EXPERIENCES OF FAMILIES LIVING WITH A FAMILY MEMBER DIAGNOSED WITH SCHIZOPHRENIA

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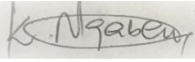**Supervisor: Dr. R. Davids**

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August 2021

DECLARATION STATEMENT

I declare that this thesis on *The experiences of families living with a family member diagnosed with schizophrenia* is my own work, and that it has not been submitted to any other university.

I declare that all the sources I have used have been acknowledged as complete references.

Khuselwa Nqabeni

Signature:

Date: August 2021

ACKNOWLEDGEMENTS

DEDICATION

This thesis is dedicated to my **parents** for their unwavering support and for always reminding me of the importance of education. Thank you for believing in me and for investing in my development. Thank you for your patience and for making me understand the value of education. To my elder sister, **Bonelwa,** thank you for your support and for believing that I can accomplish everything I want.

ABSTRACT

Mental illness has been identified as one of the major contributors to the global burden of disease in the world. The four leading causes of mental health disorders are depression, alcohol abuse, schizophrenia, and bipolar disorder. Recent studies indicate that schizophrenia is among the major mental disorders affecting more than 21 to 29 million people in the world. Family members living and caring for a relative diagnosed with schizophrenia may experience burdensome challenges in such a way that can easily generate secondary stress in various life domains such as work and family relationships, loss of quality of life as well as high social and economic costs. This led to the research questions: What are the experiences of families living with a family member diagnosed with schizophrenia and in which contexts do these experiences occur? The goal of the study was to gain an in-depth understanding of the experiences of families living with a family member diagnosed with schizophrenia. The objectives of the study were to explore the lived experiences of family members living with a family member diagnosed with schizophrenia, to describe the lived experiences of family members living with relatives diagnosed with schizophrenia, the context in which these experiences occur and to give recommendations to the inter-disciplinary teams that are providing services to families and people diagnosed with schizophrenia.

A qualitative phenomenological approach was used and the explorative as well as the descriptive study designs were employed to answer the research question. The snowball sampling technique enabled the researcher to secure seven participants from various locations within Cape Town. In-depth phenomenological interviews were conducted until data saturation was reached. The interviews were analyzed using phenomenological data analysis, which specifically focused on the textural (lived experience) and structural (context in which it was experienced). The following themes emerged from the analysed data: participants' experiences of the physical aspects of schizophrenia, their experiences of the psychological effects of the

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illness, religion as a coping mechanism for the participants, experiences of the participants on the behavior of their relatives living with schizophrenia, experiences of the participants' interpersonal relationships, their misconceptions about schizophrenia, and the effect of living with a relative with schizophrenia on their socio-economic circumstances.

Based on these findings, some recommendations for intervention specific to these experiences were advanced for the multidisciplinary teams, social workers, government, and policy makers, as well as for future research on families living and caring for relatives diagnosed with schizophrenia.

KEY WORDS: Schizophrenia, family, financial burden, deinstitutionalization, family systems theory, caregiver.

LIST OF ABBREVIATIONS

SAMHSA - Substance Abuse and Mental Health Services Administration

WHO- World Health Organization

MHCA- Mental Health Care Act

NGO- Non-Profit Organization

SADAG- South African Depression and Anxiety Group

NASEM: National Academies of Sciences, Engineering, and Medicine

NHIHCE: National Health Institute for Health and Care Excellence

FST: Family Systems Theory

DoH: Department of Health

SASH: South African Stress and Health

NIMH: National Institute of Mental Health

DSD: Department of Social Development

MEC: Member of the Executive Council

NAMI: National Alliance on Mental Health

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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Mental illness is identified as one of the major contributors to the global burden of disease in the world (Chipps, Oosthuizen, Buthelezi, Buthelezi, Buthelezi, Jeewa, Munsami, Simamane, Singh, Vaid, & Ramlall, 2015). Mental disorders are defined by the World Health Organisation (WHO, 2013) as a broad range of mental health problems with different symptoms such as abnormal thoughts, emotions, behaviour, these include schizophrenia, depression, and intellectual disabilities. The four leading causes of mental health disorders are depression, alcohol abuse, schizophrenia, and bipolar disorder (National Alliance on Mental Health of Greater Chicago (NAMH, 2013). In 2017, it was estimated that 792 million of people globally lived with a mental disorder (Ritchie & Roser, 2018). Mental illness has long been a neglected public health issue particularly in many low and middle-income countries (AbouZahr & Boerma, 2009). In these countries, health service policies receive low priority (AbouZahr & Boerma, 2009). WHO estimates that in Africa, between 40-60 million people in Nigeria alone suffer from depression, schizophrenia, and anxiety (Gberie, 2017). In South Africa, a quarter of the country's population suffer from some form of mental health related illness (Swartz, Breen, Flisher, Joska, Corrigall, Plaatjies & McDonald, 2006; Africa Check, 2018)). A rapid review report on the burden of disease in the Western Cape, stated that the prevalence of mental illness is high in the Western Cape in particular, ranging from schizophrenia to depression (Davies, Morden, Mosidi, Zinyakatira & Vallabhjee, 2019).

Deinstitutionalizing of state mental health institutions has not helped much with mental illness in SA. Deinstitutionalization was a government policy initiative that removed mental health care users from state-run institutions by placing patients back into the care of their families or

into state funded Non-Government Organizations (NGOs). Between 2015 and 2016, 1711 patients with severe mental illness and with profound intellectual disabilities were removed from mental health institutions and transferred into the care of their families and NGOs. Unfortunately, these patients were transferred to NGOs without valid licenses and without receiving proper care. This resulted in 94 patients' deaths between March and December 2016. This tragedy was regarded as an injustice and a total disregard of the human rights of patients and their families (Makgoba, 2017).

As indicated earlier, deinstitutionalization meant that patients would be placed back into the care of their families who often know very little, to nothing, about mental illness. In 2016, 75% of all discharged patients from psychiatric hospitals were placed into the care of their families (Lippi, 2016; World Health Organization, 2013). What became apparent was the negative impact mental illness had on the lives of families caring for a family member diagnosed with schizophrenia (Azman, Singh & Sulaiman, 2017). Research has shown that families have an increased risk on their psychological well-being (Iselelo, Kajula, & Malina, 2016) and experience a considerable burden on their emotional and social integrity (Monyaluoe, Mvandaba, du Plessis & Koen, 2014) when caring for their family member. A study conducted by Uys & Middelton (2014) has shown that taking care of a person with a mental illness can cause severe stress in families' life and lives, which can add to feeling burdened with caring for their relative.

1.2 PRELIMINARY LITERATURE REVIEW

Literature review in this section focuses on an introduction of the topic but a more comprehensive literature review will follow in Chapter Two and Three of this study.

1.2.1 Schizophrenia

Recent studies indicate that schizophrenia is among the major mental disorders which affect more than 21 to 29 million people around the world, that causes a great burden on the individual

and contributes to poor quality of life which increases morbidity and mortality (Budden & Summerville, 2012; Chen, Mao, Kong, Li, Xin, Lou & Li, 2016; Saha, Chant, Welham & McGrath, 2005; Chan, 2011; Ritchie & Roser, 2018). It has been estimated that around 4 to 5 million of people affected by schizophrenia live in African countries (Purgato, Adams & Barbui, 2012). Although literature on the prevalence of schizophrenia in South Africa is scanty, it has been reported that 1 in every 100 people in South Africa may be suffering from schizophrenia (Albert, 2015). In the Western Cape, high numbers of admissions of schizophrenia patients were reported as compared to other mental disorders in one of the psychiatric facilities in the Western Cape (Jacob, 2015).

1.2.2 The experiences of families living with a family member diagnosed with schizophrenia

Research has shown that families of patients living with mental conditions often experience risk factors associated with psychological well-being (Iselelo, Kajula, & Malina, 2016). These risk factors include considerable burden on their own emotional, familial processes, functioning and social integrity (Monyaluoe, Mvandaba, du Plessis & Koen, 2014) as mental illness has a negative influence on the lives of patients and on the lives of their family members (Azman, Singh & Sulaiman, 2017).

The magnitude of caring for a person with schizophrenia has been described as burdensome and leads to depression and anxiety in families (National Academies of Sciences, Engineering, & Medicine, 2016; Gater, 2015). Research found that 50% of family members taking care of fellow family members with schizophrenia developed psychological problems such as sleeping disorders and depression, to an extent where they also resultantly needed help and support (Azman *et al.*, 2017). Taking care of a family member diagnosed with schizophrenia is further exacerbated by the responsibility of ensuring that the said family member adheres to their medication as prescribed by their doctors, sleeps regularly, maintains communication and basic

daily self-care, together with continuous supervision. All these are further compounded by the burden of caregiving (Monyaluoe *et al.,* 2014; Solomon, 2010; WHO, 2012).

Families and relatives of persons with serious schizophrenia reported to be at high risk of stress-related illness than the general population (Doherty & Doherty, 2009). Living with someone diagnosed with schizophrenia is burdensome in such a way that it has the capacity to generate secondary stress in various life domains such as work and family relationships, and frequently requires high levels of attentiveness for the family (Schulz & Sherwood, 2017; Selwyn, Bhuvaneswari & Bhakyalakshmi, 2016). The elevation of stress is further compounded when there is no support, and their own physical and emotional health is ignored. Families caring for a person with schizophrenia experience problems such as the deterioration in social relationships, a lack of self-sufficiency, a decrease in activity levels, and an inability to fulfil their roles as spouses or family (The National Health Institute for Health and Care Excellence, 2016). A study conducted by Jonsson (2010), concluded that family members feeling lonely, struggle to make sense of their experiences, and have trouble in continuing to cope with the effects of the condition. Family members experience a greater feeling of not living their own lives, having difficulties to stabilize relationships, adapting to, and re-evaluating their lives and circumstances (Monyaluoe *et al.,* 2014). Living with a relative diagnosed with schizophrenia may further negatively affect family relationships by causing conflict, dissatisfaction, and disagreements among family members (The National Academies of Sciences, Engineering and Medicine, 2016).

Some families revealed that they live in fear of being injured or killed by their schizophrenic family members because of violent and aggressive behavior (Monyaluoe *et al.,* 2014). They report troublesome behavior such as being physically attacked, destruction to their properties, verbal aggression, disruption of family at night, misuse of alcohol, physical aggression, and

refusal to go to hospital as some of the aggressive behaviors displayed by their family member diagnosed with schizophrenia (Ndetei *et al.,* 2009; Monyaluoe *et al.,* 2014).

Furthermore, the lack of information about schizophrenia and support contribute to the burden of care in families. Families often report that they receive inadequate information about the illness of their relative, information such as early signs of relapse, side effects of medication and coping strategies (Lippi, 2016). Likewise, family support is seen as very significant to the effective rehabilitation and recovery of a person with mental illness (Monyaluoe *et al.*, 2014). Support to families living with relatives with schizophrenia is seen as vital to the positive mental health of other family members (Wright, Attell & Ruel, 2017). Moreover, the findings of a study conducted by Ae-Ngibise, Doku, Asante & Owusu-Agyei (2015), states that families of persons with serious mental illness agree that support from the health professionals, extended family, friends, and the community is vital in helping the family and the person with schizophrenia cope with the illness.

Added to caring for a family member diagnosed with schizophrenia, is the negative economic effects on the family. In many low to middle-income countries, most people living with schizophrenia live with their families and depend on them for financial support and everyday care (Koschorke, Padmavati, Kumar, Cohen, Weiss, Chatterjee, Pereira, Naik, John, Dabholkar, Balaji, Chavan, Varghese, Thara, Patel & Thornicrof, 2017). The findings of a study conducted by Ndetei *et al.* (2009) in Kenya shows that family finances suffer mostly due to the patient's mental illness. Families abstain from work or reduce their working hours to take care of their mentally ill family member with financial resources being diverted into caring for the patient (Ndetei *et al.,* 2009). Often the social support grant becomes the only means of financial support for many families and this is mostly used for the transportation of the schizophrenia patient to hospital (Mhaule & Ntswane-Lebang, 2009).

1.2.3 Policies and Legislation relating to mental health in South Africa

Mental health legislation is essential to ensuring a regulatory framework for mental health services and other suppliers of treatment and care, and to guarantee that the public and people with a mental illness are afforded protection from the often-devastating consequences of mental illness (Ayano, 2018). South African policy and legislation both advocate for community-based mental health service provision within a human rights framework (Lund *et al.,* 2010). There are 3 pieces of policies and legislation in South Africa that are pertinent to this study.

1.2.3.1 Mental Health Care Act 17 of 2002

The Mental Health Care Act (MHCA) 17 of 2002 is one of the legislations that was introduced to guide the health care professionals within the mental health setting to combat poor care received by mental health service users (Madlala & Sokudela, 2014). The main purpose of the MHCA is to provide care, treatment, and rehabilitation of persons with mental illness, and to set out regulations to be followed in the admission of such persons (Mental Health Care Act 17, 2002). The aims of the Mental Health Care Act 17 of 2002 are:

 "to help provide treatment to a person with severe mental illness who refuses needed treatment, and who is likely to suffer harm or cause harm to others or suffer significant mental or physical deterioration, and to protect the legal rights of a person with a severe mental illness. To make the best possible mental health care, treatment, and rehabilitation services available to the population equitably, efficiently and in the best interest of mental health care users within the links of the available resources".

The MHCA promotes the provision of community-based care to the patients (Madlala & Sokudela, 2014). Thus, when patients no longer require hospital stay, they are discharged to reintegrate with their families and into their communities.

1.2.3.2 The De-institutionalization policy

Deinstitutionalization as defined by Ashen and Snowden (2014) is a policy that mandates a change in practice of caring for people with mental illness from institutional environments to

the community. This policy places emphasis on mental health care from institutionalization to community-based care, rehabilitation, and reintegration into the communities (Mental Health Care Act, 2000, Ndetei, Pizzo, Khasakhala, Maru, Mutiso, Ongecha-Owuor, & Kokonya, 2009; Solomon, 2010).

However, to implement the policy of deinstitutionalization, Burns (2011:104) notes that South Africa is experiencing barriers in the financing and development of mental health services which result in "psychiatric hospitals remaining outdated, falling into disrepair, often unfit for human use; serious shortages of mental health professionals; an inability to develop vitally important tertiary level psychiatric services (such as child and adolescent services, psychogeriatric services, neuropsychiatric services, etc.); and community mental health and psychosocial rehabilitation services remaining undeveloped, so that patients end up institutionalized, without any hope of rehabilitation back into their communities"

A growing concern is, although mental health is a significant public health issue in South Africa, mental health services remain constantly under-resourced (Lund, Kleintjies, Kakuma & Flisher, 2010). Research shows that the policy on deinstitutionalization has not been supported by an increase in mental health resources both for patients and their families in communities (Gureje & Alem, 2012; Lippi, 2016). In some instances, no budget allocation has been made for mental health services, leading to a shortage of professionals and resources diverted when health practitioners resigned (Mthethwa, 2019). More alarmingly, there has been a lack of resources to implement the fundamental components of the Mental Health Care Act, resulting in mental health care users not having easy access to care or receiving care of poor quality (Chipps, 2012).

Adversely, the introduction of the deinstitutionalization policy by the Department of Health has led to the responsibility of care being shifted and moved onto families who act as the

primary caregivers (Panayiotopoulos, Pavlakis & Apostolou, 2013; Lippi, 2016). A conclusion can therefore be drawn that although policy and legislation are in place, they are inappropriate and ineffective.

1.3 THEORETICAL FRAMEWORK

The Family Systems Theory (FST) was crucial to this study as it emphasizes the importance of focusing on the family as a unit when exploring the experiences of families living with a relative with schizophrenia. The theory was pertinent to the understanding and putting the study of family experiences into its apt context as it emphasizes that a family functions as a unit, and has interrelated components (Knauth, 2003). FST also views the problems of the one family member (diagnosed with schizophrenia) as affecting the relationships and interactions of the larger family (O'Leary' 2011).

The diagnosis of schizophrenia in the family has an influence on how the family system operates, therefore, the interactions and relationships of the larger system will certainly be affected. The FST theory is also crucial to this study as it does not look at schizophrenia affecting the family only, but it acknowledges the strain or burden on the family's relationships when caring for a family member diagnosed with schizophrenia.

1.4 PROBLEM STATEMENT

Creswell (2013) proposes that qualitative researchers think about research problems in terms of real life and literature related problems. Previous studies reveal that families of persons with schizophrenia experience varied challenges in their everyday lives when living and caring for a family member diagnosed with schizophrenia (Mhaule & Ntswane-Lebang, 2009; Chipps *et al.,* 2015). These challenges include continuous supervision, struggle to balance work and caring of family members with schizophrenia (Monyaluoe *et al.,* 2014; Solomon, 2010; WHO, 2012; Doherty & Doherty, 2009; Selwyn, Bhuvaneswari & Bhakyalakshmi, 2016). Studies also

find that schizophrenia influences the family member's well-being, leading to high risk of stress-related illness, sleeping problems and daily self-care (Schulz & Sherwood, 2017; (Monyaluoe *et al.,* 2014). In addition, policies, and legislation, including de-institutionalization, has led to families taking the responsibility of caring for family members diagnosed with schizophrenia (Panayiotopoulos, Pavlakis & Apostolou, 2013; Lippi, 2016).

The above cited studies reveal that a member with schizophrenia has an adverse effect on the family and its members. This concern highlights the need to focus on family members and their experiences when caring for a family member with schizophrenia. Thus, the study focused on the family and their experiences with a family member diagnosed with schizophrenia. The researcher asked the following research questions when the above-mentioned factors were considered: What are the lived experiences of family members caring for family members diagnosed with schizophrenia and in which contexts do these experiences occur?

1.5 AIM OF THE STUDY

The aim of the study was to explore the lived experiences of families living with a family member diagnosed with schizophrenia.

1.6 RESEARCH QUESTION

A research question/s refers to a question that a study set out to provide answers to, it is precise and specific, it helps to define a study and is related to the research goal (Clarke, 2018). Literature review and the problem formulation resulted in the research question which the researcher aims to answer through this research which is: What are the experiences of families living with a family member diagnosed with schizophrenia and in which contexts do these experiences occur?

1.7 RESEARCH GOAL

Research goal refers to a general rationale for conducting a study (Mohajan, 2018). The goal of the proposed study emerged from the research question and was to gain an in-depth appreciation of the lived experiences of families living with a family member diagnosed with schizophrenia.

1.8 RESEARCH OBJECTIVES

Research objectives are defined by Mohajan (2018) as "specific statements indicating the key issues to be focused on in a research project". The research objectives to achieve the goal of the research were to:

- Explore the lived experiences of family members living with a family member diagnosed with schizophrenia.

- Give recommendations to the inter-disciplinary teams that are engaged in providing services to families and people diagnosed with schizophrenia

1.9 OVERVIEW OF THE RESEARCH METHODOLOGY

The following sections focused on the methodology for gathering data to meet the study objectives. The application of the research methodology will be discussed in detail in Chapter Four of this document.

1.9.1 Research approach

The qualitative research approach was used during this research to contribute to an in-depth understanding of the lived experiences of families living with a family member diagnosed with schizophrenia. Qualitative research aims at the unveiling and studying of different experiences from the perspective of the individual, and it seeks to understand a given research problem from the perspectives of the local population or research participants. Qualitative research develops the deep understanding of our social world and provides an in-depth and interpreted

detail of human behaviour, emotions, and personality characteristics (Vishnevsky & Beanland, 2008). In addition, the nature of data collected in qualitative approach is rich and deep (D'Cruz & Jones, 2014).

The qualitative approach was used to explore the perceptions and viewpoints on how people experience life and life's challenges as they care for their schizophrenic family members (Creswell, 2014).

1.9.2 Research strategy and design

Phenomenology describes the shared meaning of an individual's lived experiences of a phenomena (Creswell, 2013). The focus of the descriptions is on 'what people experience' and 'how they experience' it (Patton, 2002). The result of phenomenological research is a general description of the phenomenon, as seen through the eyes of the people who have experienced it first-hand. This strategy of inquiry was therefore chosen for this research to explore and describe the lived experiences of families living with persons diagnosed with schizophrenia.

Qualitative research is exploratory by its very nature (Creswell, 2016). Fouché & De Vos cited in De Vos, Strydom, Fouché & Delport (2011) posit that qualitative research helps us gain an understanding of a situation, phenomenon, community or individual, discovering new ideas and for increasing knowledge of the phenomenon. The first objective of this research was to explore the lived experiences of family members living with a family member diagnosed with schizophrenia as this will contribute to a better understanding of the situation in the family.

Descriptive research designs focus on presenting a picture of the specific details of a situation and focus on "how" and "why" questions (De Vos *et al.,* 2011), describing the phenomena through narrative-type descriptions (Durrheim as cited in Terre Blanche, Durrheim & Painter, 2008). Descriptive research was used in describing the findings of the research and will include narratives from interviews in Chapter Five of this document.

1.9.3 Research Population

A research population is the larger pool from which a sample is selected (Terre Blanche, Durrheim & Painter, 2006). Dumont & Sumbulu cited in Nicholas, Rautenbach & Maistry (2010) interpret a population in research as the groups of people to be studied, who exude specific characteristics. The population from which the sample for this study was selected included family members of people diagnosed with schizophrenia in the Western Cape.

1.9.4 Sampling

Qualitative researchers use non-probability sampling which is not representative of the population, and results cannot be generalized (Neuman, 2012). Sampling procedures in non-probability sampling include purposive, convenience and snowball sampling (Townsend & De la Rey, 2011). The snowball sampling technique was utilized for the current study. Snowball sampling is a "technique for finding research subjects. One subject gives the researcher the name of another subject, who in turn provides the name of a third", (Baltar & Brunet, 2012). The researcher identified family members caring for family members with schizophrenia at a support group, which referred the researcher to other family members. The researcher conducted interviews until data saturation was reached.

1.9.5 Data collection and procedures

Data collection in phenomenological studies entails in-depth and multiple interviews with participants. In-depth interviews are of long-duration, face-to-face and are conducted with the aim of achieving the desired goals (Adams & Cox, 2017) and allows the researcher to explore issues with participants through encouraging depth and rigor, which facilitates the emergence of new concepts/issues (Doody & Noonan, 2013). The researcher used the "What?" and "How?" questions, which resulted in the descriptions of lived experiences that provided an understanding of the experiences of the participants (Creswell 2003). Creswell (2013) proposes that the researcher asks two broad questions:

- What have you experienced in terms of the phenomenon?

- What contexts or situations have typically influenced or affected your experiences of the phenomenon? The researcher also used probing, which is defined by David (2011) as an interviewing technique utilized by researchers to generate more information from the participants. Other interviewing techniques such asking open-ended questions as to clarify or to seek elaboration of a participant's response was used by the researcher (this will be discussed in detail in the Methodology Chapter).

1.9.6 Data Analysis

Data were analysed by using the 'phenomenological data analysis spiral' according to Creswell (2013). This was done by following the steps of phenomenological analysis as described in Creswell, (2013:193). These steps provide a description of "what" the participants in the study experienced, with verbatim examples followed by "how" the experiences occurred, where the focus was on the context or setting in which the phenomenon was experienced.

The steps were implemented as described by Creswell (2013:193). These steps are discussed further in Chapter 4 (Section 4.10) under Data Analysis.

1.10 TRUSTWORTHINESS

The concept of 'trustworthiness' was used to denote the validity and reliability in qualitative research and to demonstrate that the evidence for the results reported is sound and truthworthy (LaBanca, 2010). The researcher applied the following four criteria: credibility, confirmability, reflexivity and bracketing to ensure trustworthiness in this study and these will be discussed in more detailed in Chapter 4 (Section 4.11).

1.11 LIMITATIONS OF THE STUDY

The limitations of the study included the fact that, there was a possibility that the research participants would not open-up entirely, as mental illness is a sensible issue. Generally, people do not feel comfortable to reveal their family secrets to strangers, especially about matters of mental illness. The assumption is that; families living with a family member diagnosed with schizophrenia have diverse lived experiences based on their family structure, functioning, as well as the degree of the illness. Although the study was done in the Western Cape and from different geographical areas, the study has potential limitations of not being applicable to all contexts, therefore transferability can only be made in similar contexts. Moreover, all study participants were females, the representation of a male gender would have benefited the study as men would have different experiences based on their gender role. The research could have benefited if equal representation was achieved, such as four from each ethnic group as most of the participants were Whites.

1.12 ETHICS STATEMENT

Ethical clearance was obtained from the Higher Degrees Committee of the Faculty of Community and Health Sciences and the Humanities and Social Sciences Research Ethics Committee of the University of the Western Cape.

Ethical considerations are specified as one of the most important principles in the research process (Saunders, Lewis & Thornhill, 2012). Fouka & Mantzorou (2011: 3) state that "research ethics involve requirements on daily work, the protection of dignity of subjects and the publication of the information in the research". These research principles include permission to conduct the study, informed consent, voluntary participation, confidentiality, and anonymity. In qualitative research, ethical considerations are important due to the in-depth nature of the study process (Arifin, 2018). In the following section, the researcher will discuss these principles and how these were achieved during this study.

1.12.1 Permission to conduct the study

The professional laws and ethics in research were introduced to prevent the abuse and exploitation of human subjects when conducting research as it is always important to protect the human subjects by applying the good ethical conduct when conducting research (Fouka & Mantzorou, 2011; Arifin, 2018). In conducting this study, the researcher wrote a research proposal that was submitted to the University of the Western Cape's Senate Research Committee and Ethics Committee for ethical approval and permission to conduct the study. The study was then approved by the above committee and the ethical clearance letter was provided (refer to APPENDIX C: Ethical clearance letter).

1.12.2 Informed consent and voluntary participation

Informed consent refers to agreement (by the participant) to participate in a research study, which means that the subject understands what participating in the research entails and its risks (Rose, Aburto Hagemann & Shahnazarian, 2009). Obtaining consent means that the participant was made aware of his or her rights, the purpose of the study, the procedures to be undergone, and that the participant must be competent to consent (Rose *et al.,* 2009; Arifin, 2018). The informed consent document was written in a language that was easily understood by the participants (Rose *et al.,* 2009). Voluntary participation in research means that participants exercise their free will in deciding whether to participate in the research activity or not (Lavrakas, 2008). Voluntary participation also entails that the participants agree to participate in the research study voluntarily and that there is no participant who is coerced or a threatened or harmed to participate in research (Vanclay, Baines & Taylor, 2013).

In this study, the researcher obtained the consent of the participants to conduct the interviews, and the participants were required to provide written informed consent (APPENDIX D: Consent form). This was done by providing the participants with an information sheet (APPENDIX C) written in the preferred language of the participants that had detailed information about the study. The participants were given time to ask questions that they had

about the study and the researcher addressed their concerns. Participants were also informed that their participation was voluntary, there would be no consequences should they decide not to participate, and that they could withdraw anytime from the study without being penalised.

1.12.3 Confidentiality and anonymity

Confidentiality and anonymity are important ethical practices in research that are designed to protect the human subjects while conducting research (Lindsey as cited in Allen, 2017). In ensuring confidentiality of the human participation, the researchers vowed not to publish any identifying information and that information would not be shared without the consent of the participants (Wiles, Crow, Heath & Charles, 2006). In conducting this study, confidentiality and anonymity of participants was preserved and ensured by concealing their names during data collection. The researcher referred to the participants for example as "participant A, B, C". The interviews were conducted in places that were chosen by the participants where their privacy was guaranteed. The interview transcripts were processed and handled by the researcher and shared with the supervisors who understand the ethical implications of research.

1.13 SIGNIFICANCE OF THE STUDY

Significance of the study is a statement that explains why the research in a particular topic was needed. It justifies the importance of the study and the contribution it has to the new knowledge, and how others will benefit (Clarke, 2018). The literature presented has added rich insight into the lived experiences of families living with a relative with schizophrenia. Therefore, the findings of the study would guide social workers to intervene appropriately with families caring for a family member diagnosed with schizophrenia. The findings of this study emphasize the importance of including families in the care plan of their relatives with schizophrenia as the primary caregivers. The findings of this study may help in the development and implementation of interventions and programs for families of persons with schizophrenia. Moreover, the

recommendations made may contribute to the effective treatment plan of the mental health care users.

1.14 DEFINING KEY CONCEPTS

Schizophrenia: Refers to a severe mental disorder which usually starts in late adolescence or early adulthood. It is often associated with disability and poor quality of life (Singh, Mattoo & Grovers, 2016).

Family: "Societal group that is related by blood (kinship), adoption, foster care or the ties of marriage (civil, customary or religious), civil union or cohabitation, and go beyond a particular physical residence" (Department of Social Development, 2013).

Caregiver: A person who (relative or non-relative) provides unpaid assistance to a person who cannot provide care to themselves (Collins & Swartz, 2011).

Psychiatric institution: An institution or facility where people with mental disorders receive care, treatment, rehabilitation, therapeutic interventions, and other related health services (Uys & Middelton, 2014).

Deinstitutionalization: Deinstitutionalization refers to the replacement of long-stay psychiatric hospitals with smaller, less isolated community-based alternatives for the care of mentally ill people (Primeau, Bowers, Harrison, Marisa & Harrison; 2013).

Mental disorder: "A positive diagnosis of a mental health related illness in terms of accepted diagnostic criteria made by a mental health care practitioner authorized to make such diagnosis" (Mental Health Care Act 17 of 2002).

Social support: "Verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one's life experience" (Hunt, 2011).

Financial burden: This is defined by US Department of Health and Human Service (n.d) as "a term used to describe problems a patient has related to the cost of medical care. Not having health insurance or having a lot of costs for medical care not covered by health insurance can cause financial problems and may lead to debt and bankruptcy. Financial burden can also affect a patient's quality of life and access to medical care. Also called economic burden, economic hardship, financial distress, financial hardship, financial stress, and financial toxicity".

Psychological distress: Psychological distress refers to a "state of emotional suffering associated with stressors and demands that are difficult to cope with in daily life" (Marklund, Kylén, Taft & Ekman, 2016: 687).

1.15 CHAPTER OUTLINE

Chapter Two focuses on the literature review explored to provide a better understanding of the experiences of families living with a family member diagnosed with schizophrenia.

Chapter Three provides a description of the family and theoretical framework in relation to the study topic.

Chapter Four unveils the application of the research methodology during this research.

Chapter Five presents the findings of the study that emerged through the data that was collected from the participants as they narrated their experiences of living with a family member diagnosed with schizophrenia

Chapter Six provides a conclusion and recommendations to multidisciplinary healthcare teams (Research Objective 2).
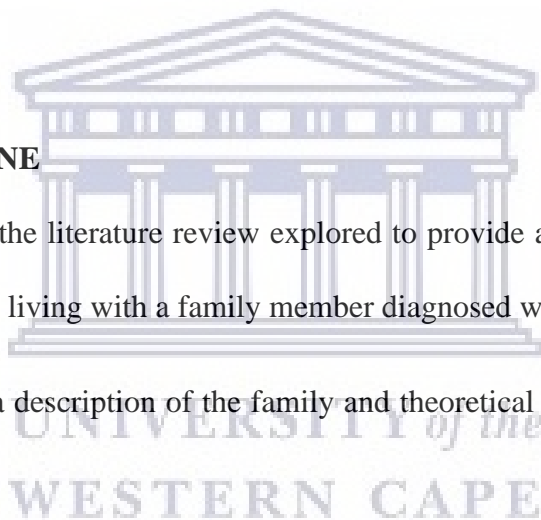
CHAPTER 2

LITERATURE REVIEW AND SOCIAL WORK INTERVENTIONS IN PSYCHIATRIC CONTEXT

2.1 INTRODUCTION

This chapter reviews the literature germane to this study. It focuses on the literature on the experiences of family members living with and caring for a family member diagnosed with schizophrenia. The focus of this chapter is split as follows; schizophrenia as a mental illness; objective experiences and subjective experiences. Furthermore, social work interventions in the psychiatric context are discussed.

In the following section an orientation on schizophrenia as a mental illness and the influence it has on the family living with a family member diagnosed with schizophrenia is presented.

2.2 SCHIZOPHRENIA AS A MENTAL ILLNESS

Mental illness symptoms are believed to be triggered by a biochemical imbalance in the brain in late adolescence or early adulthood and can result in a deterioration in patients' activities of their daily living and in an inability to sustain employment (Budden & Summerville, 2012; Lippi, 2016).

Brain abnormalities have been described as a cause of schizophrenia (Starling & Feijo, 2012). Structural deficits in the brain such as a reduced volume of gray matter and an interrupted white matter integrity have been associated with the development of schizophrenia (Karlsgodt, Sun & Cannon, 2010). The symptoms of schizophrenia are divided into two; positive and negative symptoms. Positive symptoms include hallucinations - most commonly auditory hallucinations or hearing voices, delusions, as well as disorganized speech and behavior (Starling & Feijo, 2012; Berna, Potheegadoo, Aouadi, Ricarte, Alle, Coutelle, Boyer, Cuervo-Lombard & Lombard, 2016). The negative symptoms include social withdrawal, reduced motivation, poverty of speech, a decrease in emotional range, impaired cognitive performance in domains

such as attention, concentration, memory, and planning (Starling & Feijo, 2012; Lombard, 2016). McHugh, Brown, and Lindo (2016) as well as O'Hare (2016) concur with the above observation that schizophrenia is a mental disorder that is characterized by delusions, hallucinations, disorganized speech, and behavior.

Khan, Martin-Montañez and Muly (2013) state that schizophrenia is characterized by psychosis, social withdrawal, and cognitive impairment. Rafiyah and Sutharangsee (2011) as well as Habibi, Nayer and Zadeh, (2015) state that schizophrenia is one of the most devastating mental disorders, severely affecting one's personal, social, and professional functions. They continue to state, that the affected person may experience impairment in thought processes which resultantly influence their behavior and may lead to huge conflicts and a serious effect on the family structure and order. Khan, Martin-Montañez & Chris (2013) agree that socio-demographic factors such as poverty and low social class are associated with higher rates of schizophrenia, thus stressful social environmental circumstances may be responsible for the increased risk of schizophrenia. Environmental factors such as socio-economic background, family circumstances and work environment have also been described as the cause in the development of schizophrenia (Read, 2010). An impairment that is triggered and caused by schizophrenia robs the patient's ability to remain independent in various domains of psychosocial functioning, affecting the person's ability to perform their daily activities and engage with other people. These daily activities include reduced functioning at work, school, parenting, self-care, independent living, interpersonal relationships, and leisure (Khan *et al.,* 2013). As a result of the identified impairment, patients with schizophrenia require long-term support and care which may become burdensome to their caregivers (Adeosun, 2013).

2.3 EXPERIENCES OF FAMILIES LIVING WITH FAMILY MEMBER DIAGNOSED WITH SCHIZOPHRENIA

As stated in Chapter 1, due to the policy on deinstitutionalization, families have now become the primary caregivers of their family members diagnosed with schizophrenia (Panayiotopoulos, Pavlakis & Apostolou, 2013; Lippi, 2016; Shah, Sultan, Faisal & Irfan, 2013) which may put families at a high risk of developing stress, changes in their daily routines and family functioning. It is estimated that 75% of discharged patients live with their families who often rely on family support and care post-discharge (WHO, 2013; and Lippi, 2016).

Research has shown that schizophrenia is a devastating mental disorder not only for the patient but also for their families too, affecting their independent living, productive activities, and social relationship (Hsiao & Tsai, 2011; Shah *et al.,* 2013; Galderisi, Rossi, Rocca, Bertolino, Mucci, Bucci, Rucci, Gibertoni, Aguglia, Amore & Bellomo, 2014). Families of family members diagnosed with schizophrenia reported changes to their household routines, disruption of family life, disturbance in the family environment and weakening of family relationships and taking on roles and responsibilities in the care of their patients, which negatively impacts on their health (Adeosun, 2013; Caqueo-Urizar, Gutiérrez-Maldonado, Ferrer-García, Peñaloza-Salazar, Richards-Araya & Cuadra-Peralta, 2011; Lippi, 2016). Families reported having a chaotic lifestyle and poor self-care due to the exhaustion from increased energy used on dealing with problematic patient behavior (Lippi, 2016).

Lasebikan and Ayinde (2013) classify the lived experiences of families into two dimensions. The first dimension is "objective experiences" which include effects on the household, including financial loss, effects on health, on children, and family routine; and the abnormal behaviors shown by the patient. The second dimension is "subjective experiences" which include the extent to which relatives feel that they carry a burden. Further clarity and explanations of these dimensions are discussed in the following section.

2.3.1 Objective experiences: effects on household

"Objective burden of care describes the effects of care - living on the household routines, finances, family relations, social activities and leisure" (Igberase, Morakinyo, Lawani, James & Omoaregba, 2010: 131). Chakrabarti, (2010) and Sharma (2019) further offer a description of objective experiences including the disruption of family life in domains such as work, leisure, family, and social relations, affecting the health of caregivers, dealing with problematic behaviors such as violence, suicide, and non-adherence to treatment as well as substance use and dealing with day-to-day practical problems encountered while providing care.

The following sub-sections provide a description of some of the objective burden of care that may be experienced by family members when living and caring for a family member diagnosed with schizophrenia.

2.3.1.1 Financial burden

Financial burden of care has been reported as a significant problem for the families of family members diagnosed with schizophrenia, particularly among the impoverished families from developing countries (Chakrabarti, 2010). Likewise, living with a relative diagnosed with schizophrenia can lead to reduction in household income and families may experience financial difficulties when providing care to their family members (Panayiotopoulos *et al.,* 2013). These financial difficulties include paying for medical and other related expenses (Chan, 2011; Lippi, 2016). In a study conducted by Marimbe, Cowan, Kajawu, Muchirahondo and Lund (2016), families reported that even though medication is free at government hospitals, some had to buy medication for their family members who were diagnosed with schizophrenia as medication was often unavailable at the public hospital.

Linked to the financial burden is a depressing matter of employment. Living with, and caring for a family member diagnosed with schizophrenia often means that caregivers cannot work

full time (Özden & Tuncay, 2018). Family members report experiencing difficulties in employment as they must abstain from work or reduce their working hours to spend time caring for their relatives with schizophrenia as reported by Ndetei *et al.,* (2009) and Sabanciogullari & Tel (2015). This too, is concurred by Stanley, Bhuvaneswari & Bhakyalakshmi, (2016), Caqueo-Urízar *et al.,* (2017); as well as Awad & Voruganti, (2012). who state that often family members may struggle to balance work responsibilities due to the time they must spend taking care of family members with schizophrenia (which may result in poor work performance).

2.3.1.2 Effects on health on family members

Living with a family member diagnosed with schizophrenia has dire consequences on the health and well-being of family members who are the caregivers (Mitsonis, Voussoura, Dimopoulos, Psarra, Kararizou, Latzouraki, Zervas & Katsanou, 2012). Often these family members have specific roles to perform in the family but the responsibilities of taking care of their family member diagnosed with schizophrenia can impact on their mental and physical well-being (Avasthi, 2010; Adeosun, 2013).The findings of a study conducted by Lippi (2016) revealed that families reported having a chaotic lifestyle and poor self-care due to exhaustion from increased energy expended on dealing with problematic family members diagnosed with schizophrenia behavior. Due to the burden of caring for a relative with schizophrenia, families have reported that their own physical and emotional health are ignored (Stanley *et al.,* 2016). As a result, authors such as Riley-McHugh *et al.,* (2016); Caqueo-Urízar *et al.,* (2017) have discovered that the mental and physical health of caregivers of family members diagnosed with schizophrenia have been reported to be worse than those of non-caregivers as they are at risk of developing mental disorders.

2.3.1.3 Disruption of family life and family relations

Schizophrenia is known to cause disruptions in interpersonal and family structures as mental illness has a major influence on parents, children, spouses, or partners (Johnston, 2018). The dynamics of family relationships may change when caring and living with a family member diagnosed with schizophrenia. Parents for example may experience marital conflicts and an inability to fulfil their conjugal and other roles as spouses, or even worse, this may lead to separation from a spouse (Avasthi, 2010; Caqueo-Caqueo-Urízar *et al.,* 2011). Household routines and a disturbance in the family environment due to the family member's mental illness, may be disrupted (Chakrabarti, 2010; Caqueo-Urízar *et al.,* 2011; Lippi, 2016). Family relationships can be disrupted and may cause families to experience relationship deterioration as they feel disconnected with other family members (Caqueo-Urízar *et al.,* 2011; Caqueo-Urízar, Rus-Calafell, Craig, Irarrazaval, Urzúa, Boyer & Williams, 2017). Furthermore, family relationships can be affected, causing conflict, dissatisfaction, and disagreements among family members (NASEM, 2016, Johnston, 2018). An increase in disagreements may occur, causing conflict among family members and with the family member diagnosed with schizophrenia (Caqueo-Urízar *et al.,* 2011; Awad & Voruganti, 2012).

2.3.1.4 Violent behavior towards family members

Public perception of schizophrenia is associated with increased risk for violence (Wehring Carpenter, 2011; Silverstein, Del Pozzo, Roché, Boyle & Miskimen, 2015). Families of family members diagnosed with schizophrenia have reported experiencing difficulties in dealing with dysfunctional and problematic behaviors of their relatives who are diagnosed with schizophrenia (Avasthi, 2010). Indeed, in further studies conducted by Ndetei *et al.* (2009); Monyaluoe *et al.* (2014), families reported troublesome behavior on the part of family members diagnosed with schizophrenia for example being physically attacked, destroying property

experiencing verbal aggression, and experiencing disruption of peaceful family life during the night. However, the South Together with the African Depression and Anxiety Group (2016), Silverstein *et al.* (2015: 27) states that on the contrary, "people with schizophrenia are more likely than people in the general population to be victims of crime, especially physical assaults". Victimization is reported to be higher among patients with mental disorders (Fitzgerald, De Castella, Filia, Filia, Benitez & Kulkarni, 2010) and individuals presented with mental illness are often vulnerable to victimization due to the impairment of their cognitive functions and the living conditions of these individuals (De Freitas Passos, Stumpf & Rocha, 2013).

2.3.1.4 Effects of the *illness on families when the family member is non-compliant to medication*

The burden of caring for a person with schizophrenia is intensified by the responsibility of making sure that the schizophrenic diagnosed family member adheres to their medication (WHO, 2012). Dobber, Latour, de Haan, Reimer, Peters, Barkhof and van Meijel, (2018) report that about 75% of patients with schizophrenia discontinue their medication within 18 months of diagnosis. Non-adherence to prescribed medication for schizophrenia has been noted as a worldwide issue and may be the most challenging aspect in treating patients with this ailment (WHO, 2011) and for those caring for them. Non-adherence to medication is exacerbated by the behaviors of schizophrenic patients, ranging from refusal to take medication to irregular use of the medication (Dobber *et al.,* 2018). Due to non-adherence to medication, persons with schizophrenia experience a high level of behavioral disturbance exuded by their hallucinations and delusions. This makes their families to live in fear of violence by the affected person (Shah *et al.,* 2013; Lippi, 2016).

There are various factors that may contribute to non-adherence of medication among patients with schizophrenia, these include a lack of insight about the illness, negative attitudes towards

the illness and the medication, past experiences with the illness and its treatment, substance use and lack of social support (Eticha *et al.,* 2015). Adherence to medication and treatment aid in preventing relapse which may lead to re-hospitalization, suicide attempts and delay in the recovery process (Gianfrancesco, Rajagopalan, Sajatovic & Wang, 2006; Eticha, Teklu, Ali, Solomon, & Alemayehu, 2015). Factors that are associated with adherence to medication by patients with schizophrenia include the positive attitudes towards the illness, better insight into the illness and a good support system provided by family members (Karthik, Kumar, Keswani, Bhattacharyya, Chandar, & Rao, 2014).

2.3.2 Subjective experiences: burden of schizophrenia on families

"Subjective burden refers to the extent to which the caregiver experiences distress as a result of the caregiving role" (Igberase *et al.*, 2010: 32). Subjective burden therefore consists of the negative psychological influence on the caregiver and includes feelings of loss, depression, anxiety, anger, sorrow, hatred, uncertainty, guilt, shame, or embarrassment, all of which result in much more distress and suffering (Chakrabarti, 2010).

2.3.2.1 Psychological effects on family members

Psychological effects on families caring for a family member diagnosed with schizophrenia, can result in emotional responses such as anxiety, fear, guilt, stigma, frustration, anger, and sadness (Caqueo-Urízar *et al.,* 2011). Family members may experience anger, shame, guilty, resentment and sadness when their loved ones are diagnosed with schizophrenia (Ward, 2008). Families are also at risk of developing psychological distress, anxiety, and depression as a result of consistent support and continuous care provided to their family member diagnosed with schizophrenia (Shah *et al.,* 2013). In a study conducted by McHugh *et al.* (2016) in a Jamaican hospital, the families caring and living with a family member diagnosed with schizophrenia reported that they experience anger, sadness, fear, and depression when caring for a family member diagnosed with schizophrenia. Families further reported experiencing

anger and frustration when the person diagnosed with schizophrenia displayed aggressive behavior or when there was no other family member to assist in caring for the relative (McHugh *et al.*, 2016). In some families where parents are diagnosed with schizophrenia, children often assume the role of caring for their parents (Fitzgerald *et al.,* 2010). A study conducted by Herbert, Manjula & Phillip (2013) reveal that children living with parents diagnosed with schizophrenia experience challenges in their emotional, social, and behavioral aspects of life. Herbert *et al.,* (2013) too report, that children of such parents tend to have social deficits characterized by emotional instability, aggressiveness, and social isolation, troubled relationships, difficulties in work, marriage, and struggle with issues related to poor self-esteem, and social adjustment. Furthermore, children may live their lives filled with anxiety, uncertainty and vigilance, and their needs are often neglected (McCormack, White & Cuenca, 2017).

Family members too reported their own psychological concerns about the future care of their family member diagnosed with schizophrenia. Families have reported that their emotions were dominated by worry and tension as they are concerned about the health and well-being of the person diagnosed with schizophrenia (Caqueo-Urizar *et al.,* 2011; Budden & Summerville, 2012). A study conducted by Hackman and Dixon (2011) found that aging parents who were caring for their children who are diagnosed with schizophrenia, were concerned about what will happen to their child when they are diseased. Moreover, parents reported to worry and be concerned about the health and well-being of their child, more especially on marital and employment prospects and the influence of the illness on the future of other family members (Koschorke *et al.,* 2017).

Furthermore, psychological stresses such as depression, stress, anxiety, shame, and guilt were reported by family members caring for a family member diagnosed with schizophrenia. Families have reported that caring for a loved one diagnosed with schizophrenia is stressful.

They have also reported experiencing anxiety and stress that lead to depression (Worrall, 2008). Anxiety and stress contribute to the feelings of helplessness, powerlessness and isolating family from friends and neighbours (Loga *et al.,* 2012). Moreover, Budden & Summerville (2012) note that families caring for a family member diagnosed with schizophrenia, experience shame and guilt, thinking they are to be blamed and become very much conscious of what others think of them. Families also blame each other for the condition of the family member (Caqueo-Urizar *et al.,* 2011; Budden & Summerville, 2012; Korschorke *et al.,* 2017). In a study conducted by Worrall (2008) in Australia on a group of parents who have a son or daughter diagnosed with schizophrenia, some parents felt overwhelmed by guilt and self-blame. A further study conducted by Lippi (2016) reported parents experience guilt and shame for not recognizing the symptoms earlier and they blame themselves for the cause of the illness. Family members also felt that they were incapable of caring adequately for their relative diagnosed with schizophrenia and felt criticized when the family member failed to meet societal role expectations or felt blamed and criticized for the member's behavior and for "delivering (producing) a mad person" ((Lippi, 2016; Korschorke *et al.*, 2017).

2.3.2.2 Stigmatization *as a social and community problem*

The social cost of mental illness on families, includes stigma, discrimination, and marginalization (WHO, 2012; Department of Health, 2013). Paul and Nadkarni (2014: 85) note that "conceptually, stigma constitutes three components, namely: stereotype, prejudice and discrimination. Mental illness stigma is therefore based on stereotypes that are often negative in nature (dangerous, incompetent, unpredictable, and untrustworthy)". Stigma is reported to occur when a power situation allows the co-occurrence of labelling, stereotyping, separation, status loss, and discrimination (Chen *et al.*, 2016). Stigma in mental illness is a serious social problem which has a multitude of consequences on the person affected, and can lead to increased social isolation, limited life chances, decreased access to psychiatric and medical

treatment, discrimination at work, poorer social functioning, and poor self-esteem (Chakrabarti, 2010; Caqueo-Urízar et al., 2011; Nxumalo & Mchunu, 2017).

Too often societal misinformation about schizophrenia is perceived to contribute to the stigmatization and rejection of people with schizophrenia and their families, (Hooley, 2010; Korschorke et al., 2017). Patients with schizophrenia and their families are often the primary targets of stigmatization by members of the community (Chakrabarti, 2010). As a result, families report that they do not want community members to discover and find out about their family members who are diagnosed with schizophrenia as they fear negative consequences for themselves, their family member diagnosed with schizophrenia and other family members (Korschorke et al., 2017). A study conducted by Nxumalo & Mchunu (2017: 202) in one of the Community Health Centres in KwaZulu-Natal, "participants reported experiencing stigma from the community in the form of isolation, blame and exploitation, community neglect, as well as labelling and stereotyping". Similarly, in a study conducted by Asmal, Mall, Emsley, Chiliza & Swartz (2014), families of person diagnosed with schizophrenia felt stigmatized by the community because of misinformation about the illness.

2.3.2.3 Family isolation

Stigma in mental illness is a serious issue and can contribute to family isolation (Caqueo-Urizar et al., 2011; Nxumalo & Mchunu, 2017). Family members caring for family members diagnosed with schizophrenia, report feeling lonely, struggle to make sense of their experiences, and have trouble in maintaining the effects of the illness (Jonsson, Wijk, Danielson & Skarsater, 2010). Compounding the issue of loneness, families reported to experiencing a greater feeling of not living their own lives, having difficulties to stabilize relationships, adapting to, and re-evaluating their lives and circumstances (Monyaluoe et al., 2014). Similarly, families reported experiencing isolation from other family members who

reportedly played a big part in their lives. (Worrall, 2008). Families often maintained a distant relationship with the rest of the family and friends because of a family member diagnosed with schizophrenia (Caqueo-Urizar *et al.,* 2011). Families caring and living with a family member diagnosed with schizophrenia, may not attend family gatherings or visiting friends, resulting in a significant decline in their quality of life (Habibi *et al.,* 2015). Similarly, other family members were likely to react by withdrawing from family interactions, withdrawal of support, spending more of their time with friends or doing extra-curricular activities than having contact with the family member and caring for a family member diagnosed with schizophrenia (Budden & Summerville,2012) & Lippi,2016). Research shows that family members tend to avoid social interaction, because of the unpredictable behaviors of the family member diagnosed with schizophrenia, thereby reducing their own social networking (Chakrabarti, 2010; Caqueo-Urízar et *al.*, 2011; Habibi *et al.*, 2015) resulting in family members becoming withdrawn. Likewise, they felt that "people stopped visiting them, did not invite them to functions or stopped talking to them altogether" (Korschorke *et al.,* 2017: 71).

2.4 SUPPORT FOR FAMILIES CARING FOR FAMILY MEMBERS DIAGNOSED WITH SCHIZOPHRENIA

Families are critical in the process of caregiving for their family members diagnosed with schizophrenia. The overwhelming burden of caring for these family members, requires that families have access to services and support aimed at addressing their concerns (Family Mental Health Alliance, 2006). Family support may include being provided with relevant information about the care and treatment of the illness (causes, symptoms, how to cope), proper training on how to care for the person diagnosed with schizophrenia and the availing of support and resources for both the person and family (Health Canada, 2004). However, research shows that there is inadequate help, inadequate support and inadequate community-based mental health resources for families caring for schizophrenia patients (Margetić, Jakovljević, Furjan,

Margetić & Maršanić, 2013; Chan, 2011). What is evident is the yawning gap that exists between the burden of caring for a mental ill person and mental health support and the resources in South Africa. Too often families receive minimum support or no support at all from psychiatric services (Shah *et al.,* 2013). Loga *et al.* (2012) note that families caring for family members diagnosed with schizophrenia are faced with several challenges in accessing health care services. These challenges include families not having adequate knowledge and support to care for people with schizophrenia resulting in a relapse or readmission in psychiatric facilities (Chan, 2013).

Unfortunately, in developing countries there is a lack of mental health care resources for both patients and families caring for them (Mhaule & Ntswane-Lebang, 2009; Lund, Kleintjies, Kakuma & Flisher, 2010). Caring for patients with schizophrenia is often dependent on the informal care provided by relatives, which supplements the lack of medical, occupational, and residential resources (Urizar *et al.,* 2011). In South Africa, it is estimated that 75% of people living with mental illness do not receive mental health services due to a lack of resources and because of poor health care (Schneider, Docrat, Onah, Tomlinson, Baron, Honikman, Skeen, Westhuizen, Breuer, Kagee, Sorsdahl & Lund, 2016). A study conducted by Veling, Burns, Makhathini, Mtshemla, Nene, Shabalala, Mbatha, Tomita, Baumgartner, Susser and Hoek (2018) in KwaZulu-Natal found that community mental health services are poor, and this is especially true in rural regions of the province. As alluded to earlier on in this chapter, there is a growing concern that although mental health is a significant public health issue in South Africa, mental health services remain constantly under-resourced (Lund, Kleintjies, Kakuma & Flisher, 2010). Notwithstanding South Africa's reformed and progressive mental health legislation (Mental Health Care Act 17 of 2002), various barriers still exist in financing and providing mental health services. According to the mental health policy in South Africa and the Mental Health Care Act (Act 17 of 2002), mental health patients are discharged as soon as

possible to prevent the institutionalization and its associated costs. Many patients are discharged into the care of relatives who know far too little about caring for a mentally ill family member. Although de-institutionalization has advanced at a fast rate in South Africa, supportive families to take care of these impaired patients are lacking.

The policy on deinstitutionalization has not been supported by an increase in mental health resources both for patients and their families in communities (Gureje & Alem, 2012; Lippi, 2016). In some instances, no budget allocation has been made for mental health services, leading to a shortage of professionals and resources diverted when health practitioner resigned (Mthethwa, 2019). Due to a lack of resources to implement the fundamental components of the Mental Health Care Act, care users have resultantly been deprived of easy access to care or to the reception of poor quality care (Chipps, 2012) with the majority of people with mental illnesses being treated in the community for most of the duration of their illness (Thom, 2007: 3). This too has contributed to the objective and subjective experiences of family members caring for a family member diagnosed with schizophrenia.

2.5 CONCLUSION ON LITERATURE REVIEW

This section of the Chapter provided an overview of the literature on the experiences of families living with relatives diagnosed with schizophrenia. It can be observed from the literature, that family members caring for their family members who are diagnosed with schizophrenia experience a plethora of challenges in terms of their objective and subjective experiences. Although de-institutionalization has advanced at a fast rate in South Africa, an improvement in community-based services and support to families caring for family member's diagnosed with a mental illness like schizophrenia for example, should be heightened.

The following section of this Chapter looks at the role of the social worker from within the context of psychiatric care based on various models of social work intervention.

2.6 THE ROLE OF A SOCIAL WORKER WITHIN A PSYCHIATRIC CONTEXT

This study is conducted from the social work perspective; therefore, the researcher will discuss the social work role and interventions in the psychiatric context.

2.6.1 Defining psychiatric social work

Psychiatric social work is defined by Talwar & Singh (2012: 11) as follows:

"Psychiatric Social Work, a specialized branch of Social work, which (is concerned) with theoretical as well as clinical work and the knowledge of Psychiatry-which primarily deals with problems of the mind and associated disorders".

2.6.2 Role of social worker in a psychiatric context

The role of the social worker in a psychiatric context is to provide required social services, therapeutic interventions for patients and their families, arranging referrals to external resources and agencies when needed, to participate, and to contribute as a member of the treatment team, to communicate the treatment plan with families, maintaining patients' records, monitoring their progress, planning their discharge and the after-care services (McCullough, 2011; Talwar & Singh, 2012; O'Hare, 2016). Coppock and Dunn (2010: 39) proposed that the key role of the social worker is to "prepare for and to work with individuals, families, caregivers, groups and communities to assess their needs and circumstances". People with mental health problems and their families are among the vulnerable groups in societies, therefore; the social work role within the psychiatric context includes advocating for the patients and their families (Simpson & Chipps, 2012; Brown & Ball, 2015). Advocacy refers to engaging in purposeful actions that will help people advance their human rights, opportunities, and human dignity (Loue, 2013).

Within the psychiatric context, social workers function in multi-disciplinary teams (Gould, 2010). A multi-disciplinary team as defined by Wattis & Curran (2017) involves individuals from a range of professional disciplines and backgrounds, working towards a common goal.

Giles (2016: 30) notes that "the role of social work within (a) multi-disciplinary (context) include(s) coordination between patient, family, community agencies and multi-disciplinary members". The multi-disciplinary team is responsible for combining their different expertise and skillset to discuss the mental health care users and design a care plan suitable for the individual (Gould, 2010).

2.7 SOCIAL WORK INTERVENTION

Social work interventions are based on various models which act as guidelines or as a blueprint on how social workers are to implement theories in practice (Bridges, Davidson, Soule-Odegard, Maki & Tomkowiak, 2011). While a theory explains why something happens, a practice model shows how to use a theory to create change (Donaldson & Daughtery, 2011). In this section, the researcher discusses two social work models that are applicable within the mental health context.

2.7.1 The Bio-Medical model to mental health

Engel (2012) explains that the Bio-Medical model was invented by Medical Scientists for the study of disease. Deacon (2013) argues that the Bio-Medical model, which is also known as the "Medical model" suggests that mental disorders are brain diseases and emphasizes pharmacological treatment to target presumed biological abnormalities. Havelka, Lučanin and Lučanin (2009: 303) asserts that "the Bio-Medical model attributes key role to biological determinants and explains disease as a condition caused by external pathogens or disorders in the functions of organs and body systems".

In addition, the Bio-Medical model to health suggests that diseases such as schizophrenia, major depressive disorder and attention deficit disorders are biologically-based diseases (Deacon, 2013). The Bio-Medical model according to Gould (2010: 15) "takes into account not merely the symptoms, syndrome or disease, but the person who suffers, his personal and social situation, his biological, psychological and social status".

Biological theorists hold a belief that mental illness is caused by a physical illness or injury, they view brain malfunctioning as the cause of mental illness, focusing mainly on problems in brain structure, brain chemistry, or genetic makeup (Midkiff, 2006). The main beliefs of the Bio-Medical approach according to Deacon (2013: 847); McLeod (2014); Davidson *et al.* (2016: 3) are:

- Mental disorders are caused by biological abnormalities principally located in the brain

- There is no meaningful distinction between mental diseases and physical diseases

- Biological treatment is emphasized

- The medical model holds that the making of a diagnosis, and the prescription of medications based on that diagnosis, are reasonably exact science.

- The biomedical approach to mental health focus on the genetics, neurotransmitters, neurophysiology, and neuroanatomy

- The approach argues that mental disorders are related to the physical structure and functioning of the brain

- Behaviours such as hallucinations are 'symptoms' of mental illness and are suicidal ideas or extreme fears such as phobias about snakes and so on. Different illnesses can be identified as 'syndromes', clusters of symptoms that go together and are caused by the illness.

- These symptoms lead the psychiatrist to make a 'diagnosis' for example 'this patient is suffering from a severe psychosis; he is suffering from the medical condition we call schizophrenia.

2.7.2 The Bio-Psycho-Social model to mental health

The Bio-Psycho-Social (BPS) model was developed by Dr. George Engel in 1977, proposing that to understand a person's medical condition, it is not simply the biological factors to consider, but also the psychological and social factors (Gatchel, Peng, Peters, Fuchs & Turk, 2010). The BPS model claims that "a medical model must also take into account the patient, the social context in which he lives, and the complementary system devised by society to deal

with the disruptive effects of illness, that is, the physician's role and the health care system"
(Engel, 2012: 386). In addition, the BPS model highlights the significance of understanding
human health and illness to their fullest and in all contexts. In contrast to the Bio-Medical
model, the aim of the BPS model to mental health is not to diagnose a particular illness, but to
describe and explain the problems of a particular individual drawing from a variety of
psychological theories (Davidson *et al.,* 2016). Gould (2010) argues that the Bio-Psychosocial
Model to mental health is derived from the general systems theory. The main beliefs of general
systems theory according to Gould (2010: 16) are:

- Mental states occur within individuals who are members of a whole system

- The whole system is both sub-personal, comprising physical entities such as the nervous
  system; the whole system, and the supra-personal, made up of a psychosocial context which
  exists like the layers of the onion in increasing complexity as we look outwards from the
  individual-dyad, family, community, culture, society, and environment.

The BPS model to mental health attempts to conceptualise an individual's biological and social
background, life events and the meaning that they have drawn from these experiences
(Davidson *et al.,* 2016). Kinderman (2005) notes that psychological approaches focus on
associative networks based on the neural substrate but they are developed through learning,
and they rely on theories of conditioning, perception, appraisal, and belief formation, on
propositional and implicational encoding, on mental models of the world and internalized
schemas of relationships, and so forth. The biological, psychological as well as social events
are mutually interrelated and reciprocally influenced (Gritti, 2017). Therefore, the BPS model
of mental disorder addresses the different kinds of mechanisms than exclusively biomedical
theories. It also attempts to include more than the mere mechanics of any individual system
and to look at interactions and interrelationships (Kinderman, 2005). Babalola, Noel and White
(2017) argue that the BPS model to mental health is based on a belief that there are various

simultaneous causes of mental disorder. Contrary to the Bio-Medical Model, the BPS model posits that biological, psychological, and social factors contribute to the causes of disease and treatment (Kinderman, 2005).

In addition to that, the BPS model highlights that health is more than just the absence of disease provided that the psychological and social dimensions have to be accounted for rather than purely the physical. Gritti (2017: 37) states that "the Bio-Medical model is far from being a scientific model because it fails to account adequately for all the data, namely the psychosocial concurrent variables of the diseases". Such a model, excluding psychosocial issues, determines a harmful separation of medicine, psychiatry, and psychology, even though these three disciplines are equally devoted to the treatment of diseases. Havelka *et al.* (2009) note that the BPS model takes into consideration all relevant determinants of health and disease that support the integration of biological, psychological, and social factors in the assessment, prevention, and treatment of diseases.
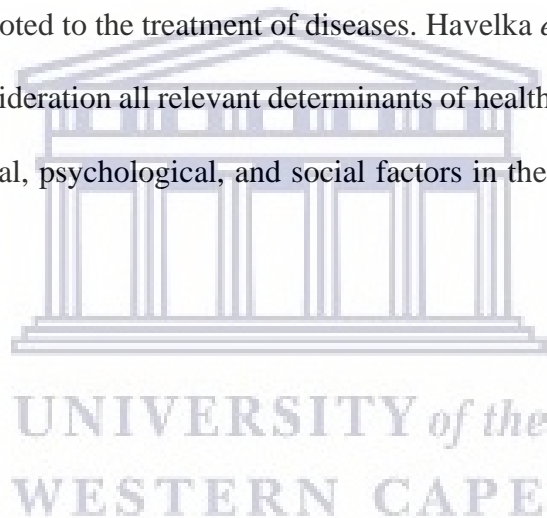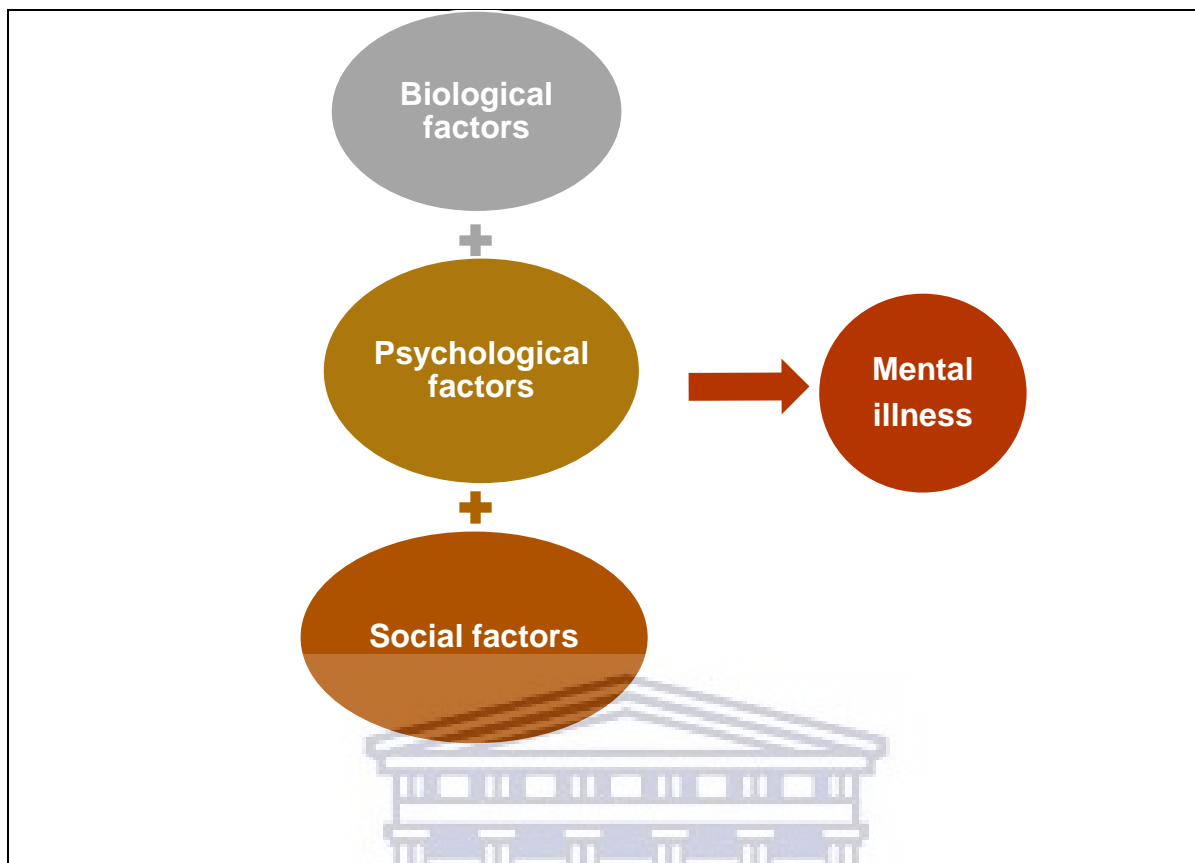
Figure 1: Multiple causes of mental disorder according to BPS model (adapted from Physiopedia, 2019)

The above diagram illustrates multiple causes of mental disorders according to the BPS model. All of these factors contribute to the development of mental disorders. The description of what each entails is provided in the following section.

Biological factors:

A study conducted by Khan *et al.* (2013: 6453) reveals that "schizophrenia has a substantial genetic empowerment with estimated heritability of about 80%". Lebowitz and Ahn (2014) also state that mental disorders are increasingly understood in terms of biological mechanisms. Biological factors encompass physiological pathology, physical health (disability) as well as generic vulnerabilities. Khan *et al.* (2013) assert that abnormality in brain structures and circuits contribute to the development of schizophrenia. South African Depression and Anxiety Group (2016: 8) contends that "1 in 10 people with schizophrenia have a parent with the

illness". In addition, damages to the brain due to difficulties encountered during the process of birth may predispose someone to developing schizophrenia (SADAG, 2016).

Psychological:

These include thoughts, emotions and behaviors such as psychological distress, fear/avoidance beliefs, coping methods and social skills. SADAG (2016) highlights that trauma such as a loss or car accident can contribute to developing schizophrenia. A study conducted by Lim, Chong and Keefe (2009) shows that exposure to prenatal stress during pregnancy contributes to the development of schizophrenia in the offspring. In addition, abuse during childhood has been associated with the high risk of developing schizophrenia later in life (Lim *et al.,* 2009). In addition, Read (2010: 10) confirms the above assertion by stating that childhood sexual, physical, and emotional abuse; childhood physical neglect; insecure attachment in childhood; bullying; war trauma; rape or physical assaults as an adult; being a refugee; racist and other forms of discrimination; and heavy marijuana use, especially early in adolescence are significant risk factors for psychosis.

Key findings of a study conducted by Sideli, Mule, Barbera & Murray (2012) revealed that childhood abuse or mistreatment consist of any act of commission or omission by a parent or another caregiver that result in harm or a threat of harm to a child. Adding to that, childhood abuse is often a chronic condition and can lead to psychiatric disorders during adulthood (Sideli *et al.,* 2012). In his study on the 'relationship between poverty and schizophrenia', Read (2010) found out that dysfunctional parenting (particularly affectionless over control) can lead to the diagnosis of schizophrenia.

Social:

Social factors that contribute to the cause of mental disorder encompasses social, socio-environmental, and cultural factors such as work issues, family circumstances and

benefits/economics, drug effects and peers. Certain population subgroups are at a greater risk of getting mental disorders because of their greater exposure and vulnerability to adverse social, economic, and environmental circumstances, interrelated with gender (WHO, 2014). Sweeney *et al.* (2015) proclaim that there is a relationship between mental illness and poor physical health and socioeconomic outcomes. To illustrate this, Read (2010: 7) notes that "poverty is a powerful predictor of who develops psychosis, and who is diagnosed 'schizophrenic' (with or without a family history of psychosis), but that poverty is more strongly related to 'schizophrenia' than to other mental health problems. A study conducted by Khan *et al.* (2013) agrees that socio-demographic factors such as poverty and low social class are associated with higher rates of schizophrenia, thus stressful social environmental circumstances may be responsible for the increased risk of schizophrenia. This was also revealed in the Literature Review section of this Chapter (Section 2.3.1.1).

2.7.3 The Recovery Model of mental illness

The Substance Abuse and Mental Health Services Administration (SAMHSA) (2019) defines mental health recovery as a journey through which people progress in their health and wellness, live self-directed lives, and strive to reach their full potential. Warner (2010) proposed that the recovery model is a social movement that is influencing mental health service development around the world. It refers to the subjective experience of optimism about an outcome from psychosis to a belief in the value of the empowerment of people with mental illness, and to a focus on services in which decisions about their treatment are taken collaboratively with the user and which aim to find productive roles for people with mental illness.

Chiu, Ho, Lo & Yiu (2010) note that the Recovery Model focuses on humanistic values, including a call for more autonomy and empowerment on the part of service users. Recovery is based on creating meaningful relationships, nurturing empowerment, and reducing barriers to employment, education, and other life goals (Brooke-Summer, 2015; SAMHSA, 2019). The

aim of the Recovery Model is to "help people with mental illnesses and distress to look beyond mere survival and existence" (Jacob, 2015:118). Jacob (2015) further states that the Recovery Model is based on two main assumptions, mainly: it is possible to recover from a mental health condition, and it is a holistic, person-centered approach in mental health. Additionally, "for many people with mental illness, the concept of recovery is about staying in control of their life rather than the elusive state of return to premorbid level of functioning," Jacob (2015:117). The process of recovery requires optimism and a commitment from people with mental illness, their families, mental health professionals, public health teams, social services, and the community (Jacob, 2015). SAMHSA (2019) asserts that the Recovery Model promotes partnership with people in recovery from mental illness and their families to facilitate behavioral system and encourage approaches that fosters health and resilience. Jacob (2015) & SAMHSA (2019) agrees that there are four major dimensions that support recovery, and these include the following:

- *Health*: For the process of recovery to be effective, people need to make choices that will support both their physical and mental well-being.

- *Home*: People need a safe and supportive home environment so as aid in the process of recovery. Slade, Amering, Farkas, Hamilton, O'Hagan, Panther, Perkins, Shepherd, Tse and Whitley (2014: 16) propose that "safe and secure permanent housing can act as a base from which people with a severe mental illness can achieve numerous recovery goals and improve quality of life".

- *Purpose:* Having meaningful daily routines such as school, work, family, and community participation are important during the recovery process and for maintaining wellness.

- *Community***:** Supportive social relationships are known to provide people with the love, emotional availability, and respect that they need to survive and thrive.

2.7.3.1 Fundamental components of recovery

- *Self-direction and person-centered:*

The implementation of recovery-oriented practice should be person-centered and they should aim at helping individuals to live a meaningful life (Slade, Amering, Farkas, Hamilton, O'Hagan, Panther, Perkins, Shepherd, Tse & Whitley, 2014). Most people who are in the process of recovery realize that they must take action to better their future, and the process of recovery is highly personal and transpires through many pathways (Ragins, n.d; SAMHSA, 2019). In addition to that, Chiu *et al.* (2010) argues that service users lead, control, exercise choice over, regulate their pathway to recovery by practicing autonomy, independence, and control of resources to achieve a self-determined life. Brooke-Summer (2015) argues that recovery as an individual journey is linked to the socioeconomic and sociocultural environments that the person finds him/herself in. In addition to that, the recovery process will differ depending on the contexts, and those that are recovering from well-resourced contexts will be able to have their needs attended to unlike those recovering within poor contexts (Brooke-Summer, 2015).

- *Empowerment and social networks:*

WHO (2010) notes that empowerment is a multidimensional social process through which individuals and groups obtain better understanding and control over their lives. As a result, they are empowered to change their social and political environment to enhance their health-related life conditions. Warner (2010:4) believes that "a central tenet of the recovery model is that empowerment of the user is important in achieving good outcome in serious mental illness". For the recovery to be effective, Ragins (n.d) notes that it is important for someone else to believe in them before they are strong enough to believe in themselves and to start concentrating on their strengths rather than their losses. Individuals that are recovering from mental illness need to be included and empowered to take part in societal activities such as

politics to improve their well-being (World Health Organization, 2010). Warner (2010) agrees with this view by stating that an important means of empowering patients is to include them in decisions pertaining to their illness. Here, reference can be made for example to the policy on deinstitutionalization where patients and those caring for them can be part of the decisions pertaining to their health and care (a section in Chapter 1 of this study).

Furthermore, in mental health contexts, the key to empowerment is the elimination of formal or informal barriers and the transformation of power relations between individuals, communities, services, and governments (WHO, 2010). For recovery to be effective, one's environment needs to offer opportunities and resources for them to make meaningful choices (Brooke-Summer, 2015).

In addition, Jacob (2015: 118) contends that "the environment, which provides for personal growth, developing resilience to stress and adversity and allows people to develop cultural and spiritual perspectives, is also crucial". SAMHSA (2012) proposes that communities have strengths and resources that help as a basis for recovery. The process of effective recovery is strongly linked to social inclusion, and the key role of the mental health and social services is to help people regain their place in the communities, take part in activities (such as education, training volunteering and employment opportunities) and utilize opportunities for growth along with everyone else (Jacob, 2015). The Literature Review section of this study provided evidence of stigmatization for example, by community members when family members diagnosed with schizophrenia are not fully integrated into their communities (Section 2.3.2.2).

- *Hope:*

SAMHSA (2019) states that hope is the 'catalyst' of the recovery process. Ragins (n.d: 2) states that "in the blackest (darkest) times of despair what's needed first is hope as a light at the end of the tunnel, some idea that things can get better, that life will be more than the present

destruction". SAMHSA (2012: 4) states that the belief that recovery is real provides an essential and motivating message of a better future - that people can and do overcome the internal and external challenges, barriers, and obstacles that confront them. Chiu *et al.* (2010) believes that recovery provides the essential and encouraging message of a better future - that people can and do overcome the barriers and obstacles that challenge them.

- *Support and relationships:*

People affected by mental illness require a lot of support to create their own recovery plans, set their own goals and map processes (Jacob, 2015). Jacob (2015) clarifies that a well-organized system of support from friends, family and professionals is necessary for an optimum recovery. It has been noted by SAMHSA (2012) that family members, peers, health providers, faith groups, community members, and other partners form a vital support network during recovery in mental health. In addition, through these relationships, people engage in new roles that lead to a better sense of belonging, personhood, empowerment, autonomy, social inclusion, and community participation.

2.8 CONCLUSION

Interventions for families living with a relative diagnosed with schizophrenia are essential to assist them in coping with their everyday lives. Moreover, these interventions are aimed at equipping families living with a person diagnosed with schizophrenia with the necessary skills to improve home-based care. The interventions presented could prove to be successful and effective when implemented from a social work perspective. As indicated at the beginning of this Section, these social work models act as guidelines or as a blueprint on how social workers can understand and implement effective solutions in practice, in relation to rendering social work services in a psychiatric context.

The next Chapter unveils the Theoretical Framework, namely the Family Systems Theory (FST), underpinning the study and implementing social work from a family system perspective.

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CHAPTER 3

THEORETICAL FRAMEWORK FOR THE STUDY

3.1 INTRODUCTION

In this Chapter, the researcher outlines the Family Systems Theory as a theoretical framework that underpins the current study. It briefly explores the origin of systems and family systems theory, giving a clear definition of family, family structure and family functioning. The chapter further discusses the family structure and family functioning for families caring for family members diagnosed with schizophrenia which include family roles, caring responsibilities, family communication and family adaptation.

3.2 GENERAL SYSTEMS THEORY (GST)

During the 1940's, biologist Ludwig Von Bertalanffy (1901–1972) was generally acknowledged as the founder of the General Systems Theory (GST). GST is "a theory that stresses the importance of exploring the world at the level of systems made up of interdependent and interacting parts" (O'Leary' 2011: 289). It provides a theoretical framework for the foundation of various micro-level approaches, known as systems theories (Whitchurch & Constantine, 2009). One of those systems theories is the Family Systems Theory, introduced by Murray Bowen (1974). This theoretical framework will be used to explain the family system, in the context of a family member living and caring for a family member diagnosed with schizophrenia.

3.3 THE FAMILY SYSTEMS THEORY (FST)

The Family Systems Theory was used as a theoretical framework for this study. The theory places emphasis on exchanges of behavior and interaction between members in a family (Johnson & Ray 2016). This means that whatever affects the one member of the family, will affect the other family members since families are interrelated and intertwined (Green Paper

on Families, 2010; Skyttner, 2005). The family system is therefore considered the primary system to which a person belongs, and that if anything happens to one member of the family, the whole family system is affected (Seligman & Darling, 2009).

Within the Family Systems Theory approach, relationships and character traits are built and reinforced within the family (Johnson & Ray, 2016). These characteristic traits include managing stress and crisis efficiently, effective, and positive communication patterns, sense of spiritual well-being, and appreciation and affection (Seligman & Darling, 2009). Families are not only seen as groups with individuals that function independently, but the family is viewed as a system whereby change in one part of the system influences other interrelated parts of the system (Kaplan, Arnold, Irby, Boles & Skelton; 2014). Parts of the systems include members who are attached by relationships with one another that sustain and enhance their survival (Knauth, 2003). These relationships may include among others: parents, spouses, and siblings. Therefore, the family as a system is best understood by focusing on the whole system such as its individual family members, as well as the interactions and relationships that are happening among the family members (Thomas & Priest, 2016).

Unlike individually oriented theories such as the Social Cognitive Theory which views the individual as the focus, the Family Systems Theory is based on the notion that families are the point of focus in developing methods of working together in order to respond to daily life challenges (Paley, Lester & Mogil, 2013). Working together as a whole can then be to the benefit not only to one individual but to all members in the family. Family systems theory is therefore an approach in understanding human, and in this case family, functioning with a specific focus on the interactions among and between members in the family (Watson, 2012).

Family Systems Theory is based on the following components as described by Bowen (1976):

1. *Family systems have interrelated elements and structure:*

    A family is perceived as a system because it has elements (family members) with different characteristics, exhibit coherent behaviors, have regular interactions with each other, and they are interdependent on one another (Paley *et al.,* 2013).

2. *Family systems interact in patterns:*

    The family establishes patterns of interaction, which preserve the family's equilibrium and provide guidance to their functioning. This contributes to maintain a balance and to ensure the existence of harmoniously structured relationships between family members (Catalan, 2018).

3. *Family system has boundaries:*

    Family boundaries help regulate the family functioning and differentiate between the various subsystems to maintain an equilibrium in the family (Catalan, 2018). The boundaries within the family system and subsystems, which encompasses spouses, parents, and siblings, are established to regulate, and protect the autonomous roles of each subsystem, as well as the overall integrity of the larger family system (Briggs & Morgan, 2017). Boundaries within the family can range from being open to close boundary system. The open boundary systems allow elements and situations outside the family to influence it. It may even welcome external influences. Unlike the open boundary system that allows external influences, closed boundary systems do not allow external influences and it is isolated and self-contained (Briggs & Morgan, 2017).

    Likewise, communication and flow of information into and from the family are regulated by these boundaries. Patterns of communication in families are linked to relationships, as it is through communication that relationships are formed in families (Davids, Roman & Schenck, 2020). Communication may challenge interactions affecting parenting roles and

responsibilities negatively. Insufficient explanations for decisions made may lead to misunderstandings affecting family boundaries, and decisions

4. *Families' system uses messages and rules to shape members:*

Families have definite patterns of rules and strategies that govern their interaction (Catalan, 2018). If rules are too rigid or too blurred, confusion may arise, increasing the risk of family instability and dysfunction (Greenberg & Greenberg, 2008). Family rules are agreements, which control and limit family member's behavior (Paley *et al.,* 2013). Subsystems (spouses, parents, and children) may, however, have their own rules that are not necessarily applicable to the larger system (Briggs & Morgan, 2017). Through rules, family members learn what is permitted or expected within a family.

To further the discussion on family, a definition of family is provided in relation to the structure and functioning in the following section.

3.4 DEFINING FAMILY IN RELATION TO STRUCTURE AND FUNCTIONING

3.4.1 Definition of family

Family is a social phenomenon and has proven to be difficult to define (Floyd, Mikkelson, & Judd, 2006). Family can be defined as "a societal group that is related by blood (kinship), adoption, foster care or the ties of marriage (civil, customary or religious), civil union or cohabitation, and go beyond a particular physical residence" (DSD, 2012: 11). A broader definition states that a family is a self-defined group of intimates, who create, define, and maintain themselves and their interactions through relationships, which consist of boundaries that may evolve over time (Turner & West, 2013).

People from diverse populations conceptualize the term "family" differently. In a study conducted by Thompson, Seo, Griffith, Baxter, James, & Kaphingst (2015), participants defined family with a focus on its structure (biological or legal ties) and its functions

(caretaking or financial support). In some populations, people define family to include the extended family and fictive kinship, which may not reflect the structural or biological definition (Thompson *et al,* 2015). Family is further defined as the supportive environment in which people with disabilities, the sick and the most vulnerable and aged are cared for. It is the primary source of individual development in which family relationships are the most important sources of social support for many people (Powell, Blozendahl, Geist & Steelman, 2010). Additionally, to many individuals; family remains the main element of their social and material support system throughout their lives DSD, 2012, Shukla, 2013; Dai & Wang, 2015).

3.4.2 Family defined through its structure

Family is firstly defined by structure. A family structure according to Pasley and Petren (2016: 1) refers to a concept that "reflects relationships at the juncture of biological relatedness, marital and partnership status, and living arrangements". Family structure refers to different family forms identified as single-parent families, married or cohabiting parent families, blended families, one adult with adopted child(ren), extended families and child-headed families (Voydanoff, 2001; Holborn & Eddy, 2011; DSD, 2012). Dinisman, Andresen, Montserrat, Strózik and Strózik (2017) note that the family structure has evolved over the last century; and the notion of 'family' has become more fluid and there is no 'standard family' anymore. A family structure within the South African context varies among cultures, and each cultural group has traditions, which serve to maintain family life, and ways of adapting to changing circumstances (Amoateng, Richter, Makiwane & Rama, 2004).

3.4.3 Family defined through its functioning

Although families are unique, they should not be confined strictly to its structure, but also to the processes and functions which encompass the interrelated relationships, interactions, roles, and boundaries (Isaacs, Roman, & Savahl, 2018; Morison, Lynch, & Macleod, 2016). In South Africa, the concept of family has transformed and evolved, which has resulted in the emergence

of different family formations that have had an influence on the family functions (Makiwane, Makoae, Gumede & Vawda, 2017). Berge, Wall, Larson, Loth, and Neumark-Sztainer (2013) state that family functioning refers to the organizational properties and interpersonal interactions among familial members, including warmth, closeness, roles, problem-solving, adaptability, behavior control, and communication.

Epstein, Baldwin, and Bishop (1983) identify six features of a healthy, well-functioning family, namely: the ability to solve problems, effective communication, appropriate role allocation, affective responsiveness, empathetic affective involvement, and the application of flexible behavior control. These features include how family members communicate, relate, and maintain relationships, make decisions, and solve problems, and about how family collaborate to achieve its goals, cohesion, and adaptability (Lewandowski, Palermo, Stinson, Handley & Chambers, 2010; Roman, Schenck, Ryan, Brey, Henderson, Lukelelo, Minnaar-McDonald & Saville, 2016).

Communication has been described as an important function within the family as it allows members to make their needs, wants, and concerns known to each other (Peterson & Green, 2009; Fa'alu, 2016). It is described as the cornerstone of strong family functioning, and it is important in enhancing cohesion and fostering positive relationships among family members (Gottaman, 2011; Borden, 2014). Good communication can help the family system to maintain a sense of stability, help to alleviate fears and worries, and it helps the family to develop mechanisms to adapt to changes in their environments (Thomas & Priest, 2016) and may even help with family cohesion.

Family cohesion refers to "the degree of togetherness or closeness or emotional bonding that family members have toward one another" (Vandeleur, Jeanpretre, Perrez & Schoebi; 2009: 1205). Family cohesion, which includes the level of support and commitment through supportive family involvement, family bonding as well as family climate, has an influence on

family functioning (Gonzales, Dumka, Millsap, Gottschall, McClain, Wong, Germán, Mauricio, Wheeler, Carpentier & Kim, 2012).

However, such closeness or emotional bonding can be disrupted when a family member is diagnosed with a mental illness which will result in a dysfunctional family system. When the family system is experiencing changes, due to a mental illness, the family functioning is disrupted, which has the potential to bring an imbalance in the family system until an adjustment occurs (Martire & Helgeson, 2017). When the family cannot function according to its 'normal' state, the family is then experiencing a disequilibrium (Martire & Helgeson, 2017). Disequilibrium in the family functioning is described by Kaiser, McAdams & Foster (2012) as a state of destabilization that occurs when the family is experiencing unfamiliar situations. The family's ability to adapt and respond to the changes and developments that influence the family will be challenged and the family stability will be threatened (Silburn, Zubrick, De Maio, Shepherd, Griffin, Mitrou, Dalby, Pearson & Hayward, 2006). These families could then be 'at risk' (Roman, Isaacs, Davids & Xin-Cheng Sui, 2016).

3.5 FAMILIES CARING FOR A FAMILY MEMBER DIAGNOSED WITH SCHIZOPHRENIA

The Family Systems Theory has been highly persuasive in the study of recurrent psychiatric disorders (Miklowitz, 2004). Patterson and Garwick (1994) states that when a family member is diagnosed with schizophrenia, family structure, routine, boundaries, and rules are likely to change to allow flexibility and adapt to the unexpected changes brought by the illness.

A family member diagnosed with schizophrenia can cause considerable changes in how the family operates. A diagnosis of schizophrenia in the family can have considerable impact not only on the affected individual, but also on the people closest to them resulting in tensions, breakdown of relationships, and a lack of understanding between family members (Golics, Basra, Finlay & Salek, 2013).

The deinstitutionalization of mental health patients, supported by the White Paper Act of 1997, the Mental Health Care Act 17 of 2002, and National Health Act 61 of 2003 (as discussed in Section 1.2.3.2 in Chapter 1) for example, has led to the role of family members now caring for the family member diagnosed with schizophrenia, and the recognition of the high level of burden of care placed on family members. Deinstitutionalization refers to the shift in caring for mental health care users from the hospitals back into the care of communities and families (Shen & Snowden, 2014). The high level of burden placed on family members due to the deinstitutionalization can result in the weakening of family functioning. The uncertainty about how to care for a member with schizophrenia can cause high levels of anxiety and stress and the family unit can be at risks as explained by Roman, Isaacs, Davids & Xin-Cheng Sui, (2016).

As stated before, family roles and responsibilities play an important part in the functioning of the family (Dai & Wang (2012) as "normal routines and roles help support individual family members and sustain the family as a unit" (Sono *et al.,* 2008: 586). However, the occurrence of schizophrenia in the family can necessitate family members to assume more roles and responsibilities to maintain the family equilibrium (Johnson & Ray, 2016). These roles and responsibilities can exert an enormous amount of influence in a family's everyday lives as there will be a shift in terms of roles and responsibilities that may need to be fulfilled towards providing care and support towards the person diagnosed with schizophrenia. Changes in the roles within the family structure encompass the role of caregiving for the relative with schizophrenia (Caqueo-Urízar *et al.,* 2017.

The role of caregiving often comes at a cost for the family and the primary family member caring for a family member diagnosed with schizophrenia, who loses a series of opportunities for his/her personal growth. In a study conducted by Caqueo-Urízar, Rus-Calafell, Craig, Irarrazaval, Urzúa, Boyer and Williams (2017) found that changes in the roles within the family include the role of caregiving for the caring of a relative with schizophrenia. Caregiving

responsibilities towards a family member with schizophrenia include the monitoring of medication, watching for any signs of a relapse, providing on-going support such as shelter and food, as well as the protection of the person with schizophrenia (Sono, Oshima & Ito, 2008; Botha & Booysen, 2014) as discussed in Section 2.3.1.3 of Chapter 2.

Often, family members have to quickly adjust to this new role of "informal care" or role reversal for which they feel unprepared for (Addington & Burnett, 2004), this included children. A study conducted by Golics *et al.* (2013) on the impact of disease on family members: a critical aspect of medical care, established that family members may need to share caregiving responsibilities and other roles such as providing for the family in cases where it is the parent that has a mental illness. When a parent has schizophrenia, the parent may experience difficulties in fulfilling their roles with the result that adult children will assume the new roles and responsibilities relating to caregiving (Nieto-Rucian & Furness, 2019). Boydell, Seeman & McKeenver (2011) found that children of parents with schizophrenia revealed that children had to live independently as their parents were not able to fulfil their parental role. In their study on adult attachment in children raised by parents with schizophrenia, Duncan & Browning (2009) established that those adult children reported that trust and intimacy issues created difficulties for them to form secure adult relationships as they grew up in an environment where they had to take on the responsibility of taking care of their parents with mental illness.

Furthermore, the diagnosis of schizophrenia within a family can blur the boundaries due to role confusion (King, 2016). Unclear and blurred boundaries in terms of caring for a family member diagnosed with schizophrenia can put a strain on relationships within families. When boundaries concerning roles and responsibilities are ambiguous, tension and confusion may arise within the family (Seligman & Darling, 2009) often impacting on how information is communicated (Briggs & Morgan, 2017). A family member diagnosed with schizophrenia may

find it difficult to communicate their needs to their families as the illness may hinder their ability to communicate openly and clearly (Fa'alau, 2016). These hindrances may not only cause the person's inability to express themselves but may lead to paranoia with unreasonable demands put on others or showing any concern for others (Behavioural Health Evolution, 2016). Therapists working with families with a family member diagnosed with schizophrenia have noted communication patterns in families to be unclear, confusing, and conflicting at times (Gottaman, 2011). In addition to unclear, vague, and ambiguous communication, these families were seen to have a culture of shared denial of feelings and to be overly involved or "enmeshed" with each other. These communication patterns were observed as displaying dysfunctional family structures and relationships. A study conducted by Caqueo-Urízar *et al.* (2017) found that when a family member is diagnosed with schizophrenia, communication in families suffers and deteriorates. The findings of the study show that family members communicate less with the person with schizophrenia as there are barriers such as the ill person not understanding the content of their communication (Caqueo-Urízar *et al.*, 2017).

3.6 FAMILY ADAPTATION

Javadian (2011: 1) defines family adaptation as "the ability of a family system to change its power structure, role relationships and relationship rules in response to situation and developmental stress". Positive coping skills have been found to have high impact on adaptability of families experiencing mental illness (Caqueo-Urízar *et al.*, 2017). Researchers have noted that families who have a family member diagnosed with schizophrenia, high family cohesion and adaptability are vital in maintaining family functioning. As described earlier, family cohesion is characterized by warmth, nurturance, time together, physical intimacy, and consistency (Boyraz & Sayger, 2011) but schizophrenia has the potential to disrupt the family equilibrium, requiring the family to establish a new approach to its functioning (Hsin-Yang & Pearson (2002).

Family reactions and family adaptation to a family member diagnosed with schizophrenia can cause them and the family to be thought of as different. The goal is to achieve as much of an equilibrium in the family as possible; however, this can be difficult to achieve when family members try to balance their responsibilities and take on new roles. It can be challenging to maintain an equilibrium or balance of the family system, especially when the family's self-regulating efforts to maintain stability are threatened (Davies, 2016; Greenberg & Greenberg, 2008). For us to get to a state of balance again, the family may need to adapt or make changes in the functioning of their family

The family's adaptation to a member diagnosed with schizophrenia may also depend on the family's cultural and ideological beliefs. In their study, Grover, Davuluri & Chakrabarti (2014) established that families of patients with schizophrenia were involved in religious communities to carry out their religious practices, receive support from the clergy in adapting with the illness. However, on the other end of the spectrum, the schizophrenia diagnosis of a family member may bring the family together and strengthen family bonds and relationships as the family members pull together to support each other, and help the affected member (Golics *et al.*, 2013; Lawrence, 2012; Bottomley, Finlay & Salek, 2013).

3.7 SOCIAL WORK AND A FAMILY-CENTRED APPROACH WITH FAMILIES

Family interventions that are aimed at directly improving the well-being of families are necessary, as well as therapeutic interventions to address the fears, symptoms of depression and anxiety (Lippi, 2016). Intervention is defined by Zamboni (2016) as action taken by social workers to directly provide service or support to individuals in need. The researcher will discuss two types of interventions, namely: psycho-educational and peer support groups for families from a family system perspective later in this section (Sections 3.7.1 and 3.7.2).

Having a family member diagnosed with schizophrenia can be traumatic for the family (O'Hare, 2016). Thus Zahid & Ohaeri (2010) note that interventions to support families are necessary to improve the quality of home-based care for families and their relatives with schizophrenia. It is noted that the majority of people with mental illness and their families received minimal or no information about their diagnosis, or about the treatment and support available to them (Budden & Summerville, 2012). Sweeney, Air, Zannettino & Galletly (2015) contends that the development of effective clinical mental health support and interventions for individuals and family need a coordinated and strong mental health system supported by social as well as health policy whose primary aim will be to address the socioeconomic disadvantage in mental health cohorts.

Therefore, as part of an early intervention, Budden & Summerville (2012) believe that there is a need for public awareness and education to be targeted on families with history of schizophrenia. Interventions such as psycho-education and peer support groups are aimed at providing people with schizophrenia and their families with information about early signs of a relapse and the side effects of medication (Lippi, 2016).

3.7.1 Psycho-educational interventions
Psycho-education refers to the process of providing education and information to the persons with schizophrenia and their families about mental disorders, their treatments, personal coping techniques, and resources (Reyes, 2010; Chan, 2011). Bhattacharjee, Rai, Singh, Kumar, Munda & Das (2011: 104) proposed that: "the term psycho-education comprises systemic, didactic psychotherapeutic interventions, which are adequate for informing persons with mental illness and their families about the illness and its treatment, facilitating both an understanding and personally responsible handling of the illness and supporting those afflicted in coping with the disorder". This intervention is aimed at providing crucial information and training to the families of persons with schizophrenia to change the attitudes and health

perceptions in families living with a relative with schizophrenia, teaching skills such as problem solving and communication so as to increase the family's coping ability with their situation and to work together with mental health practitioners as part of an overall clinical treatment plan for their ill family members (Urizar *et al.,* 2011; Chan, 2011; Vaghee, Salarhaji, Asgharipour, & Chamanzari, 2015). Psycho-education is commonly delivered through individual or group programs, and involves clinicians taking on the role of information-provider, and patients and family caregivers as participants (Sin, Gillard, Spain, Cornelius, Chen & Henderson, 2017). Urizar *et al.* (2011: 101) note that "group-based intervention enables families to share experiences with others in similar situations, which can provide comfort and facilitate the expression of feelings about the disorder, thereby improving coping skill".

Education and awareness for people with schizophrenia and their families directly influence the treatment and recovery process—without an understanding of the illness, families are less likely to fully participate in a proper treatment plan, and families are less likely to know how to help the person (Zahid & Ohaeri, 2010). Dixon, Adams & Lucksted (2010:5) note that: "assessing the needs of family members is the pillar of relation and cooperation between the family and the therapist. Family members may blame themselves for the illness of their member, may feel helpless and need to gain more knowledge". Families living with relatives with schizophrenia often provide emotional and financial support, housing, and advocacy to their ill relatives (Habibi *et al.,* 2015). Thus Johnston (2018) proclaims that it is critical to provide the family with psycho-education on schizophrenia as they need to understand the type of symptoms the affected person has and what may trigger them. In addition, SADAG (2016) states that a psycho-education intervention can help the family and patient to cope better with the situation. In addition, psycho-education can help families to understand that they are not the cause of the illness, a mentally ill person can be difficult to deal with and that if they learned

to be calmer and more focused on their dealings with the mentally ill family member, that person is likely to respond in a calmer manner as well (O'Hare, 2016). In a study conducted by Thara, Padmavati, Lakshmi & Karpagavalli (2009), it was found that mental health professionals consider that educating the family members of patients with schizophrenia on numerous aspects of the illness not only helps them to cope better, but also leads to more certain developments in the clinical status and functioning of the patients. Therefore, empowering families to acquire and apply the various strategies to improve their quality of life is of paramount importance. Key findings of a study conducted by Sharif, Shaygan and Mani (2012) shows that family psycho-education demonstrated positive effects in reduction of family burden and patient's symptoms immediately and one month after the intervention. Providing psycho-educational interventions and support groups and emphasizing the importance of family and cultural needs of the families can enhance their psycho-social health and reduce the patients' risk of re-hospitalization (Chien & Wong, 2010).

3.7.2 Peer support groups for families

Watson and Meddings (2019) explain that peer support refers to mutual support provided and received by people who have their own experiences of distress and recovery. Peer support services are intended to bring together people with similar life experiences, culture, living environments, social status, concerns, and daily challenges (Fan, Ma, Ma, Xu &Caine, 2018). Repper and Carter (2011) propose that peer support assumes that people who have similar experiences relate better and can therefore offer more reliable empathy and validation. Chan (2011) and Watson and Meddings (2019) report that mutual support groups were developed as a "self-help" organization for people with mental disorders and their families whose needs were not met by the mental health professionals, and they are based on an understanding of another's situation through the shared experience of emotional and psychological pain. Mutual support groups are "participatory and involve giving and receiving help and learning to help

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themselves, as well as sharing experiences and knowledge about common concerns" (Chan, 2011: 345). In mutual support groups, "the relationships peers have with each other are valued for their reciprocity; they give an opportunity for sharing experiences, both giving and receiving support and for building up a mutual and synergistic understanding that benefits both parties" (Repper & Carter, 2011: 394). Thus, it is mostly described as encouraging a wellness model that focuses on strengths and recovery, their positive aspects, and their ability to function effectively and supportively (Repper & Carter, 2011).

Family support groups promote mutual respect, allow the sharing of information and practical strategies, and are proven to assist people affected with schizophrenia and their families to lessen the occurrence of a relapse as well as to improve their compliance with treatment as prescribed by the medical practitioners (Asmal *et al.,* 2014; Fan *et al.,* 2018). Mutual support groups for families of persons with schizophrenia provide families with opportunities to develop knowledge and skills on caring for a relative with schizophrenia with peer support, creating a harmonious family life, and engaging professionals as collaborators instead of authoritative experts (Pekkala & Merinder, 2010).

3.8 CONCLUSION

In this Chapter, the Family Systems Theory was discussed in relation to building a theoretical understanding of the family caring for a family member diagnosed with schizophrenia. Knowledge of their experiences brings about understanding of the context in which these families live. Evidently, the occurrence of schizophrenia in the family has an influence on how the family functions as there is a need for changes to be made to the family system. Therefore, the Family Systems Theory was applicable in exploring the lived experiences of families living with a family member diagnosed with schizophrenia. Family centered interventions were discussed to better understand the social work interventions with families living with a relative

with schizophrenia. The presented interventions provided an evaluation on their effectiveness with families.

The next Chapter discusses the Methods used to achieve the objectives of this study.

CHAPTER 4

RESEARCH METHODOLOGY

4.1 INTRODUCTION

Research is an activity of systematic enquiry that seeks answers to a problem (Joubert, Ehrlich, Katzenellenbogen & Karim. 2010). Research can be understood as a process which begins with problem identification, followed by the formulation of research questions or objectives. Naidoo (2011: 47) describes that "in science, research is the diligent systematic enquiry into (the) nature and society to validate and refine existing knowledge and to generate new knowledge". The purposes of research include the exploration, description, and explanation of phenomenon (Igwenagu, 2016). In addition, the research methodology considers and explains the logic behind research methods and techniques (Welman, Kruger & Mitchell, 2005).

The researcher has provided an overview of the research methodology in Chapter One. This Chapter encompasses a detailed discussion of the application of the Research Methodology in this study. A qualitative researcher often begins with general research questions rather than with specific theories and will use inductive reasoning considerably [moving from the particular to the general] (Leedy & Ormrod, 2005 cited by Fouché & Delport in De Vos *et al.,* 2011). The Chapter will provide the research question for the study, goal and objectives, a detailed description of the research approach, research design, and strategy of inquiry as well as population and sampling techniques that were utilized. The Chapter will further provide a detailed discussion on how the data was collected and analyzed, as well as how the researcher maintained the trustworthiness of the study.

4.2 RESEARCH QUESTION

A research question is defined by Ritchie, Lewis, Nicholls and Ormston (2013) as a question that a research study/project sets out to answer. Defining the research question is a significant

step in research as it narrows the research aim and objectives down to specific areas on what will be learnt or questions to be answered in the study (Creswell, 2013; Doody & Baily, 2016).

Research questions are significant as they guide the researcher's choice of methodology, methods, sample, sample size, data collection instrument and data analysis techniques (Doody & Bailey, 2016). The researcher was interested in the lived experiences of family members living and caring for a family member diagnosed with schizophrenia, which resulted in the following research questions:

1. What are the experiences of families living with a family member diagnosed with schizophrenia

2. In which contexts do these experiences occur?

4.3 RESEARCH GOAL AND OBJECTIVES

The concept goal, aim and purpose are often used interchangeably. Research goals are general guidelines that explain what the researcher wants to achieve at the end of their study (Thomas & Hodges, 2010; Tully 2014). Research goals are broader, more abstract conception of something which is planned to happen or to be achieved (De Vos *et al.,* 2011). Doody and Bailey (2016) report that the research question, goal, and objectives must be inextricably linked. Therefore, the goal of the study originated from the research question to gain an in-depth understanding of the lived experiences of families living with a family member diagnosed with schizophrenia.

Research objectives refer to the detailed statements indicating the focus of a research project in order to achieve the goal (Thomas & Hodges, 2010). The research goal leads naturally to determining the objectives (Doody & Bailey, 2016). However, the research objectives are more specific than the research goal and they relate directly to the research question (Grove, Gray & Burns, 2014). Research objectives "should be stated using action verbs that can be evaluated

such as 'to describe', 'to identify', 'to measure' or 'to compare" (Doody & Bailey, 2016: 22). The objectives of this study were to:

- Explore the lived experiences of family members living with a family member diagnosed with schizophrenia.

- Give recommendations to the inter-disciplinary teams who are engaged in providing services to families and people diagnosed with schizophrenia

4.4 RESEARCH APPROACH

A research approach includes plans and procedures for research that includes the steps from broad assumptions to detailed methods of data collection, analysis, and interpretation (Mthembu, 2017). There are various approaches to research, which include qualitative, quantitative, and mixed method approaches. The researcher utilized a qualitative approach research due to the nature of the research question and to achieve the goal of the research. Qualitative research is a form of inquiry in which researchers make an interpretation of what they see, hear, and understand. The qualitative research approach is used when there is a matter that needs to be explored with the purpose of describing and understanding the phenomena from the participant's viewpoint (Fouché & Delport in de Vos *et al.,* 2012; Creswell, 2013). Human experiences, feelings, opinions, and their very existence are too complex to be presented and represented in numerical terms, therefore qualitative research seeks to provide us with an in-depth understanding and appreciation of how things became the way they are (Patton, 2002; Abdullahi, Senetal, Schalekamp, Amzat & Saliman, 2012). Therefore, qualitative research aims to understand, describe, and sometimes explain social phenomena 'from the inside' in several ways. This approach seeks to understand how people construct the world around them, the "why" and "how" to describe experiences, thoughts, and perceptions in depth and that offer rich insights (Luna & Price, 2012; Fouché & Delport in de Vos *et al.,* 2012*;* Flick, 2018).

The researcher decided to utilize a qualitative approach as it would contribute to an in-depth understanding of the lived experiences of families from their own viewpoint in living with a member diagnosed with schizophrenia. The researcher could potentially comprehend and interpret the "why" and "how" and understood how the families construct the situation when living with a family member diagnosed with schizophrenia. The chosen approach had a positive influence on the findings of the study given that the participants were given an opportunity to express their lived experiences about the phenomena in question. The researcher focused on understanding the meaning that participants attached to the problem, not the meaning that the researcher would bring to the research or writers from the literature (Creswell (2009).

The qualitative approach is exploratory and gathers data from small samples to enable an in-depth analysis (Abdullahi *et al.,* 2012). The researcher was interested in exploring the in-depth experiences of the participants about the phenomena under scrutiny; thus, the use of a qualitative approach allowed the researcher to obtain rich information.

4.5 RESEARCH DESIGN

Research design is defined by de Vaus (2011) as a "plan or strategy" that researchers need to follow before commencing with data collection. In addition, the purpose of research design "is to ensure that the evidence obtained enables us to answer the initial question as unambiguously as possible" (de Vaus, 2011:6). For this study, explorative and descriptive research designs were used. The researcher explored a phenomenon to learn more and obtain new knowledge to understand the participants who are living and taking care of a family member diagnosed with schizophrenia.

An exploratory research design aims to produce new knowledge about a relatively under-researched or emerging topic (Fouché & de Vos cited in de Vos *et al.*, 2011; Neuman, 2012;

D'Cruz & Jones, 2014). Problems are explored to provide insights into a phenomenon and focuses on the discovery of new ideas and thoughts (Babbie, 2010; Creswell, 2016).

The researcher wanted to give an in-depth picture of the lived experiences of family members living with a family member diagnosed with schizophrenia and therefore also utilized a descriptive research design. Descriptive research is interested in describing the characteristics of a particular individual or group (de Vaus, 2011). The aim of the descriptive design is to provide accurate information. Descriptive questions lead to more detailed understanding of the phenomena being studied (D'Cruz & Jones, 2014). Chapter Four (Findings Chapter), provides a detailed description of the lived experiences and contexts of the family members that were explored

4.6 STRATEGY OF INQUIRY: PHENOMENOLOGY

The researcher used a phenomenological strategy of enquiry. Phenomenology aims at the description of the lived world and consists of concepts and structures of the "lived experience" to give form and meaning to it (Fouché & Schurink cited in de Vos, *et al.,* 2011; Suter, 2012). Researchers are concerned with an understanding of social and psychological phenomena from the perspectives of the people involved and how they experienced it through interviews, stories or observations when using phenomenology as strategy of inquiry (Welman *et al.,* 2005; Connelly, 2010; Creswell, 2013). This strategy of inquiry focuses on the nature of the experience from the participant's point of view and the reason for using this strategy is to obtain a deeper appreciation and meaning of everyday experiences (Patton, 2002; Connelly, 2010; Ritchie *et al.,* 2013). Phenomenology was used to describe the core problem; therefore, this description consists of "what" and "how" they experience it.

Creswell (2016) emphasizes the following aspects in utilizing phenomenology as a strategy of inquiry:

- It focuses on the exploration of a single phenomenon (the experiences of families in living with a family member diagnosed with schizophrenia).

- Focuses on the exploration of the context in which the individuals experience the phenomenon, which is the context within the family structures in this research.

- The researcher brackets him/herself out of the to avoid bias, which the researcher has discussed in this Chapter 4 (Sections 4.7.4.3) and

- Reports on the essence of the experience by way of a rich, authentic, and detailed word picture, which will be done in the Findings Chapter (Chapter 5) of this research.

In conducting this phenomenological study, there were three procedures that the researcher needed to be aware of, that consisted of:

1) The bracketing of a researcher's own experiences about the phenomenon under study (Section 4.7.4: Trustworthiness).

2) Collecting data from participants who have first-hand experience about the phenomena being studied (Section 4.7.2 Data collection).

3) Analyzing the data, generating themes and sub-themes (Section4.7.3: Data Analysis and Chapter 5: Findings of the study) (Creswell, 2013). The researcher has obtained description of what the families' experiences while living with a relative diagnosed with schizophrenia, with quotations from the interviewees.

4.7 POPULATION OF THE STUDY

A population in research refers to an entire group of persons, objects or events with common, binding characteristics or trait (Neuman, 2012). Welman *et al.,* (2017:52) note that "population is the study object and consists of individuals, groups, organizations, human products and events, or the conditions to which they are exposed". Population can also be defined as the

"target group" and the full set of cases from which a sample is derived (Gentles, Charles, Ploeg, & McKibbon, 2015; Welman *et al.,* 2018).

Ritchie *et al.,* (2013) identify three key questions that the researcher needs to address in defining the population for the study:

- Which group or subpopulation is of central interest to the subject matter of the study? This includes deciding which population will be able to provide the richest and most relevant information. The family members living with a person diagnosed with schizophrenia were the population which could provide the richest and most relevant information in this research. These family members must have had their domicile in the Western Cape.

- Are there subsets of the central population that should be excluded? This might be because of specific circumstances or experiences for example, children or people who are terminally ill. The siblings of people with Schizophrenia should have been older than eighteen years and

- Are there additional groups or subpopulations that should be included because their views, experiences would bring a contrasting or some complementary insights to the enquiry? The researcher was interested in the family members with lived experiences and therefore excluded other groups from this research.

Therefore, the population for this research study consisted of 7 family members who are living with a family member diagnosed with schizophrenia.

4.8 SAMPLING

Sampling in research refers to the process of selecting participants from the population to take part in the research to study the phenomenon under investigation (Neuman, 2012). The purpose of sampling is to collect cases, events or actions that will enhance the researcher's understanding about the phenomenon under investigation (Bradshaw Atkinson & Doody, 2017). When sampling strategies for social research are described, a key distinction is made

between probability and non-probability samples (Ritchie *et al.,* 2013). Qualitative studies employ non-probability sampling, which means that "researchers rarely determine the sample size in advance and have limited knowledge about the larger group or population from which the sample is taken from" (Neuman, 2012: 141). The sampling process best able to achieve this within qualitative studies and in particular qualitative description designs is the convenience or purposive sampling (Parahoo, 2014). Qualitative inquiry focuses on depth in relatively small samples because of the emphasis in intensive contact with participants, and the findings are not to be applied in other contexts (Patton, 2002; Creswell, 2016).

Non-probability (purposive) sampling was undertaken in this study as it purposely selected participants who assisted the researcher in discovering, understanding, and gaining knowledge into the research problem. Phenomenological research uses "purposive sampling to identify participants who can explain the phenomena of interest and can describe or communicate their experience. Hess-Biber & Leavy (2011) identifies 16 different types of purposive samples, however, for this research, voluntary and snowball sampling were employed. Snowball sampling, also known as chain referral sampling, is utilized when the researcher is experiencing difficulties in accessing subjects who meet the sampling criteria (Johnson, 2014; Naderifar *et al.,* 2017; Sharma, 2017). In this sampling strategy, "the researcher asks the first few samples, who are usually selected via convenience sampling, if they know anyone with similar views or situations to take part in the research" (Naderifar *et al.,* 2017: 2). Snowball sampling is regarded as efficient as compared to other sampling strategies (Sadler, Lee, Lim & Fullerton, 2010). Participants for this study were purposefully selected from a support group of parents and siblings of family members diagnosed with schizophrenia residing in the Western Cape.

The following criteria were identified for the selection of participants:

- Participants had to have experienced the central phenomenon under investigation, therefore the participants had to be parents, siblings or a family member living and caring for a family member diagnosed with schizophrenia.

- Male and females could be included from all racial groups who lived within the proximity of the Western Cape.

- Participants had to be 18 years of age or older and had to give an informed consent for the interviews.

The selection of participants was done with the assistance and permission of a Local Support Group in the Western Cape. The Local Support Group provides support to families of persons with schizophrenia. A letter of intent was given to the facilitator of the support group about the research as well as explaining the aims and objectives of the research (Appendix B). The researcher was provided with the opportunity to engage in a meeting with these family members where she introduced the research project.

The prospective participants were informed of the research explaining confidentiality and making a request to family members to volunteer to be interviewed (Appendix C) and explained what consent meant (Appendix D). There was a positive response to the members of the support group where some family members agreed to participate voluntarily in the study and some members recommended other parents whom they knew who would meet the criteria of the study.

4.9 METHODS OF DATA COLLECTION

Bradshaw, Atkinson & Doody (2017) state that data collection involves the use of data to understand and explain the phenomenon. Flick (2018:18) proclaims that "the major aim of collecting qualitative data is to provide materials for an empirical analysis of a phenomenon that a study is about". Colorafi and Evans in Bradshaw *et al.* 2017) propose that data collection

methods in qualitative research include interviews, focus groups, observation, or document review.

4.9.1 In-depth individual interviews

Qualitative interviews can be semi-structured or unstructured. Unstructured interviews are interested in understanding the experiences of people and the meaning they make out of that experience (Greef in de Vos *et al.*, 2012). Unstructured interviews are discursive and allow the researcher and participants to explore an issue at hand. In semi-structured interviews, the researcher is interested in gaining a detailed picture of a participant's beliefs or perceptions on a particular topic. The researcher has a set of predetermined questions on an interview schedule, but the interview will be guided by the participants (Greef in de Vos *et al.*, 2012).

Phenomenology explores how human beings make sense of what they experience and to gather such data one needs to conduct in-depth interviews with people who have experienced the phenomenon directly; that is, they have "lived experiences" as opposed to second-hand experience (Patton, 2002). In-depth interviews allow a deeper and lengthier conversation between the interviewer and the interviewee (Abdullahi *et al.*, 2012). In-depth interviews generally cover the duration of thirty minutes to more than an hour (Jamshed, 2014).

The researcher made use of in-depth interviews as a tool of unstructured interviews in this phenomenology study (Neuman, 2012). This assisted the researcher to understand the lived experiences of family members living with a family member diagnosed with schizophrenia. The use of an in-depth interview is highly desirable for obtaining information based on emotions, feelings, experiences, sensitive issues, and insider experience, privileged insights, and experiences (Dilshad & Latif, 2013).

4.9.2 Preparation of participants for an interview

Participants need to be prepared for unstructured interviews Greeff (in de Vos *et al.,* 2012). A list of potential names was provided to the researcher from the support group facilitator. Each participant was contacted telephonically, informing them of the research, and after consenting verbally, the participants decided upon the time and venue for the proposed interview.

Some of the interviews were conducted in the participant's home, and in places that were chosen by the participants because participants' felt safe and comfortable, such as coffee shops. The environment in which the interviews were held needed to be quiet to avoid disturbances and to have clear recordings (Kelly in Terre Blanche *et al.,* 2006). The interview should be conducted in a place that provides privacy, comfortable and that is easily accessible (Greeff in de Vos *et al.,* 2012).

4.9.3 Starting the interviews

The interview started with the researcher introducing herself (name and University) and the purpose of the study which is to the to explore and describe the lived experiences of families living with a family member diagnosed with schizophrenia as well as the context in which they experienced it and to provide the possible recommendations for social work intervention for family members living and caring for family members diagnosed with schizophrenia (Appendix C). Participants were also informed that their participation was voluntary and that their consent to participate in the research would be required. Participants were also informed about the ethical considerations around the research and what they entailed. This explanation provided the participants some idea of what the study entails and the process of the interview, with the view of making the participants more comfortable with the interview process.

The researcher also discussed the information sheet (Appendix C) with the participants where an explanation was given on how the interview will be conducted, the approximate time required, confidentiality was explained and the participants' consent to record the interview

was discussed. The participants were then given time to read the information sheet and sign the consent form (Appendix D) to indicate that they were willing to participate in the research.

Establishing rapport before the interview was important as has a positive effect on the interview process. Building good rapport with the participants opens many doors for the researcher and leads to the collection of valuable information (Welman *et al.*, 2005). Rapport can be achieved by listening attentively, showing interest, understanding and respect for what the participant says (Greeff in de Vos *et al.,* 2012). All the participants felt comfortable to conduct the interviews in English which allowed for participants self-expression of their phenomena and the researcher did not want to use any interpreters, as this could possibly dillute the meaning expressed by the participants. The researcher interviewed the participants until data saturation was reached, and no new information was obtained during the interviews. Data saturation refers to a point in the data collection process where there is no new information is further attained and when further coding is no longer feasible (Fusch & Ness, 2015).

In addition, interviewing skills are important, especially in phenomenological research where only two questions are asked and the researcher wants rich information on lived experiences, such as in this study. Likewise, establishing rapport is an important factor to collect rich data and information. in de Vos *et al.,* 2012).

Interviewing skills used during data gathering

The quality of an interview depends largely on the skills of the researcher as an interviewer. The researcher should be able to create a conversation with an interviewee, not a question-and-answer session (Kelly in Terre Blanche *et al.,* 2006). The following skills are beneficial during the interview:

i.   *Appearance and demeanour of the interviewer*: The way in which the researcher dresses should represent the respondents he/she wishes to interview. Interviewers should be

pleasant and need to be genuine in their intentions (Jarbandhan & De Wet, 2006). The researcher dressed professionally but in such a manner that the participants did not feel uncomfortable in their own environment.

ii. *Recording responses accurately*: The interviewer should record the information in an accurate manner, and no attempt should be made to rephrase, summarize, or correct grammatical errors (Jarbandhan & De Wet, 2006). With the permission of the participants, the researcher recorded the interviews and used the recordings to assist with the transcribing of the interviews as the participants provided them. This assisted with the data analysis and findings of the research.

iii. *Open-ended questioning and probing:*. Researchers engaged in phenomenological study should not decide based on predetermined questions but should formulate questions/probes based on the cues and information shared by the participants (Chan, Fung & Chien, 2013). During this research, the researcher started with a main question: Tell me how it is to live with a family member with schizophrenia in the house? The participant explained specific experiences living with a family member and the researcher then asked questions about the context in which these experiences occur.

Probing includes the application of other interviewing techniques to seek elaboration of a participant's response. The researcher should probe when the respondent has provided incomplete or irrelevant responses (David, 2011). Probing questions should only be asked when the participant has become comfortable with the interview (Kelly cited in Terre Blanche, Durrheim & Painter, 2006). Probing was done when the researcher wanted to elicit more information from the points made by the participants. The researcher asked probing questions such as: What contexts or situations have typically influenced or affected your experiences of the phenomenon? When the participant explains an experience for example that the person gets angry and destructive, the researcher would ask for example: What happens when the person gets angry? What are the

reasons why the person gets angry? The researcher clarified and summarized answers during the interviews as the researcher wanted to be clear on some of the responses (De Vos *et al.,* 2005).

iv. *Listening skills and non-verbal behaviour:* When conducting interviews, the researcher needs to be aware his/her own and participant's body language (Kelly in Terre Blanche *et al.,* 2006). The researcher too made use of silence as it helped participants to reflect on their own words, to ensure that she listened more to what the participant was saying and talking less during this research as well as probing contributed to this. The effective use of silence was seen as positive since it led participants to contemplate on their responses.

Ending an interview

The researcher should "ask the participant if there is anything more that they have to say" at the end of the interview (Kelly in Terre Blanche *et al.,* 2006: 301). In ending the interviews with participants, the researcher allowed the participants to ask questions if they had any and explained that the researcher would make contact again after transcribing the interviews so that the participants could verify the information. The researcher also informed the participants that a social worker would be available should participants need to debrief after the interview. The participants were also reminded about confidentiality in that all information recorded and written would be handled and stored away confidentially. The researcher expressed words of gratitude to the participants for participating in her research. The researcher then thanked the participants for their time, stored the tape recorder in a safe place and had written process notes as reflexivity and bracketing measures.
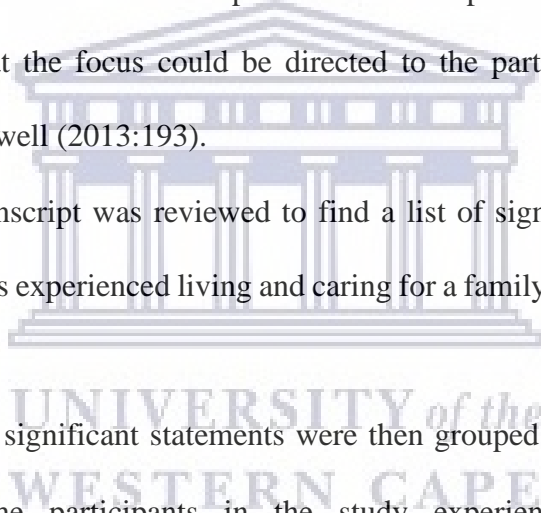
4.10 DATA ANALYSIS

Data analysis is a process of converting large amounts of data collected into themes and patterns to make sense out of it (Kalawuchi, 2004). Neuman (2012) notes that there is no single approach in analyzing qualitative data that is acceptable. Qualitative data analysis generally

follows an inductive approach in the sense that explicit theories are not exposed to the data, rather the data is allowed to "speak for themselves" by the occurrence of conceptual categories and themes (Suter, 2012).

As discussed briefly in Chapter One (Section 1.9.6) of this study, data was analyzed using the phenomenological analysis. Phenomenological analysis uses a specific data analysis, which was followed by the researcher during this research process as described by Creswell (2013:193).

- Firstly, the researcher began with a "description of his own experience of the phenomenon". The researcher had to put aside her own personal experiences about the phenomena, so that the focus could be directed to the participants in this study as articulated by Creswell (2013:193).

- Secondly, each transcript was reviewed to find a list of significant statements about how the participants experienced living and caring for a family member diagnosed with schizophrenia.

- Thirdly, the list of significant statements were then grouped thematically together to describe "what" the participants in the study experienced and "how" they experienced it.

- Fourthly, a detailed description was provided of what the participants in the study experienced and how they experienced it was provided. This is called the "textural description" (what happened) where verbatim examples were compared and contrasted with existing literature.

- Fifthly, a compound description that presented the essence of what the participants experienced and how they experienced it was compiled, while comparing and contrasting the findings to the respective existing literature (Chapter 5).

An independent coder was used in the analysis of the data. The independent coder used the same measure of analysis as those stated above, which contributed to the rich data and trustworthiness of this study.

The presentation of the findings of the data will be follow in the subsequent Chapter (see Chapter 5) where the researcher presented the themes and sub-themes in a table format.

4.11 DATA VERIFICATION AND TRUSTWORTHINESS

Numerous strategies have been developed to evaluate the trustworthiness of qualitative data. These strategies include credibility, transferability, dependability, and confirmability (Guba & Lincoln in Baxter & Jack, 2010).

The methods of trustworthiness used during this research are indicated in table 4.1

Table 4.1: Trustworthiness implemented during the research

STRATEGY	CRITERIA	APPLICATION
Credibility	Prolonged and varied field experience	The researcher spent time with the support group before conducting interviews.
	Reflexivity	Field notes were taken.
	Triangulation	Different sources include multiple copies of interviews that the researcher used from verbatim recordings.
	Member checking	The researcher ensured that the information she had was a true reflection of the participants' experiences. Feedback of the findings was also communicated to the participants.
Transferability	Thick description	This is a complete description of methodology, verbatim transcriptions of interviews and literature control of findings.

	Dependability audit	The respondents verified results of data analysis and confirmed data and summarizing at the end of the interview.
Dependability	Thick description	Research methodology in detailed description.
	Code-recode procedure	Data analysis was done and discussions with the Supervisor and Co-supervisor followed for consensus.
Confirmability	Triangulation	Multiple copies of interviews, literature control, direct quotes in findings.
	Reflexivity	Reflexivity and field notes during research. Bracketing in phenomenology.
	Member checking	The content of the interviews and findings were discussed with the participants.

4.11.1 Credibility

Credibility refers to the "truth value" of the data or the views of participants and their interpretation and representation by the researcher (Baxter & Jack, 2010; Polit & Beck, 2012). The credibility of data can be enhanced by having "prolonged engagement" with the participants in their contexts so that rapport and trust with the participants can be built, while learning more about their cultures (Baxter & Jack, 2010; Creswell, 2013). Cope (2014:89) notes that to "support credibility when reporting a qualitative study, the researcher should demonstrate engagement, methods of observation, and to audit trails".

The researcher planned to audio-record the interviews, to take some field notes, and to make observations during the interviews. The researcher did a persistent observation- that is paying attention to the participant's non-verbal behaviors so as to provide depth to the study (Cope,

2014). Interviews were done until data saturation was reached. The data collection process was followed by the process of interview transcriptions and member checking was done with the participants. Member checking is done to determine the accuracy of the findings through taking the final report or transcripts back to participants and determining whether these participants feel that they are accurate (Creswell, 2016).

4.11.2 Transferability

Sutton & Austin (2015) state that transferability in qualitative research refers to what extent the findings of the study can be transferred to other contexts and participants. Moreover, transferability of a study is attained when the study under investigation has produced enough information to provide evidence of the participant's experiences (Cope, 2014). Transferability is possible when the context in which the research is conducted has similar characteristics with another context where some knowledge could be transferred (D'Cruz & Jones, 2014).

The researcher utilized two strategies, namely, verbatim transcriptions of the interviews and literature control to substantiate the direct quotes from the participants.

4.11.3 Dependability

D'Cruz & Jones (2014) explain that dependability is the substitute concept to reliability which is related to replicability of research. In qualitative research, a study would be considered dependable if the study findings were replicated with similar participants in similar conditions (Cope, 2014). A qualitative researcher can use inquiry audit in order to establish dependability, which involves an outside person to review and examine the research process and the data analysis in order to ensure that the findings are consistent and could be repeated (Schurink *et al* cited in de Vos *et al.,* 2011 and Guba *et al.* 2010). The dependability of the study was achieved through a dependability audit where the participants verified the results of data analysis and confirmed data and summarizing at the end of the interview.

4.11.4 Confirmability

To achieve confirmability, the researcher has to ensure that he/she report on what the participants said during the data collection process. The research must remain objective. "Confirmability refers to the researcher's ability to demonstrate that data represent the participants' responses and not the researcher's biases or viewpoints" (Cope, 2014:89). Confirmability of the data can be achieved by providing direct quotes from the transcribed interviews and descriptions of the participant's demographics (Cope, 2014; Bradshaw *et al,* 2017). The researcher utilized the member-checking process to verify the accuracy of the data and to ensure that she report on the information provided by participants was not biased by the researcher (Bradshaw et al, 2017). The researcher also recorded some notes on a journal to confirm the data provided by the participants (Baxter & Jack, 2010). The researcher also made use of an independent researcher who did the data analysis with the researcher which also contributed to confirmability, as well as reflexivity and bracketing.

4.11.5 Reflexivity and bracketing

Cope (2014) explains that reflexivity in qualitative research refers to the researcher's awareness that the researcher's values, background, and experience with the phenomenon under investigation can affect the research process. Patton (2002: 64) proclaims that "being reflexive involves self-questioning and self-understanding". In qualitative research, researchers are the "key instruments", therefore they must avoid being biased in the process (Cope, 2014). According to May & Perry (2014:109), introducing a reflexive practice into qualitative research enables both an examination of the grounds upon which claims to know the social world are based and an exploration of the strengths and limitations of forms of knowledge. Patton (2002: 66) has posed the following questions during the process of reflexivity. The researcher should reflect on: "How participants know what they know? What shapes and has shaped their

worldview? How they perceive me? Why? How do I know? How do I perceive them?" The following questions should be asked about those who receive the study (audience): "How do they make sense of what I give them? What perspectives do they bring to the findings I offer? How do they perceive me? How do I perceive them?" The researcher should ask the following questions as a qualitative researcher: "What do I know? How do I know what I know? What shapes and has shaped my perspective? With what voice do I share my perspective? What do I do with what I have found?"

The researcher too, used a reflexive journal to reflect and note thoughts and feelings to bracket perceptions and subjectivity while ensuring reflexivity and bracketing (Baxter & Jack, 2010).

Chan *et al.* (2013: 305) note that "bracketing is a methodological device of phenomenological inquiry that requires (a) deliberate putting aside (of) one's own belief about the phenomenon under investigation or what one already knows about the subject prior to and throughout the phenomenological investigation". In phenomenological studies, researchers put aside their experiences and take a fresh perspective on the phenomena under investigation (Creswell, 2013). Through the strategy of bracketing, the researcher's experiences about the phenomenon does not influence the participants' understanding of the phenomenon under investigation. Bracketing was especially important for the researcher because she has previously worked within a psychiatric facility as a social work student. She had to ensure that her experiences and Social Work training would become handy in the research.

Reflexivity and bracketing were also of utmost importance for the researcher because participants were from different racial, cultural, and socio-economic backgrounds, which influenced their lived experiences. The researcher is Xhosa speaking, a woman and is undertaking her tertiary education and has also practiced work-related education in a psychiatric facility in her fourth year as a Social Work student. She therefore had to reflect on

her own beliefs, experiences, and perceptions and how these would potentially influence the research.

4.12 CONCLUSION

This Chapter discussed a Methodology that was followed for this study. A qualitative research approach was successfully implemented to help the researcher understand the lived experienced of family members living with a family member with schizophrenia. In-depth and rich information was obtained from the participants which was analyzed to make sense of data that was collected from in-depth interviews using phenomenological questions. The methods that were used in this study allowed the participants to freely discuss and explain their experiences of living with a family member diagnosed with schizophrenia. The trustworthiness of the study was determined, and the researcher utilized reflexivity and bracketing to effectively strengthen the study.

The following Chapter will discuss the Findings of this study.

CHAPTER 5

PRESENTATION AND DISCUSSION OF THE FINDINGS

5.1 INTRODUCTION

The preceding Chapter provided a lucid and intelligible portrayal of how the research methodology was implemented. A qualitative approach with a phenomenological strategy of inquiry to achieve the first objective of this research: To explore the lived experiences and the context in which the lived experiences of family members living with a person diagnosed with schizophrenia. In this Chapter, the reader will discuss the findings of the data that emanated from the data analysis. The research findings are presented in relation to the study objectives which are:

- To explore the lived experiences of family members living with a family member diagnosed with schizophrenia.

- To give recommendations to the inter-disciplinary team in providing services to families and people diagnosed with schizophrenia.

Phenomenological data analysis was employed as described in the Research Methodology Chapter. The "what" is being explained as experienced by the participants, and verbatim descriptions are provided, followed by "how" the experiences happened, are the focus of this Chapter.

There were seven female participants who participated in this study, over the age of eighteen years. At the time of data collection, all the participants indicated that they were assuming the caregiver responsibilities. All participants in this study had been living and providing care to a relative diagnosed with schizophrenia for more than seven years. The identifying details of the participants were protected by referring to them as "Participant A or Participant B".

In the study, there were seven themes identified with eighteen sub-themes. In the following section the demographic profiles of the participants are presented.

5.2 DEMOGRAPHIC PROFILES OF PARTICIPANTS

The demographic details of the family members who participated in the study are presented in Table 4.1. The term "demographic" as noted by Lee and Schuele (2010) refers to characteristics of a population. This demographic information includes data such as race, gender, age, marital status, level of education, and is necessary for the determination of whether the individuals in a particular study are representative of the target population for the purpose of generalization (Lee & Schuele, 2010: 347). Allmark (2004) proclaims that representation of diversity in qualitative research is vital to ensure that samples from different backgrounds (age, race, and gender) are represented and can benefit from the study. The profiles provided important data about the participants in the study, namely gender, age, level of education, years spent in caring for the family member with schizophrenia, as well as the relationship to the family member.

Table 5.1 provides the following variables of the participants: age, language, level of education, relationship to family members and years of experience caring for a person diagnosed with schizophrenia.

Table 5.1: Demographic details of participants

Participant	Area of residence	Home language	Gender	Age	Level of education	Relationship to the family member	Years' experience caring for the family member
A	Claremont	English	Female	75	College	Mother	10
B	Rondebosch	English	Female	65	Postgraduate	Mother	21
C	Mfuleni	isiXhosa	Female	33	Grade 11	Sister	10
D	Cape Town	English	Female	57	High school	Mother	27
E	Mfuleni	isiXhosa	Female	64	Grade 8	Mother	16
F	Khayelitsha	isiXhosa	Female	35	Grade 12	Mother	22
G	Claremont	English	Female	64	Degree	Mother	7

5.2.1 Age and gender

The participants who participated in this research were all females older than 30 years of age. All the participants were mothers to the patients, except for one who was a sibling taking care of her brother. The researcher could not find men to participate in the study as most of the families' primary caregivers were females. This could be due to the lack of research on the experiences of men as caregivers of relatives with schizophrenia and due to several societal and cultural demands, where women are mainly the providers of informal care for their relatives with schizophrenia and other serious mental illnesses. (Sharma *et al.,* 2016).

5.2.2 Area of residence

As discussed in the Literature Review Chapter (section 1.2.1), schizophrenia is prevalent in low and high socio-economic backgrounds. The sample size of participants came from diverse areas of residence and socio-economic backgrounds. Diversity in research is essential for the reporting of findings, generalization of study results, and prevents some populations receiving more benefits from the study (University of California San Francisco, 2021).

5.2.3 Language

The language spoken by four of the participants who took part in the study was English. Three of the participants' home language was IsiXhosa.

5.2.4 Level of education

Two of the participants acquired university education, while one parent acquired college education. Two of the parents matriculated, and two had left school without passing matric.

5.2.5 Years of caring for a person diagnosed with schizophrenia

Most of the participants had more than 10 years' experience of living and caring for a relative with schizophrenia. Three parents had between 20-27 years of experience while one parent had 16 years' experience. The other 2 parents had an experience of 7-10 years living and caring of a family member diagnosed with schizophrenia.

Participants in the study constituted a heterogeneous group in terms of age, household, relationships, educational and socio-economic profiles. The group united around a common phenomenon of experiences relating to living with a family member who is diagnosed with schizophrenia. Although there were some general experiences of caring for a relative with schizophrenia, there were also diverse experiences. The experiences of these family members living with a family member diagnosed with schizophrenia, will be presented in the following section of the research report.

5.3 PRESENTATION OF FINDINGS: KEY THEMES AND SUB-THEMES

In this section, the researcher will discuss the themes and sub-themes that emerged from the data analysis to respond to the research aim and objectives. The main focus of this research was on the experiences of families living with a family member diagnosed with schizophrenia. There were seven main themes that emerged from the data analysis and seventeen sub-themes. The themes will be supported by quotes from the participants as well as the existing literature to substantiate the sub-themes. The following Table 4.2 reflects the themes and sub-themes that emerged from the data analysis.

Table 5.2: Themes and sub-themes

Themes	Sub-themes
Theme 1: Participant's experiences of the physical aspects of schizophrenia	**1.1:** Experiences about the influence of the family members illness on participants' health. **1.2**: Experiences of participants with regards to the effectiveness of psychiatric medication. **1.3:** Experiences of participants during relative's psychotic episodes.

	1.4: Experiences of participants on relative's adherence and non-adherence to treatment
	1.5: Experiences of participants on the use and abuse of substances by relative.
Theme 2: Participants experiences of the psychological effects of the illness	**2.1:** Experiences of stress when living and caring for a relative with schizophrenia.
	2.2 Experiences of participants regarding the burden of care on their psychological well-being.
	2.3 Experiences of uncertainty on future care for the relative with schizophrenia.
	2.4 Experiences of acceptance of the relative having schizophrenia.
Theme 3: Religion as a coping mechanism for participants	
Theme 4: Experiences of participants on the behavior of the relative with schizophrenia	**4.1:** Experiences of aggressive behavior by the relative and the influence on safety of the relative and others.
	4.2: Experiences of participants on personal hygiene by the relative with schizophrenia.
Theme 5: Experiences of participants on interpersonal relationships	**5.1** Experiences of participants on the relative's ability to develop relationships.
	5.2: Experiences of participants on the family functioning with a member diagnosed with schizophrenia.

	5.3: Influence of relative's illness on friendships and social activities of family members.
	5.4: Experiences of social support networks available to participants and the relative with schizophrenia.
Theme 6: Misconceptions about schizophrenia leading to stigmatization	
Theme 7: Influence of living with a relative with schizophrenia on socio-economic circumstances	**7.1:** Employment opportunities for persons with schizophrenia. **7.2:** Influence of the illness on employment of family members. **7.3:** Financial burden of the illness.

5.3.1 THEME 1: PARTICIPANTS EXPERIENCES OF THE PHYSICAL ASPECTS OF SCHIZOPHRENIA

In this theme, what emerged was the participant's experiences of physical aspects of schizophrenia when taking care of a family member diagnosed with schizophrenia. In Chapter 2 (section 2.3.1 and 2.3.2), the Literature Review indicated that taking care of a family member with schizophrenia causes both objective and subjective burdens to other family members. The literature reviewed showed that living with and caring for a family member with schizophrenia has consequences on the caregiver's health, their sleeping pattern, families are at high risk of developing stress and changes in household duties, and suffering abuse (verbally and physically) by the relative diagnosed with schizophrenia (Lippi, 2016; Galderisi *et al.,* 2014).

Under this theme, numerous sub-themes emerged, namely experiences of family members health, experiences with regards to the effectiveness of medical health medical treatment,

experiences on relative's behavior, experiences on adherence and non-adherence to medical treatment, and the use and abuse of substances by the relative with schizophrenia.

The researcher will discuss these sub-themes under the guidance of the participants' narratives.

5.3.1.1 *Sub-theme 1.1: Experiences about the influence of the family members' illness on participants' health*

Families living and caring for family members with schizophrenia reported that they experienced problems with their own physical health when living with a family member diagnosed with schizophrenia (Pearson, 2015; Brain, Kymes, DiBenedetti, Brevig & Velligan, 2018). Living and caring for such a family member takes a considerable toll on the family members who put their own health at risk (Fekadu *et al.,* 2019). A study conducted by Flyckt, Löthman, Jörgensen, Rylander & Koernig (2013) shows that family members/caregivers spend about half of their week on care-related activities when caring for a family member diagnosed with a mental illness Therefore, it could be assumed that by taking on these caring responsibilities, the participants' health could be affected. The following statements were shared by the participants to highlight their experiences living with a relative with schizophrenia and how it affected their general health particularly affecting their high blood pressure:

Participant C: "I remember very well when he got sick, that affected my high blood pressure and I got admitted to hospital. It is difficult shame."

Participant E: "It was very difficult for me in my health. I have high blood pressure; I sometimes see that it is very high with him. I have to take care of my health".

Furthermore, participants of this study also shared their experiences on how living and caring for a relative with schizophrenia has influenced their sleeping patterns. The following statements were shared by the participants in this regard:

Participant B: "So he's awake all night and I couldn't sleep while he's pacing up all night".

Participant C: "Sometimes he stays up all night and wake up during the night and leave the house, I can't sleep".

Added to the feeling of these unpredicted behaviors and exhaustion, providing care to the relative with schizophrenia can result in the caregivers having little to no time to attend to their own needs and to self-care as their care is centered and focused on the family member who is diagnosed with schizophrenia (Ntsayagae, Poggenpoel & Myburgh, 2019; Sharif, Basri, Alsahafi, Altaylouni, Albugumi, Banakhar, Mahsoon, Alasmee & Wright, 2020). One of the participants shared her experience on how living with and caring for a relative with schizophrenia has resulted in her neglect of herself:

Participant D: "And the one thing that I have learnt from all of this and I'm never used to make time for myself".

From the above statements, it is clear from participant's experiences that living and caring for a family member diagnosed with schizophrenia has an influence on the health of family members. Also, the experiences shared by the participants concur with the literature by Mitsonis *et al.,* (2012) that living and caring for a relative with schizophrenia has severe consequences on the health of primary caregivers. The consequences for the person caring for them can be those of an experience of a burnout, loss of energy and time to care for themselves.

5.3.1.2 Sub-theme 1.2: Experiences of participants with regards to the effectiveness of psychiatric medication

Psychiatric medical treatment is critical in the management of mental illnesses (Saha, Sugar, Torous, Abrahao, Kıcıman, & De Choudhury, 2019). Depending on the prevalence of their use, psychiatric medications can either relieve or aggravate the mental illness burden at both personal and societal levels (Rosenblat, Kakar, & McIntyre, 2016). In addition, the use of psychiatric medication is only worthy if the benefits are greater than their side effects (Moncrieff, Cohen & Porter, 2013). The use of prescribed anti-psychotics can help in

preventing a relapse and helping minimize the cravings and maintaining abstinence from addictive drugs (Behavioural Health Evolution, 2016).

Individuals have different subjective responses to the prescribed psychiatric medication. The participants of this study referred to medication and medical treatment as they shared their experiences on how their relatives with schizophrenia responded positively to the prescribed medications which alleviate some of their stress and their comments were:

Participant A: "...but I mean actually he has improved quite a lot. He has never been good as he is now on the medication".

Participant B: "Umh he doesn't suffer from disorder thinking now that he is on treatment (medication) that helps him a lot. He can live a fairly normal life".

Participant C: "I can say the treatment (medication) is somehow working"

Participant D: "there are days he's not good, but then there are days when he's good. Ever since he is on meds it's become a bit easy"

Participant E: "... now he is better now that he is taking treatment (medication). Since he got back, others do say that he is better"

From the above quotes made by the participants, it is clear that prescribed psychiatric medication is helpful in alleviating the symptoms of the illness. When taken as prescribed, it seems that participants experience a more satisfying life and experience less symptoms as compared to when they are not on medication. This is supported by the National Institute of Mental health (2021) that psychiatric medication or antipsychotics can prove to be effective in alleviating the severe symptoms. The experiences shared by participants on the effectiveness of medication concurs with the literature reviewed in Chapter 2 (Section 2.3.1.4) that revealed that adherence to medication and positive support assists in successful recovery and may add to the relief of family members living and caring for them.

However, the following sub-themes present contrasting views on how families experience their family members diagnosed with schizophrenia when they are having psychotic episodes or when they do not adhere to their prescribed medication.

5.3.1.3 Sub-theme 1.3: Experiences of participants during relative's psychotic episodes

As discussed in Chapter 2 (Section 2.2), schizophrenia is a psychotic illness that is characterized by symptoms such as delusions and hallucinations (Brain *et al.,* 2018). Delusions are defined by SADAG (n.d) as "firmly held beliefs that you hold with complete conviction although they are based on distortions or exaggerations of reasoning and/or misunderstandings of situations or events". Hallucinations entails seeing, hearing, or feeling things that do not exist. To highlight the experiences of delusions, the following statements were shared by two of the participants:

Participant D: "Paranoia was the next thing so he then believed that everybody at the college was talking about him…he started having delusions and he had like major delusions".

Participant E: "He would slap people because he believes they are talking about him".

In addition to having episodes of delusions, relatives diagnosed with schizophrenia were also very demanding in their behavior. One of the participants shared her experience of her brother's demanding and disruptive behavior. The participant highlighted that:

Participant C: "If you give him food that he does not want he will throw it at you, … if he asks for money and we don't have it he will get angry and kick things around the house. He must get everything that he want".

The participant further stated that her family member diagnosed with schizophrenia will sometimes hallucinate and imagine that he is seeing animals, or he will take off his clothes causing community members to label him as a rapist due to his troublesome behavior:

Participant C: "we have wounds because of him. When he sees a baby, he would throw them away, claiming that he is seeing a dog. Even now he is saying that we are snakes, frogs. When he comes to the house and finds you eating, he can just grab your food. And he do the same thing on the streets. He used to take off his clothes in the street and come back home without any clothes. He was found naked and he was talking to kids, so that's why people said he is a rapist. He can smash kids and throw them outside. Sometimes he even takes the new clothes that we bought him and throw them in the bin".

The experience shared by this participant concurs with the literature discussed in chapter 2 (Section 2.3.1.4) that revealed that families living with a family member diagnosed with schizophrenia reported troublesome behavior such as physical aggression and violence due to the delusions (Ndetei *et al.,* 2009; Monyaluoe *et al.,* 2014; Lippi, 2016). Hallucinations and delusions are most common symptoms of schizophrenia (Mhaule & Ntswane-Lebang, 2012).

5.3.1.4 Sub-theme 1.4: The experiences of participants on family members' adherence and non-adherence to medication

Non-adherence to medication comprises a range of patient behaviors, from refusal of medication to irregular use or partial change of daily medicinal doses (Higashi *et al.,* 2013). Non-adherence to medication may be due to various factors that affect a relative with schizophrenia. For participants, the caregiving role would include monitoring and administering the patient's medication, observing signs of any relapse, and their mental state (Ntsayagae *et al., 2019*) to see that family members, adhere to and take their medication. The participants of this study experienced how their family members have been resistant to taking medication resulting in a relapse or re-hospitalization.

The following statements were shared by the participants of their experiences regarding the family member's non-adherence to medication causing them to become sick:

Participant A: "...he has been quite ill for some time but he refused to be on treatment medication".

Participant D: "...he was very much treatment resistant to medication ... because he doesn't really like taking tablets and stuff.

Participant E: "... after some time he stopped taking the treatment".

Participant G: "Over the years he has been on and off medication. He gets very bad when he gets off medication. He just said he is not going to take medication and when we could see he is becoming very paranoid".

The above quotations from the participants correspond with the literature reviewed in Chapter 2 (section 2.3.1.4) that family members diagnosed with schizophrenia may not adhere to medication, refuse to go to the hospital for follow-up appointments, or decide to stop taking their medication. Moreover, non-adherence to medication might be possibly caused by poor insight into the illness, denial of the illness, being afraid of been stigmatized, lack of social support, and involuntary admission as stated by Higashi *et al.,* (2013). The following statements by participants are indicative of the family member's poor insight into their illness and denial of having the illness:

Participant A: "Well he didn't believe he was ill. He didn't want to believe he was ill, so you know if you admit to medication then you're ill"

Participant D: ". And then he was hospitalized, but involuntarily because he was very much medication resistant. He does not have an insight in terms of... he still says today he does not have mental illness.

It can be observed from the above statements that often people suffering from schizophrenia find it difficult to accept that they have the illness, they refuse to take their medication which can then leave the primary caregiver with the responsibility of reminding them to take their medication. The involuntary admission and relapse may also be an indication that the relative

with schizophrenia does not have any insight and knowledge on the illness and the medication. In some instances, the person may stop taking the medication because they feel better- which may lead them to believing that the medication is no longer needed (Behavioural Health Evolution, 2016).

In contrast to the above statements, one participant had a positive experience whereby the family member adhered to their medication through family support, making sure that he was taking his medication on time: The participant mentioned that:

Participant C: "He was discharged after three months and he was taking his treatment (medication) and he stayed with us. We are taking his treatment (medication) from the clinic and he goes for check-up there. ...before he leaves in the morning, he calls my brother to give him his treatment (medication). And he comes home in the evening and take his treatment (medication)".

The literature reviewed in Chapter 2 (Section 2.3.1.4) on adherence and non-adherence to psychiatric medication indicates that factors such as positive attitude towards the illness, better insight into the illness, and positive support system contribute to the family members' adherence to medication (Karthik *et al.,* 2014).

5.3.1.5 Sub-theme 1.5: Experiences of participants on the use and abuse of substances by the family member diagnosed with schizophrenia

Millier *et al.* (2014) state that substance abuse by people with schizophrenia has been found to be common, and it may be a contributing factor to psychotic behaviors such as hallucinations and delusions. Persons with schizophrenia may use substances to reduce the side effects of the disease or medical treatment (Winterer, 2010). Participants shared their experiences on how the use of substances such as dagga and alcohol by the family member with schizophrenia contribute to their behavior.

The following statements were shared by two of the participants with regards to the use of dagga and alcohol by their relative with schizophrenia:

Participant D: "So he became ill when he started smoking weed, so it triggered his illness".

Participant C: "Others would give him alcohol but they know that he is not well and that will make things worse and he will be violent".

These experiences shared above by the participants concur with the literature reviewed in Chapter 2 (section 2.3.1) on the objective experiences of families that substance use among persons diagnosed with schizophrenia is prevalent (Chakrabarti, 2010; Sharma, 2019). Asher and Gask (2020) describes that drug misuse by persons with schizophrenia is common, and that it is associated with poorer outcomes. Ward (2008) also confirms that a person using substances is less likely to follow a treatment plan and that can worsen the symptoms of psychosis.

The following theme centers on the psychological effects of the illness on participants which includes stress, the burden of care, uncertainty of the future care of the family member and acceptance of the family member with schizophrenia often affecting the psychological well-being of the participants.

5.3.2 THEME 2: PARTICIPANTS EXPERIENCES OF THE PSYCHOLOGICAL EFFECTS OF THE ILLNESS

While recovering at home, the family member diagnosed with schizophrenia requires a substantial amount of care and support making living with and caring for a family member diagnosed with schizophrenia very demanding. The introduction of the deinstitutionalization policy as discussed in Chapter 1 (Section 1.1) regarding the shift of psychiatric care from the formal hospital to the community-based organizations and families, has caused many families to become the main source of support to their relatives who are suffering from mental illness.

As a result, the role of caring for the family member with mental illness falls onto families. Thus, it is most likely for them to experience psychological exhaustion due to the demanding roles of caring for a family member diagnosed with schizophrenia (Miller *et al.,* 2014). Moreover, the caregiving responsibilities can have an emotional burden on caregivers' emotional well-being (Gater, Rofail, Tolley, Marshall, Abetz-Webb, Zarit & Berardo, 2014).

In relation to the psychological effects experienced by the participants in this study, the participants shared how the burden of care affected their psychological well-being. The following sub-themes discuss participants shared experiences of stress, uncertainty of the future care and acceptance of the family member diagnosed with schizophrenia.

5.3.2.1 Sub-theme 2.1: *Experiences of stress when living and caring for a relative with schizophrenia*

Stress as described by Fink (2010: 5) refers to "perception of threat, resulting in anxiety discomfort, emotional tension, and difficulty in adjustment". Living with a family member diagnosed with schizophrenia has indirect influence on the families' mental health. Chronic mental disorders negatively affect patients and their families alike and they can become a major cause of stress (Bademli & Duman, 2016). Families are the primary source of support and care for a relative with schizophrenia; therefore, they can be expected to be experiencing an overwhelming amount of stress as they are adjusting to the changes in their families. The participants have shared their experiences as stressful, difficult, and painful in relation to living with and caring for the relative with schizophrenia:

Participant A: "… It was a really difficult time… It is stressful".

Participant B: "Those were the dark days; it was absolutely terrible… It was incredible stressful".

Participant C: "it's very painful my sister".

In Chapter 2, the Literature Review (Section 2.3) demonstrates that living with and caring for a family member diagnosed with schizophrenia causes stress in families' lives (Shah *et al.,* 2013). The above narratives by participants provide insight into their experiences of living with and caring for a relative with schizophrenia. The participants described their experiences as being "stressful", this signifies the burden that the illness has on them. (Ntsayagae *et al.*, 2019) and Sharif *et al.,* 2020) concur that living with and caring for a relative with schizophrenia can lead to the family feeling overwhelmed and full of anxiety, putting the family under various stressors.

5.3.2.2 Sub-theme 2.2: Experiences of participants regarding the burden of care on their psychological well-being

The burden of care may encompass psychological challenges that can be experienced due to the caregiving role (Alfonso, Ramly, Kantar, Wang, Eisemann, Staffenberg, Shetye & Flores, 2020). Brain *et al.* (2018) point out that living with a relative with mental illness feels like a burden due to the demanding roles of caring for a person diagnosed with schizophrenia. During the interviews, participants described their experiences as draining, consuming their time and energy as they constantly watch out for them or remind them of what to do. The following quotes were shared by the participants:

Participant C: We have to always watch him as he can do anything, anytime. I'm not working because I'm watching him. You see if someone is leaving there should be someone who is left with him and watch the kids".

Participant D: "...it's heart breaking more than anything. It is very hard to see that they are so dysfunctional. So, you constantly you have to tell them that you need to go and shower. You need to cut your nails. You need to clean... put clean clothes on, so on and on".

Participant E: "I am always watching him. When he goes out, when he talks and when he does things, I am always watching him… to make sure he does not get up into no good. Like if he is talking, I am watching him not to beat anyone".

These comments concur with Baurer, Koepke, Sterzinger and Spiessl, 2012; Gater *et al.,* (2014) who state that caring for a relative with schizophrenia puts demanding roles on family members which leads to feelings of being overwhelmed and in constant distress and feeling overstrained. Also, the above quotations from the participants agree with the literature reviewed in Chapter 2 (Section 2.3.2) that points to caring care for a family member with schizophrenia can be burdensome to the family (McFarlane, 2016).

In contrast, two of the participants shared that living with a relative with schizophrenia is not an entirely negative experience. The two participants shared their positive experiences as follows:

Participant A: "He is functioning better independently… my son has been quite helpful"

Participant B: "You know he is very helpful; he is considerate. He is quite motivated, which lot of people aren't".

Kulhara, Kate, Grover, and Nehra (2012) agree that living and caring for a family member diagnosed with schizophrenia is not always linked to negative consequences, but also experiences of subjective gains and gratification such as finding meaning and a greater sense of inner strength. Furthermore, these experiences shared by the participants relate to the theoretical framework as discussed in Chapter 3 (under Family Adaptation, Section 3.6) that the diagnosis of schizophrenia in a family member may bring the family together and strengthen family bonds as families pull together to support each other and the affected family member (Golics *et al.*, 2013; Lawrence, 2012).
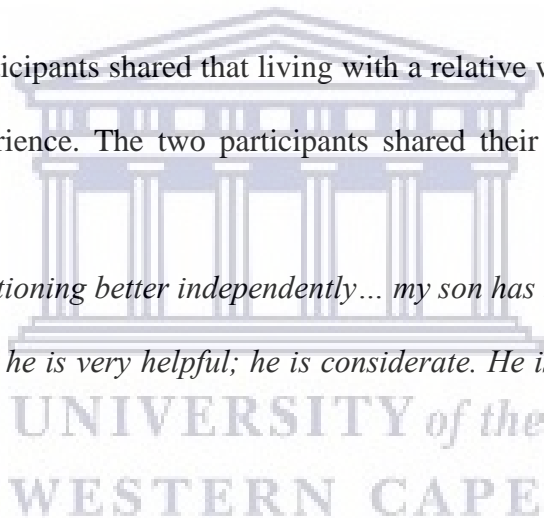
The above illustrations show that families and caregivers may have different psychological challenges and experiences with regards to the burden of care when living and caring for a family member with schizophrenia.

5.3.2.3 Sub-theme 2.3: Experiences of uncertainty on future care for the relative diagnosed with schizophrenia

This sub-theme deals with the uncertainties they have when living with a family member diagnosed with schizophrenia. These uncertainties relate to relatives diagnosed with schizophrenia loneliness, isolation, concerns about the future and the care when participants are deceased. Participants reported some specific concerns about the future for their relatives. The concerns of participants were expressed as follows:

Participant A: "He is an extra person to worry about his future when we die. What is going to happen to him, where is he going? I really don't know because he could be very isolated then. Sitting in a flat, you know". So, I don't know, I can't see the future where he is concerned.

Participant D: "...The biggest concern as a parent with these kids is, what's going to happen when we are not around anymore. That is the first thought in the morning and my last thought at night"

Participant F: "I think about her future. Who is going to take care of her if I die? That is my worry because I think about that when I am sick, I take care of myself. If I don't, she won't have anyone to take care of her. People won't like her".

These findings concur with Roman *et al.,* (2016), that the care and future of the family members diagnosed with schizophrenia tends to weigh heavily on the participants as they are the caregivers. Furthermore, they concur with authors McCann, Lubman and Clark (2011) and Lippi, (2016), who state that living with a relative with schizophrenia is perceived as a sad experience due to the reflections about a changed life for the relative with schizophrenia.

5.3.2.4 Sub-theme 2.4: Experiences of participants on acceptance and adaptation of the relative diagnosed with schizophrenia

Family members living and caring for a family member with schizophrenia realize earlier on that there will be a responsibility for them to care for their family member for the rest of their lives especially in the context of deinstitutionalization. They will have to adapt accordingly and will experience a slow change to their own lives and to the lives of their family and its members (Lippi, 2016). Participants shared that living and caring for a relative diagnosed with schizophrenia, has resulted in them learning how to adapt to the illness as part of their lives and daily routines. The following quotes were shared by the participants to highlight how they have learnt to accept and adapt to the illness and the relative with schizophrenia:

Participant A: "You see initially you got to learn how to treat the person. You cannot go on treating them the same way you would treat someone who is not ill. Be careful what you say, mustn't raise voices, you got to keep calm".

Participant B: "... there are certain ways in which they are different and there are certain things that cause stress, and they might not be able to do you know that a regular person would.

Participant C: "...it will be difficult, and we have to accept it because his condition is not curable but can be treatable". We do not have a problem even if he takes our food. He even swears at us but we understand him, he is our brother. Sometimes he gets angry, and we would understand again that this person is sick".

Participant D: "I have begun to realize that you can't really get them to do something. There are certain things they can do and certain things they cannot do".

Participant F: "...living with her is nice because I am used to her. I have accepted her situation. I love her because she is my child. I now understand her better".

The above quotes that were shared by the participants concur with McCann *et al.* (2011) who posit that families and caregivers of persons with schizophrenia start the process of coming to terms with the illness of their relative at a certain point. These experiences expressed by participants relate to the Theoretical Framework discussed in Chapter 3 (Section 3.6) that the occurrence of schizophrenia in the family requires the whole family to develop new and positive coping mechanisms to adapt with the illness. In addition, participants accepted the change brought by the illness to the person, accepting the circumstances, and being accessible to their relative with schizophrenia for support (McCann *et al.*, 2011). The participants' experiences on acceptance of the changes and situation might be seen as the familys' coping strategy to the illness as the family system adapts in response to the illness as discussed in the Theoretical Framework Chapter (Psycho-educational interventions (Section 3.7.1).

5.3.3 THEME THREE: RELIGION AS COPING MECHANISM FOR PARTICIPANTS

Families adopt an array of ways to cope with their relative who is diagnosed with schizophrenia and the illness itself. Religion is a form of a coping mechanism that assists persons to deal with various life circumstances (Das, Punnoose, Doval & Nair, 2018). Coping can be understood as the process of managing internal and external demands of a person or environment that are considered as strenuous or exceeding the resources of the person (Grover & Pradyumna, 2015). Ae-Ngibise, Doku, Asante and Owusu-Agyei (2015) suggest that families of persons with mental illness implement different coping strategies to deal with the illness. One of this coping mechanism includes the person's belief that God is in control and above everything, He can heal, and take care of their concerns (Sharif *et al.,* 2020).

Some participants shared their experience of using religion as a coping mechanism. The following quotes were shared by the participants of how God is their strength and hope:

Participant E: "I trust God that He will help us. That's the other thing that is giving me strength".

Participant F: "What gives me hope is that God will help us. And I will have the energy to pray to God to help us, and I will feel right and have hope".

The experiences of participants are similar to the studies conducted by Grover and Pradyumna (2015) and Ntsayagae *et al.* (2019) that families turn to religion as a coping mechanism as they are optimistic and hopeful that God will heal the relative with schizophrenia. These findings concur with Smola, Gearing, Alonzo, Baldwin, Harmon & McHugh (2013), who argue that families who have relatives with schizophrenia, religion may have significant influence on how they understand, treat, and manage the illness.

5.3.4 THEME 4: EXPERIENCES OF PARTICIPANTS ON THE BEHAVIOUR OF THE RELATIVE DIAGNOSED WITH SCHIZOPHRENIA

A relative with schizophrenia may present difficult behaviors due to the psychosis. Behaviors such as violence and threats to harm self are the experiences that were shared by participants. Monyaluoe *et al.* (2014) state that families living and caring for a relative diagnosed with schizophrenia experiences troublesome behavior by the relative with schizophrenia. The following two sub-themes describe the participant's experiences of aggressive behavior by a relative with schizophrenia, and concerns about the safety of the relative and for other family members, as well as a general lack of personal hygiene by a relative diagnosed with schizophrenia.

5.3.4.1 Sub-theme 4.1: Experiences of aggressive behavior by the relative with schizophrenia and the influence on safety of the relative and others

Within the context of this study, aggression refers to "disposition, a willingness to inflict harm, regardless of whether this is behaviorally expressed, and physical harm is sustained" (Serper, 2011: 897). It has been noted that aggression committed by patients with schizophrenia is a

major public health concern affecting patients and their families, (Serper, 2011). These aggressive behaviors by the relative with schizophrenia can be verbal – yelling, ridicule, criticism, followed by damage to property, violent threats of harm and physical violence towards objects and families as attested by Hsu & Tu (2013).

The following statements shared by the participants describe the aggressive behavior of family members diagnosed with schizophrenia as they become angry when they do not get their own way or just being angry for having this illness:

Participant B: "So certain things made him angry if I disagree with him and I prefer not to".

Participant C: "... if he asks for money and we don't have it he will get angry and kick things around the house. He must get everything that he want".

Participant D: "He does gets angry, last week he was angry at the illness. He was angry at having mental illness…he shouts before he used to break his cupboard doors".

The above quotations from the participants concur with the literature reviewed in Chapter 2 (Section 2.3.2.1) that indicated how families living with relatives with schizophrenia experience aggressive behavior by an ill relative (Monyaluoe *et al.,* 2014). As a result, families reported experiencing fear for their own safety and that of the relative with schizophrenia.

The following statements of participants' experiences were shared by the participants describing the violent behavior of the family member with schizophrenia and how their safety was compromised:

Participant B: "…and he was violent then. He would often attack me. uh…few occasions when he tried to stab me with the knife. There was once when I walked too close to him and I found him in the garden and he threw me into the glass window and it cut me".

Participant C: "He was violent, he was using knives to stab us. Sometimes he would put knife or axe under his pillow so that he can attack us".

The experiences shared by the participants are like the study conducted by Hsu & Tu (2013) that violence, particularly by the relative with schizophrenia is most common. Esbec and Echeburúa (2016) state that often the violent behaviors by the relative with schizophrenia are directed to the family which is evident in the participant's comments above. People with schizophrenia may also attempt to commit suicide as a result of the illness and how it impacts on their thought processes. When experiencing extreme psychotic episodes, patients threaten their families to kill themselves. The overall mortality rate has been found to be twice to three times as high for patients with schizophrenia as compared to the general population (Bushe, Taylor & Hauka, 2010). The literature reviewed in Chapter 2 (Section 2.3.1.4) show that relatives diagnosed with schizophrenia attempt to commit suicide (Sharma, 2019).

During the interviews, two of the participants shared their experiences on how the family members with schizophrenia attempted to commit suicide due to their psychosis, they shared the following statements:

Participant B: "He told me that he is going to the mountain to kill himself and he disappeared".
Participant C: "...he once took a rope and knife and wanted to hang himself while we were at home".

Participants also shared their concerns about the safety of their family members who are diagnosed with schizophrenia. A study conducted by Brain *et al.* (2018) assent that caregivers of persons with schizophrenia expressed their concerns about the safety of other family members and that of the relative diagnosed with schizophrenia. Their concerns about the safety were related to the person's behaviors as well as worries that they might be victimized by members in the community.

Participant C: "...people beat him up because of his behaviour. Even now he just lost his tooth, someone beat him, and maybe he took something. We were once called by someone who is a police officer at Khayelitsha that a mob was going to kill him because he is a rapist. And others will make videos of him, laughing. People are taking advantage of him because he won't know who beat him up. Sometimes he comes home injured, we are worried about his safety".

In addition, families are concerned about the safety of the relative with schizophrenia as they sometimes become victims of violence themselves. In the literature reviewed in Chapter 2 (Section 2.3.1.4), it was noted that victimization is higher in persons with schizophrenia than it is with the general population. This is due to them being vulnerable and the impairment of their cognitive functions (De Freitas *et al.,* 2013).

5.3.4.2 Sub-theme 4.2: Experiences of participants on personal hygiene by the relative with schizophrenia

Participants also shared how the occurrence of schizophrenia has influenced daily activities such as self-care and personal hygiene of the family member diagnosed with schizophrenia. A study conducted by the Missouri Department of Mental Health, (2011), showed how the occurrence of schizophrenia is associated with a deterioration from a previous level of functioning in areas such as self-care.

Two of the participants shared how their relatives diagnosed with schizophrenia are not bathing and maintaining their personal hygiene. The following statements were shared by the participants of their experiences with regards to how their family members lack an interest in their personal hygiene:

Participant C: "he doesn't like bathing. If we want him to bath my other brother has to force him to bath".

Participant D: "He is unwashed most days and completely unkempt. He does the same every day. We literally have to beg him to remove his clothes to have a wash".

Due to the impact of the illness on psychosocial functioning, the person diagnosed with schizophrenia may find difficulties in maintaining good personal self-care which is associated to poor quality of life (Arsova, Bajraktarov, Barbov & Hadzihamza, 2014). The above quotes by the participants concur with the study conducted by Gater *et al.* (2014) that people with schizophrenia tend to neglect themselves due to psychosis, and as a result they must be reminded about their personal hygiene. Also, a similar study conducted by Chaturvedi (2017) concurs with the experiences shared by the participants that families who have relatives with schizophrenia experience concerns with regards to self-care and personal hygiene, such as cleanliness and bathing. It is therefore evident from the above discussion that people with schizophrenia find it difficult to maintain their self-independence and self-care due to their illness.

5.3.5 THEME FIVE: EXPERIENCES OF PARTICIPANTS OF INTERPERSONAL RELATIONSHIPS

As discussed in the Theoretical Framework, Cchapter 3 (Section 3.4.3), it is anticipated that the occurrence of schizophrenia in the family will have an influence on the family and on interpersonal relationships. The participants shared their experiences on how living with a relative with schizophrenia has influenced their personal relationships. The following 4 sub-themes emerged from the interviews: ability of the relative with schizophrenia to develop relationships, influence of the illness on friends and social activities, experiences on the family functioning with a member diagnosed with schizophrenia, and experiences on the support networks available for the relative with schizophrenia and families.

5.3.5.1 Sub-theme 5.1 Experiences of participants on the relative's ability to develop relationships

Persons diagnosed with schizophrenia find it difficult to be around people (Ward, 2008). The participants shared that they noticed a decline in their relative's social interactions due to the illness. The following statements were shared by the participants highlighting the family member's decline or withdrawal from social activities and engagements.

Participant A: "At first they withdraw, don't want to be in public or join you for lunch"

Participant B: "He is socially withdrawn"

Participant D: "...he is room-bounded. He is in his room ninety nine percent of the day. He refuses to go out. Last week I took him to the movies and go to the restaurants. And he will only go during the day when there is not lot of people. And when the family comes to visit, he still stays in his room".

Participant G: "he doesn't like going out…. He has got no social relationships. He has got no friends, partner, he is not interested in making relationships".

Participant A: It's very difficult for people with schizophrenia to have normal friends. His old friends he is still in touch with them but doesn't really see them you know. They can't fit him into their lives. Because it's difficult".

The above narratives by the participants are supported by Miller *et al.* (2014) who state that due to the impairment brought by the illness, the rate of developing close, intimate interpersonal relationships is very low and much impaired because of the illness.

Even though some participants experience difficulties with regards to the social activities of their family members. One participant reported to having a positive experience with regards to the daily activities of her son. The participant shared that:

Participant A: "Recently he made a completely new friend, Umh somebody across the water-way from us. He often goes out for coffee with or dinner.

The experiences shared by the participants above concur with the literature that argues that passiveness and loneliness have been found to form a major part of the lives of people with schizophrenia, accompanied by experiences of very little meaning in life, and they are emotionally withdrawn, (Eklund, Hermansson & Håkansson, 2012; Missouri Department of Mental Health, 2011).

5.3.5.2 Sub-theme 5.2: Experiences of participants on the family functioning with a family member diagnosed with schizophrenia

Family functions as discussed in Chapter 3 (Section 3.4.3) include the method in which the family as a system works, which includes interpersonal interactions and communication among family members (Günindi, Tezel Şahin & Demircioğlu, 2012; Berge *et al.,* 2013). McFarlane (2016) note that schizophrenia has a potential to bring disturbance in the organization of most families and families may experience a variety of changes, including alienation of siblings, marital conflict; severe disagreement regarding support versus behavior control; even divorce. Some participants have shared their experience of how the illness of their child has influenced or affected parent/partner relationships. The following quotes were shared by the participants to highlight their experiences on how the illness has influenced their relationships with their partners when their child is diagnosed with schizophrenia:

Participant B: "... me and his father got divorced back at the time because of him. My husband didn't understand all this. He is not a compassionate person by nature, so he gave me an ultimatum and his behaviour was very difficult after my son was diagnosed and he said I must agree not to see him again or he wants a divorce".

Participant D: "I had a partner during the time my kid got the illness. He couldn't cope, we separated because of my kid's illness".

The above quotations from the participants correspond with the findings of the study by Brain *et al.* (2018) that romantic and family relationships can be negatively affected by the occurrence of schizophrenia in the family. One of the participants has shared how she must take care of her brother at home and her family at the same time as she is married. The participant shared that:

Participant C: "I'm married and then I had to be here so that I can help out and watch him. Since I talk to my husband and told him everything he understands"

Living with and caring for a relative diagnosed with schizophrenia tends to be seen as having a negative influence on the family relationships and roles (Penning & Wu, 2016). Some of the participants have shared that the occurrence of the illness has caused family disturbance or conflict in their family which included a breakdown in relationships and conflict:

Participant A: "in the past my husband and son had a difficult relationship when he was ill. You know my husband would say he has bad behaviour and want to lose his temper. They didn't have a close relationship".

Participant B: "My husband kicked him out of the house.

The experiences shared by these participants corresponds with the literature on family, that when a family system experience changes due to schizophrenia, the family functioning will be disrupted which can result in imbalance in the family system (Martire & Helgeson, 2017). Likewise, for families to function optimally, families living with and caring for a relative with schizophrenia need social support. Social support from other family members is important in reducing the burden. As discussed in Chapter 3 (Section 3.7.2), family is seen as an important source of support for the relatives diagnosed with schizophrenia and their caregivers. The

participants of this study have shared their experiences on how their extended families and friends have been supporting them:

Participant A: "I have my daughter for support really. My friends help indirectly by... you know I can talk to them, so that's an indirect help".

Participant B: "My brother came to be with me and to offer support. They were incredible supportive; you know my friends and my parents. So, I had a lot of support".

Participant D: "during the day his brother is at home, and it also gives me time for break from that environment. My ex-husband recently stepped on board. I have a sister whose son also has schizophrenia and my mom. So, she and my sister has always been my support system because they understand the illness if I needed help, I would run to them".

Participant E: "I have my daughter and my older son are supporting me".

The above discussion therefore confirms the statement made by McFarlane (2016) that schizophrenia has the potential to disturb or to bring conflict in the organization of most families who experience a myriad of challenges and changes, including marital conflict; severe disagreement leading to divorce. Chadda, (2014) has identified social support as a positive indicator causing family members to feel less stressed and overburdened.

5.3.5.3 Sub-theme 5.3: Influence of the relative's illness on friendships and social activities of family members

The occurrence of schizophrenia in the family does not only bring negative influences on the social activities of the relative diagnosed with schizophrenia, but also, on other family members, particularly caregivers. As discussed in Chapter 1 (Section 1.1), the deinstitutionalization of mental health services from state institutions into communities has put more responsibilities on families, with their social lives being affected (Tan, Yeoh, Choo, Huang, Ong, Ismail, Ang & Chan, 2012).

Similarly, the participants of this study shared their experiences on how living with the relative diagnosed with schizophrenia has influenced their social interactions. The participants shared how they can no longer engage in activities they usually do such as socializing with friends. The following quotes were shared by the participants to highlight their experiences on how the illness has negatively influenced their social lives:

Participant A: "But the difficulty recently is the acknowledgement that I cannot do what my friends are doing".

Participant D: "you become very isolated as a parent of a child that has got mental illness.

Participant F: "I am not able to do things that other people are doing because I always need to be there for her".

The experiences shared by the participants correspond with the literature reviewed in Chapter 2 (Section 2.3.1) that the social activities of family members living with and caring for a relative with schizophrenia are negatively influenced as they are not in the position to interact freely or have limited opportunities to engage with other people due to their caring roles (Ae-Ngibise *et al.,* 2015; Chen, Zhao, Tang, Jin, Liu, Zhao, Chen & Lu, 2019). In addition, Miller *et al.* (2014) note that the burden of caregiving often leads to loss of social contact outside the family as the family members assuming the caring roles must replace their social activities such as visiting friends, with spending more time with the family member with schizophrenia, as illustrated by the comments made by the participants.

5.3.5.4 Sub-theme 5.4: Experiences of participants on social support networks available to participants and the relative with schizophrenia

The provision of support from the health care professionals, community organizations, and from other service providers is important for the families and persons with severe mental illness as it associated with improved family quality of life, functioning, and reduction of stress

(Crabb, Owen, Stober & Heller, 2020). The social support networks as discussed in Chapter 3 (Section 3.7.2) include peer support group for families, health professionals, and religious communities.

Schizophrenia is a very serious and disruptive mental illness, as a result, families of relative with schizophrenia need their own support systems as the responsibility to care for the person remains with them (Ae-Ngibise *et al.,* 2015). The participants have shared their experience of several social support systems that they receive, including church, support groups, health care professionals, and the community. The following quotes were shared by the participants:

Participant E: "Even at church, the pastor used to come and pray here, and the church ladies. That really give me hope".

Participant B: "I mean the saving grace was a psychiatrist at Valkenberg who was very supportive you know and my daughter. And he kept my son in hospital while she was in matric year because there is no way she could have made it through.

Participant D: "you have Valkenberg, and you have outpatient programmes that you can attend. If it weren't for that outpatient programme I would never have survived this illness."

The experiences shared by the participants corresponds with the findings of the study by Ae-Ngibise *et al.* (2015) that support, which include providing relevant information about the illness, from health care professionals is vital in assisting the family and the relative with schizophrenia to cope with the illness.

Clearly, the principle of Ubuntu still prevails in societies that we live in as one of the participants shared how the community supported them with regards to their relative diagnosed with schizophrenia. The participant stated that:

Participant C: "Others help us by getting him home when they see him maybe at the taxi rank and some neighbours would help to bring him home".

Thus, Zahid and Ohaeri (2010) confirm what was discussed in the Theoretical Chapter (Section 3.7.2), stating that the peer support groups for families plays an important role in the management of the illness within the family, these include seeking advice and encouragement, sharing concerns with the social networks, seeking advice from religious ministers, and attending religious services. Moreover, community support includes seeking information from others, seeking assistance from community programs and health professionals (Zahid & Ohaeri, 2010).

5.3.6 THEME 6: MISCONCEPTIONS ABOUT SCHIZOPHRENIA LEADING TO STIGMATISATION

Misconception is defined by Nishanthi and Revathi (2017: 645) as "a set of negative attitudes and beliefs that motivate individuals to fear, reject, avoid, and discriminate against people with mental illness". There are various beliefs and misconceptions about schizophrenia. It is believed that different cultures have different approaches to mental health and mental illness, thus people have different views on what causes mental illnesses, and some people prefer consulting wise men or traditional healers (Dunn, 2016; Agau & Bodilsen, 2017). This was evident in the following quote made by the participant:

Participant C: "...we started going to the traditional healers for help. We thought and believed that he was bewitched because he said that he is seeing witches".

Symptoms of psychotic illnesses such as schizophrenia cause fear and distrust in people who may associate them with witchcraft, possession by demonic spirits, and the devil. It is evident from the above statement that often people have different views and opinions about what causes schizophrenia based on their cultural and religious beliefs. This is confirmed by Agau and

Bodilsen (2017) who state that people still endorsed culturally accepted causations of schizophrenia such as evil spirits, curses, and witchcraft.

As discussed in the Literature Review (Section 2.3.2.2), schizophrenia is associated with stigma. Budden and Summerville (2012) note that schizophrenia is an intimidating illness that is difficult to grasp at first, as a result it requires constant learning to be able to control its influence on the self and family. Due to these misconceptions and lack of knowledge about mental illness, people living with mental illnesses are being called names. Participants shared their experiences on how their relatives diagnosed with schizophrenia are being stigmatized by members in their communities through name calling:

Participant B: "A lot of ignorant people tend to think that if you're diagnosed with schizophrenia it's... you're a psychopath".

Participant C: "... he is like someone who is losing his mind".

Participant D: "People don't understand mental illness. People literally look at people with mental illness and think they are joke or they are threat. People will laugh at people that walks around and talk to themselves, because people lack knowledge about that".

Participant E: "They saw him as someone who is a lunatic, madman".

The above quotations by the participants relate to a study conducted by Egbe, Brooke-Sumner, Kathree, Selohilwe, Thornicroft and Petersen (2014) who state that the common misconception about schizophrenia in communities is the strongly held belief that persons diagnosed with schizophrenia are deliberately pretending to be sick, and deliberately acting out the symptoms of the illness. Also, the participant's experiences confirm with Ward (2008: 215) that schizophrenia is a "split personality, with patients being labelled as "maniac, monster, or madman". It is evident from the above discussion that people lack information on what schizophrenia is and what causes it. These beliefs and misconceptions about schizophrenia

could be an indication of a lack of proper information, awareness and insight into the illness, and that could delay people in seeking medical help.

People have different understandings of schizophrenia as an illness. Their understanding and insight into the illness are influenced by the type of information that is available to them as well as their cultural and spiritual beliefs. The above quotes are evident to what is stated by Asmal *et al.* (2014) that people lack knowledge about schizophrenia. This results in people with schizophrenia being given ill-treatment by the public. Moreover, families are not aware of how to treat the family member with schizophrenia as they are not educated and equipped on how to interact with the person.

5.3.7 THEME SEVEN: INFLUENCE OF LIVING WITH A RELATIVE WITH SCHIZOPHRENIA ON SOCIO-ECONOMIC CIRCUMSTANCES

The socioeconomic influence of schizophrenia on the person or their families include the loss of income, inability to work and to make productive contributions (WHO, 2013). The literature reviewed in Chapter 2 (Section 2.2) revealed that the economic influence of living with a relative with schizophrenia include providing financial support to the relative such paying for medical appointments, food, accommodation, and other caregiving related costs (Koschorke *et al.,* 2017). In some circumstances, the family members assuming the caregiving responsibilities must minimize their working hours or leave work at all to take care of the relative with schizophrenia (Ndetei *et al.,* 2009).

The socioeconomic influence of the illness on families as shared by the participants are addressed by 3 sub-themes: employment of the relative with schizophrenia, influence on the employment of family members, and financial burden on the family.

5.3.7.1 Sub-theme 7.1: Employment opportunities for persons with schizophrenia

Often employment is an important part of the journey towards recovery (Rinaldi, Killackey, Smith, Shepherd, Singh, & Craig, 2010). A study conducted by Millier, Schmidt, Angermeyer, Chauhan, Murthy, Toumi & Cadi-Soussi (2014) found that persons diagnosed with schizophrenia have lower rates of employment and independent living than the general population do. Some of the participants shared their experiences on how their family members diagnosed with schizophrenia are struggling to find employment opportunities. The following quotes were shared by the participants: *Participant A: "I wrote to all my friends and contacts and said listen if you're throwing out stuff, you know maybe if you want to sell stuff but can't sell it- all these things my son is doing this market and he can sell the stuff and we can sell at the charity shops".*

Participant G: "He is not able to function in a workplace because he always feels all the time being watched out and harassed".

Added to the barriers to finding employment for persons diagnosed with schizophrenia is the stigma and discrimination as stated by Bouwmans, de Sonneville, Mulder & Hakkaart-van Roijen (2015). Employment does not only provide financial independence, but it also improves activities and social interactions, provide structuring and occupying time, sense of personal achievement, improves quality of life, and possibly lead to better treatment compliance in persons with schizophrenia (Midin *et al.,* 2011; Bouwmans *et al.,* 2015). However, from the participant's experiences, it can be concluded that persons diagnosed with schizophrenia find it difficult to find employment. These experiences shared by the participants concur with the literature reviewed in Chapter 2 (Section 2.2) that persons living with schizophrenia find it difficult to sustain employment due to the symptoms (Lippi, 2016).
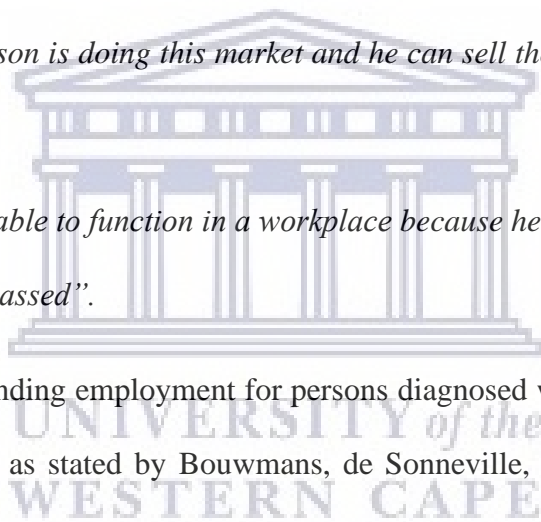
5.3.7.2 Sub-theme 7.2 Influence of the illness on employment of family members caring for the relative diagnosed with schizophrenia

The reviewed literature (Section 2.3.1.1) suggest that the costs of informal care include having to take time off from work, work less hours and take less responsible roles so as to attend to the needs of the relative with schizophrenia Brain *et al.* (2018). In addition, the caregivers of the relatives with schizophrenia have reported that they have to sell their belongings as well as their resources, involve themselves in menial jobs to financially support their families (Ae-Ngibise *et al.,* 2015).

The participants have shared their experience of how living with and caring for the relative with schizophrenia has influenced their employment opportunities with some having to care for their family members full time resulting in living off the social grant:

Participant B: "And I had to close one of my businesses".

Participant D: "I had to resign my job when he was very ill. And I had to give up my job, but because I'm a single mom I had to go back to work because he can't work and I needed to have an income. So, I now work three days in a week. So, I have two days that I don't work so that I have time to spend with him".

Participant F: "We depend on the grant money and when it is finished, we will be left with nothing. I am not working; I am taking care of her".

Participant C: "I'm not working because I'm watching him."

The above experiences shared by the participants concur with the study conducted by Addo, Agyemang, Tozan, Nonvignon (2018) that discovered that families and caregivers of relatives with schizophrenia find themselves unemployed or having to work reduced hours due to the caring responsibilities. In addition, these economic influences of the illness might result in long term economic effects on the family (Fekadu *et al.,* 2019).

5.3.7.3 Sub-theme: 7.3 Financial burden of the illness

The financial burden associated with living and caring for a family member with schizophrenia include medical treatment, transport to and from clinical appointments, and household bills such as food, electricity, and other basic necessities (Azman *et al.,* 2019). Participants shared their experiences on how living with a relative with schizophrenia has influenced the family's finances from paying medical aid bills, transport fees, institutional payments and debt incurred:

Participant A: "We are retired and we don't have a lot of money. I do everything else, medical aid, doctors. I'm paying for the medical aid. I have to buy his clothes… everything requires money, especially if that person isn't working".

Participant B: "So financially you know had terrible sort of influence on the family…beside for paying for Hope House. There is the cost of paying for home that accommodates him. I buy him clothes, medication. I mean not psychiatric medication; you know medical dental and petrol for his- he does drive".

Added to the financial burden; one of the participants stated that due to the family member's behavior they have to pay for the damages caused by him. The participant mentioned that:

Participant C: "Sometimes people come and report him that he took their belongings, be it money, phone etc. and we have to pay".

Participants C comment is in line with Brain *et al.* (2018) who state that the financial burden experienced by the family's results from the money the family has to spend in replacing or repairing the properties damaged by their relative with schizophrenia.

These quotes confirm what is stated by Mokwena and Ngoveni (2020) that families do not only experience financial difficulties due to high unemployment among the family and the relative with schizophrenia, but further costs related to caring for the relative with schizophrenia. The

literature reviewed in Chapter 2 (Section 2.3.1.1) that living with and caring for a relative with schizophrenia causes financial burden to the family concurs with the experiences shared by the participants above.

Mokwena and Ngoveni, 2020 concur with Crowe & Brinkley (2015) that families with relatives with schizophrenia take the financial responsibility for the costs associated to the health care of a member with schizophrenia which adds to the decreasing of family finances.

5.4 CONCLUSION

The phenomenology question posed was "What are the lived experiences of families living with a family member diagnosed with schizophrenia? The experiences of the participants indicated the burden they experience in living with a relative with schizophrenia, which include the influence on finances, employment, health and well-being, relationships, stress, non-adherence to medication, and the society's misconceptions about schizophrenia. The experiences of the participants were worsened by the relative's uncooperative behavior which include aggressiveness, and the lack of support systems and access to information. The consequence of deinstitutionalization and lack of support seems to add to the burden of caring for a family member diagnosed with schizophrenia. It is therefore evident that families caring for a relative diagnosed with schizophrenia have a great need to be heard and be supported.

The following Chapter will provide conclusions and recommendations from the study.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

The aim of the study was to gain an in-depth understanding of the experiences of families living with a family member diagnosed with schizophrenia. The aim of the study was accomplished through achieving the set objectives, which were to:

- Explore the lived experiences of family members living with a family member diagnosed with schizophrenia.

- Give recommendations to the inter-disciplinary teams engaged in providing services to families and people diagnosed with schizophrenia.

A qualitative research approach that aimed at exploring and describing the phenomenon was used to reach the aim of the study. The first objective which is the exploration of the lived experiences of families living with a family member diagnosed with schizophrenia was done during the research process as described in Chapter 2 of this study (Literature Review). The second objective will be achieved by this Chapter by focusing on providing recommendations to multi-disciplinary teams that are engaged in providing services to persons diagnosed with schizophrenia with special reference to services for family members as this study considers the family systems theory perspective in Chapter 3. The findings of this study were integrated with literature control as well as the Theoretical Framework of the study.

6.2 CONCLUSION

This section summarizes the findings that have been made in the research findings in Chapter 5. Each of the themes that were identified and discussed in the chapter 5 will be briefly summarized here. The themes and sub-themes are illustrated in Chapter 5 - Table 5.2 (themes and sub-themes).

6.2.1 Conclusion and implications of demographic profile of participants

The study sample consisted of 7 participants, all adult females. Literature also concurred that due to several societal and cultural demands, women are mainly the providers of informal care for their relatives with schizophrenia and other serious mental illnesses (Sharma *et al.,* 2016). A conclusion can be made that women again fulfilled the traditional caring role for their relative with schizophrenia. The implication is that gender is still a deciding factor when caring for a family member diagnosed with schizophrenia.

6.2.2.1 Theme one: Participants experiences of the physical aspects of schizophrenia

In describing this theme, in which participants experienced physical effects of living and caring for a family member diagnosed with schizophrenia, the following conclusions were reached:

6.2.2.1.1 Sub-theme 1.1: Experiences about the influence of the relatives' illness on participants' health

- All of the participants felt their health, and their sleeping pattern were influenced by the relatives' illness, putting families at high risk of developing stress.

- Participants experienced exhaustion from these caring responsibilities which resulted in participants having little or no time to attend to their own physical needs and/or taking care of themselves.

- Participants were concerned about their own health issues, for example their high blood level/pressure and whether it is too high or too low.

6.2.2.1.2 Sub-theme 1.2: Experiences of participants with regards to the effectiveness of psychiatric medication

- Based on the data under this heading, it emerged that participants experienced some relief when family members were adhering to their medication.

- The participants felt that the medication taken by the family members diagnosed with schizophrenia was helping in alleviating the psychotic symptoms and thereby reducing their own fears and stress when caring for a family member diagnosed with schizophrenia.

- It can be assumed that if ill relatives do not take their medication, family members living with them may experience fear and anxiety.
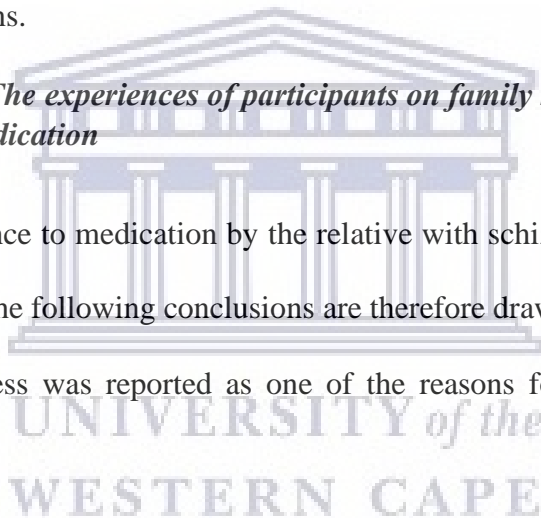
6.2.2.1.3 Sub-theme 1.3: Experiences of participants during relative's psychotic episodes

- Psychotic episodes led to conflict and troublesome behaviour at home and on the streets. Families experienced aggressive behaviour such as physical aggression and violence due to the delusions and hallucinations.

6.2.2.1.4 Sub-theme 1.4: The experiences of participants on family members' adherence and non-adherence to medication

In this theme, non-adherence to medication by the relative with schizophrenia was shared by most of the participants. The following conclusions are therefore drawn:

- Poor insight into the illness was reported as one of the reasons for the non-adherence to prescribed medication.

- Non-adherence to the medication has caused the relatives to relapse and numerous admissions occurred.

- Experiences of involuntary admissions was shared by the participants as the relatives with schizophrenia believed that they are not sick.

- If family members did not take their medication the caregiving role would include monitoring and administering the patient's medication, observing signs of relapse, and their mental state

6.2.2.1.5 Sub-theme 1.5: Experiences of participants on the use and abuse of substances by the family member diagnosed with schizophrenia

In describing this theme, in which participants experienced the context of their relatives' use and abuse of substance, the following conclusions were reached:

- The use and misuse of substance was the most common cause for a relapse and the non-adherence to medication.

- The use of substances such as dagga and alcohol by the family member with schizophrenia contribute to their violent behaviour.

- In some instances, the use of substances triggered the illness.

Most of the participants in this study shared that living with and caring for a family member with schizophrenia has influenced their own health as they at times fail to look after themselves. The participants shared that when the relative with schizophrenia is compliant with medication, the psychotic symptoms become alleviated. However, non-adherence to medication causes feelings of fear as the relative will demonstrate troublesome behaviour. Also, this is especially true when the relative with schizophrenia is abusing substances.

6.2.2.2 Theme two: Participants experiences of the psychological effects of the illness

Under this theme, the researcher discussed the participants' experiences about the psychological effects of living and caring for a relative with schizophrenia. The following conclusions highlight the psychological impact of living with a relative with schizophrenia on the carers.

6.2.2.2.1 Sub-theme 2.1: Experiences of stress when living and caring for a relative with schizophrenia

- Participants felt stressed when living with a family member diagnosed with schizophrenia.

- They felt overwhelmed by the responsibilities that comes with the illness while adjusting to the changes in their families and their family lives.

- Words such as painful, difficult, and absolutely terrible were used to describe participants' experiences of stress when they live with and care for a relative who has been diagnosed with schizophrenia

6.2.2.2.2 Sub-theme 2.2: Experiences of participants regarding the burden of care on their psychological well-being

- Participants experience psychological exhaustion due to the demanding roles of caring for the family member.

- Participants experienced psychological burden due to the constant awareness having to know the whereabouts of family members causing them to feel frustrated, drained and experiencing loss of energy keep an eye on the relative with schizophrenia for their own safety.

- The constant reminders for relatives with schizophrenia to take care of themselves, such as bathing, putting on clean clothes, and other self-care aspects also led them to a feeling of being psychologically exhausted.

6.2.2.2.3 Sub-theme 2.3: Experiences of uncertainty on future care for the relative diagnosed with schizophrenia

- As the primary caregivers, participants were concerned about the future of the relative with schizophrenia.

- Concerns were raised on the relative's future care, loneliness, and isolation when they are deceased.

- These concerns tent to weigh heavily on the participants as they are the caregivers.

6.2.2.2.4 Sub-theme 2.4: Experiences of participants on acceptance and adaptation of the relative diagnosed with schizophrenia

- Families learn to adapt to the changes brought by the illness on the family functioning.

- Families learnt how to live with the relative with schizophrenia, how to treat them, understanding the illness better, and learning about the medications.

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- Acceptance of the changes and situation was seen as a family coping strategy to the illness as the family system adapts in response to the illness.

In conclusion, most of the participants highlighted the psychological effects of living and caring for a family member with schizophrenia on the participants by describing their psychological experiences and the uncertainty about the future care of their family members

6.2.2.3 Theme three: Religion as coping mechanism for participants

The following conclusions highlight religion as a coping mechanism:

- Religion seem to be a form of coping mechanism that assisted participants to deal with the family members diagnosed with schizophrenia.

- Participants turned to religion as a coping mechanism as they are optimistic and hopeful that God will heal their relative with schizophrenia.

In summary, some participants found religion to be helpful and used it as a coping mechanism believing that God will help them and their family member with schizophrenia.

6.2.2.4 Theme four: Experiences of participants on the behaviour of the relative with schizophrenia

The findings of this theme led to the following sub-themes and conclusions.

6.2.2.4.1 Sub-theme 4.1: Experiences of aggressive behavior by the relative with schizophrenia and the influence on safety of the relative and others

- Aggression committed by persons with schizophrenia was a major concern for families.

- The relative with schizophrenia gets easily angered when they do not get certain things done their way.

- Participants were verbally and physically abused by their family member.

- The violent behavior caused the participants to fear for their own safety and that of other family members.
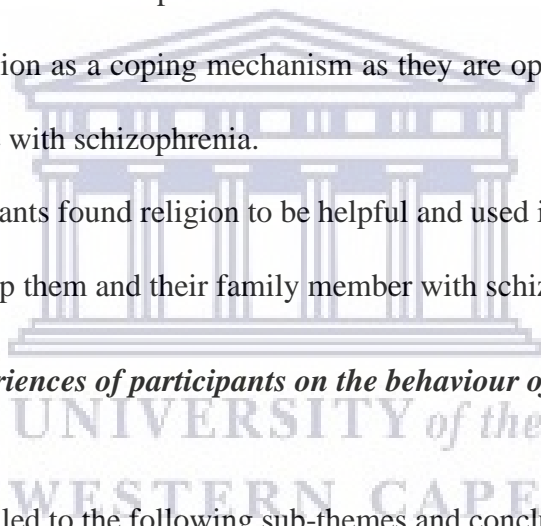
6.2.2.4.2 Sub-theme 4.2: Experiences of participants on personal hygiene by the relative with schizophrenia

- Participants noticed that family members with schizophrenia functioning in areas such as self-care deteriorated over time.

- Participants also became aware that over time, the family member diagnosed with schizophrenia may find it difficult to maintain good personal self-care and that the relative's ability to independency and judgement deteriorates due to the illness.

6.2.2.5 Theme five: Experiences of participants of interpersonal relationships

Participants shared that living and caring for a relative with schizophrenia caused disruptions on interpersonal relationships of the relative with schizophrenia and that of the participants. The following conclusions highlighted the influence of the illness on interpersonal relationships.

6.2.2.5.1 Sub-theme 5.1 Experiences of participants on the relative's ability to develop relationships

- The occurrence of schizophrenia influences a person's ability to build and maintain relationships.

- The symptoms of the illness makes it difficult to socialize with others as they tend to isolate themselves.

6.2.2.5.2 Sub-theme 5.2: Experiences of participants on the family functioning with a family member diagnosed with schizophrenia.

- Family dynamics were challenged such as breakdown in relationships, alienation of siblings, marital conflict; severe disagreement regarding support versus behaviour control; even divorce.

- In managing the illness, support from other family members and extended family is necessary for optimal functioning.
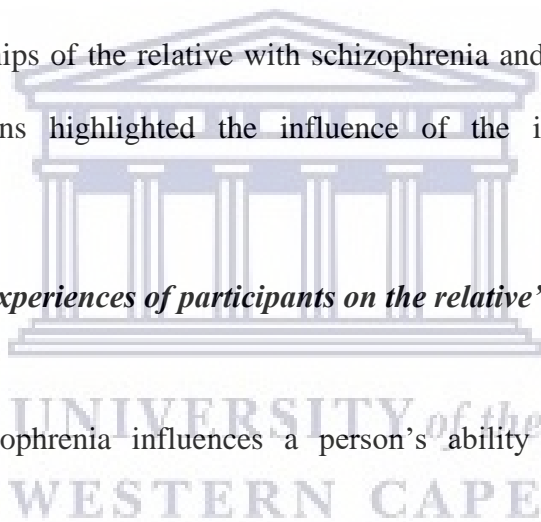
6.2.2.5.3 Sub-theme 5.3: Influence of the relative's illness on friendships and social activities of family members

- Caregivers felt that caring living and caring for a family member who is diagnosed with schizophrenia impacts on their own social interactions.

- The findings suggest that participants have limited opportunities to freely engage with other people or have time for social activities, due to their caring roles.

6.2.2.5.4 Sub-theme 5.4: Experiences of participants on social support networks available to participants and the relative with schizophrenia

The following conclusions give an indication how participants experienced support available to them:

- Some of the participants received support from their churches and Pastors.

- Health care professionals were found to be supportive by other participants in helping them manage the relative with schizophrenia.

- The outpatient family support groups were useful in helping some participants to learn more about managing the illness.

- Participants also felt supported by community members by bringing their relative with schizophrenia home when they see them on the streets.

Based on the data received under this theme, the researcher concludes that it is often hard to form and maintain social relationships. The occurrence of schizophrenia in a family has an impact on how the family functions as there will be changes in the family. This could lead to family relationships being fractured. Also, when children are diagnosed with schizophrenia, this can influence or affect parent/partner relationships. Therefore, accessing various support systems that can assist the family can be helpful when managing the illness.

6.2.2.6 Theme six: Misconceptions about schizophrenia

Under this theme, the findings revealed that some families have different perceptions about the occurrence of schizophrenia and the following conclusions were drawn:

- Due to a lack of information, lack of awareness and cultural beliefs, some participants thought their relative with schizophrenia were bewitched, and consulted with traditional healers.
- There is a lack of understanding by community members about schizophrenia.
- A lack of information about schizophrenia often leads to stigmatization and labelling the ill person and the family members by members in the community.

These experiences have shown that a lack of adequate information has resulted in participants experiencing fear for their family members diagnosed with schizophrenia, for example fearing that they will be stigmatized and labelled by community members. A lack of information on the disease and its treatment, by community members was a concern for participants. This study concludes that people should be informed about different types of mental illnesses, its treatment, its effects on families and on the person diagnosed with the illness.

6.2.2.7 Theme seven: Influence of living with a relative with schizophrenia on socio-economic circumstances

The caring of a relative with schizophrenia can also affect families economically. The following conclusions are drawn about the socio-economic influence of schizophrenia on families.

6.2.2.7.1 Sub-theme 7.1: Employment opportunities for persons with schizophrenia

- Persons with schizophrenia experience difficulties in finding employment.
- The psychotic symptoms makes it difficult for persons with schizophrenia to function at the workplace.

- Stigma and discrimination associated with schizophrenia contribute to the lower rates of employment for persons with schizophrenia.

6.2.2.7.2 Sub-theme 7.2 Influence of the illness on employment of family members caring for the relative diagnosed with schizophrenia

- Often caring for the relative with schizophrenia requires the carers to abandon their employment and attend to the caring responsibilities.

- In some instances, the cares have to work less hours or take more time off from their work.

- Some participants who had businesses had to close down to look after the relative with schizophrenia.

The conclusion drawn is that, often family members have to make selfless sacrifices in order to provide care for their family member diagnosed with schizophrenia which often means forfeiting employment opportunities.

6.2.2.7.3 Sub-theme: 7.3 Financial burden of the illness

- Financial burden in the families included paying for the relative's medication, transport for doctor's appointment, paying bills, and purchasing clothes for the relative with schizophrenia.

- This influences the family's finances negatively as the relative with schizophrenia is not working.

- In some instances, families have to compensate for the damages caused by the relative with schizophrenia.

In conclusion the financial implications often means that families experience financial losses which leads to the financial burden of caring for such a family member.
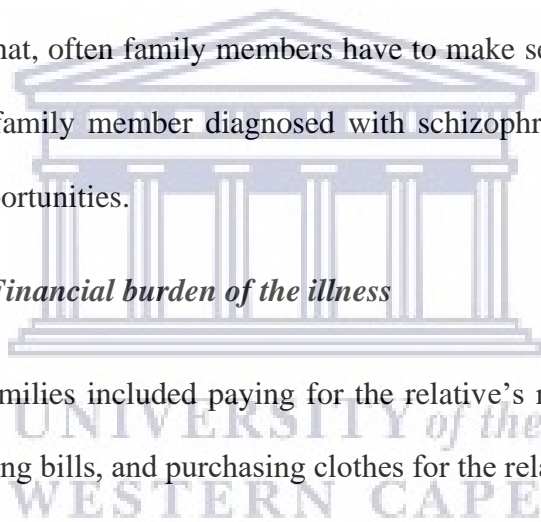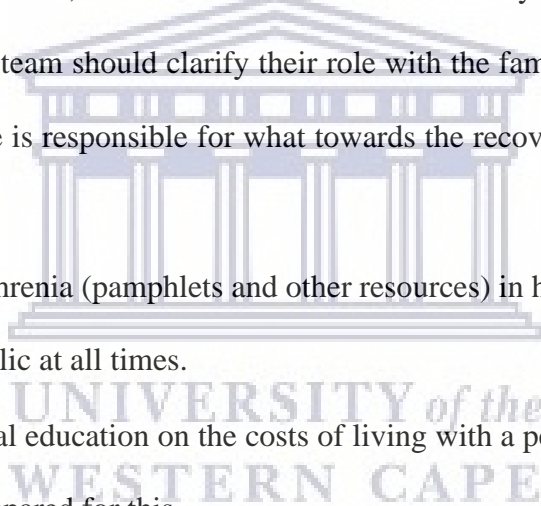
6.3 RECOMMENDATIONS

This section will discuss recommendations that emerged from the findings of this study. The recommendations are directed to multi-disciplinary team members, social workers, government, and policy makers, as well as for the future research.

6.3.1 Recommendations for multi-disciplinary team members

- The multi-disciplinary team members in health facilities play an important role in the recovery of the persons with schizophrenia and their families. Therefore, it is of paramount importance that families and persons with schizophrenia are provided with all the necessary information in helping them manage the illness, this include referrals to community resources.

- Each discipline within the team should clarify their role with the families as they are at times not aware which discipline is responsible for what towards the recovery of their relative with schizophrenia.

- Information about schizophrenia (pamphlets and other resources) in health facilities should be made accessible to the public at all times.

- There is a need for financial education on the costs of living with a person with schizophrenia as families seem not be prepared for this.

- Upon discharge, there should be a clear explanation on where the person with schizophrenia will attend a follow-up session with the psychiatrist, including information on what to do in case of a relapse.

- There is a need for support groups for families of persons with schizophrenia.

- There is a need for community education to raise awareness on mental illness to curb the stigmas and stereotypes around mental illnesses.

6.3.2 Recommendations for social workers

- Social workers should be trained on how to work with families using different models of mental health.

- There is a need for post-discharge support services for persons with schizophrenia and their families.

- Referrals to appropriate community resources should be made to increase the support for the persons with schizophrenia and their families and encourage compliance.

- Social workers should advocate for the needs of persons with schizophrenia in communities, workplace, and places of learning.

- Continuous Professional Development should be encouraged and have social workers trained in providing mental health services.

6.3.3 Recommendations for government and policy makers

- Mental health should be prioritized in terms of resource allocation as the current studies indicate that there is a lack of resources, including financial resources that are allocated for mental health.

- The mental health policies and legislations should be reviewed to ensure that they are effective and serve their purpose.

- There should be measures put in place in ensuring that the set policies are implemented in health and other institutions.

- There is a need for more community-based organizations and resources to provide support to the persons with schizophrenia as the aim is on reintegrating them back into their communities.

- To address the financial burden experienced by the families, the government should consider providing social relief grants to cares of persons with schizophrenia.
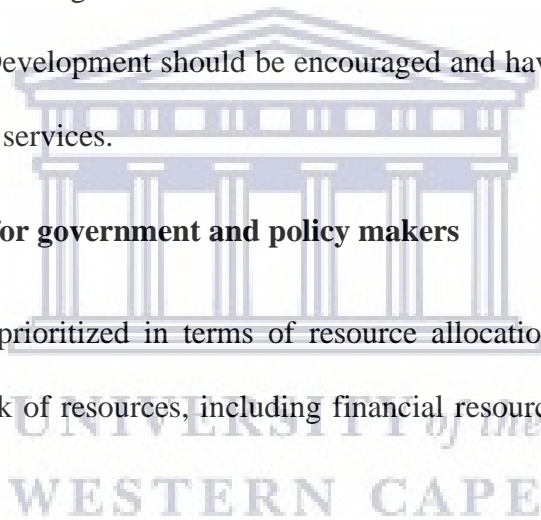
- Funding and sponsorship should be provided to community-based organizations and other stakeholders who are engaged in raising awareness about mental health.

- The labour laws and legislations should advocate for the employment of persons with schizophrenia and other serious mental illnesses.

- The media can be used to address the stigma and stereotypes surrounding schizophrenia thereby providing all the necessary information about mental illness.

6.3.4 Recommendations for future research

- Future research need to be conducted on male family members as informal caregivers to their relatives with schizophrenia as this study particularly had females as caregivers.

- Some participants have indicated that the services they received from the health facilities were not adequate. To address this, future research can look into the experiences of caregivers with regards to the services they receive from the health institutions.

- This study was conducted with participants from families residing within Cape Town which is urban community. Research can be conducted with families from rural communities (different setting, context, culture).

- Higher Education curriculum should consider having mental health as a specialized field.

- Future research should explore and develop guidelines and models for functioning in families of persons with serious mental illness.

6.4 CONCLUSION

The research question for the study was: What are the lived experiences of family members caring for family members diagnosed with schizophrenia? The research question was answered using a qualitative research approach to explore the lived experiences of families living with a relative with schizophrenia. The literature reviewed suggested that living with a relative with schizophrenia has an influence on the family. This include an influence on the family finances,

family relationships, family functioning, health of other family members, and the psychological well-being of other family members and caregivers.

Adding to this, families struggle with non-compliance to medication by the relative who is diagnosed with schizophrenia which is exacerbated by the abuse of substances. These lead to difficult behaviours such as violence and self-harm and that contributes to stress. The safety of the relative with schizophrenia and other family members is of great concern. The FST framework allowed the researcher to explore the family structure and its functioning within the context of having a relative with schizophrenia and how the illness impacts on these structures and functioning within the family. The utilized methodology allowed the researcher to collect relevant information from the participants, leading to the data analysis which yielded the themes and sub-themes that were detailed in this report. The experiences of participants as presented and discussed in Chapter Five highlight the challenges experienced in living and caring for a relative with schizophrenia. Recommendations on measures to be considered to improve the services and for future research are provided.

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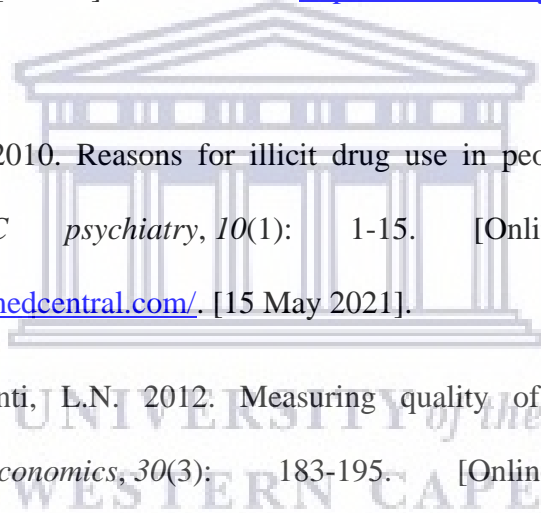
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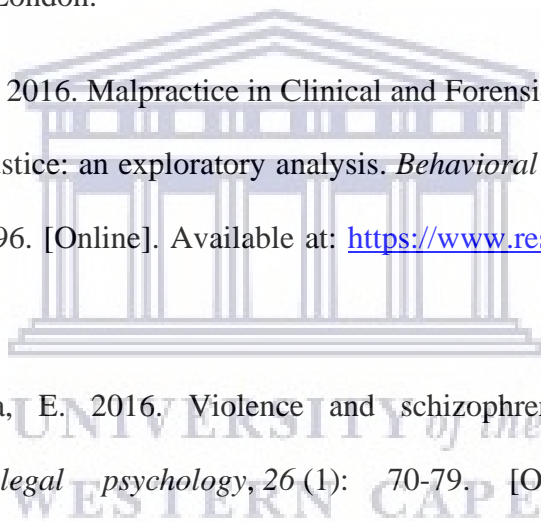
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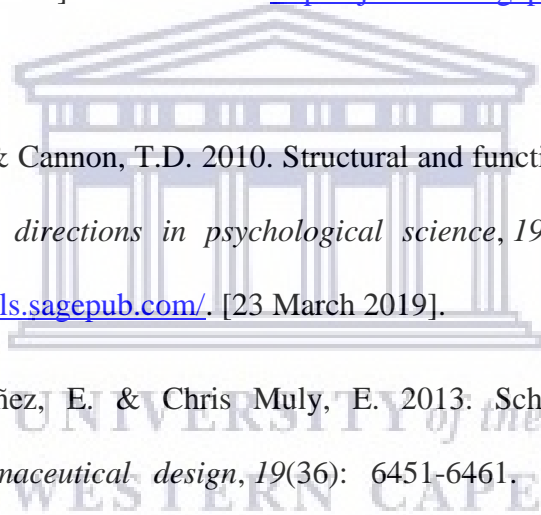
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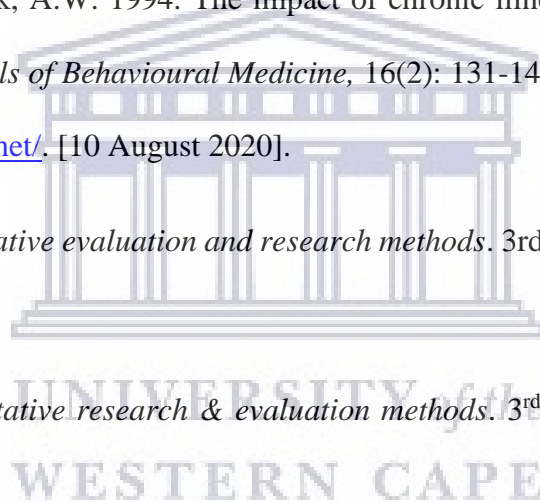
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APPENDICES:

APPENDIX A: ETHICS CLEARANCE LETTER

OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535
South Africa
T: +27 21 959 4111/2948
F: +27 21 959 3170
E: research-ethics@uwc.ac.za
www.uwc.ac.za

13 September 2019

Ms K Nqabeni
Social Work
Faculty of Community and Health Science

Ethics Reference Number: BM19/7/1

Project Title: Experiences of families living with a family member diagnosed wit schizophrenia.

Approval Period: 30 August 2019 – 30 August 2020

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

BMREC REGISTRATION NUMBER –130416-050

APPENDIX B: PERMISSION LETTER FROM THE SUPPORT GROUP

CAPE SUPPORT FOR MENTAL HEALTH

NPO: 040-491
P O Box 236, Rondebosch, Cape Town, 7701
capesupport@eject.co.za

Ph/fax: 021-671 1573

24th May 2019

<u>To whom it may concern</u>

Cape Support for Mental Health is a support group for the parents, relatives and carers of people living with schizophrenia. This serves to confirm that Ms Khuselwa Nqabeni, student number 3467366, has consent to interview members of our organisation for her Master of Social Work thesis.

Regards

Ms Raydie Syms

Chairperson

UNIVERSITY *of the*

WESTERN CAPE

APPENDIX C: INFORMATION SHEET

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

E-mail: 3467366@myuwc.ac.za

INFORMATION SHEET

Project Title: Experiences of families living with a family member diagnosed with schizophrenia

What is this study about?

This is a research project being conducted by Khuselwa Nqabeni at the University of the Western Cape. We are inviting you to participate in this research project because you have knowledge in living with a family member diagnosed with schizophrenia. The purpose of this research project is to explore and describe the experiences of families in living with persons affected with schizophrenia and to give recommendations to the inter-disciplinary team in providing services to families or people diagnosed with schizophrenia.

What will I be asked to do if I agree to participate?

You will be asked to participate in interviews that will be conducted about the experiences of families in living with and providing care to persons diagnosed with schizophrenia.

The interviews will be conducted at your home and it will take approximately 30 minutes.

Would my participation in this study be kept confidential?

The researcher undertake to protect your identity and the nature of your contribution. To ensure your anonymity, the researcher will not use your real name during the interview and when transcribing the interviews. The data will be kept in a locked cabinet and data will be on the computer where only the researcher and her supervisors will have access to it. In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

There may be some risks from participating in this research study. You will provide information which might contribute to you being emotional or which might influence the way you perceive these things. All human interactions and talking about self or others carry some amount of risks. The researcher will minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during your participation in this study.

Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. Service delivery to you, your family or the person with a mental illness will not be influenced by the participation in the research.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the experience of families regarding relatives with schizophrenia, caring for them and living in a family with a member with schizophrenia. We hope that, in the future, other people might benefit from this study through improved understanding of the influence mental illness has on caregivers and families.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Khuselwa Ngabeni from the Social Work Department at the University of the Western Cape. If you have any questions about the research study itself, please contact Khuselwa at cell phone number: 078 466 7817 or email at: 3467366@myuwc.ac.za.
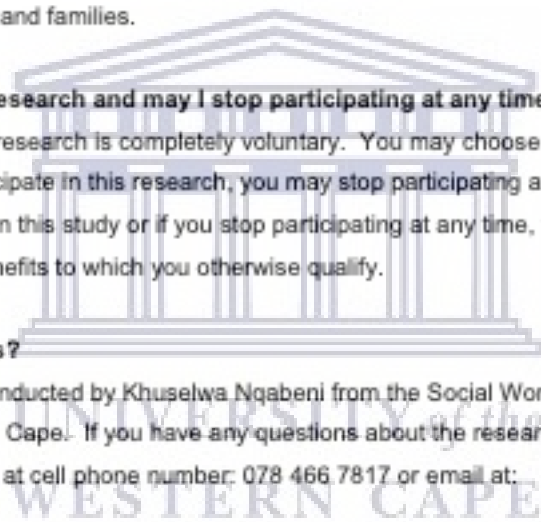
Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Research supervisor: Dr A. Beytell

Social Work Department

Tel: (021) 959 2821

Email: ambeytel@uwc.ac.za

Head of Department: Dr M. Londt

Social Work Department

Tel: (021) 959 2277

Email: mlondt@uwc.ac.za

Dean of the Faculty of Community and Health Sciences:

Prof A. Rhoda

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

University of the Western Cape Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville 7535

Tel: (021)

Email:

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

APPENDIX D: CONSENT FORM

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

E-mail: 3467366@myuwc.ac.za

CONSENT FORM

TITLE OF RESEARCH PROJECT: EXPERIENCES OF FAMILIES LIVING WITH A FAMILY MEMBER DIAGNOSED WITH SCHIZOPHRENIA

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I agree that the interview can be audio-recorded.

Participant's name..................................

Participant's signature.....................................
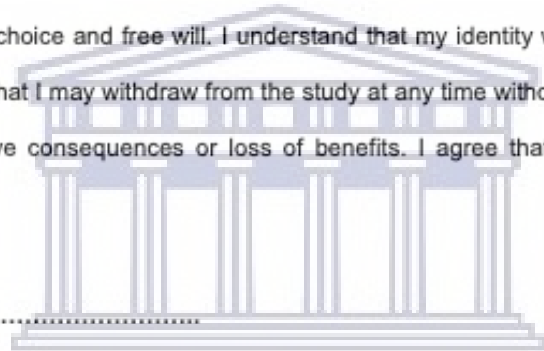
Date..........................

APPENDIX E: INTERVIEW SCHEDULE

Interview schedule for the experiences of families living with a family member diagnosed with schizophrenia

Date of interview: _____ **Pseudonym:**_____

Introductions: My name is Khuselwa Nqabeni and I will be conducting this research. As someone that lives with person affected with schizophrenia it will be good to interview you. I hope to use this information for my research and to give recommendations to the health care workers in providing services to families or people diagnosed with schizophrenia. This interview should take about 1 hour.

> *Main question*: Tell me how it is to live with a family member with schizophrenia in the house?

- What have you experienced in terms of the phenomenon? The researcher will ask: Tell me about your experiences living with a family member diagnosed with schizophrenia?

- What contexts or situations have typically influenced or affected your experiences of the phenomenon? When the participant explains an experience e.g. that the person gets angry and destructive the researcher will ask for example: What happens when the person gets angry? What are the reasons why the person gets angry?

## APPENDIX F: EDITOR'S CERTIFICATE

THE EDITING CENTRE

10 ANISE ST

BARDALE 1

KUILSRIVER

CAPE TOWN

CELL: 0817214984

CERTIFICATE OF EDITING

To whom it may concern:

This letter confirms that the Dissertation detailed below was edited by the professional English-language editing staff at **The Editing Centre** and was finalized on the 23rd of Aug2021.

Best Regards,

Mambambo John (PhD)
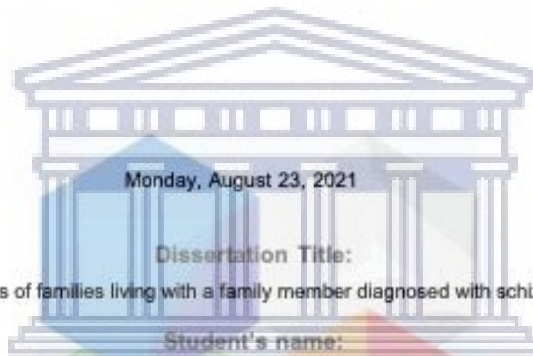
Monday, August 23, 2021

Dissertation Title:

Experiences of families living with a family member diagnosed with schizophrenia

Student's name:

Khuselwa Nqabeni

Supervisor:

Dr. R. Davids

Co-Supervisor:

Dr. A. Beytell

To validate this certificate, please call Dr. J. Mambambo on the contacts above.

The Editing Centre makes no claim as to the accuracy of the research content or objectives of the researcher. However, the text as edited is endorsed as grammatically correct. If you have any questions or concerns, please contact us at 0817214984.