responsible for their illness. This finding indicates the absence of a critical support structure which has the impact to result in an array of emotional and practical challenges being experienced by the caregiver. In terms of patient behaviour, some patients were experiencing positive symptoms of schizophrenia influenced by non-adherence and substance abuse. These factors were a major cause of stress with the caregiver having not only to deal with these factors, but also with the impact thereof on the behaviour of the patients.

- **Conclusions**

The majority of participants experienced caregiver burden. This burden was exacerbated by environmental influences on patient behaviour, as well as by lack of much needed support and financial resources. Caregiver's emotional wellbeing was affected by stressors related to caring and providing for the patients, as well as anxiety related to stigma and fear for their loved ones due to stigma. Stigma played a major role in people not being educated on schizophrenia and mental illness in general. Biological factors influencing the patient's behaviour resulted in participants experiencing stress which affected their emotional wellbeing. Caregivers were further subjected to emotional distress by influences in their external environment such as stigma and lack of support in their role as caregiver. This indicates an interaction between biological, psychological and social components in the participants' environment resulting in the challenges being experienced and consequently leading to caregiver burden.

- **Recommendations**

Social workers and other health and allied health professionals should be employed in either government or non-governmental departments with health and psychosocial functioning as one of their core functions, focussing on:

- Identifying families with patients with schizophrenia and exploring the needs of these families with regards to practical and emotional support.
- Collaboration between departments to address issues related to mental health and to come up with strategies to address the needs of family affected by mental health.

4.3.2.5 Theme 5: Support to families living with schizophrenia

This theme focused on both internal and external support services to the caregiver. Internal referring to the family system within the home and external referring to the community and community-based resources. Four sub-themes emerged from this theme, including education and support, social work services, community awareness and needs identified by caregivers.

- **Key findings**

The lack of support services across all four sub-themes was a prominent finding. Caregivers were not provided with any support. Education on mental health and schizophrenia were identified as not being available compared to that of Tuberculosis and HIV, for example. Only two participants in the study identified ever having had contact with a social worker. None of the eight participants had ever received therapeutic services focusing on support, education or coping skills to enable the caregiver to cope with role transition and the impact of the role on their emotional and mental health. Participants revealed that they had never heard of or attended community awareness programmes on schizophrenia, there was no frame of reference to base any ideas for such programmes and it was difficult for them to identify their needs in terms of support. One participant was of the opinion that professionals could do nothing to help, as they don’t care. The lack of resources was viewed as a lack of interest by those who are supposed to provide services. The reason for lack of services was the lack of resources aimed at addressing vital mental health issues.

- **Conclusions**

The lack of support services are very closely linked to a lack of community-based resources. All four of the sub-themes are very closely linked to each other. Social work services and community awareness programmes have the similar aim of educating, raising awareness and thus providing support and much needed information and skills. Due to a lack of these services, caregivers are not receiving relevant education and training on mental health and schizophrenia specifically. This consequently results in certain needs developing. These needs were conveyed in sub-theme four, which focused on caregiver needs. A common denominator in this sub-theme was a need for an improvement in quality of life, whether it be by means of financial assistance, assistance with regards to food, physical care or emotional support.

None of the caregivers participating in this study have received quality support services and needs focused intervention by a social worker with regards to them as caregivers specifically. All of the participants also identified never having been to a programme focussing on raising awareness on schizophrenia in their community. Individual and family education and training had either never been provided or not in such a manner that it had improved participants' knowledge base and skills with regards to coping and living with schizophrenia. This information provides insight into the gap in service delivery focussing on mental health issues in rural areas in South Africa and displays of how little importance mental health services in rural areas are. Support services are a vital element forming part of the treatment process and which affects both the patient's functioning and caregiver burden. Social components such as the absence of community-based resources and support services to caregivers have thus influenced the psychological component of functioning in the caregiver, resulting in participants experiencing caregiver burden. Skills and knowledge are important factors enabling caregivers to cope with mental illness. Due to a lack of these factors, participants were not equipped with coping mechanism to live and cope with mental illness in a constructive manner.

- **Recommendations**

Caregivers of patients with schizophrenia should be educated on the nature of schizophrenia and training should be provided with the specific aim of focussing on the caregiver, for example, equipping the caregiver with the necessary skills to cope with schizophrenia.

Support services in the form of individual and group therapy should be provided to the caregiver. Community support groups for caregivers of schizophrenia should be established in the different communities within Upington.

All departments and organisations responsible for providing mental health services should be encouraged to develop and implement programmes to raise awareness on schizophrenia in an attempt to educate community members, sensitizing them on the issues of mental health and schizophrenia, to ultimately eradicate stigma.

4.4 Recommendations for future research

Larger scale research should be conducted on schizophrenia in the Northern Cape Province to identify vital needs of both patients and families as well as to identify gaps in service delivery, resources needed and best practices already being implemented in an effort to improve services delivery to mental health care users and their families.

Future research should focus on identifying and developing programmes aimed specifically at providing services to families, with the core focus on these services being support and education.

Future research should identify the needs of mental health care users with schizophrenia and focus on developing and implementing strategies to treat schizophrenia more effectively. Apart from pharmacological treatment, other methods of treatment should be included such as therapeutic services, social skills training and community awareness. The latter is important in assisting mental health care users to be more functional members of society as well as to address the issue of stigma.

4.5 Conclusive remarks

It is evident that caregivers play a very important role in the functioning of mental health care users with schizophrenia. Most of the participants in this study did not describe their experience of caregiver as negative in relation to the care they provide for their loved ones. Caregiver burden experienced by caregivers are related more too external environmental influences and lack of resources and services, rather than patient behaviour. Throughout all of the themes emerging from the data, lack of support in different forms was identified as a challenge experienced by caregivers. Education on mental illness and schizophrenia specifically, can greatly contribute to the way the function of caregiving is executed. Education on the nature of the illness and support to families can equip caregivers to manage the illness more effectively while simultaneously coping better with their role as caregiver. This can ultimately result in relieving the burden of care.

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6. ANNEXURES

6.1 Annexure 1: Permission to perform empirical research

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work and Criminology

6 August 2018

Ref.: Sharika R.V Selborne
Tel.: 071 971 9246
E-mail: u17228649@tuks.co.za

The Acting Director
Department of Health
ATT: Mr Seema
ZF Mgcawu District Office
52 Schroder Street, Middelpos
Upington
8801

Dear Sir

REQUEST FOR PERMISSION TO PERFORM EMPIRICAL RESEARCH: SHARIKA R.V SELBORNE

The abovenamed student is registered for the Master in Social Work (Healthcare) programme at the Department of Social Work and Criminology, University of Pretoria.

A requirement besides the coursework modules in the first year is to conduct research and write a mini-dissertation, resulting from a research project, under the supervision of an appointed supervisor, namely Dr C.L Carbonatto. The research will only proceed once a departmental Research Panel and the Faculty Research Ethics Committee has approved the proposal and data collection instrument(s). The following information from the research proposal is shared with you, although a copy of the research proposal will be provided to you if needed.

The envisaged title of the study is: The experiences of caregivers of mental health care users with schizophrenia in Upington, Northern Cape. The goal of the study is: To explore the experiences of caregivers of mental health care users with schizophrenia in Upington.

The objectives of the study are:

- To describe and contextualise schizophrenia using a biopsychosocial approach;
- To explore and describe the biopsychosocial experiences and challenges of caregivers of mental health care users 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 by professionals 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.

The envisaged target group of the study is: Familial or non-familial caregivers of persons with schizophrenia. The empirical part of the study will entail conducting personal interviews using an interview schedule with the participants.

This request will require practical assistance from your staff in sharing the details of this study with their clients as potential participants, using an information letter which will be provided. If persons are interested in partaking voluntarily, they will provide their contact details to your staff and the researcher will collect it in order to contact them. They will be required to sign an informed consent form before an appointment for the interview is arranged with them. No costs will be incurred by this request.

Possible benefits for your organisation can be summarised as follows:

- The study will help professionals to better understand the nature of the caregivers' experiences and the source of problems experienced by the caregiver.
- The study will provide recommendations that will help to improve the delivery of services to both mental health care users with schizophrenia and their caregivers in the sense that it can be used to formulate programmes and intervention strategies to help the caregiver cope with caring for a person with schizophrenia.

A copy of the final report results will be made available to your organisation after completion.

It would be appreciated if you will please consider the above request favourably and grant permission on a letter with a formal letterhead for the student to proceed with the project, at your earliest convenient date.

Yours sincerely,

Dr C.L Carbonatto
Senior lecturer and Supervisor

Selborne

Ms SVR Selborne
Researcher

6.2 Annexure 2: Ethics clearance approval University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Research Ethics Committee

10 July 2019

Dear Miss SRV Selborne

Project Title:	The experiences of caregivers of mental health care users with schizophrenia in Upington, Northern Cape
Researcher:	Miss SRV Selborne
Supervisor:	Dr CL Carbonatto
Department:	Social Work and Criminology
Reference number:	17228639 (HUM028/0219)
Degree:	Masters

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 10 July 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.

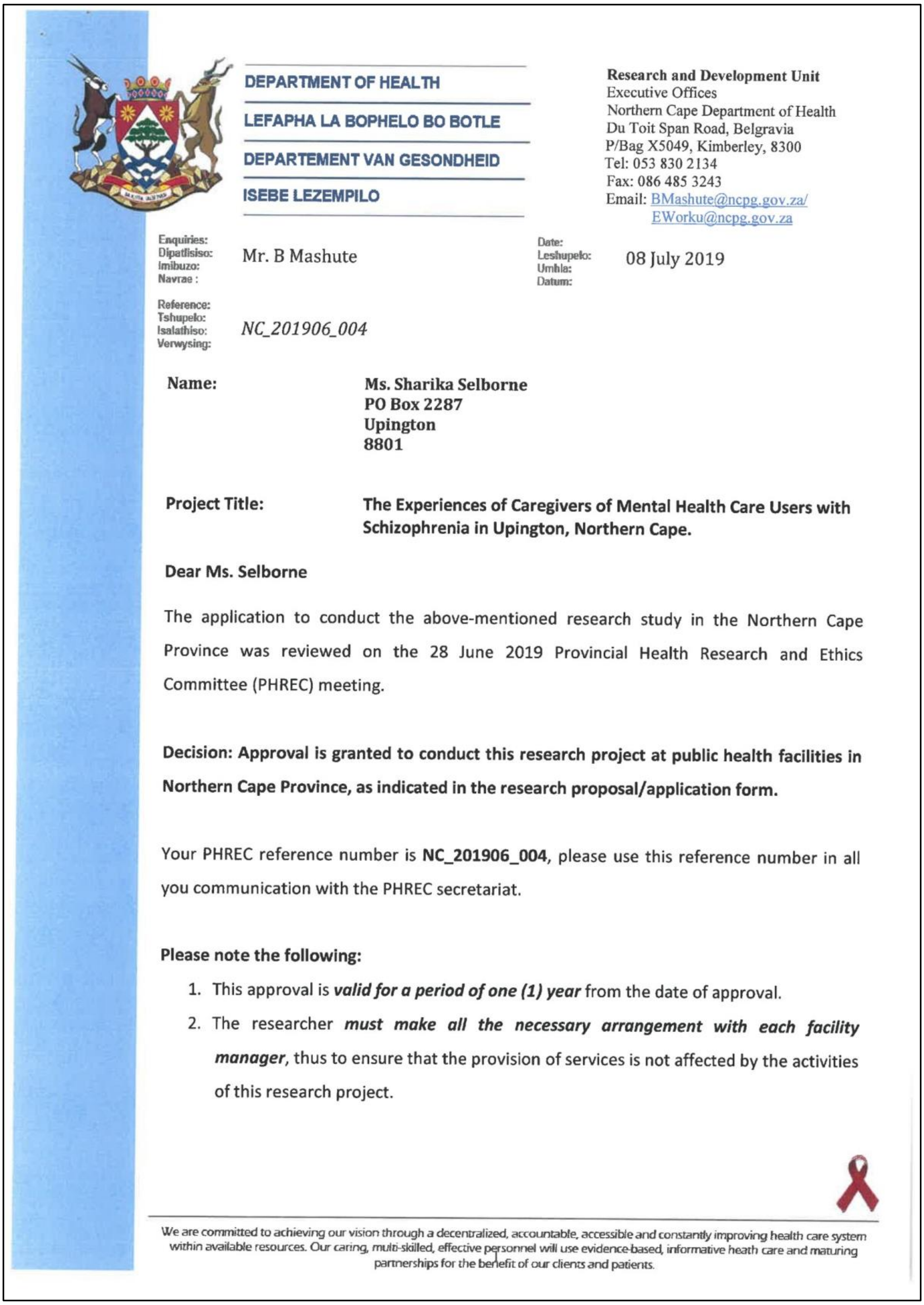
Sincerely

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 Bomotho

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 Mokalaoa

6.3 Annexure 3: Ethics Clearance Approval Department of Health



DEPARTMENT OF HEALTH
LEFAPHA LA BOPHELO BO BOTLE
DEPARTEMENT VAN GESONDHEID
ISEBE LEZEMPILO

Research and Development Unit
Executive Offices
Northern Cape Department of Health
Du Toit Span Road, Belgravia
P/Bag X5049, Kimberley, 8300
Tel: 053 830 2134
Fax: 086 485 3243
Email: BMashute@ncpg.gov.za/
EWorku@ncpg.gov.za

Enquiries: / Dipatlisiso: / Imibuzo: / Navrae : Mr. B Mashute

Date: / Leshupelo: / Umhla: / Datum: 08 July 2019

Reference: / Tshupelo: / Isalathiso: / Verwysing: *NC_201906_004*

Name:

Ms. Sharika Selborne
PO Box 2287
Upington
8801

Project Title: **The Experiences of Caregivers of Mental Health Care Users with Schizophrenia in Upington, Northern Cape.**

Dear Ms. Selborne

The application to conduct the above-mentioned research study in the Northern Cape Province was reviewed on the 28 June 2019 Provincial Health Research and Ethics Committee (PHREC) meeting.

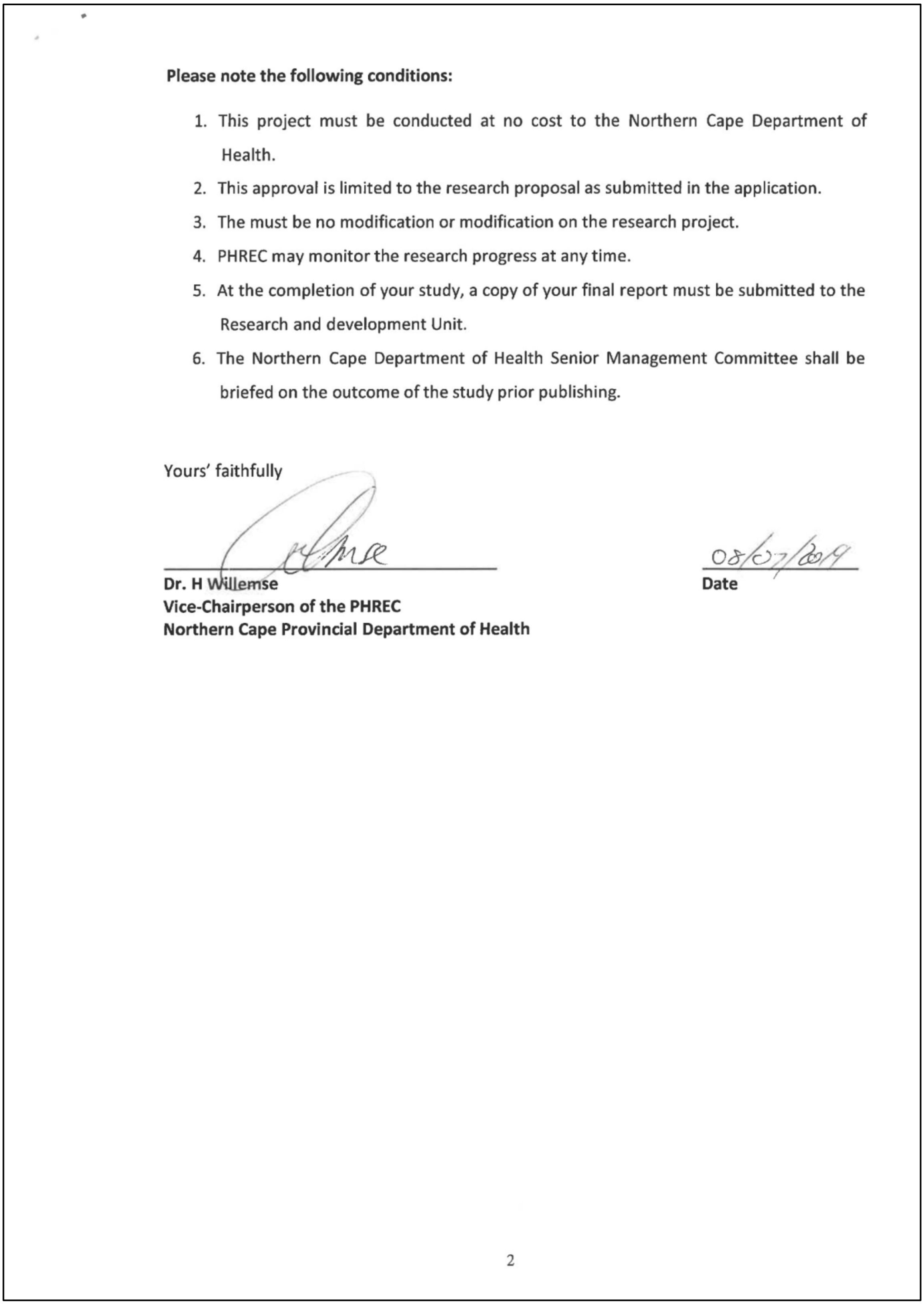
Decision: Approval is granted to conduct this research project at public health facilities in Northern Cape Province, as indicated in the research proposal/application form.

Your PHREC reference number is **NC_201906_004**, please use this reference number in all you communication with the PHREC secretariat.

Please note the following:

1. This approval is ***valid for a period of one (1) year*** from the date of approval.
2. The researcher ***must make all the necessary arrangement with each facility manager***, thus to ensure that the provision of services is not affected by the activities of this research project.

We are committed to achieving our vision through a decentralized, accountable, accessible and constantly improving health care system within available resources. Our caring, multi-skilled, effective personnel will use evidence-based, informative heath care and maturing partnerships for the benefit of our clients and patients.



Please note the following conditions:

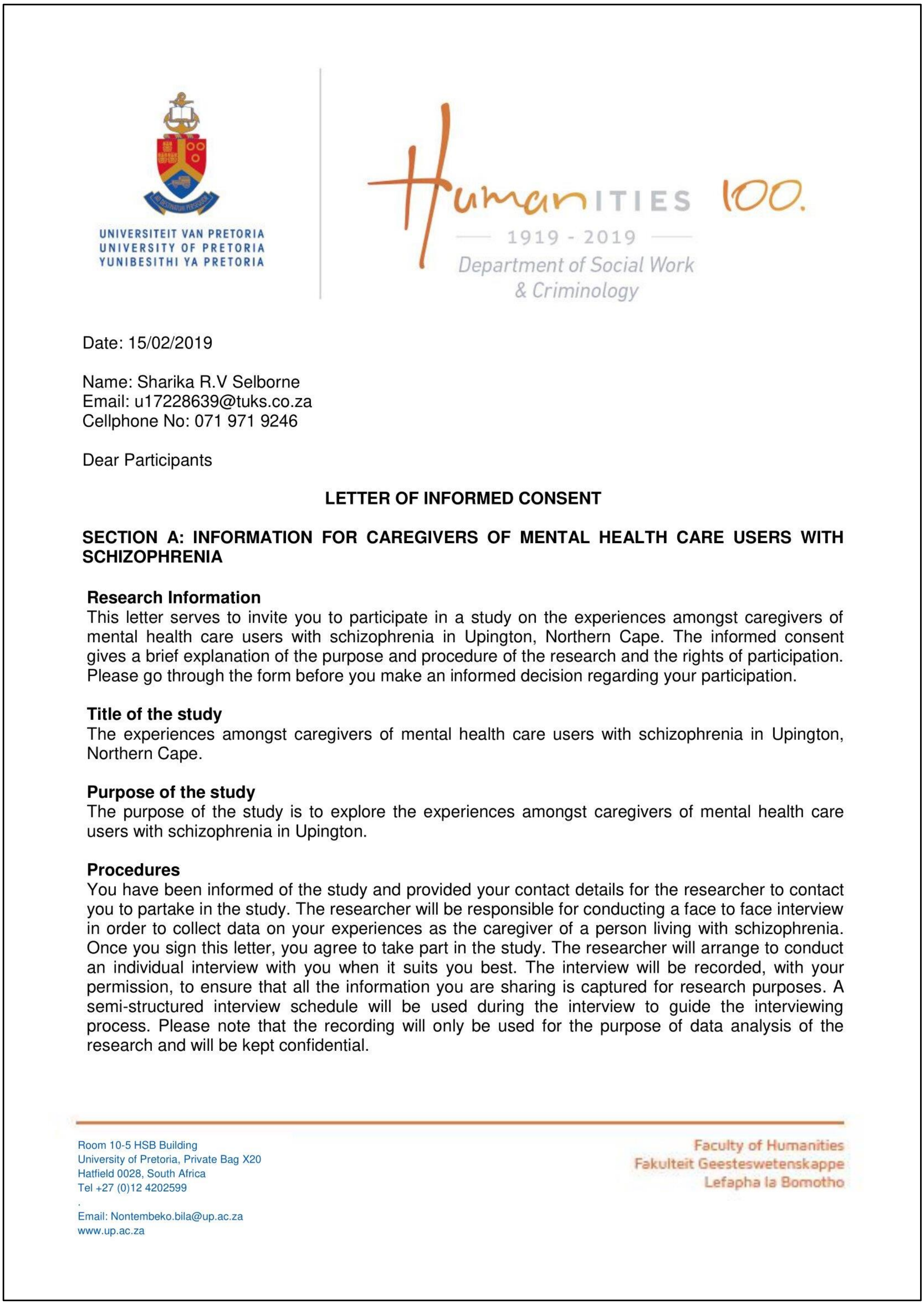
1. This project must be conducted at no cost to the Northern Cape Department of Health.
2. This approval is limited to the research proposal as submitted in the application.
3. The must be no modification or modification on the research project.
4. PHREC may monitor the research progress at any time.
5. At the completion of your study, a copy of your final report must be submitted to the Research and development Unit.
6. The Northern Cape Department of Health Senior Management Committee shall be briefed on the outcome of the study prior publishing.

Yours' faithfully

Dr. H Willemse
Vice-Chairperson of the PHREC
Northern Cape Provincial Department of Health

08/07/2019
Date

6.4 Annexure 4: Letter of Informed Consent



UNIVERSITEIT VAN PRETORIA
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YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Department of Social Work
& Criminology

Date: 15/02/2019

Name: Sharika R.V Selborne
Email: u17228639@tuks.co.za
Cellphone No: 071 971 9246

Dear Participants

LETTER OF INFORMED CONSENT

SECTION A: INFORMATION 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 Upington, Northern Cape. 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 Upington, Northern Cape.

Purpose of the study
The purpose of the study is to explore the experiences amongst caregivers of mental health care users with schizophrenia in Upington.

Procedures
You have been informed of the study and provided your contact details for the 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.

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Hatfield 0028, South Africa
Tel +27 (0)12 4202599
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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

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. The researcher will comply with UP's policies regarding plagiarism when writing the final research report.

Access to the researcher
You may contact the researcher using the contact details provided above for the duration of the study, should 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 sign the following section on the next page if you agree to participate voluntarily in the study.
Yours sincerely,

……………………
Researcher

UNIVERSITEIT VAN PRETORIA
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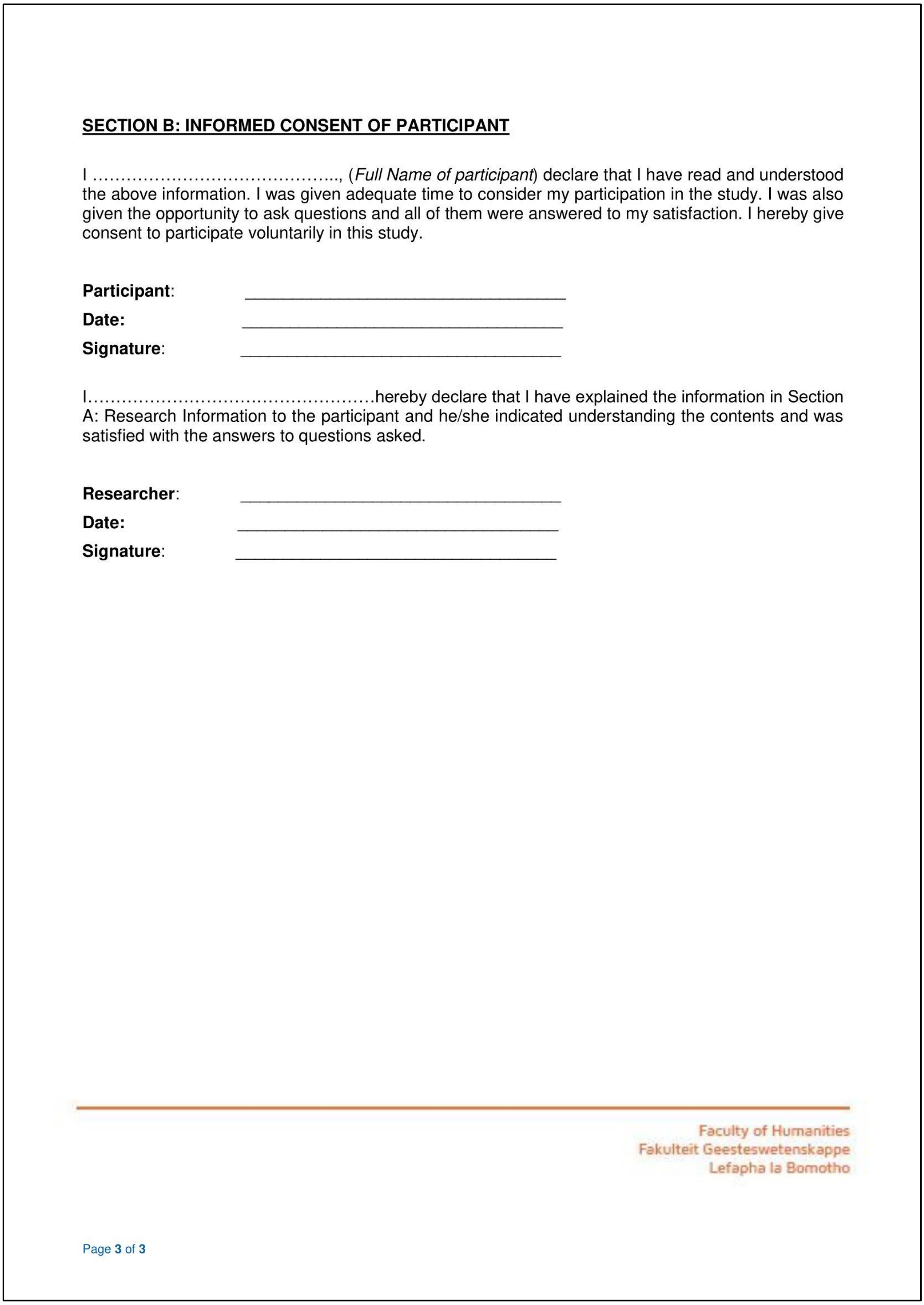
YUNIBESITHI YA PRETORIA



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: ___________________________________

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

6.5 Annexure 5: Letter of Informed Consent - Afrikaans

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019
Department of Social Work
& Criminology

Datum: 15/02/2019

Naam: Sharika R.V Selborne
Epos: u17228639@tuks.co.za
Selfoon Nr: 071 971 9246

Geagte Deelnemers

INGELIGDE TOESTEMMINGSBRIEF

AFDELING A: VORM VIR VERSORGERS VAN GEESTESGESONDHEIDSORG GEBRUIKERS MET SKISOFRENIE

Navorsingsinligting
Hierdie brief dien om u uit te nooi om deel te neem aan 'n studie oor die ervarings van versorgers van geestesgesondheidsorgverbruikers met skisofrenie in Upington, Noord-Kaap. Die ingeligte toestemmingsvorm gee 'n kort uiteensetting van die doel en prosedure van die navorsing en die regte vir deelname. Gaan asseblief deur die vorm voordat u 'n ingeligte besluit oor u deelname neem.

Titel van die studie
Die ervarings van versorgers van geestesgesondheidsorgverbruikers met skisofrenie in Upington, Noord-Kaap.

Doel van die studie
Die doel van die studie is om die ervarings van versorgers van geestesgesondheidsorg gebruikers met skisofrenie in Upington te ondersoek.

Prosedures
U is van die studie ingelig en het u kontakbesonderhede verskaf vir die navorser om u te kontak om deel te neem aan die studie. Die navorser sal verantwoordelik wees om ‘n gesig-tot-aangesig-onderhoud met u te voer, om data oor u ervarings as versorger van 'n persoon wat met skisofrenie leef, in te samel. Sodra u hierdie brief onderteken het, stem u in om deel te neem aan die studie. Die navorser sal reël om 'n individuele onderhoud met u te voer wanneer dit u die beste pas. Die onderhoud sal met u toestemming aangeteken word om te verseker dat al die inligting wat u deel, vir navorsingsdoeleindes vasgelê word. ‘n Semi-gestruktureerde onderhoudskedule sal tydens die onderhoud gebruik word om die onderhoudvoering te lei. Let asseblief daarop dat die opname slegs vir die analise van die navorsing gebruik sal word en vertroulik hanteer sal word.

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Lefapha la Bomotho

Risiko's en ongemak
Let asseblief daarop dat die navorser nie u of die geestesgesondheidsorgverbruiker onder enige risiko of ongemak sal stel met die inligting wat u sal deel nie. Daar is 'n moontlikheid van emosionele skade wat verband hou met die deel en verkenning van u ervarings om te sorg vir 'n persoon met skisofrenie. Die navorser sal ‘n ontladingsessie met u hou nadat die onderhoud afgehandel is en indien u 'n behoefte aan berading ervaar, sal u na 'n professionele berader verwys word vir intervensie. U is vry om nie vrae te beantwoord wat u tydens die onderhoud ongemaklik sal laat voel nie.

Voordele
U ontvang geen vorm van vergoeding / kompensasie / aansporings vir deelname aan die studie nie. Die studie gaan egter oor die verbetering van geestesgesondheidsdienste en die vermindering van die versorgingslas vir die versorgers van geestesgesondheidsorgverbruikers deur middel van intervensiestrategieë wat daarop gemik is om versorgers in hul versorgingsrol te help. Die bevindinge van hierdie studie kan ook help om die ervarings van versorgers beter te verstaan.

Deelnemers se regte
U deelname aan die studie is geheel en al vrywillig en u kan enige tyd en sonder negatiewe gevolge vir u of u familielede onttrek. As u van die studie wil onttrek, sal alle data wat tydens u onderhoud versamel is, vernietig word.

Vertroulikheid
Die inligting wat tydens die onderhoud gedeel word, word vertroulik gehou en sal slegs vir die doel van die studie gebruik word. Die navorser sal u ook nie in die verslag by naam identifiseer nie, slegs deur gebruik te maak van ’n pseudoniem (skuilnaam) om u identiteit te beskerm. Die enigste persone wat toegang tot die data het, sal die navorser en die studieleier wees.

Data gebruik en berging
Let asseblief daarop dat die data wat ingesamel word in die toekoms gebruik kan word vir verdere navorsingsdoeleindes, 'n joernaal publikasie of konferensiereferaat. Die data wat ingesamel word, sal in die Departement Maatskaplike Werk en Kriminologie, Universiteit van Pretoria gestoor word vir die tydperk van 15 jaar soos vereis vir argief en moontlike toekomstige navorsingsdoeleindes. Die navorser sal voldoen aan UP se beleid ten opsigte van plagiaat tydens die skryf van die finale navorsingsverslag.

Toegang tot die navorser
U kan die navorser kontak met die kontakbesonderhede wat hierbo verskaf word vir die duur van die studie, indien daar enige vrae of onsekerhede rakende die studie en u deelname is. Dit moet duidelik gestel word dat die navorser se rol is om navorsing te doen en nie berading of terapeutiese dienste te verskaf nie.

Teken asseblief die afdeling op die volgende bladsy indien u toestemming verleen om vrywillig deel te neem aan die studie.

Die uwe,

....
Navorser

AFDELING B: INGELIGTE TOESTEMMING VAN DEELNEMER

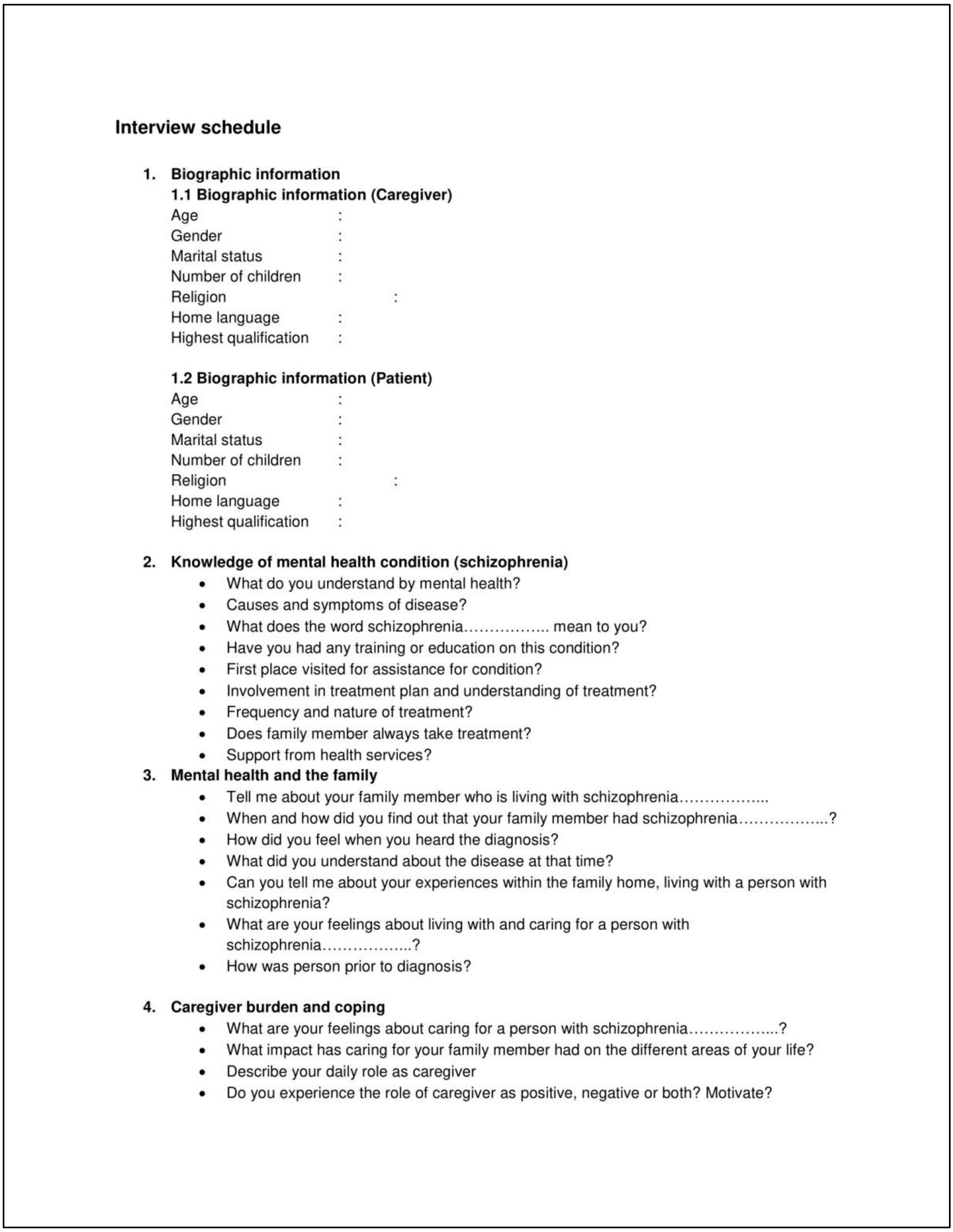
Ek ...., (Volle Naam van Deelnemer) verklaar dat ek die bogenoemde inligting gelees en verstaan het. Ek het genoeg tyd gehad om my deelname aan die studie te oorweeg. Ek het ook die geleentheid gehad om vrae te vra en almal is tot my bevrediging beantwoord. Ek gee hiermee toestemming om vrywillig aan hierdie studie deel te neem.

Deelnemer: ____________________________________
Datum: ____________________________________
Handtekening: ____________________________________

Ek .... verklaar hiermee dat ek die inligting in Afdeling A: Navorsingsinligting aan die deelnemer verduidelik het en dat hy/sy het die inhoud verstaan en tevrede was met die antwoorde op vrae gevra.

Navorser: ____________________________________
Datum: ____________________________________
Handtekening: ____________________________________

6.6 Annexure 6: 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 (Patient)

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

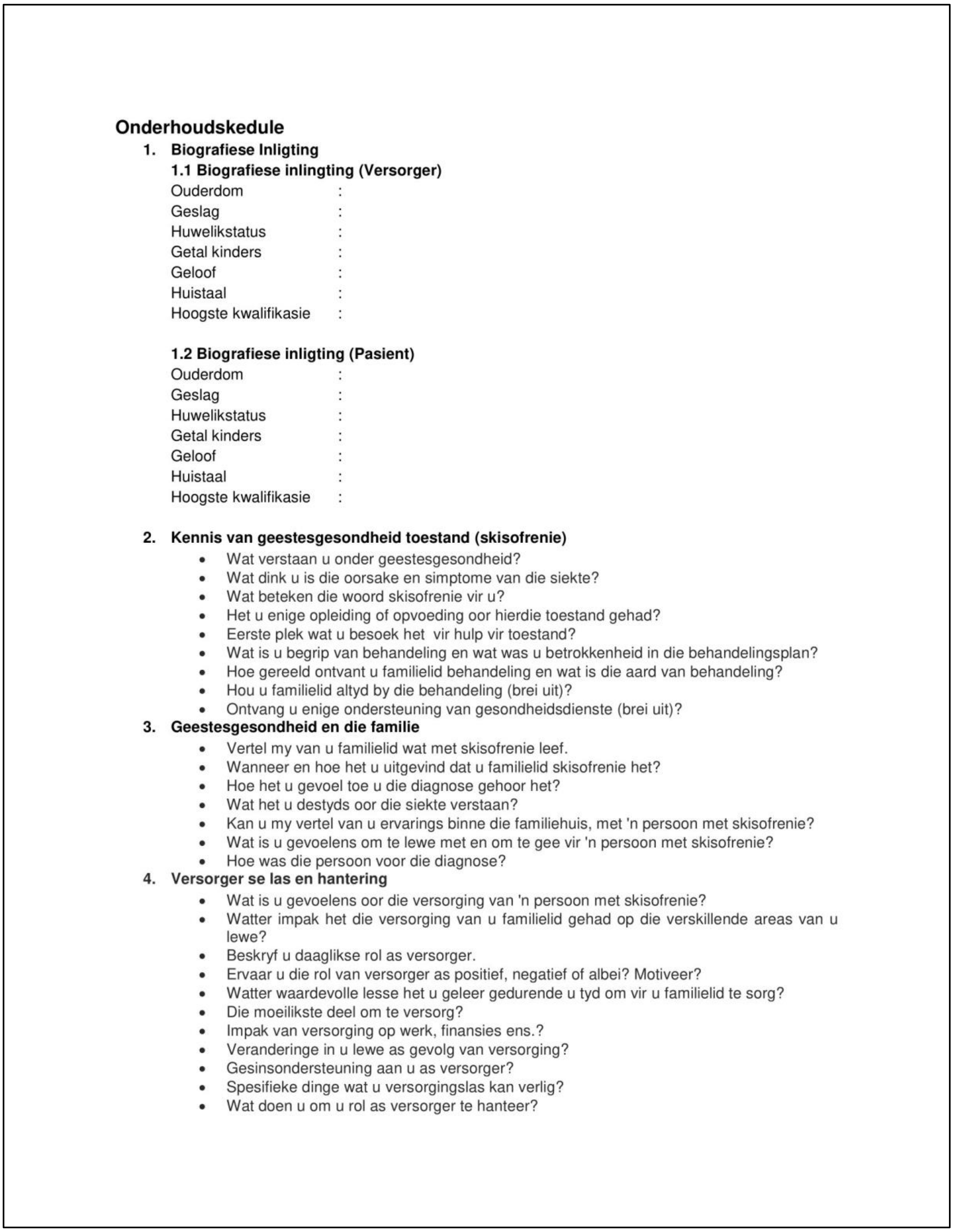
2. **Knowledge of mental health condition (schizophrenia)**
   - What do you understand by mental health?
   - Causes and symptoms of disease?
   - What does the word schizophrenia…………….. mean to you?
   - Have you had any training or education on this condition?
   - First place visited for assistance for condition?
   - Involvement in treatment plan and understanding of treatment?
   - Frequency and nature of treatment?
   - Does family member always take treatment?
   - Support from health services?
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……………...?
   - How did you feel when you heard the diagnosis?
   - What did you understand about the disease at that time?
   - Can you tell me about your experiences within the family home, living with a person with schizophrenia?
   - What are your feelings about living with and caring for 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
   - Do you experience the role of caregiver as positive, negative or both? Motivate?

- What valuable lessons have you learnt in your time caring for your family member?
- Most difficult thing of caregiving?
- Impact of caregiving on work, finances etc.?
- Changes in life because of caregiving?
- Family support to you as caregiver?
- Specific things that could lighten your caregiving burden?
- What do you do to cope with your role as caregiver?

5. **Stigma**
    - What has been the impact of the diagnosis regarding your relationships with your neighbours, peers, church, social circles you are part of?
    - How do you think the community views persons with mental health condition such as schizophrenia……………...?
    - What are your views regarding the effects of stigma and discrimination on people who are living with schizophrenia…………….. and their families?
    - How do people treat you and your family member in your community?
    - Do you receive any support from them?
    - Do you or family member get treated differently?
6. **Services**
    - What resources are there in community for psychiatric treatment or care?
    - What services are there in your community for people living with schizophrenia……………...?
    - Are these services accessible? Please explain how you have to access these services?
    - What services are there in your community that provides support and education to caregivers?
    - What are your needs with regards to support and caring for a person with schizophrenia……………...?
    - What services do you think you and your family member need? Why?
    - What are your views on community participation in programmes directed at educating and creating awareness on mental health?
    - What services do you think are needed in your community to create awareness, educate people and provide support for families? Why?
    - Have you ever participated in similar programmes in the past?
7. **Relationships**
    - How has schizophrenia affected your relationship with your family member/patient?
    - How has schizophrenia affected your relationships with other family members (within the home)?
8. **Social work intervention**
    - Any interaction with/referral to a social worker regarding loved one?
    - What kind of assistance did they give?
    - Your experience of their intervention?
9. **Recommendations**
    - Do you have any recommendations for programmes for caregivers in your community?
    - Any recommendations for professionals in this field?
    - Any procedure or treatment that is helpful to you as caregiver?
    - Do you have any recommendation for services to families in your community?
    - Who do you think should provide these services?

6.7 Annexure 7: Interview Schedule - Afrikaans



Onderhoudskedule

1. **Biografiese Inligting**

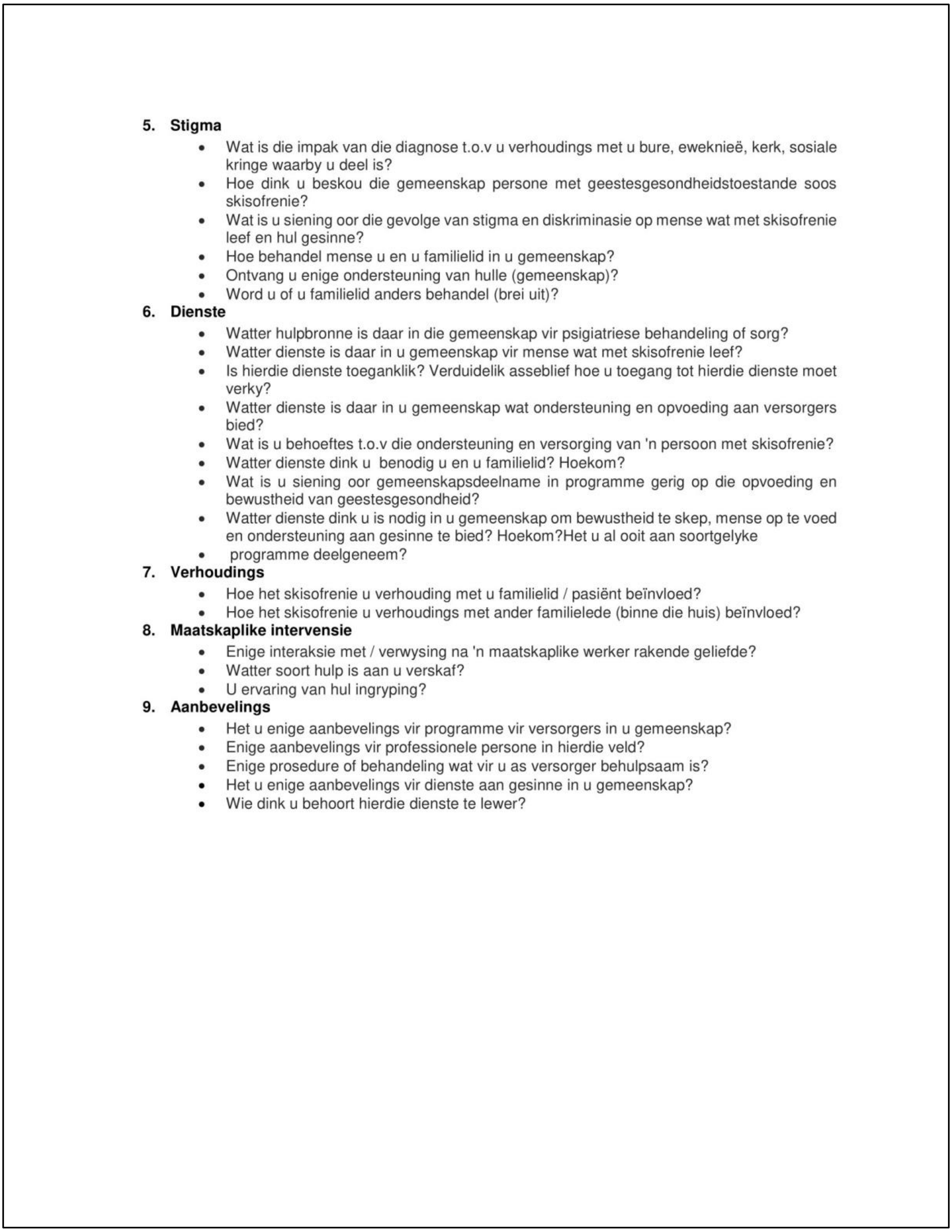
1.1 Biografiese inlingting (Versorger)

Ouderdom :
Geslag :
Huwelikstatus :
Getal kinders :
Geloof :
Huistaal :
Hoogste kwalifikasie :

1.2 Biografiese inligting (Pasient)

Ouderdom :
Geslag :
Huwelikstatus :
Getal kinders :
Geloof :
Huistaal :
Hoogste kwalifikasie :

2. **Kennis van geestesgesondheid toestand (skisofrenie)**
    - Wat verstaan u onder geestesgesondheid?
    - Wat dink u is die oorsake en simptome van die siekte?
    - Wat beteken die woord skisofrenie vir u?
    - Het u enige opleiding of opvoeding oor hierdie toestand gehad?
    - Eerste plek wat u besoek het vir hulp vir toestand?
    - Wat is u begrip van behandeling en wat was u betrokkenheid in die behandelingsplan?
    - Hoe gereeld ontvant u familielid behandeling en wat is die aard van behandeling?
    - Hou u familielid altyd by die behandeling (brei uit)?
    - Ontvang u enige ondersteuning van gesondheidsdienste (brei uit)?
3. **Geestesgesondheid en die familie**
    - Vertel my van u familielid wat met skisofrenie leef.
    - Wanneer en hoe het u uitgevind dat u familielid skisofrenie het?
    - Hoe het u gevoel toe u die diagnose gehoor het?
    - Wat het u destyds oor die siekte verstaan?
    - Kan u my vertel van u ervarings binne die familiehuis, met 'n persoon met skisofrenie?
    - Wat is u gevoelens om te lewe met en om te gee vir 'n persoon met skisofrenie?
    - Hoe was die persoon voor die diagnose?
4. **Versorger se las en hantering**
    - Wat is u gevoelens oor die versorging van 'n persoon met skisofrenie?
    - Watter impak het die versorging van u familielid gehad op die verskillende areas van u lewe?
    - Beskryf u daaglikse rol as versorger.
    - Ervaar u die rol van versorger as positief, negatief of albei? Motiveer?
    - Watter waardevolle lesse het u geleer gedurende u tyd om vir u familielid te sorg?
    - Die moeilikste deel om te versorg?
    - Impak van versorging op werk, finansies ens.?
    - Veranderinge in u lewe as gevolg van versorging?
    - Gesinsondersteuning aan u as versorger?
    - Spesifieke dinge wat u versorgingslas kan verlig?
    - Wat doen u om u rol as versorger te hanteer?



5. Stigma

- Wat is die impak van die diagnose t.o.v u verhoudings met u bure, eweknieë, kerk, sosiale kringe waarby u deel is?
- Hoe dink u beskou die gemeenskap persone met geestesgesondheidstoestande soos skisofrenie?
- Wat is u siening oor die gevolge van stigma en diskriminasie op mense wat met skisofrenie leef en hul gesinne?
- Hoe behandel mense u en u familielid in u gemeenskap?
- Ontvang u enige ondersteuning van hulle (gemeenskap)?
- Word u of u familielid anders behandel (brei uit)?

6. Dienste

- Watter hulpbronne is daar in die gemeenskap vir psigiatriese behandeling of sorg?
- Watter dienste is daar in u gemeenskap vir mense wat met skisofrenie leef?
- Is hierdie dienste toeganklik? Verduidelik asseblief hoe u toegang tot hierdie dienste moet verky?
- Watter dienste is daar in u gemeenskap wat ondersteuning en opvoeding aan versorgers bied?
- Wat is u behoeftes t.o.v die ondersteuning en versorging van 'n persoon met skisofrenie?
- Watter dienste dink u benodig u en u familielid? Hoekom?
- Wat is u siening oor gemeenskapsdeelname in programme gerig op die opvoeding en bewustheid van geestesgesondheid?
- Watter dienste dink u is nodig in u gemeenskap om bewustheid te skep, mense op te voed en ondersteuning aan gesinne te bied? Hoekom?Het u al ooit aan soortgelyke
- programme deelgeneem?

7. Verhoudings

- Hoe het skisofrenie u verhouding met u familielid / pasiënt beïnvloed?
- Hoe het skisofrenie u verhoudings met ander familielede (binne die huis) beïnvloed?

8. Maatskaplike intervensie

- Enige interaksie met / verwysing na 'n maatskaplike werker rakende geliefde?
- Watter soort hulp is aan u verskaf?
- U ervaring van hul ingryping?

9. Aanbevelings

- Het u enige aanbevelings vir programme vir versorgers in u gemeenskap?
- Enige aanbevelings vir professionele persone in hierdie veld?
- Enige prosedure of behandeling wat vir u as versorger behulpsaam is?
- Het u enige aanbevelings vir dienste aan gesinne in u gemeenskap?
- Wie dink u behoort hierdie dienste te lewer?