

**Experiences and coping
strategies of caregivers of
people living with mental illness
in Emfuleni Local Municipality**

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for the degree *Master of Social Work* at the
North-West University

Supervisor:

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DECLARATION

I declare that “Experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality” is my own work. All sources used or referred to have been specified and recognised by means of validated references.

DEDICATION

This dissertation is dedicated to my beloved family, who have always encouraged me to pursue my education. Thank you for your unconditional love and continuous support in all my endeavours. You have been the wind beneath my wings!

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I thank God, Almighty for the strength, wisdom and resilience He gave me throughout this journey.

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ABSTRACT

Inspired by an experience during block practicums as a 4th year Student Social Worker at Vaal Mental Health, an organisation working with people living with mental illness and their families. The researcher observed different challenges experienced by caregivers of people living with mental illness, and became aware of the extent of the problem. In addition, the researcher saw the need to conduct research on how caregivers experienced and coped with caring for a person living with mental illness. The results of this study will contribute to the ongoing body of information in social work departments and contribute to the knowledge base about mental health within the area of Emfuleni Local Municipality. The aim of the study was to portray the experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality. The study was divided into two research objectives which were: to describe the experiences of caregivers of people living with mental illness in Emfuleni Local Municipality; and to ascertain the coping strategies of caregivers of people with mental illness in Emfuleni Local Municipality. The research followed a qualitative research approach and Qualitative Descriptive research design. Twelve participants (12) between the ages of 18 and 70 years were selected using purposive sampling. Participants were selected from three mental health care facilities, namely Johan Heyns CHC, Levai Mbatha CHC, and Vaal Mental Health Organisation. Six (6) caregivers from Johan Heyns CHC, three (3) caregivers from Levai Mbatha CHC, and three (3) caregivers from Vaal Mental Health Organisation participated in the research study. The findings of this study evidenced that caregivers of people living with mental illness in Emfuleni Local Municipality assumed healthcare roles such as supervising medication, treatment schedules, bathing, and feeding the persons with mental illness. They expressed a whole spectrum of emotions ranging from anger, fear and frustration in reaction to the behaviour of the person with mental illness; feelings of helplessness and confusion from the disruptive behaviour of the person with mental illness; feeling emotionally drained and exhausted; putting own health at risk; and experiencing financial difficulties and family conflicts. The study also revealed that caregivers used social support (family and friends, spousal, and professional support), religious practices (praying, reading the bible, faith in God), counselling and intervention services (assistance from social workers, psychologists, police, and other professionals), creativity, distraction, and motivation (attachment, love, sense of responsibility) as coping strategies. The findings of the investigation then informed the recommendations arrived at, about best practices and plans that need to be considered to rise to the current challenge as a matter of urgency in this social and health arena.

Keywords: experiences, mental illness, coping strategies, caregiver, Emfuleni Local Municipality

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CHAPTER ONE

INTRODUCTION TO THE STUDY

1.1 Introduction and rationale to the study

The World Health Organisation (WHO) estimated that one in four families has one member diagnosed with a mental illness and that mental illnesses will constitute the largest global burden of disease within a decade (WHO, 2001) (as cited by Rahmani, Ranjbar, Hosseinzadeh, Sajjad, Dickens, & Vahidi., 2019). WHO indicated that a substantial number of people within families are living with mental illness and there is a possibility that mental illness will continue to have an impact on people who are directly or indirectly affected by it. This impact varies and can interfere, and sometimes delay some facets of life.

To start with, Terzungwe and Ph (2016) confirmed that caregivers of people living with mental illness may consequently neglect their physical, emotional, psychological, and social health while caring for a person living with mental illness. Rahmani et al. (2019) further postulated that problems which may affect caregivers of people living with mental illness are: absenteeism at work; financial burden; and lack of social relationships or social activities causing the inability to function effectively. Rahmani et al. (2019) added that caregiving may influence caregivers themselves, which may directly affect the care provided to mental illness patients.

Arevalo-Flechas, Acton, Escamilla, Bonner, and Lewis (2013) found that caregivers of persons diagnosed with schizophrenia (mental illness) experience higher subjective and objective caregiver burden; lower general health; and lower social, physical, and emotional functioning. Arevalo-Flechas et al. (2013) further outlined that a typical caregiver may be responsible for caregiving for a person living with a mental illness while juggling the demands of being an employee and working. Grover, Nehra, Malhotra, and Kate (2017) allude to the fact that there is an increasing dependency of mental illness patients on caregivers, with the role of caregiving being to manage the mental illness.

However, caregiving is also associated with positive aspects of satisfaction and pride, which both come from fulfilling the role of a caregiver, finding meaning, and finding purpose in life (Grover et al., 2017). Monteiro, Santos, Kimura, Baptista, and Dourado (2017) found that emotion-focused coping mechanisms were the most used among caregivers. These coping strategies are associated with spirituality. Additionally, problem-solving coping reduces the impact of psychological distress, while dysfunctional coping mechanisms increase the caregiver's burden. Terzungwe and Ph (2016) however, postulated that mental illness in Ghana is viewed by many as manifestations of diabolical manipulation. Therefore, caregivers of people diagnosed with mental illness need emotional and psychoeducational support to effectively cope and provide care for their mentally ill relatives. Terzungwe and Ph (2016) further found that coping strategies used by caregivers of family members living with a mental illness include beliefs, attitudes, spiritual assistance, and healthcare services.

In South Africa, the burden of mental illness is reported to be very high, with a prevalence of mental illness estimated to be one in three (Monnapula-Mazabane & Petersen, 2021). In the face of this adversity, there is a gap in treatment, with approximately 75% of people living with a mental illness not having access to any type of treatment (Monnapula-Mazabane & Petersen, 2021). Formal community mental health services that is, residential facilities, centres, rehabilitation services, and other organisations and institutions are scarce in South Africa; there is a huge reliance on informal community mental health services provided by primary caregivers or families (Monnapula-Mazabane & Petersen, 2021).

Shilubane and Mazibuko (2020) found that some primary caregivers associated mental illness with witchcraft. Therefore, they sought help from traditional healers before consulting with medical doctors or clinicians, thus defaulting treatment in patients. As a result, this treatment default in patients living with mental illness causes an increased emotional and psychological burden on their caregivers. Shilubane and Mazibuko (2020) further found that most of the caregivers from South African families use acceptance as the main coping mechanism in caregiving for patients living with mental illness.

In October 2015, the Life Esidimeni tragedy in Gauteng, South Africa where 144 patients with mental illness died in undignified conditions led to recommendations by the Gauteng Department of Health (GDOH) regarding human rights and healthcare of people with mental illness (Robertson, Moosa, & Jeenah., 2021). These patients were transferred from Life Esidimeni to unsuitable Non-Government Organisations (NGOs) and hospitals where they were not well taken care of. It was recommended that specialist psychiatric expertise should be provided for patients with severe mental illness and primary caregiving should be provided for patients with moderate or uncomplicated mental illness. These primary caregivers included families of persons living with mental illness and carers at NGO's and psychiatric hospitals. These caregivers were not well trained to provide mental care services to the patients and experienced lack of funding (Robertson et al., 2021).

1.2 Problem statement and research questions

In 2021, the researcher was doing her block practicum as a 4th-year student social worker for a Non-Profit Organisation (NPO), Vaal Mental Health Organisation, situated in a township called Sebokeng under the Emfuleni Local Municipality, Gauteng. She worked along with social workers working with adults and children diagnosed with mental illnesses. During this block practicum placement period, there was a case reported where a caregiver (woman) was physically assaulted by her son who was diagnosed with substance-induced disorder and schizophrenia; she was bleeding to the point where she had to be taken to the hospital for medical care. Post-intervention of taking the caregiver to the hospital, there were no follow-ups done on how the caregiver was doing physically and emotionally as the social worker had quite a number of cases to attend to. There was another case where a caregiver came to the organisation to report that her brother, who was diagnosed with Schizophrenia, physically attacked the whole family, and vandalised everything in the house. Another case reported was of a caregiver who was often physically assaulted by her grandson who was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and Conduct disorder, this 15-year-old child physically assaulted everyone in the house, he smoked substances and had other behavioural problems (stealing and absconding from school), which negatively impacted the caregiver. Lastly, there was another caregiver from a Child and Youth Care Centre (CYCC) in

Meyerton, Gauteng who reported that she wanted one of the children (diagnosed with Anxiety disorder) who was a resident at their centre and a client at Vaal Mental Health Organisation to be transferred to another CYCC because she could not put up with his problematic behaviour of attempting to commit suicide multiple times, refusing to physically care for himself and taking treatment. She further stated that the child's behaviour is traumatic to other children and to her as a caregiver.

There was a substantial number of cases reported to social workers by caregivers of people living with mental illness each week during this period. The researcher also observed that some of the caregivers of children living with mental illness were struggling to financially care for their children who lived with mental illness because these children require special care and have special needs. Some caregivers were struggling financially because they did not have identity documents to apply for government grants and some were still in the process of applying for identity documents. Most of these caregivers who were burdened were from African low-income households.

There were a vast number of reports by caregivers who were emotionally exhausted from caring for their children living with mental illness and needed to be assisted by the social worker to apply for alternative care. Furthermore, the researcher observed that most caregivers used social services to cope with their problems as they reported issues that they experienced with caregiving for their family members with mental illness to social workers. These caregivers were then referred to psychologists and psychiatrists for further assistance. Some of the caregivers were referred to the South African Police Service (SAPS) to intervene on issues of violence caused by a person living with mental illness within the family.

Approximately 248 cases relating to caregivers of people with mental illness were carried forward between the months of July and November 2021 according to Vaal Mental Health Organisation statistics. Inspired by this experience, the researcher became aware of the extent of the problem and saw the need to conduct research on how caregivers experienced and coped with caring for a person living with mental illness.

To describe the experiences and coping strategies of caregivers of people living with mental illness, the following research questions were asked.

1.3 Research question

A research question is a question that a research project aims to answer. Research questions set out new insights and send the researcher on a mission to identify and collect data (Mattick, Johnston, & de la Croix., 2018).

This study proposed the main research question aligned to the aim of the study:

- What are the experiences and coping strategies of caregivers of people living with mental illness in the Emfuleni Local Municipality?

In addition, this study proposed two research questions aligned to the objectives of the study:

- What are the experiences of caregivers of caring for people living with mental illness in the Emfuleni Local Municipality?
- What are the coping strategies of caregivers of caring for people living with mental illness in the Emfuleni Local Municipality?

1.4 Research aims and objectives of the study

The aim and objectives of the study were conceptualized as follows:

1.4.1 Aim

To describe the experiences and coping strategies of caregivers of people with mental illness in the Emfuleni Local Municipality.

1.4.2 Objectives

The objectives were set as follows:

- To describe the experiences of caregivers of people living with mental illness in the Emfuleni Local Municipality.

- To ascertain the coping strategies of caregivers of people living with mental illness in the Emfuleni Local Municipality.

1.5 Contribution of the study

It is necessary to conduct this study because the stress on family caregivers is overwhelming and there is a need to conduct research on that. Understanding variations in the coping strategies of caregivers of a mentally ill family member is essential for further possible intervention by mental health professionals to assist the caregiver. This study will contribute to the knowledge base about mental health within the area of Emfuleni Local Municipality. After the findings of the study, it is hoped that social workers employed in mental health host settings could work on developing interventions to assist caregivers of people with mental illness and not only the patients or clients through a multidimensional intervention plan, for example, the creation of support groups for caregivers to provide counselling or any other form of assistance.

The results of this study will contribute to the ongoing body of information in social work departments. Other mental health institutions and organisations such as psychiatric hospitals and counselling centres in the Emfuleni Local Municipality, like, Sebokeng hospital, Empilisweni clinic, Family and Marriage Society of South Africa (FAMSA) in Sebokeng, the South African National Council on Alcoholism and Drug Dependence (SANCA) in Vanderbijlpark, Kopanong Hospital in Vereeniging and LIFELINE may benefit from this study by having knowledge on the topic with the hope of further developing interventions for caregivers of people living with mental illness as they directly work with families of people diagnosed with mental illness.

1.6 Scope and demarcation of the study

The study was conducted in Emfuleni Local Municipality, Gauteng Province, focusing on three institutions. The institutions included Vaal Mental Health Organisation, Johan Heyns Community Health Centre, and Levai Mbatha Community Health Centre. 12 participants of caregivers of people living mental illness were selected and were the population of the study. Six (6) caregivers from Johan Heyns CHC, three (3) caregivers from Levai Mbatha CHC, and three (3) caregivers from Vaal Mental Health Organisation participated in the research study.

The motivation for focusing on these three institutions is that the researcher conducted her practicums at Vaal Mental Health and is familiar with the issues experienced by caregivers at the organisation and she travelled along with caregivers and their children with mental illness to Levai Mbatha CHC and Johan Heyns CHC for psychiatric evaluation and treatment with a psychiatrist. Practically, the researcher observed and spoke with some of the caregivers who are clients of these three institutions. These three institutions count among their staff, social workers, nurses, psychologists, and psychiatrists who work directly with caregivers of people living with mental illness. These mental health professionals within these institutions were able to identify the prospective participants for this study, who provided rich insight and were able to make this study feasible.

Furthermore, the three institutions were selected because they represented a town and township context where mental health service is provided in Emfuleni Local Municipality. In terms of literature on caregivers of people living with mental illness, the researcher established that there is a dearth of literature pertaining to the topic in this local municipality. Previous studies have focused mainly on other African countries and South Africa at large without focusing on specific small regions within South Africa and this creates a gap in literature. Some of the studies from other African countries which address experiences of caregivers of person living with mental illness include Gloria et al., (2018), Mc Nally (2011), and Ndeti, Pizzo, Khasakhala, Maru, Mutiso, Ongecha-Owuor, and Kokonya (2009) . In addition, some of the studies which generalise South African results in regards to experiences of caregivers of people living with mental illness include Guruyah (2015), Monnapula-Mazabane and Peterson (2021), and Ntsayagae, 2013). Subsequent to this, the researcher deemed it justifiable to conduct the research study in this local municipality to further the ongoing discussions on caregivers of people living with mental illness in Gauteng province, particularly in the Emfuleni Local Municipality.

1.7 Limitations and delimitations

During the study process, there were existing limitations and delimitations which emerged that affected the results of the study and needed to be taken into consideration.

1.7.1 Limitations

- Most of the participants came from low income households, followed by middle income households, and none came from high income households. Therefore, the experiences of high income households were not represented.
- The study was conducted only in Vaal Mental Organisation, Johan Heyns CHC, and Levai Mbatha CHC in Emfuleni Local Municipality and not the whole of Gauteng. Therefore, external validity and generalisations of the findings might be limited.
- Getting permission from the Department of Health and Social Development was very stressful. The waiting period to receive permission affected the time frame of the study but did not affect the findings because permission was finally granted.

1.7.2 Delimitations

- Only caregivers of people living with mental illness who were clients at Vaal Mental Health Organisation, Johan Heyns and Levai Mbatha CHC were included in the study.
- All caregivers cared for one or more adults or children diagnosed with a specific mental illness.
- The focus of the study was only on the caregivers caring for patients living with mental illness and not patients living with mental illness.
- No limit on gender and socioeconomic condition was put on the participants.

1.8 Ethical considerations

The entire section of ethics is discussed in detail in Chapter Three under ethical considerations. The following process was followed to conduct the study:

- The study was approved by the Health Research Ethics Committee of the North-West University. The researcher then requested and secured legal permission from the Department of Social Development and Department of Health as they are both departments to which mental health organisation/institutions affiliate and from which they receive support and funds.
- The inclusion criteria included that participants should all reside in the Emfuleni Local Municipality; be caregivers (either male or female) of people living with a mental illness; all be aged 18 to 70 years; can communicate in either English or Sesotho; and

receive services from Vaal Health Organisation, Levai Mbatha Community Health Centre and Johan Heyns Community Health Centre.

- The exclusion criteria applied if participants had mental difficulties that delay comprehension of speech as they would not be able to provide important information. In addition, are visually impaired and deaf. A participant would not be able to read an informed consent as the researcher is not trained about the system of braille. The researcher is also not trained to communicate in sign language. The time frame of the research would be delayed if the researcher was to receive such training.
- The researcher briefed the mediators (social workers and professional nurses who recruited participants) about the study. The mediators were able to explain the study to caregivers in the language they understood best (English or Sesotho). The independent person (a Bachelor of Social Work Honours graduate) was also able to explain the informed consent process to the participants in the language they understood. Recruitment material and informed consent forms were translated to Sesotho.
- Prospective participants were individually approached by the independent person at the respective organisation and Community Health Centres in a private room to explain the informed consent process. All participants were given a suitable time (a maximum of 72 hours) to direct questions to the independent person or raise concerns to thoroughly understand what is being asked of them.
- After 72 hours, prospective participants who showed interest in the study, were expected to sign the informed consent form in front of the independent person at the respective organisation and community health centre in a private room. The participants were not to be given consent forms to avoid loss or accidental defacement thereof in their homes.

Roshaidai and Arifin, (2018) provide guidance with respect to ethics. The following ethical considerations were kept in mind:

- The purpose of the research study was explained to all participants. They were provided with informed consent forms, and it was clarified that the semi-structured interviews would be audio recorded. (see ANNEXTURES A and B for informed consent forms and interview transcript, ANNEXTURE C)

- Participants were not misled into participating and were clearly told about what was expected of them.
- Participation was voluntary, and participants were allowed to withdraw from the research study at any time without being implicated in any way.
- No harm was done to any participants.
- During interviews, no participant was forced to answer any question if they were uncomfortable with it.
- The researcher made further provision for credibility by adopting a well-established research method.
- All participants were assured of confidentiality of the interviews.
- The researcher ensured honesty by establishing rapport with the participants.
- The researcher also ensured she had adequate knowledge to conduct semi-structured interviews and data analysis.

1.9 Definitions of terms

The following definitions are significant for the study:

1.9.1 Mental illness

It is reflected in the Mental Health Care Act 26 of 2020 that mental illness is a disorder of perception, mood, thinking, or memory that impairs behaviour, judgement, and capacity to recognise reality (Mental Health Care Act 26 of 2020).

For the purpose of this study, the researcher was not selective, but rather focused on all types of mental illnesses as a whole e.g. schizophrenia, bipolar disorder, anxiety disorder, major depressive disorder and other types of mental illnesses to avoid gathering limited information.

1.9.2 Experience

Experience is the knowledge and skill that one has gained through doing something for a period. Experiences are effects that happen to an individual that influence the way one thinks and behaves (Hornby, 2017).

1.9.3 Coping strategies

Coping strategies are specific behavioural and psychological efforts to minimise stressful events. These strategies include all the cognitive, emotional, and behavioural measures adopted by an individual in response to specific internal and/or external demands that exceed his or her resources (Monteiro et al., 2017).

1.9.4 Caregiver

A caregiver is a person, relative or non-relative, responsible for caring after a person who cannot look after himself or herself in all or some aspects (Martin & Pierson, 2010). This type of caregiving is informal and is likely to be provided without any monetary reward (Soltys & Tyburski, 2020). The care may also be supplemented by residential social welfare and health institution carers as part of their work (Martin & Pierson, 2010). This type of caregiving is formal and is likely to be provided with the aim of receiving monetary value (Soltys & Tyburski, 2020).

For the purpose of this study, caregivers referred to informal caregivers who are relatives or non-relatives providing care to a person living with mental illness. These caregivers live with the individual that they are caring for who is living with a mental illness.

1.10 Preliminary literature Review and Theoretical framework

1.10.1 Preliminary Literature Review

A summary of relevant literature concerning the topic and objectives of the study is provided in this section, while a full literature review will be provided in detail in Chapter Two.

Sin, Henderson, Cornelius, Chen, Elkes, Woodham. Hernandez, Spence-Polin, Batchelor, and Gillard (2020) state that the responsibility of caring often means that caregivers of people with mental illness experience increased vulnerability to ill health. Furthermore, caregivers' psychiatric morbidities are correlated with the amount of care they provide; that is the higher amount of care provided lead to poorer mental health. Poor mental health in caregivers can negatively impact their caregiving capacity.

Marimbe, Cowan, Kajawu, Muchirahondo, & Lund (2016: 1) state that caring for a family member with mental illness places a challenge on family caregivers and has been shown to have an impact on the caregiver's quality of life. However, the extent of the caregiver burden is often difficult to assess, and as a result, is frequently ignored. Mental health services are inadequate in low-to middle-income households, in contrast with high-income households, where community-based resources are relatively more available.

It is described in Coetzee (2016:39) that although the majority of mental illness family research has focused on the negative consequences of caregiving among family members of persons who has a mental illness, an increasing body of literature has described positive aspects of caregiving for a person living with mental illness. Caregivers have pointed out that their relationship with their relatives was only characterised by challenges, but also love, commitment, and joy. This love and commitment towards their relative with a mental illness motivated them to seek and access mental health services. Furthermore, caregivers of children with mental illness have also reported increased levels of satisfaction once they had adjusted to the requirements of caregiving (Coetzee, 2016:40). Lastly, it has also been stipulated that caregivers gain enhanced efficacy and skills from their caregiving roles for children living with mental illness.

In a South African study by Mkabile, Shelton, and Swartz (2021:7) it has been reported that some caregivers accept that giving birth to, or caring for a child with mental illness was God's will. These caregivers would then take their children to churches to pray for deliverance. In addition, caregivers reported empowering themselves by learning new home-based skills to better manage individuals with mental illness in their homes. The use of respite care, where mentally ill relatives were admitted to the hospital to alleviate the effects of caregiving led to caregivers being relieved from caring for their relative with mental illness (Ntsayagae, Poggenpoel. & Myburgh, 2019:8). It has been discussed in this study Mokgothu (2012:24) that caregivers play a role in increasing treatment compliance in patients with mental illness by supervising and monitoring the drug intake and taking the patient to doctor's appointments.

(Mokgothu, 2012) found that most of the caregivers reported using external resources as reinforcement to support their mentally ill family members. This included the South African Police Service, mostly to assist them apprehend their aggressive and violent mentally ill family

members. The caregivers reported the need for their mentally ill family member to go back to the hospital, if there is a need to, as it was to the advantage of the whole family. Some caregivers reported assistance by their neighbours when they are not around to care for the mentally ill family member.

1.10. 2. Theoretical Framework

For this study, the researcher saw it appropriate to be guided by the following theory along with models to describe the experiences and coping strategies of caregivers of people living with mental illness.

1.10.2.1. Ecosystem's theory

The ecosystem theory postulates that no client system can be understood apart from its social or environmental context. The theory is formulated to ensure that full attention is paid to the case, reducing the risk of isolating the client system from its environment. The theory provides a guideline on what to focus on, what needs to be examined, and what the limitations of the case are (Sowers & Dulmud, 2008). This theory helped the researcher to keep in mind the strengths or limitations that present with caregiving as a significant barrier or contribution to providing effective care to patients living with mental illness. In this study, caregivers revealed some negative experiences associated with caregiving which appeared as limitations to providing effective care. In addition, some of the coping strategies expressed by caregivers in response to caring for a family member with mental illness proved to be a point of strength.

Furthermore, this section presents models on which this study is built, namely, the family resilience model, the multidimensional model, and the stress process models which are closely related to the ecosystem's theory.

1.10.2.2 The family resilience model

The family resilience model helps practitioners distinguish and identify patterns on how family life relates to resilience (Welch & Harrist, 2017). The model has to do with identifying objects in family lives that deserve to be described. The family resilience theory raises concern that construct family actions and experience of its meaning to the family (Welch & Harrist, 2017).

Resilience in the face of a mental illness requires the flexibility of roles and responsibilities. Family identity may be implicated in the early diagnosis of a mental illness (Welch & Harrist, 2017). It is revealed in a study by Hogan and John-langba (2016) which states that resilience posits that difficulties that families face during the course of a lifetime are part of human experience. Henceforth, some families appear to be able to handle these difficulties while others are too overwhelmed to cope. An individual's resiliency within a family is determined by the interaction of risk and protective factors. In this study, caregivers revealed that their value for family, love for people and a sense of responsibility towards their care recipients motivated them to continue their role of caregiving without giving up, which shows resilience.

1.10.2.3 Multidimensional model

The multidimensional model is an integrative outpatient treatment model that targets the interconnected domains of a family member's development within these contexts, and the circumstances and processes that create dysfunction (Liddle, Dakof, Henderson, & Rowe., 2011). The model works in four domains, namely, changes in the family member, functioning of the parent and parenting, family environment, and external systems that influence the family member and family.

The multidimensional model is a comprehensive process that not only identifies problems, symptoms, and co-occurring disorders, but also identifies risk and protective factors in all relevant domains, so that these aspects can change (Liddle et al., 2011).

Through conducting semi-structured interviews, the researcher sought to answer critical questions about the functioning of the caregivers' life domain. It is based on empirically derived knowledge of family members' problems and their life contexts as well as strengths, to provide a combination of assets and weaknesses that the family member, family, and other systems bring (Liddle et al., 2011). The model addresses factors underlying emotional and behavioural symptoms that occur with mental illness, more especially family relationship factors, parenting practices, family conflict, and communication. These factors influence a range of negative developmental outcomes (Liddle et al., 2011).

1.10.2.4 Stress process model

According to Yu, Liu, Xiao, & Kraemer (2020), the stress process model of caregivers indicate that caregiving is a stressor, which can result in psychological distress. The impact of caregiving is influenced by a variety of variables, including experience tied to one's kinship, social support, demographic background, coping, and culture. The model is comprised of four domains: background and context of stress (these are the socio-economic characteristics of the caregiver); stressors (includes primary and secondary stressors); mediators of stress (social support and coping explain the variability in responses to caregiver burden); and finally, outcomes of stress (includes physical and mental well-being of the caregiver). Caregiving stressors impact caregivers' emotional distress both directly and through mediating factors. When associating stress with caregiver-coping, it is mentioned that in order to establish coping strategies it must first be established how the caregiver has appraised a situation, have they judged it as irrelevant, stressful or stressful? (Hogan & John-langba, 2016).

The theoretical framework discussed in this section framed the experiences of caregivers of people living with mental illness and their coping strategies measured to deal with challenges that came with caring for such an individual.

1.11 Research methodology

The research methodology discussion at this point is merely a brief explanation of the methodology of the study and this is explained in detail in Chapter Three.

This study followed a qualitative research approach. This research approach is an iterative process in which understanding of the phenomenon is achieved by making new significant distinctions resulting from getting closer to what is being studied or researched (phenomenon) (Aspers & Corte, 2019). The researcher used a qualitative research approach to acquire information about the experiences and coping strategies of caregivers caring for people with mental illness. The researcher acknowledged and understood the participants' experiences and coping strategies as perceived from their reality.

Furthermore, this study followed a Qualitative Descriptive (QD) research design. This design is used as a method that provided a rich description of the caregivers' experiences and how they cope with caring for a person living with mental illness. The findings produced in a qualitative descriptive research study provide given data, which is the voice of the participants' experiences

(Rainbow, Dolan, & Farland., 2021). Sandelowski, (2000) (as cited by Bradshaw, Atkinson, & Doody., 2017:3) alludes that qualitative descriptive research design is a method that researchers can claim unashamedly without resorting to methodological acrobatics. Descriptions always depend on participants' perceptions, sensitivities and inclinations. The description in qualitative descriptive research studies features the participants' presentation of the facts in everyday language (Sandelowski, 2000) (as cited by Bradshaw, Atkinson, & Doody., 2017:3). Qualitative description is more interpretive.

Sandelowski (2000) (as cited by Bradshaw, Atkinson, & Doody., 2017:3) further postulates that qualitative descriptive research studies offer a comprehensive summary of an event in the everyday terms of the event. Researchers conducting qualitative descriptive research studies stay closer to their data and to the surface of the participants' words and events. Therefore, in this study the researcher described the caregivers' experiences and coping strategies in the participants' own language of preference, which is Sesotho or English. Usually open-ended or semi-structured interviews are used in qualitative descriptive research design (Neergaard, Olesen, Andersen, & Sondergaard., 2009). In this study, the researcher used semi-structured interviews to describe the experiences of caregivers and ascertain how they cope with caring for a person living with mental illness. The researcher ensured that a complete description of the participants' experiences is captured by thoroughly understanding what the participants laid out. The researcher was interested in the -what, who, where and why of the participants' experiences and coping strategies.

Data, in the form of audio recordings, were stored in a password-protected device (personal laptop), and transferred to the researcher's password protected e-mail for backup. In terms of crosschecking data analysis, transcripts were shared with the researcher's co-coder (Dr Ejoke-UFS) through password protected e-mails. Data in the form of hard copies were locked in the researcher's secure cabinet in the NWU research commons with no access to others to ensure adherence to ethical guidelines. Written (transcripts) and electronic data (recordings) will be stored for 5 years (per the standard policies) and destroyed once they are no longer needed, this is to ensure the truthfulness of the transcriptions.

Written informed consent forms with the participants' personal information will be destroyed per the North-West University's research procedures. Consent was obtained regarding access to the data by the researcher's supervisor and other researchers to reach an agreement on the interpretation without exposing the participants' personal details at any interim stage.

The sampling method that was used for this study is purposive sampling. Purposive sampling forms part of the non-probability selection procedure. Non-probability sampling is when participants are selected based on non-random standards and not all individuals have an opportunity to be involved (Padgett, 2016). This type of sampling is based on selecting a group out of novelty, people who can deliver information to be researched through their knowledge and skills (Ames, Glenton, & Lewis., 2019).

The researcher selected the sample based purely on her knowledge and credibility. This sampling procedure fitted well into this study because the researcher chose a specific sample who can deliver the information through their knowledge and skills. Prospective participants who are not caregivers of people living with mental illness, did not have the opportunity to be part of this study.

For this study, the sample was drawn from the Emfuleni Local Municipality and made up of caregivers aged 18 to 70 years old (men and women) of people living with mental illness. The researcher limited the study to three institutions (Vaal Mental Health organisation, Johan Heyns Community Health Centre (CHC) and Levai Mbatha Community Health Centre) since the institutions are the most dominant in providing services to people living with mental illness within the municipality. These three institutions are made up of social workers, professional nurses, psychologists and psychiatrists who directly work with caregivers of people living with mental illness. These mental health professionals within these institutions were able to identify the prospective participants for this study, making this research study feasible.

Regarding data collection process, the researcher approached Vaal Mental Health Organisation, Johan Heyns CHC, and Levai Mbatha CHC to request goodwill permission to conduct the study. The researcher also requested legal permission from the Department of Health and Department of Social Development as they are departments under which mental health organisations and institutions affiliate and from which they receive support and funding. After approval was secured from Vaal Mental Health, Johan Heyns CHC, Levai Mbatha CHC, Department of Health, and Department of Social Development, the researcher then scheduled a visit to the institutions to explain the purpose of the visit and the study. The following were discussed: request of mediation, the benefits of the study, the number of participants needed for the study, refreshments and transport costs to be provided and the estimated time each interview will take.

Semi-structured interviews were used as a method of data collection so that the researcher has a thorough understanding of caregivers' experiences. In this study, the researcher asked open-ended rather than closed ended questions and the sequence of the questions were narrow to broad. The researcher administered the interviews herself. The participants were asked one question at a time, this allowed the researcher to enquire more through minimal changes, paraphrasing and clarification, to get detailed information and encouraged participants to share information.

Lastly, the researcher followed the Thematic analysis process by Braun and Clarke (2006) (as cited by Maguire & Delahunt, 2017) to analyse data. The goal of the researcher was to identify patterns in the data set and use these patterns to address the research study. This enabled the researcher to come up with themes from the gathered data. Braun and Clarke (2006) (as cited by Maguire & Delahunt, 2017) provide a six phase-guide for Thematic analysis which were adopted in this study, namely: (1) become familiar with the data set; (2) generate initial codes; (3) search for themes; (4) review themes; (5) define themes; and (6) write up. The researcher utilised the services of an independent co-coder (Dr Ejoke. Ufuoma. PhD Faculty of Humanities, Department of Psychology, University of the Free State,). The purpose of analysing the data independently was to guarantee agreement on the themes identified by the researcher from the data.

Information gained from the semi-structured interviews enabled the researcher to describe the experiences of caregivers caring for people living with mental illness and ascertain their coping strategies. The qualitative research approach combined with the Qualitative Descriptive research design was appropriate for the purpose of the study.

1.12 Layout of the study

- Chapter One:** Introduction to the study. The chapter provides background information of the study.
- Chapter Two:** Literature review. Topics related to caregivers of people living with mental illness are the focus of this chapter.
- Chapter Three:** The research methodology that was used in this study is discussed. Ethical issues and trustworthiness get amplified in this chapter.

Chapter Four: This chapter focuses on data presentation, analysis and interpretation of research findings. Responses from the qualitative measurement are presented, followed by the analysis and interpretation of the data.

Chapter Five: This chapter presents a summary, conclusions and recommendations. Final conclusions of the study are presented and prospects for further research recommended.

1.13 Conclusion

The purpose of this chapter was to introduce the study and outline the research questions and objectives. The problem of caregiver experiences and their coping strategies with caregiving for a person living with mental illness was argued. Ethical considerations with respect to this research was highlighted. A theoretical framework of the research study was outlined to guide the process of describing experiences and coping strategies of caregivers of people living with mental illness and the methodology utilized to achieve the objectives of this research study was clarified. In the following chapter, literature that is related to caregiving in the form of informal caregiving, mental illness, and providing insight into the experiences of caregivers of people living with mental illness and their coping strategies is discussed.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

Paul and Rialp (2020) postulate that a literature review provides a comprehensive overview of literature related to a theory/method/theme and synthesizes prior studies to strengthen the foundation of knowledge. A subject improves when prior research studies are synthesised logically based on the results of prior research studies. A literature review contributes significantly for methodological, conceptual, and thematic development of different domains. Thus, a literature review provides readers with an understanding of the research topic, help identify research gaps and signal future research avenues. It also places the current study within the parameters of current research and discourse on the topic.

For a literature review, Paul and Rialp (2020:3) further point out the following need to be considered to develop an impactful literature review:

- Topic selection: well-crafted literature reviews tend to be impactful.
- Article search and inclusion criteria using keywords: researchers must use their knowledge, judgement and experience many times for deciding upon clear selection criteria of articles in their sample.
- Identification of streams and time of the review.
- Appropriate title: writing a literature review implies using past and present research to explore the future.
- Research gaps and importance of directions for future research: researchers are required to identify key research gaps based upon prior research.
- Table/figures: researchers need to understand well how tables and figures tend to be structured.
- Rigor and relevance: a literature review is supposed to thoroughly synthesize a significant and important research area.

Thus, the purpose of this literature review is to draw together relevant knowledge on caregiver experiences and coping strategies with caring for mental illness patients and connect the literature and the research findings. The following process was applied to review all the relevant past and current research on the topic of caregiver experiences and coping strategies with caring for mental illness patients.

SABINET, ProQuest, Scopus, EBSCOhost, Web of Science, Google Scholar, Science Direct, Sage Publications, Emerald Insights, and Boloka Institutional Respiratory: NWU were the databases and search engines utilised in the search. The focus of the electronic search was to find the whole text, which decreased the possibility of overlooking significant studies. Furthermore, a researcher consulted with the librarian to access more articles and books.

The following inclusion criteria were used to help identify relevant research studies using key words regarding the topic of caregiving and mental illness patients:

- Chapters in books.
- Full-text journal articles;
- Higher degree papers.

The studies and research papers covered current and past research that could address the research questions for this study.

The following exclusion criteria were used:

- Duplicate reports of an equivalent study.
- Non-researched documents.
- Studies that are not in English.

The literature consulted providing a deeper understanding of the problem of caregiving for people living with mental illness and coping strategies of these caregivers. The literature is provided with a focus on the following classifications: explaining informal caregiving, experiences of caregivers of people with mental illness, what mental illness is; and coping strategies of caregivers of people with mental illness.

2.2 Explaining informal caregiving.

In this study, caregivers refer to “informal caregivers”. Roth, Fredman, and Haley (2015) define an informal caregiver as a typical person who provides some type of unpaid, ongoing assistance with activities of daily living to a person diagnosed with a chronic illness or disability or to an older adult who is unable to manage independently. A caregiver can simply be the co-residing spouses of persons with a chronic illness who provides some informal care. Gerain and Zech (2019:1) state that informal caregivers are individuals voluntarily caring for a relative or a friend facing illness, disability, or any condition requiring attention. Many individuals provide care for a spouse, family member, friend, or neighbour who needs help with personal care or running the household (Bom & Doorslaer, 2019). In addition, Roth et al. (2015:310) confirms that caregivers differ in the relationships they have with their care recipients (e.g. child, spouse, adult, elder, other relative, in-law or friend); their living arrangements (e.g. co-residing or no living with the care recipient); whether the person is a primary caregiver or someone who provides supplementary support; and the clinical condition of the care recipient (e.g. mental illness, stroke, cancer, frail, etc.).

Moura, Teixeira, Amorim, Henriques, and Nogueira (2022) allude to the fact that the delivery of informal caregiving is defined as the unpaid assistance directly provided to individuals with limited autonomy, by a non-professional person with whom they have a social relationship. Family and friends assume a central role in maintaining the individual’s health, particularly in conditions of disability. They represent a fundamental resource in patients’ care. Becoming an informal caregiver is something that most people will experience during their lifetime (Zarzycki, Morrison, Bei, & Seddon, 2023). Bom, Doorslaer, and Van (2019:629) postulate that informal caregiving can be very demanding and might lead to physical and emotional strain. Gerain and Zech (2019: 1) further support that it is widely accepted that being an informal caregiver puts a person at risk of poorer mental health.

Gerain and Zech (2019:2) further explain informal Caregiver Burnout stating that:

The first reference to burnout in informal caregiving was made in 1986. A study drew attention to “Spouse Burnout Syndrome”, because some spouses of patients with chronic illnesses showed symptoms compared to those experienced by “formal caregivers” in burnout. In this view, caregiver burnout can be defined as a syndrome in response to the stress that the caregiving may represent. The caregiver may experience emotional exhaustion, which is a feeling of being emotionally drained when facing the caregiving situation. Informal caregivers may also experience depersonalisation (detached response in the relationship to the care

recipient), personal accomplishment. This dimension of personal accomplishment highlights that the caregiver may gain a sense of fulfilment through providing care and finding meaning. In the context of burnout of caregiving, this positive sense of accomplishment is often reduced.

Determinants: Caregiver's Characteristics

Caregivers remain human beings with personal motives, emotions, and cognitions that should be considered when aiming at understanding informal caregiver burnout. The characteristics of the caregiver can be divided into three main groups: *background and sociodemographic, psychological, and physical factors* (Gerain & Zech., 2019:5).

Background and Sociodemographic Factors

The effect of other gendered issues such as caregiving being more frequent among women than men has led to other studies finding no relation between gender and caregiver burnout. Regarding the caregiver's age, no stable effect has been found. Caregivers who are still working while providing care may represent a protective factor in the sense that it relieves the caregiving strain by providing an emotional distraction.

Psychological factors

Individuals experience a diverse set of emotions when caregiving, related to the relationship with the recipient, the caregiving role, the gravity of the care recipient's condition, and their own life. Emotional regulation is particularly essential to them and plays a significant role in their caregiving experience. Cognitions, especially dysfunctional thoughts and perceived competencies also play an important role in the caregiving experience. Intrinsic motivation to care appears to be a protective factor for informal caregiver burnout.

Physical State

The physical health of caregivers is a factor that determines their involvement in caregiving. Healthy caregivers often take more responsibility in caregiving.

In addition, Moura et al. (2022) mentioned that caring for patients entails a rapid adjustment to the short and long-term effects of the illness, requiring varying degrees of caregiving. This often represents a sudden and life-changing demand for informal caregivers, who might feel unprepared to assume this role and its responsibilities. Such adjustments may be overwhelming for caregivers, leading to impairments in certain aspects of their life. The combination of these impairments with the socioeconomic repercussions of the illness, care recipients, and caregivers unmet, can lead to a significant deterioration of caregivers' quality of life.

Therefore, the quality of care provided will impact on patients' recovery, imposing substantial costs for healthcare and social systems. Thus, guaranteeing caregivers' well-being is a challenge and should be a priority for health and social policies, practices, and services (Moura et al., 2022).

Roth, Fredman, and Haley (2015: 310) state that informal caregiving is often described as a burdensome role that has all the hallmarks of a chronic stress experience. The burden associated with caregiving has been assessed over decades using a measure developed by Zarit, Reever, and Bach-Peterson (1980) in their seminal paper and confirmed that 'although family caregivers perform an important service for society and their relatives, they do so at considerable cost to themselves' (Roth et al., 2015:310). Informal caregivers would be expected to experience high levels of stress when they do not have sufficient internal (information, skills, coping, behaviours) and external (finances, help from other family, formal care) resources to adapt to caregiving situations. Many caregivers experience both positive and negative effects simultaneously. Informal caregivers may experience both emotional distress and psychological satisfaction and growth, effects that are not assumed to be different ends of the continuum. Indeed, the positive experiences of caregiving could potentially hinder some of the possible stress related health consequences.

Zarzycki et al. (2023: 1-2) allude that providing care and support presents a significant global challenge, especially for the most rapidly growing parts of the population. The prevalence of informal caregiving varies across the world but caregiver contribution to the sustainability of health and social care systems is important. Despite this, there is limited understanding of the factors that underlies, promote and maintain motivations and willingness to provide informal caregiving. Understanding motivations and willingness to provide care is significant as it has

implications for caregivers and care recipients' well-being, and assessment and care planning processes that are in place to support caregiving relationships.

It also has implications for the wider society, enhancing positive motivations to care and continue caring is increasingly significant given the ageing demographic, societal expectations, family care provision and the potential costs to society to alternative care. As motivation is multifaceted, different factors contributing to the influence on motivation should be considered. It follows, therefore, that identifying the factors underlying motives for providing care, exploring the interrelationships between different motives and considering the influence of these motives on caregiver behaviour and outcomes will help in efforts to support and sustain caring relationships (Zarzycki et al., 2023: 2).

Zarzycki et al. (2023:2) further explain that norms of perceived obligation towards family members and ethnicity have previously been shown to have a predictive value for motivations and the exchange of informal caregiving. Caregiver motivation may impact significantly on outcomes for both caregivers and care recipients. This includes both positive and negative influences on caregiver health and well-being and the quality of the caregiving relationship. Alongside the concept of motivations to provide care, willingness to perform informal care tasks addresses more behavioural aspects of caregiving with current and future orientations towards providing support for an individual.

2.3 Experiences of caregivers of people with mental illness

Monteiro et al (2018:259), in a study conducted in Brazil, established that the stress and burden associated with caring for people with mental illness not only affects the health of caregivers and increase their mortality risk, but also decreases the quality of caregiving. In India, more than 90 % of patients with chronic mental illness live with their families (Narayanan, 2021:2). These caregivers play significant roles, including managing care, supervising medication, looking after financial needs and taking the patient to the hospital or clinic.

There is research evidence to support that caring for a loved one with mental illness impacts health and psychological well-being of the caregiver (Narayanan, 2021:2). This toll on the caregiver's physical and psychological well-being is a cause of "caregiver burden". Burden in

caregiving can be both objective and subjective. Objective burden includes financial loss; occupational and socioeconomic costs; and effects on health and family and subjective burden includes the personal experience of the caregiving stress.

Kamal (2014) alludes the role of the caregivers entrusted with the task of taking care of their relative with mental illness has become increasingly important because of deinstitutionalisation. Deinstitutionalisation is the movement of hospitalised patients with mental illness from long-term hospitalisation to community care. One of the consequences of deinstitutionalisation is that family members are forced to assume the role of caregivers. Informal caregivers are not fully equipped to provide care to patients with severe mental illness. In most cases, the caregiver has no formal training and finds caregiving burdensome. Kamal (2014:3) further describes that a relationship between the amount of caregiving and the severity of the patient's symptoms has been found. The caregiver's distress was higher if the patients' level of symptoms was severe. On the contrary, the caregiver's distress was lower when the level of the patient's symptoms was mild or low.

Stigma forms an important part of the experience of caregivers of persons living with a mental disorder in Sub-Saharan Africa. 75% of caregivers of people with schizophrenia (mental illness) reported being stigmatised in Ethiopia, with over 37% hiding family members with a mental illness from the community (Marimbe et al., 2016). This issue has been attributed to the misunderstanding of the identification or cause of mental disorders. For instance, Schizophrenia and other mental illness in Ghana are viewed by many as manifestations of diabolical manipulation (Gloria et al., 2018).

Caregivers of family members living with a mental illness get more ill and have a weaker immune system more often than those who are not caregivers (Terzungwe & PH., 2016) because they feel overcome by the caregiving burden. Terzungwe & Ph (2016) further state that little is known about predictors of positive aspects felt by informal caregivers. Predictors of negative aspects of caregiving, such as burden, anxiety, depression, among others differ from predictors of positive aspects. There are gender differences with regard to caregiving satisfaction (Terzungwe & Ph, 2016).

For women caregivers, a greater satisfaction in caregiving correlates with lower levels of anxiety and depression. In contrast, male caregivers find more positive aspects related to

caregiving when they are less educated, healthier, or have better social networks. There are also differences in caregiving satisfaction related to kinship between the caregiver and the care recipient (Terzungwe & Ph, 2016:2). For spouses, caregiving satisfaction does not correlate with care recipient symptoms, the amount of time spent in caregiving, and caregiver health; however, it is associated with greater emotional wellbeing. It has been found in this study (Gonani, 2019) that “caregiving for a person with mental illness is not easy. It consumes time, energy, and financial resources. It sucks out strength and determination. It turns simple ideas of efficacy and hope into big question marks. It can amplify anguish and desperation. It can divide the self. It can bring out family conflicts”.

In South Africa, the burden of mental illness is reported to be very high, with a prevalence of mental disorders estimated to be one in three. In the face of this adversity, there is a gap in treatment, with approximately 75% of people living with a mental illness not having access to any type of treatment (Monnapula-Mazabane & Petersen, 2021:1). Formal community mental health services, that are, residential facilities, centres, rehabilitation services, and other organisations and institutions are scarce in South Africa; there is a huge reliance on informal community mental health services provided by primary caregivers or families (Monnapula-Mazabane & Petersen, 2021:2).

In a study by Gurayah (2015:196) conducted in rural South Africa it was discussed that the magnitude of the caregiver’s tasks increases with the patient’s mental illness progression. Gurayah (2015:196) mentioned that there is an implicit understanding in South African culture and African culture that one must care for one’s loved ones, as embodied in the concept of ‘ubuntu’. This concept of collectivism means that the individual is a part of the community and needs to fulfil their obligations to the collective. This provides an explanation for the strong sense of responsibility that the caregivers of people with mental illness express in caring for their relatives.

Financial stress increases as a result of caring for a person with mental illness (Gurayah, 2015). Funds are needed for food, medication and transport costs to go for medical treatment. There is a need for constant supervision when caring for an individual with severe mental illness.

Performing caregiver tasks increases the daily workload of the caregiver. These tasks include dealing with problematic behaviour and helping with bathing and feeding, when the patients is unable to help themselves.

Mkabile (2019:5) established in a study conducted in Khayelitsha, Cape Town, that caregivers of children living with mental illness reported that these children were stigmatized, had no friends, experienced both physical and sexual abuse, and some were neglected and excluded from community activities. As a result of this maltreatment towards these children, it had an impact on the emotional well-being of the caregivers. Mkabile (2019:5) further mentioned that some of the caregivers stated that they do not receive support from extended family or community members. As a result, they had to give up their employment because there was no alternative care. In addition, the caregivers reported that they themselves developed mild mental health issues because of caring for a child with mental illness.

Although the status of mental health services in South Africa has improved, mental health services are still marked by discriminatory divisions fossilised in the apartheid era when access to healthcare facilities for black people was severely compromised. Black caregivers are still required to travel long distances to access basic mental health services in institutions where service providers often do not speak their languages, and where as a result, they struggle to express themselves and to understand what is being said to them (Mkabile et al., 2021). The provision of services in a language that is not well understood by caregivers can lead to the perspective of the caregiver being at odds, with the clinician/healthcare professional not being aware of the concerns of the caregiver.

In this study (Ntsayagae, 2019:5) conducted in Johannesburg, Gauteng it has been found that an enormous time and support is spent in providing care. Caring requires numerous sacrifices about social and occupational life. Through providing care, caregivers become victims of physical and emotional exhaustion. As a result, feelings of frustration and defeat arise when their mentally ill relative refuses to take food and medication, or to even bath. The caregiver's lifestyle must change to accommodate the caregiving role. This causes the caregiver to have less time for themselves. Role shifts can affect the family dynamics as it sometimes contribute to disagreements among family members (Ntsayagae, 2019:5-6). In addition, caregivers experience feelings of helplessness when they cannot do something about the patient's

condition and when they are fearful of his/her aggressive behaviour. Furthermore, caregivers experience feelings of powerlessness, they reported thoughts related to self-worth and hope. These emotions can affect ones' sense of well-being. Shame over people living with mental illness remain unabated. Mental illness has always been negatively publicised in black societies, as a result caregivers face prejudice because of misconceptions about mental illness (Ntsayagae, 2019:5).

In the Emfuleni Local Municipality, Gauteng, caregivers of people with mental illness receive mental health services on behalf of their care recipients from the following government institutions: Vaal Mental Health Organisation, Johan Heyns Community Health Centre, Levai Mbatha Community Health Centre, Sebokeng Hospital, Kopanong Hospital, Empilisweni Community Health Centre, Lebohang Naledi Centre and other private institutions. According to MMC Tsokolibane in her speech during the Health Summit 2021, in Emfuleni Local Municipality, the municipality still faces the challenge of implementing and rolling out mental health services that are accompanied by necessary planning and budgeting processes. This means that services to caregivers of people with mental illness will be a delayed matter soon. As a result, there will be an increase in caregiver burden.

There are no studies about caregivers of people with mental illness within the Emfuleni Local Municipality that exist in the following electronic searches: SABINET, ProQuest, Scopus, EBSCOhost, Web of Science, Google Scholar, Science Direct, Sage Publications, Emerald Insights, and Boloka Institutional repository: NWU. This implication can cause mental health professionals and residents of Emfuleni Local Municipality to become unaware of the existence of different issues that caregivers of people living with mental illness experience around this demographic area. Therefore, solutions will not be found to assist these caregivers to better cope, leading to more distress on them. A great deal of time was spent in trying to locate this research topic relating to Emfuleni Local Municipality, and it is non-existent. This further implicates research studies in Gauteng province and South Africa making other countries receive more immediate attention than South Africa when it comes to this topic. This study further aims to describe the experiences of caregivers of people living with mental illness and ascertain how they cope with their experiences generally, here at home.

2.4 What is mental illness?

Wittchen and Beesdo (2022) state that mental illnesses (also termed mental disorders) vary widely, in terms of presenting problems, severity, associated impairment, duration, and risks. The current version of Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) has now adopted a largely descriptive approach with operationalised criteria for disorders.

WHO (2022:8) describe mental illness according to the International Classification of Diseases 11th Revision (ICD-11), which is a syndrome characterised by clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental process that underlie mental and behavioural functioning. These disturbances are usually associated with distress or impairment in personal, family, social, educational, occupational, or other domain of life.

2.4.1 Types of mental illnesses

Cao, Wang, Baranova, and Zhang (2022: 1) postulate that Anxiety Disorder (ANX), Schizophrenia (SZ), Major Depressive Disorder (MDD), Obsessive Compulsive Disorder (OCD), Bipolar Disorder (BD), Posttraumatic Stress Disorder (PTSD), and Anorexia Nervosa (AN) are major mental illnesses that mainly affect adults, while Autism Spectrum Disorder (ASD), and Attention Deficit Hyperactivity Disorder (ADHD) typically occur in children.

Table 2.4.1.1 Types of mental illnesses (American Psychiatric Association, 2013)

MENTAL ILLNESS	DESCRIPTION
ANX	Anxiety Disorder refers to anticipation of a future concern and is more associated with muscle tension and avoidance behaviour. Types of anxiety disorders: • Generalised Anxiety Disorder Involves persistent and excessive worry that interferes with daily activities. This ongoing worry and tension may be accompanied by physical symptoms,

such as restlessness, feeling on edge or easily fatigued, difficulty concentrating, muscle tension or sleep problems.

- **Panic Disorder**

The core symptoms of panic disorder are recurrent panic attacks, overwhelming combination of physical and psychological distress. During an attack several of these symptoms occur in combination, palpitations, trembling, chest pain, feeling dizzy, nausea, etc.

- **Phobias**

A specific phobia is excessive and persistent fear of a specific object, situation or activity that is generally not harmful. Patients know their fear is excessive, but they cannot overcome it. These fears cause such distress that patients go to extreme lengths to avoid what they fear.

- **Social Anxiety Disorder**

A person with social anxiety disorder has discomfort about being embarrassed, humiliated, or rejected in social interactions. People with this disorder avoid the situation or endure it with anxiety.

- **Separation Anxiety Disorder**

A person with separation anxiety disorder is excessively anxious about separation from those with whom he or she is attached. Physical symptoms of distress often develop in childhood, but symptoms can carry through adulthood.

SZ

Schizophrenia involves active symptoms of delusions (fixed false beliefs held despite clear and reasonable evidence), hallucinations (hearing, seeing, smelling, tasting, or feeling things that are not there), disorganised speech and thinking, and lack of motivation. It can be characterized by episodes in which the person is unable to distinguish between real and unreal experiences. The severity, duration, and frequency of symptoms can vary. Not taking medication as prescribed, the use of alcohol or illicit drugs, and stressful situations tend to increase symptoms.

MDD

Major Depressive Disorder is a mental illness that affects how you feel, think and behave causing persistent feelings of sadness and loss of interest

	in previously enjoyed activities. MDD can lead to a variety of emotional and physical problems. It is a chronic illness that usually requires long term treatment.
OCD	Obsessive Compulsive Disorder is a mental illness in which people have recurring, unwanted thoughts, ideas or obsessions. To get rid of unwanted thoughts, they feel the need to do something repetitively (compulsions). The repetitive behaviours such as constant hand washing, mental acts like counting or checking on things, can interfere with a person's daily functioning. Not performing the behaviours often causes great distress. Obsessions: persistent thoughts or impulses that cause distressing emotions such as fear, disgust, or anxiety. Compulsions: mental acts or repetitive behaviours that a person feels the need to perform in response to an obsession.
BD	Bipolar Disorder is a brain disorder that causes changes in a person's energy, mood, and ability to function. People with bipolar disorder experience deep emotional states that occur during different periods, called mood episodes. These mood episodes are called manic/hypomanic/depressive. Different types of Bipolar Disorders include Bipolar I, Bipolar II, and Cyclothymic Disorder.
PTSD	Posttraumatic Stress Disorder is a mental disorder that may occur in people who have experienced or witnessed a traumatic event. An individual may experience this as emotionally or physically harmful, and may affect physical, mental, social, and/or spiritual well-being. Examples include natural disasters, accidents, war, abuse, and bullying.
AN	Anorexia Nervosa is characterised by self-starvation and weight loss resulting in low Body Mass Index (BMI). Dieting behaviour in anorexia nervosa is driven by an intense fear of gaining weight. Some persons with anorexia nervosa also intentionally binge eat and or purge by vomiting or laxative misuse.
ASD	Autism Spectrum Disorder is a complex development condition involving persistent challenges with social communication, repetitive behaviour, and

restricted interests. The degree of impairment in functioning because of these challenges varies between individuals with autism.

ADHD **Attention-Deficit Hyperactivity Disorder** is one of the most common mental illnesses affecting children. Symptoms of ADHD include inattention, hyperactivity and impulsivity. ADHD is a chronic disorder and is known to impact the individual in many aspects of their life. ADHD can lead to poor self-esteem and social functioning in children when not appropriately treated.

2.5 Coping strategies of caregivers of people with mental illness

2.5.1 What are Coping strategies?

Coping strategies are behavioural or cognitive responses made by an individual in response to a life event (Geriani, Satish, & Savithry., 2015). They can also be defined as efforts required to manage specific external and/or internal demands that are appraised as exceeding the resources of the person (Coetzee, 2016:343). Additionally, coping requires a cognitive reappraisal of the situation to manage it properly. Coping strategies involves a process by which an individual contends with or deals with a situation to alleviate or relieve stress. It enables the individual to remain unaware of unpleasant reality as if it did not exist (Ntsayagae et al., 2013).

2.5.2 Types of coping strategies

2.5.2.1 Problem solving coping.

Coetzee (2016:74) describes problem-focused coping as strategies that attempt to change the stressor by directly reducing its negative impact on the person. Furthermore, the use of problem-focused coping has been described as more effective in caregiver stress. It attempts to solve the problems that are responsible for high levels of stress. Problem solving coping is related to lower levels of burden (Geriani et al., 2015:1). This type of coping strategy is mostly employed by caregivers. It includes active coping, planning instrumental support, and religious scale) (Ganjiwale, Ganjiwale, Sharma, & Mishra., 2016).

2.5.2.2 Avoidance coping/dysfunctional coping

Avoidance coping is associated with higher levels of distress (Geriani et al., 2015:1). It includes self-distraction, denial, behavioural disengagement, self-blame, and substance use (Ganjiwale et al., 2016: 345). There's literature which shows the difference in coping between Hispanic caregivers and other ethnic groups, it was observed that the use of avoidance as a coping strategy was higher in Mexican-American caregivers of people living with mental illness than white caregivers (Are, Acton, Houston, Bonnner, & Lewis., 2014).

2.5.2.3 Emotion-focused coping

Emotion-focused coping involves effortless strategies that a person utilises to minimise the negative emotional outcomes of stress (Rahmani et al., 2019). Coetzee (2016:75) postulates that emotion-focused coping attempts to regulate and lesson the emotional impact of stressful situations, e.g., changing the meaning of an event without changing the reality of the relationship between the person and event (Coetzee, 2016:75). It includes self-controlling, positive reappraisal, escape-avoidance, venting, humour, acceptance, and emotional support (Geriani et al., 2015:4), (Ganjiwale et al., 2016: 345). It has been noted that women tend to use more emotion-focused coping strategies whilst men utilise more problem-focused strategies (Gurayah, 2015:195). It has been considered as the most successful strategy to reduce emotional distress in the short run. However, the use of emotion-focused coping could reduce the efficacy of coping over time, because the source of emotional distress is not directly addressed (Coetzee, 2016). Results in a study by Hogan and John-langba (2016) reveal that many participants in the face of ongoing stress in their role as caregivers found that in order to cope they would cut off emotional responses to the person living with mental illness. This is not healthy for the wellbeing of caregivers and even though it helped them cope in the short term, it caused emotional problems for them and their care recipients.

2.5.2.3 Physical coping

Physical coping includes caregivers using alcohol, smoking, medication, relaxation, sleeping, and overeating to help them cope (Hogan & John-langba, 2016). Additionally, the stress of caregiving pushes some caregivers to behave in ways they would not typically behave. This

situation is detrimental to the health of caregivers and well-being of the person living with mental illness.

2.5.2.4 Psychological coping

Psychological coping includes emotional (crying, upset, and denial), and cognitive (positive thinking, information, problem solving, wishing the situation would go away, looking for an unseen benefit, or hoping for a cure someday) ways of coping (Hogan & John-Langba, 2016:618) (Du Plessis, Poggenpoel, Myburgh, & Temane., 2021). This is consistent with findings in a study done by Hogan and John-langba (2016) where it was evident that taking small steps and being patient helped caregivers cope with their caring life.

2.5.2.5 Behavioural coping

Behavioural coping includes engaging in hobbies and action-oriented pursuits (Hogan & John-Langba, 2016:618). Furthermore, behavioural coping mechanisms of keeping busy were found to be common coping strategies in caregivers of people living with mental illness.

2.5.2.6 Social coping

Social coping includes social support, community resources, spiritual support, professional support, and support groups (Hogan & John-Langba, 2016:618). Hence, helping the caregiver cope and finding which support systems help, will not only improve family functioning and promote caregiver well-being but will ultimately help the person living with mental illness.

2.5.3 Prevalence of coping strategies in caregivers

The use of coping strategies reported in this study (Sharif, Basri, Alsahafi, Altaylouni, Albugumi., 2020) were divided according to their effectiveness. Acceptance, religiosity, and spirituality-related coping strategies emerged as the main effective coping mechanisms. The caregivers of patients with mental illness believed that all hardships experienced would be

reduced by praying and seeking refuge from God. In Islamic belief, “God’s will be above all” and, thus, religion plays a significant role in symptom formation, management, and acceptance.

On the other hand, the less effective coping emerged as avoidance, and engagement with the person’s hallucinations and delusions. A similar finding has been noted in a Malaysian study, where caregivers reported that there was a tendency to seek out traditional faith healers to cure mental disorders, as there is a societal sense of believing in evil spirits and possession (Sharif et al., 2020). There’s literature which shows the difference in social support between Hispanic caregivers and other ethnic groups, it was observed that the use of avoidance as a coping strategy was higher in Mexican-American caregivers of people living with mental illness than white caregivers (Are, Acton, Houston, Bonnner, & Lewis., 2014). Hispanics were less prone to seek professional (mental health services) help, but rather involved their families, while white Americans turned more to seek professional help (Are, Acton, Houston, Bonner, & Lewis., 2014). This might have been due to differences in the socio-economic status among the two ethnic groups.

Rahmani et al. (2019:151) pointed out that when avoidance is used to minimise exposure to a stressor, this is considered less effective. On the other hand, continual avoidance of a stressor could be an ineffective coping strategy and result in future depressive symptoms in caregivers of mentally ill patients. This study showed that caregivers used the strategy of seeking for information on the patient’s illness and treatment to avoid readmission and a higher rate of relapse. Rahmani et al. (2019:152) further supports that male caregivers are more resilient in providing care for people with mental illness and using more action oriented, persistent, and firm approaches. In Iranian culture, male caregivers of the family are more likely to have commitment and socialisation than women, therefore they try to cope with the problems by solving them directly and managing the source of stress.

Based on the findings in this study Rahmani et al. (2019:152), age was positively and significantly correlated with coping strategies, as caregivers’ age increases, their ability to deal with their problems increases and they can cope with stressors caused by living with a mentally ill family member. In addition, the education level had a correlation with caregiver’s coping, more highly educated caregivers could get a better job, more support resources and higher salaries to help them deal with their problems. On the other hand, caregivers who lost their jobs

due to caregiving responsibilities and who are unemployed, suffered more distress because they have less resources to meet their caring demands.

Based on a study by Monteiro et al. (2017:261-267) it has been discussed that religious coping was combined with other emotional coping strategies. Problem-focused coping strategies mostly used active coping interventions, in which caregivers concentrate the efforts on doing something about the problem-situation, and planning, in which the caregiver tries to come up with a strategy about what to do or thinks hard about what steps to take. The analysis of dysfunctional coping strategies showed that they are not beneficial to approach caregiver problems. Dysfunctional strategies such as escape, and avoidance are considered negative for the caregiver.

Studies such as Arevalo-Flechas (2013), Monteiro et al. (2018) , Narayanan (2021), Rahmani et al. (2019), and Terzungwe & Ph (2016) have mainly focused on caregivers of individuals who are diagnosed with “schizophrenia and Alzheimer’s disease” and have not inclusively focused on all caregivers of persons living with “any” mental illness. These studies are solely based on individual “experiences” or on “coping mechanisms” of caregivers of people living with mental illness and not both factors in the same study. McNally (2011) alludes that there is a need for more qualitative studies on caregiver experiences to provide rich insights into the realities of caregiving. McNally (2011) further explains that previous studies have mainly focused on the negative experiences of caregivers of persons living with a mental illness creating an unbalanced view of caregivers’ experiences and creating a gap in understanding the social experiences associated with mental illness. Therefore, the researcher intends to investigate both experiences and coping strategies of caregivers of people living with mental illness in this single research study.

Caregivers of people living with schizophrenia (mental illness) in India endorsed proactive styles of coping which included anticipating potential problems and actively finding solutions. Caregivers reported anticipating needs for hospitalisation, medication, and planning by seeking advice from primary care doctors or friends to support them in their caregiving duties (Narayanan, 2021:91). In addition, caregivers engaged in behavioural coping strategies that distract them to help them cope, like cooking, pursuing a hobby, watching movies or listening to music. This method was described as helping caregivers to relax and forget about their worries even if it is only temporary. Other caregivers used psychological coping by engaging

in imaginary wishful thinking during times of leisure which in their words helped transport them to a changed reality where things were alright, and their loved ones were illness free (Narayanan, 2021:93).

McNally (2011:7) in a study about 'perceptions of caring for children with disabilities' conducted in Tanzania, it is mentioned that other caregivers believed that God would help them through their problems and some asked for strength from God to continue with their responsibility of caring for their relative with a mental illness. Some participants had a positive attitude (hopes and beliefs) towards the future. This relates to the patient making progress and getting better in the future. These caregivers of persons living with mental disabilities were supported by a centre in their area. This centre allowed them to earn a small living which enabled them to cope.

The most used coping strategy in Zimbabwe was seeking assistance from traditional healers. This was informed by the belief that mental illness was linked to witchcraft. This was done to manage the patients' symptoms and reduce the caregivers' anxiety about the illness. To cope financially, caregivers required financial assistance either from the government or donors (Hogan & Johan-Langba, 2016:5). In addition, it has been found that caregivers mentioned that they required training to deal with mental illness. They requested written material and information so that they would have knowledge about the symptoms of a specific mental disorder.

In this study by Hogan and John-Langba (2016:620) about coping strategies of caregivers of people diagnosed with severe mental illness in South Africa, it was established that the positive social coping strategies used by caregivers of people with mental illness included: making use of services and facilities available, working or keeping busy, knowledge of mental illness, support from close friends and families, faith, and finding the right mental health professional. Support from the hospital or clinic staff, looking after self and using challenges to grow, patience, engaging with others with the same experiences also played a huge role in coping. Furthermore, some of the negative coping strategies were: ignoring the relative who is living with a mental illness or cutting off emotions, taking on all the responsibility of the mentally ill or controlling them, using verbal threats, and using medication to cope. Some of the caregivers in a study by Mahomed & Pretorius (2022), expressed using prayer and the reliance on God to give them strength and understanding to manage their role as caregivers, while others used

music and books to help bring a sense of calmness and clarity that enabled them to cope with their challenges.

The findings in this study by Shilubane and Mazibuko (2020:416-417) indicated that a strong support system is an important part of the coping milieu. It has been reported that support helps caregivers to manage the challenges more successfully because they can listen to more similar stories from others with similar situations. Caregivers of children diagnosed with Autism Spectrum Disorder (mental illness) used acceptance as a way of coping. Once they accepted that their children are gifts from God, they were happier. These caregivers also accepted the diagnosis without question, which made their lives easier.

Shilubane and Mazibuko (2020) postulate negative coping strategies such as alcohol, drug use, and self-isolation. Most caregivers reported non-disclosure of their relative's mental health status, to avoid discrimination. Caregivers strongly felt that social groups are instrumental in helping them learn more about mental illness, how to support their family members with mental illness, and cope with the responsibilities related to caregiving (Monnapula-Mazabane & Petersen, 2021). Du Plessis et al. (2021) noted that some caregivers of people living with mental illness attempted to avoid conflict or confrontation with the affected person as a way of providing care and coping. These caregivers used cognitive and behavioural strategies to cope with the burden or stress because of caregiving.

2.6 Conclusion

In this chapter, caregiving was clearly defined as informal caregiving. It is discussed that informal caregivers are those close relatives or friends who care for a person who is ill or unable to care for themselves without any financial reward. Experiences of caregivers of people living with mental illness includes psychological, emotional, physical and financial burden which have a negative impact on the daily functioning of the caregiver. However, some caregivers find meaning in caring for a person with mental illness. Caregivers feel a sense of emotional reward by fulfilling a role of providing care. The most common types of mental illnesses have been distinguished as schizophrenia, bipolar disorder, major depressive disorder, anxiety disorder, autism spectrum disorder, anorexia nervosa, attention deficit hyperactivity disorder, obsessive compulsive disorder, and posttraumatic stress disorder. Caregivers use a number of

coping strategies to cope with the challenges of caring for a person with mental illness, these include, inter alia: problem solving, emotion-focused, avoidance/dysfunctional, behavioural, physical and social coping strategies.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents the research methodology of the study in detail. Research methodology according to Mishra and Alok (2019) is the approach in which research troubles are solved thoroughly. It is the science of studying how research is conducted systematically. In this chapter the researcher explains the different steps taken to study a research problem. In this chapter, there is a discussion about the type of research adopted for it. This study used fundamental research specifically basic research as its choice. The study relied on Constructivism philosophical assumption and Qualitative Descriptive design were adopted and discussed. There is also a full discussion on population and sampling, data collection, analysis, and presentation. Lastly, this chapter will discuss the research ethics.

3.2 Type of Research

The type of research adopted for this study is basic research. Ellaway and Hecker (2022) mentioned that basic research is concerned with establishing knowledge, theories, frameworks, and techniques in the basic science that can form the basis for applied research. The data provided in this study contribute to the social work profession by increasing knowledge on experiences and coping strategies related to caregiving for a person with mental illness.

3.3 Research Philosophy/Paradigm

Research paradigm according to Bailey (1982:24) (as cited by Kankam 2019:85) represent the mental window through which the researcher views the world. This attests to the fact that the right application of research philosophy in research offers the effective direction for researchers to investigate the research problem. In addition, Babbie (2011:32) (as cited by Kankam 2019:85) strongly upheld that social scientists have developed paradigms for understanding social behaviour. Conducting research into human behaviour usually requires the adoption of a research paradigm with the aim of improving the credibility and generalisability of the study

(Kankam, 2019). Research paradigms are the tools whereby researchers ask “why” questions. They are the frameworks within which research questions are framed, pertinent empirical data identified, and potential explanatory conclusions generated to answer the research questions (Nairn, 2019).

The philosophical world view or research paradigm used in the study was constructivism. Grover (2015:3) discussed that constructivism worldview is of the belief that: every individual has their own reality of objects or subjects and people develop subjective meanings of their own experiences. The researcher needed to understand the phenomenon from a perspective of the research participants. Furthermore, constructivism gave full weightage to caregiver differences which make them unique in sense of identity. This allowed the researcher to use a more open-ended data collection method which gave research participants freedom to respond (Grover, 2015).

3.4 Research Approach

Research approach is a general technique that researchers follow when conducting a study. It informs the choice of research methods that consists of the designs and frameworks employed for a research study (Kankam, 2020:165). It is based on the procedure used for gathering data and analysis. The overall decision involves which approach should be used to study a topic (Grover, 2015:1). This research approach is an iterative process in which understanding of the phenomenon is achieved by making new significant distinctions resulting from getting closer to what is being studied or researched (phenomenon) (Aspers & Corte, 2019). Consequently, in this research study a qualitative approach was pursued to collect data by interviewing caregivers of people living with mental illness. As the aim of this research study was to describe the experiences and coping strategies of caregivers of people with mental illness, qualitative approach was deemed the most relevant to use.

3.5 Research Design

Research design can be considered as the structure of research that holds all the elements, in short it is a plan of the proposed research work (Akhtar, Shah, Rafiq, & Khan., 2016). Furthermore, a research design is the arrangement of conditions for the collection and analysis

of data in a manner that aims to combine relevance to the research purpose. The research design selected for this study, was Qualitative Descriptive (QD) research design. This design was used as a method that will provide a rich description of the caregivers' experiences and how they cope with caring for a person living with mental illness. The findings produced in QD research design provide given data, which is the voice of the participants' experiences (Rainbow et al., 2021). Sandelowski (2000) (as cited by Bradshaw, Atkinson, & Doody., 2017:3) alludes to the fact that QD research design is a method that researchers can claim unashamedly without resorting to methodological acrobatics. Descriptions always depend on participants' perceptions, sensitivities and inclinations. The description in QD research design features the participants' presentation of the facts in everyday language (Sandelowski, 2000) (as cited by Bradshaw, Atkinson, & Doody., 2017:3). Qualitative description is more interpretive.

Sandelowski (2000) (as cited by Bradshaw, Atkinson, & Doody., 2017:3) further postulates that QD research design offer a comprehensive summary of an event in the everyday terms of the event. Researchers conducting this type of study seek descriptive and accurate counting of events. In addition, researchers conducting QD research design stay closer to their data and to the surface of the participants' words and events. Therefore, in this study the researcher described the caregivers' experiences and coping strategies in the participants' own language of preference, which is between Sesotho or English.

Usually open-ended or semi-structured interviews are used in qualitative QD research design (Neergaard et al., 2009). Hence, in this study, the researcher used semi-structured interviews to describe the experiences of caregivers and ascertain how they cope with caring for a person living with mental illness. The researcher ensured that a complete description of the participants' experiences is captured by thoroughly understanding what the participants lay out. The researcher was interested in the what, who, where and why of the participants' experiences.

Doyle, McCabe, Keogh, Brady, and McCann (2020:444) allude that a QD research design recognises the subjective nature of the problem, the different experiences participants have, and presents the findings in a way that resembles the terminology used in the research questions. This design is best aligned with constructionism and critical theories that use naturalistic and interpretative methods. Therefore, researchers are concerned with understanding the individual human experience in its unique form. This type of design requires

flexible research processes that are inductive and dynamic but do not change data beyond recognition from the phenomenon being studied (Doyle et al., 2020).

Bradshaw, Atkinson, and Doody (2017) point out that researchers using a QD research design address from the outset, their theoretical positioning, congruence between methodology and methods, strategies to establish rigor, and the analytical lens through which data is conducted. The goal of QD research design is not discovery as in ground theory or exploring as in phenomenology. The two main elements constant with QD research design are learning from the participants and their descriptions, and second, using this knowledge to influence interventions. The findings from these studies can often be of special relevance to practitioners and policy makers (Sandelowski, 2000) (as cited by Bradshaw, Atkinson, & Doody., 2017:3).

Kim, Sefcik, and Bradway (2017:24) state that QD research design uses thematic and content analysis. These data analysis approaches allow researchers to stay close to the data, with minimal transformation during data analysis. Such interpretation is low inference, which allows readers familiar with the topic to recognize their own experience of the phenomenon in the findings of the study. Representation of study findings is expected to be straightforward, including comprehensive descriptive summaries, and accurate details. Hence, in this study the researcher used thematic analysis to analyse data.

3.6 Population and Sampling

A population is made up of a set of individuals with one or more common qualities (Asiamah & Oteng-abayie, 2017). In other words, a population is a set of all the units which possess variable characteristics under study and from which findings of research can be drawn.

In this study, participants from the ages of 18 to 70 years were selected. An average adult is categorised to be 18 plus years in South Africa. The researcher specifically aimed to select adults with an age limit of 70 years, as some elderly people above the age of 70 years might have health complications which might delay the process of data collection. In addition, the majority of adults assumed the role of caregiving. There was no specific gender for participation; all genders participated in the research study. Participants were caregivers of people living with mental illness. The researcher specifically delineated the population to Emfuleni Local Municipality located in The Vaal, Gauteng province. The focus of the study

was on three institutions, namely Vaal Mental Health Organisation, Johan Heyns CHC, and Levai Mbatha CHC, found in Emfuleni Local Municipality. The population of the study received services from these three institutions. The study focused on 12 participants. Six (6) participants from Johan Henyns CHC, three (3) participants from Vaal Mental Health, and another three (3) participants were recruited.

The sampling strategy used for the study was purposive sampling. Purposive sampling forms part of the non-probability selection procedure. Non-probability technique is when participants are selected based on non-random standards and not all individuals have an opportunity to be involved (Padgett, 2016). Moreover, purposive sampling avails of accessible participants, but it provides the additional advantage of facilitating the selection of participants whose qualities or experiences are required for the research study (Bradshaw, Atkinson, & Doody., 2017:3).

Thomas (2022) further discusses that with purposive sampling, the researcher determines who should be involved in the sample based on several characteristics such as subject matter expertise. The type of purposive sampling the researcher used is maximum variation sampling, Thomas (2022:4) explains that maximum variation sampling is recognised as vast and varied sampling, the researcher captures a diversity of views about the object of interest. The researcher obtained information about different experiences and coping strategies from the interviews with participants. Each participant was unique in their own way.

Campbell, Greenwood, Prior, Walkem, Young, & Bywaters (2020) pointed out that purposive sampling is used to yield useful information and is a way of identifying cases that will use limited research resources effectively. Staller (2021) mentioned that “combining all of these scholars’ thoughts we might state that purposive sampling is about identifying the most appropriate, information-rich, useful, broad-ranging, and plentiful data available to gain insight by creatively solving puzzles with convincing evidence”. In other words, the researcher exercised her judgement by selecting prospective participants, selecting a specific location, or artefact that helped accomplish research objectives.

3.6.1 Sample Inclusion and Exclusion Criteria

- Participants were caregivers of people living with mental illness.

- Participants were adults from the ages of 18 to 70 years. The participants had to be proficient in English or Sesotho, as the interviews would be conducted in English or Sesotho. Sesotho interviews were translated to English.
- Participants were residents of Emfuleni local municipality and received services from Vaal Mental Health Organisation, Levai Mbatha CHC, and Johan Heyns CHC.

Participation in the study would not have been possible if:

- Participants had mental difficulties that delay comprehension which delay comprehension of speech.
- Participants were visually impaired and deaf.

3.6.2 Sample Size and Motivation

According to Bradshaw, Atkinson, & Doody (2017:4), qualitative sample size tends to be small because of the emphasis on intensive contact with participants and the findings are not expected to be generalizable. Therefore, there is no fixed rule to establish the most appropriate sample size in qualitative research, instead several factors should be considered. These include careful consideration of the research design, sampling procedure, and the relative frequency of the phenomena being researched. Hence, an adequate sample size is one that sufficiently answers the research questions and aim.

Bradshaw, Atkinson, & Doody (2017:4) further concur that data saturation can be considered to apply to the point where no new information emerges from the study participants during data collection, when the ability to obtain new information has been attained and when additional coding is no longer feasible or when enough information is gathered to replicate the study. In the study, the sample size was determined by enumerated stance (the minimum number of participants were set) and data saturation.

3.7 Data Collection

Muhammad & Kabir (2018:202) define data collection as the process of gathering and measuring information on variables of interest, in an established systematic fashion that enables one to answer stated research questions, test hypothesis, and evaluate outcomes. The goal for

all data collection is to capture quality evidence that translates to rich data analysis and allows the building of credible answers to research questions. Furthermore, qualitative data collected is in the form of words or sentences, such data collection captures emotions, or subjective perceptions of participants. Qualitative data collection tends to be more open-ended, rely more on interactive interviews, and findings are not generalizable to any specific population (Muhammad & Kabir, 2018). Interviews give the most direct and straightforward approach to gathering detailed and rich data regarding a particular phenomenon (Barrett & Twycross, 2018).

3.7.1 Data Collection Procedure

Firstly, the researcher approached the three institutions (Vaal Mental Health Organisation, Levai Mbatha CHC, and Johan Heyns CHC) to request goodwill permission to conduct the research study. The researcher personally approached and requested for legal permission from the Department of Health (DH) and Department of Social Development (DSD) to conduct the study. DH and DSD are departments to which mental health and health institutions affiliate and from which they receive support and funds. Once the approval from the institutions, DH and DSD was secured, the researcher scheduled a visit to the three institutions and the following were explained: The purpose of the visit and the study, the benefits of the study to caregivers of people living with mental illness, the community, and mental health practitioners, the number of participants needed for the study, the type of data collection method, the estimated time it would take for each interview, refreshments and transport costs for the participants, and request for mediation

Secondly, following the discussion, and the director and managers' approval, the following process took place: The director and managers were made aware that they would be gatekeepers between the participants, institution, and researcher. Mental health practitioners (included social workers and professional nurses) who directly worked with caregivers of people living with mental illness at the institutions were requested to be mediators. They were selected because they will be able to identify caregivers of people living with mental illness and they have knowledge on research processes.

The researcher gave each mediator a brief explanation on what the study was all about. Mediators were able to recruit/identify caregivers of people with mental illness as they directly worked with them. The mediators met caregivers during their appointments and discussed the study to them. The researcher employed a Social Work Honours graduate to be the independent

person. The graduate was selected because she was neutral. The informed consent process was clearly explained to the independent person. There were meetings scheduled in each institution between the mediator and independent person to discuss how the independent person will get hold of the prospective participants after they have shown signs of interest to participate in the study to the mediator.

Thirdly, after participants' responses regarding participation was positive, they were individually approached in the form of a meeting by the independent person at the respective organisation and Community Health Centres in a private room to explain the informed consent process in the form. All participants were given a suitable time (a maximum of 72 hours) to direct questions to the independent person or raise concerns to thoroughly understand what is being asked of them. After 72 hours, prospective participants who showed interest in the study, were expected to sign the informed consent form in front of the independent person at the respective organisation and community health centre in a private room. The participants were not to be given consent forms to avoid loss or accidental defacement thereof at their homes. The research procedure and consent forms were explained in the language they understood best, which is English or Sesotho. It was also explained to the participants that they could withdraw from the interview anytime they felt the need to do so, and they would not be implicated in any way.

Lastly, the researcher used interviews as a method of data collection. Semi-structured interviews were used so that the researcher has a thorough understanding of caregivers' experiences. The researcher administered the interviews herself using her password protected personal laptop. The participants were asked one question at a time, this allowed the researcher to enquire more through minimal changes, paraphrasing and clarification, to get detailed information and encourage participants to share information. The interviews were conducted in Sesotho or English. All the interviews were audio-recorded with the permission of the participants. In this study, all interviews were conducted in a safe, private and quiet room in the institutions without access to a third person. Interview questions and period of the interview were the same for all the participants, which was between 45 minutes and 1 hour. The interview questions were divided into two sections which are demographic information and semi-structured interview questions.

3.8 Data Analysis

Vignali, Hallier, and Stanton (2016) concur that qualitative data analysis is a process of the description, classification, and interconnection of phenomena with the researcher's concepts. First, the phenomenon under study needs to be described precisely. The researcher needs to be able to interpret and explain the data; therefore, a conceptual framework needs to be developed and data classified. After that, concepts can be built and connected to each other. According to Flick (2013:4) (as cited by Vignali, 2016:8) qualitative data analysis has the following aims: to describe a phenomenon in some or greater detail, compare several cases on what they have in common or on the differences between them, and develop a theory of the phenomenon under study from the analysis of empirical material. In this study, several steps were followed to analyse data. The researcher used Thematic Analysis to analyse data. According to Braun & Clarke (2006) (as cited by Maguire & Delahunt, 2017) thematic analysis is the process of identifying patterns or themes within qualitative data. The co-coder used the Atlas. ti version 23 software to analyse data to get enough insight into the themes gathered in the transcripts. Six steps of thematic analysis proposed by Braun & Clarke (2006) (as cited by Maguire & Delahunt, 2017) were adopted.

1. Become familiar with the data

Listening to audio recordings repeatedly enabled the transcriptions to come alive during the analysis. Notes were made and the researcher jotted down early impressions. The researcher read and re-read the transcripts. This was done to be very familiar with the entire data before going any further.

2. Generate initial codes

The researcher started to organise data in a meaningful and systematic way. Coding reduces lots of data into small chunks of meanings. Theoretical thematic analysis is concerned with addressing research questions and analysing the data with this in mind. Each segment of data that addressed research questions was coded in each transcript. Open-coding was used; that means there were no pre-set codes, but developed and modified the codes while working through the coding process. Preliminary ideas about codes were developed. After modifying preliminary codes, new codes were generated.

3. Search for themes

A theme is a pattern that captures something significant or interesting about the data. A theme is characterised by its importance (Braun & Clarke, 2006) (as cited by Maguire & Delahunt,

2017). Several codes were produced that related to research questions. Thereafter, codes were organised into broader themes. Themes were predominately descriptive, that is, they described patterns in the data relevant to the research questions.

4. Review themes

During this phase, the researcher reviewed, modified and developed the preliminary themes that were identified in Step 3. Furthermore, the researcher checked if they make sense, this point was useful to gather all the data that is relevant to each theme. Data was read which associated with each theme and considered whether the data support it. Atlas.ti made this process much quicker and easier.

5. Define themes

This is the final refinement of the themes and the aim was to identify the essence of what each theme is about (Braun & Clarke, 2006) (as cited by Maguire & Delahunt, 2017). The researcher asked herself the following questions: what was the theme saying? If there are subthemes, how do they interact and relate to the main theme? How do the themes relate to each other?

6. Write- up

Lastly, the researcher wrote findings in Chapter 4.

3.9 Trustworthiness of Data

Based on Pilot and Beck (as cited by Connelly, 2016:435) trustworthiness or rigor of a study refers to the degree of confidence in data, interpretation, and methods used to ensure the quality of a study. In each study, researchers should establish the protocols necessary for a study to be considered worthy of consideration by readers (Amankwaa, 2016) (as cited by Connelly, 2016:435). Qualitative studies apply the following evaluation criteria: credibility, dependability, confirmability, transferability, and authenticity to test for the trustworthiness of the research findings or results (Guba & Lincoln, 1994) (as cited by Lemon & Hayes, 2020) and (Connelly, 2016).

3.9.1 Credibility

Credibility is defined as a strategy in qualitative studies that is applied to control the degree to which research results and the process of data analysis are trustworthy (Korstjens & Moser, 2018). Lemon & Hayes (2020) describe that member checking refers to when you prove your understanding of what you have detected with those observed. Member-checking was applied after the writing of findings in this study by allowing a few of the participants who participated in the semi-structured interviews to evaluate the results and the conclusions to check whether their views, opinions, and responses were correctly elaborated or not. By undertaking this process, it allowed the research's findings to gain validation. The credibility of the study was through the description of research questions, setting of the research study where it was carried out, research design, and sampling method. In this study, the researcher went to some of the participants, to ascertain whether the transcribed data was a truthful version of their experiences and coping strategies. All this was done in a private room with only the researcher and participant at the respective organisation and community health centre to avoid other parties having access to the findings of the study and without the caregiver feeling stigmatised in front of other parties.

3.9.2 Transferability

Lemon and Hayes (2020) explain that transferability is parallel to external validity and seeks to ensure that the research findings are generalised to another context. In determining transferability in this study, the researcher explained the full account of the research context. This procedure allowed the researcher to validate the methods used in collecting data and the whole procedure of data analysis. The transferability of this research study was established using theoretical frameworks and a Qualitative Descriptive research design.

3.9.3 Dependability

Nowell, Norris, White, & Moules (2017) state that dependability is the extent to which research findings can be duplicated with similar topics in a similar setting. This shows that dependability is apprehensive about whether one can achieve the same outcomes or not. In this study, the researcher will keep all records of documents and materials in data collection, analysis, and presentation according to NWU research standard procedure to ensure that the results of this

study in terms of experiences and coping strategies of caregivers of people with mental illness in Emfuleni Local Municipality is familiar from time to time if the study is conducted in the same place using the same methodology by different researchers.

3.9.4 Confirmability

Lemon and Hayes (2020) define confirmability as when research findings can be collaborated by other researchers. For this study, a data audit was used as a strategy to determine confirmability. The researcher allowed research experts in the Faculty of Health Sciences to outline the research step-by-step using the decisions made and procedures described. This was done by unveiling the documents and materials used in data gathering and analysis to inspect the confirmability of these research findings. The findings were submitted to the Health Research Ethics Committee (HREC) for ethical assessment and validation to guarantee ethical demeanour.

3.9.5 Authenticity

Based on Pilot and Beck (2014) as (cited by Connelly, 2016:436) authenticity is the extent to which researchers show a range of different realities and realistically convey participants' lives. In this study, the researcher selected appropriate participants as the study sample to ensure that the study becomes rich and authentic.

3.10 Research ethics

According to Roshaidai and Arifin (2018) the protection of human subjects through the application of appropriate ethical principles is important in any research study. In a qualitative study, ethical considerations have a particular resonance due to the in-depth nature of the research study process. The concern of ethical issues become more salient when conducting face to face interviews with vulnerable participants. They may potentially become uncomfortable while expressing themselves during the interview session.

3.10.1 Confidentiality and Anonymity

Confidentiality

Petrova, Dewing, and Camilleri (2016) state that the principle of confidentiality requires the researcher to possess certain personal and professional attributes such as honesty and respectfulness to the participants in the study. A researcher ought to act on the participants' behalf; that of having an autonomous respect to those who may be 'vulnerable' by empowering them to control their personal information. Fostering privacy and keeping to a commitment are other aspects of ensuring confidentiality.

In this study, the researcher demonstrated that she valued the participants' needs and built rapport. This required establishing honest and reciprocal relationships with participants and researcher adhering to the ethical principles of non-maleficence, necessity of participants' privacy and the imperative of obtaining informed consent. The following are ways the researcher ensured confidentiality:

- The researcher would not and never have disclosed interview responses from the participants to any party (included mediators at the respective institutions, friends and family) or in public places. The researcher interviewed the participants individually.
- When the phone call of the prospective participant was answered by someone else during the informed consent process, the details of the study were not revealed to that individual. Instead, the independent person asked for a better time to call the prospective participant to schedule a meeting to discuss the informed consent process at the respective institution. Information regarding the details of taking part in the study was not discussed over the phone. Telephone/cell phone contact is the most accessible form of contact among all the others.
- All interviews were conducted in a private and quiet room in the respective organisation, and community health centres without access to a third person.
- The participants' data is stored in a lockable cabinet where access is restricted to the researcher only.
- All the data that was stored on the laptop, was password protected and will be kept for a period of five years.

Anonymity

Marx (as cited by Novak, 2014) stated that to be fully anonymous means that a person cannot be identified. The following are the methods the researcher adopted to ensure anonymity of participants:

- There were no videos and/or pictures taken during data collection to protect the identity of participants.
- Names and physical addresses of participants were not recorded in the findings of this study.
- Verbatim transcription was conducted in a private room using earphones where recordings will not be heard by outsiders.
- Personal identifying information of the participants was removed when transcribing data.
- All participants were referred to by their pseudonyms in the verbatim quotes. However, participants were notified that their demographic information will be used for reporting data from the qualitative analysis.

3.10.2 Privacy

Wright (2004) postulates that privacy is anything from the state of being alone or undisturbed, and the freedom from interference from public attention. The researcher used the following four categories proposed by Wright (2004:2) to ensure that participants had privacy in the form of information privacy, bodily privacy, privacy of communication and territorial privacy.

1. Information privacy covers the collection of personal information. Information was collected through interviews in Vaal Mental Health Organisation, Levai Mbatha CHC, and Johan Heyns CHC. The researcher had arranged with the management at all three institutions to provide available space on the day of data collection. The door was closed during data collection to avoid noise or any access to a third party. Consent to audio record interviews was requested from the participants.
2. Bodily privacy covers the protection against invasive procedures such as genetics tests and drug administering. In this study, no physical tests were made as it was not the scope of this study. The mediator, independent person, and researcher kept a 1meter distance with the participant during interactions to refrain from making the participant feel uncomfortable in any way possible.
3. Privacy of communication covers the security of forms of communicating. In case of the use of telephones for interview appointments, the researcher would ask the participant if they were able to talk privately. Data related information was communicated face to face with the participants privately.

4. Territorial privacy concerns the setting of limits on intrusion into participants' environments such as the workplace, public, and domestic place. The study was conducted at the respective organisation and Community Health Centres where the participants received services from.

3.10.3 Deception of Participants

Corey (1993) (as cited by (Strydom & Delport, 2011)) allude to the fact that deception involves withholding information, or offering incorrect information to participants. In this study, there was no misinformation of participants regarding the study. The research study was conducted in an honest manner during the whole period of the research project. Every process of the study was discussed, including the purpose and rationale, ethics, benefits, and publication of results. In addition, the researcher clarified and answered all questions and concerns the participants had.

3.10.4 Beneficence

Morrison and Furlong (2014) explain that beneficence involves more than just avoiding doing harm. It advocates a level of selflessness and kindness that is absent from doing damage. A researcher must observe the principle of beneficence and justice by maximizing the benefits and minimizing risks, as well as avoiding bias in the process of recruiting participants (Piasecki & Dranseika, 2019). In considering risk versus benefit, the participants were exposed to possible psychological harm. The participants could have experienced the risk of being traumatised during interviews as they revealed information that could trigger psychological trauma. In case of psychological distress, the researcher gave the participants short breaks from the interview. If short breaks were not assisting, a social worker or psychologist from the respective organisation or institution was requested to provide counselling should participants experience such psychological trauma. Moreover, the researcher funded transport costs for the participants to attend interviews to avoid making them feel economically strained. In the study, no physical or social harm was experienced by the participants.

3.11. Conclusion

In Chapter 3, this research adopted basic research as the type of research, which aims to establish knowledge. The research paradigm adopted in this study is constructivism. Constructivism concur that people have subjective meanings of their own experiences. The research approach discussed is qualitative research approach, followed by a Qualitative Descriptive (QD) research design. QD is naturalistic in its form, less theoretical, and method of data collection used is semi-structured interviews. The population sample was adults of 18 to 70 years who are caregivers of people living with mental illness, residing in Emfuleni local Municipality, and receiving services from Vaal Mental Health Organisation, Levai Mbatha CHC, and Johan Heyns CHC. The sample was purposively selected. Trustworthiness of data discussed included credibility, dependability, confirmability, transferability, and authenticity. Lastly, research ethics formed an integral part of the discussion. Among others, confidentiality and anonymity, privacy, deception of participants, and beneficence were discussed.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS, AND INTERPRETATION

4.1 Introduction

This study, which aimed to describe the experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality, adopted a Qualitative Descriptive research design to achieve its objectives. This chapter presents the qualitative findings of the study using Atlas.ti version 23 for data analysis. The use of this Atlas.ti facilitated the results from the software as qualitative data was networked and projected. Findings are used in qualitative studies. Results were discussed according to research questions. The chapter discusses the process of data analysis, coding, demographic profile of participants, findings relating to research questions and a summary.

4.2 Process of data analysis

Data was analysed based on the data amassed from a total of 12 participants who are caregivers of people living with mental illness in Emfuleni Local Municipality, Vaal, Gauteng Province, South Africa. Below is the procedure used in analysing the data collected for this study explained.

Table 4.1 Analytical process for data analysis (Lester, Cho, & Lochmiller., 2020)

PHASE	EXPLANATION
PHASE 1: PREPARING AND ORGANISING DATA FOR ANALYSIS	Audio recordings were gathered from interviews.
PHASE 2: TRANSCRIBING THE DATA	Interviews were transcribed in preparation for further data analysis. It served as an opportunity to set up the data so that it can be imported into Atlas. ti. Transcription also served as an opportunity for the researcher to become familiar with the data set. For Thematic analysis, verbatim transcription

	was used to capture every word from the participant and serve as an accurate record of the interview.
PHASE 3: BECOME FAMILIAR WITH THE DATA	The researcher became aware of the gaps in the data set and this initial understanding informed the researcher to conduct a more detailed analysis.
PHASE 4: MEMOING THE DATA	Memos, are in simple terms, conversations with ourselves. Memos captured parts in the data set where statements were of significance.
PHASE 5: CODING THE DATA	A code is a descriptive word or phrase that assigns meaning to the data related to the researcher's analytical interpretation. In thematic analysis, coding occurred in multiple phases.
PHASE 6: MOVING FROM CODES TO CATEGORIES AND FROM CATEGORIES TO THEMES	Categories were made up of individual codes that were related. This formation represented an important step in the production of themes. Themes were inclusive of all the underlying sub-themes, categories, description of the content, the relationships between them, and the similarities and differences observed.
PHASE 7: MAKING THE ANALYTIC PROCESS TRANSPARENT	This process was greatly assisted by Atlas. ti. This software allowed figures and network linkages to be exported into WORD format.

4.3 Coding

In this study, the interview transcripts were analysed (coded) using Atlas. ti. version 23. According to Soratto, Pires, and Friese (2020:2), it is a valuable software for data analysis in qualitative research and can be used with a variety of theoretical frameworks and data analysis methods including Thematic analysis.

Thematic analysis is the method of data analysis for the qualitative phase of the present study. The thematic analysis describes a research technique for the arbitrary interpretation of the data through a methodological coding and theme- or pattern-identification process (Braun & Clarke, 2020). The coding process was effectively managed in Atlas. ti. software.

The transcript was auto-coded through the use of a text search tool to depict participants' understanding and opinions of their experiences and coping strategies as caregivers to people living with mental illness in Emfuleni Local Municipality.

Using the text search tool allowed the researcher to become more familiar with participants' voices, and caregivers' experiences as regards caring for people with mental illness. This exercise allowed the researcher to begin the coding process.

According to Saldaña (2015:4), a code is a word or a brief phrase to which the researcher assigns a particular piece of data. Whether the researcher uses lump or split coding affects how much code is produced. Split coding refers to breaking the part up into separate portions, whereas lump coding refers to assigning a single code that encapsulates the substance of a section (Saldaña, 2015:23). The researcher used a lump coding approach for this exploration. Saldaña (2015:3) describes 32 different coding techniques used in the guidebook. The descriptive coding method was mostly used in this study, which Saldaña (2015:88) notes is appropriate for practically all qualitative explorations and is especially helpful for a researcher who is still learning how to code. Words or short phrases were used in descriptive codes to describe the data.

4.4 Demographic Information

This section presents information relating to the number of participants in this research study, age, number of dependants with mental illness, level of education, and source of income used to attain saturation for this qualitative study. A total of 12 participants who are caregivers of persons with mental illness in Emfuleni Local Municipality were interviewed in this research study. The demographic information of the participants was required during the informed consent and data collection process to allow the identification of trends tied to age, level of education, source of income, and number of dependants in order to provide deeper insights into experiences and coping strategies of caregivers of people living with mental illness within Emfuleni Local Municipality. Table 4.2 presents the participants' number of dependants with mental illness, age, level of education, and source of income.

Table 4.2 Demographic Information of Participants

Participant no.	Age	No. of dependants	Level of education	Source of income

		with Mental illness		
1	52	1	NQF 5 Generic management	Employed
2	55	1	Bachelor of Education	Employed
3	27	1	Grade 8	Unemployed/dependant on family member
4	40	2	Grade 12, Programming and Safety	Self-employed
5	67	2	Grade 12	State pension
6	50	1	Bachelor of Education	Self-employed
7	68	1	Standard 6	Private pension
8	32	1	Grade 12	Employed
9	43	1	Grade 12	Self-employed
10	52	1	Grade 10	Unemployed/dependant of family member
11	43	1	Intermediate life supporting	Employed
12	63	1	Standard 1	Old-age grant

As indicated in table 4.2, typical caregivers are early to late middle aged with a low to medium education level and from a low to medium economic class. This is in agreement with a similar study by Cormican, Meskell, and Dowling (2022) on psychosocial vulnerability among carers of persons living with chronic illness. This study found that the demographic characteristics of caregivers include those who come from low to middle income and often unemployed or ceased employment due to the nature of caring. In Emfuleni Local municipality, the reason for this distribution in the psychosocial conditions of caregivers is due to the socio-economic factors, educational and economic history of the place.

4.5 Findings related to research questions of the study.

Findings of the two research questions are presented in this section; these research questions include: (I) What are the experiences of caregivers of caring for people living with mental illness in Emfuleni Local Municipality? (II) What are the coping strategies of caregivers of caring for people living with mental illness in Emfuleni Local Municipality?

Following the coding process, the codes were categorized into five (5) main themes, nineteen (19) sub-themes, and twenty-three (23) categories. Generally, these three organizational levels were used to present findings. These codes and categories are presented in Tables 4.3, Figure 4.1, Table 4.4 and Figure 4.12 as the themes and sub-themes for this study. The next section details the empirical findings of the study.

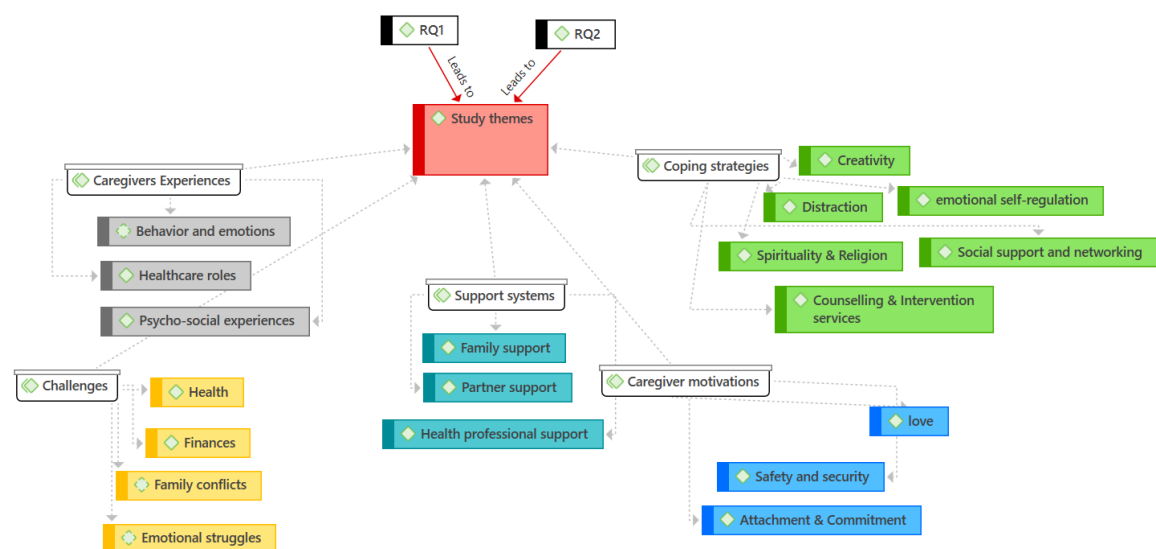


Figure 4.1 Research themes of the study

Research Question 1: What are the experiences of caregivers of caring for people living with mental illness in the Emfuleni Local Municipality?

Table 4.3 Themes of the study

THEMES AND SUB-THEMES	CATEGORIES
1. Caregiver Experiences	

1.1 Healthcare Roles	• Monitoring and supervision • Health condition management
1.2 Psycho-social experiences	• Fear • Frustration • Anger • Rejection • Personal hygiene • Social isolation • Transportation difficulties
1.3 Behaviour and emotions	• Developmental delays • Bullying • Mental illness behavioural manifestation
2. Challenges	
2.1 Emotional struggles	• Feelings of helplessness • Uncertainty • Mental exhaustion • Unhappiness
2.2 Health	• Strained Work-life balance • Deteriorating health
2.3 Finances	• Job insecurity • Financial strain
2.4 Family conflicts	• Strained marriage • Strained caregiving • Child vulnerability

Note: SA, means section A of the transcript document (ANNEXURE C) which is separated into 2 parts (SA1, SA2). SA1 addresses statements relating to caregivers' experiences and SA2 is concerned with caregivers' statements about their challenges. P1-P12 implies the participants' pseudonyms. As there were 12 participants interviewed. Therefore, as part of establishing the

trustworthiness of the study findings for example, a quotation labelled “SA1, P4” means that it can be traced in section A1 of the transcript and it is the statement of Participant 4. This applies throughout the chapter.

EMPIRICAL FINDINGS ON CAREGIVERS' EXPERIENCES OF CARING FOR PEOPLE LIVING WITH MENTAL ILLNESS IN THE EMFULENI LOCAL MUNICIPALITY

4.5.1 CAREGIVER EXPERIENCES

The first theme “Caregiver experiences” consist of the following sub-themes: healthcare roles, psycho-social experiences and behaviour and emotions. The next section detail each of these sub-themes.

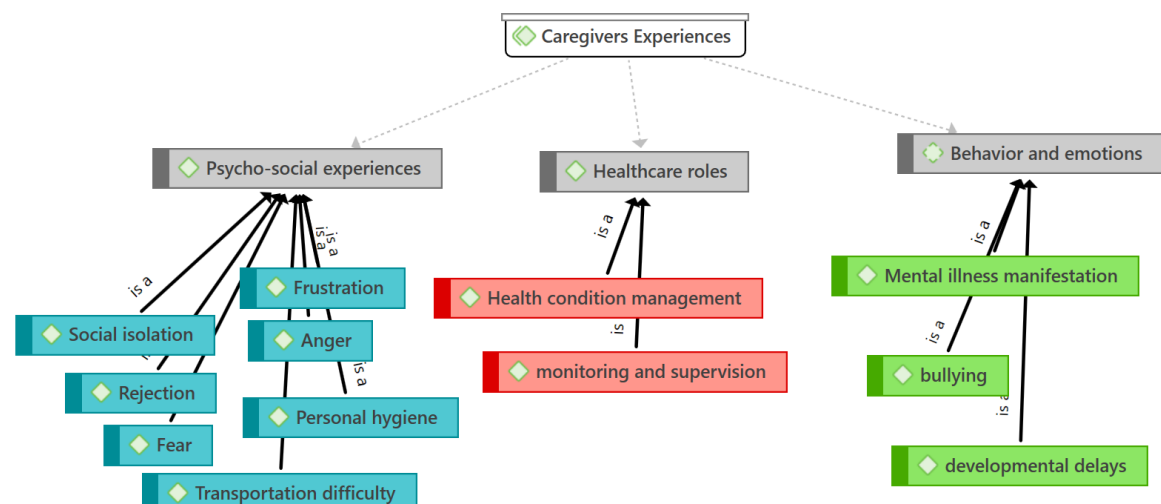


Figure 4.2: Caregiver experiences

4.5.1.1 HEALTHCARE ROLES

Healthcare is the total societal effort, whether private or public, that attempts to guarantee, provide, finance, and promote health. Healthcare roles consist of measures for maintaining and improving health, prevention, control of the diseases, injuries, and other disorders, efficient treatment and rehabilitation. The sub-theme “Healthcare roles” is categorised into monitoring and supervision, and health condition management.

MONITORING AND SUPERVISION

Nearly all the statements of the caregivers reflect that they often provide monitoring and supervision roles (i.e. participant four (4), seven (7), ten (10) etc.). They explained that the monitoring and supervision experience was informed by the mentally ill people's inability to remember occurrences and events around them. Their forgetfulness thus requires constant supervision. They were reported to have wounds that they were unaware of in very delicate parts of their body. They even forget to take their medication because some are suffering from dementia and sometimes refuse to take their medication because it makes them tired. Participants four (4), seven (7), and ten (10) had to supervise the medication intake of the person with mental illness.

Below are participants' words:

...I supervise their medication. If I see any odd change in them, I make sure that I inform the psychiatrist here at the clinic. It's is a very huge responsibility to care for someone that has mental illness (SA1, P4)

...I reminded him that he needs to take medication because when he was young he was taken to a specialist who prescribed him eltroxin because his thyroid is not working properly. He does not take medication for his physical and mental health. I have to inform the doctor to give him the eltroxin medication for his thyroid because he becomes very down if he does not take it. I have also discovered changes in his health, he becomes fat and dumb. Therefore, he should take all of his medication (SA1, P7)

...I collect medication on her behalf because she goes to school unless when it is her date to see her psychiatrist for her session, she then skips school for that day (SA1, P10).

Monitoring and supervision was one of the experiences faced by some caregivers. Caregivers had to ensure that their family members are well monitored and supervised in everything that they do to manage their mental illness. Caregivers had to go to mental health centres to collect medication on behalf of the person living with mental illness due to the severity of the illness and some due to incapability of the person with mental illness. The findings about monitoring and supervision are consistent with that of Gloria, Osafo, Goldmann, Parikh, Nonvignon, & Kretchy (2018), who concluded that caregivers need to constantly be on guard due to the inclination of mental illness patients who show signs of behavioural problems and experienced

a treatment related burden which is to ensure that medication is taken and psychiatric centres are accessed.

HEALTH CONDITION MANAGEMENT

Half of the caregivers in this research ensured that the mental illness condition of their family members is managed. They do this by taking their family members to the nearest clinics and hospitals for psychological and psychiatric assistance. This results to patients getting medication to treat their mental illness. Participant six (6) reported that the medication used to treat his son's aggression because of mental illness helped him to stay calm. Participant five (5) reported that the medication helped her restless sister to sleep. Participant two (2) conducted her own research on different types of mental illnesses which might match with his son's symptoms as she was confused and further went to consult with mental health professionals regarding that matter.

Below are participants' words:

...I did my own research to search for symptoms which align with his behaviour then I realised that he might have both the disorders. He is epileptic and the doctors told me that there is an over secretion of a certain chemical in his brain causing an imbalance. He was affected while doing matric and was diagnosed with major depression at that time...I took him to a psychologist and psychiatrist at the hospital (SA1, P2)

...I've been trying to get the help for it. Okay. I came to Johan Heyns Community Health Centre. They gave us antibiotics. I was then given a referral letter to Sebokeng Hospital where they gave us dressing and they made her take a biopsy and mammogram. They didn't give us any medication at Sebokeng hospital. The wound was still oozing. In December I took her to a private clinic. A private doctor referred us to Chris Hani Baragwanath academic hospital a week ago. They took a biopsy and x-rays of her. At one stage she took the wrong medication. She has lost that ability...the one with Alzheimer's took the medication of my second sister who has dementia and I think that is how she became forgetful (SA1, P5)

...Caring for a person with mental illness is difficult. It is my responsibility to make sure that she eats and is taken to the clinic to get medication. When I

discover something odd about his behaviour I tell the psychiatrist about it
(SA1, P6)

Caregivers had to convince the person living with mental illness of the importance of taking medication because some are unable to see the importance of taking medication. It also shows that caregivers advocate with healthcare professionals in managing the mental illness. Caregivers also ensured that those who are incapable or struggle to bath or feed themselves are clean and well fed. Hopper (2020) postulates that Maslow's hierarchy of physiological needs refers to basic needs like drinking when thirsty or eating when hungry. Furthermore, these needs are the most essential. Therefore, caregivers ensured that physiological needs of their family members with mental illness are met.

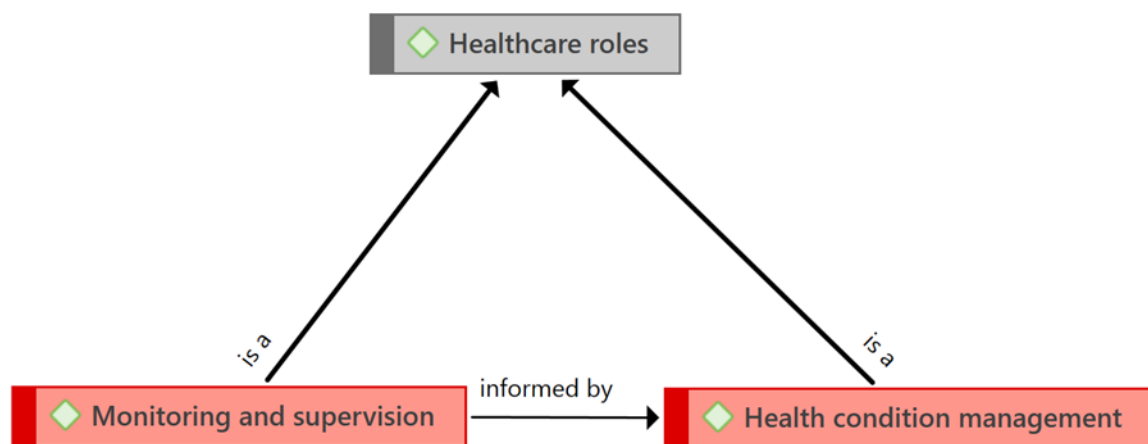


Figure 4.3: Healthcare roles

4.5.2 PSYCHO-SOCIAL EXPERIENCES

Psychosocial experiences include factors such as quality of life, stigma, and mental health outcomes (Zia, Mugo, Ngure, Odoyo, Casmir, Ayiera, Bukusi, Heffron., 2021). The sub-theme psycho-social experiences consist of the following categories: fear, frustration, anger, rejection,

social isolation, personal hygiene and transportation difficulties.

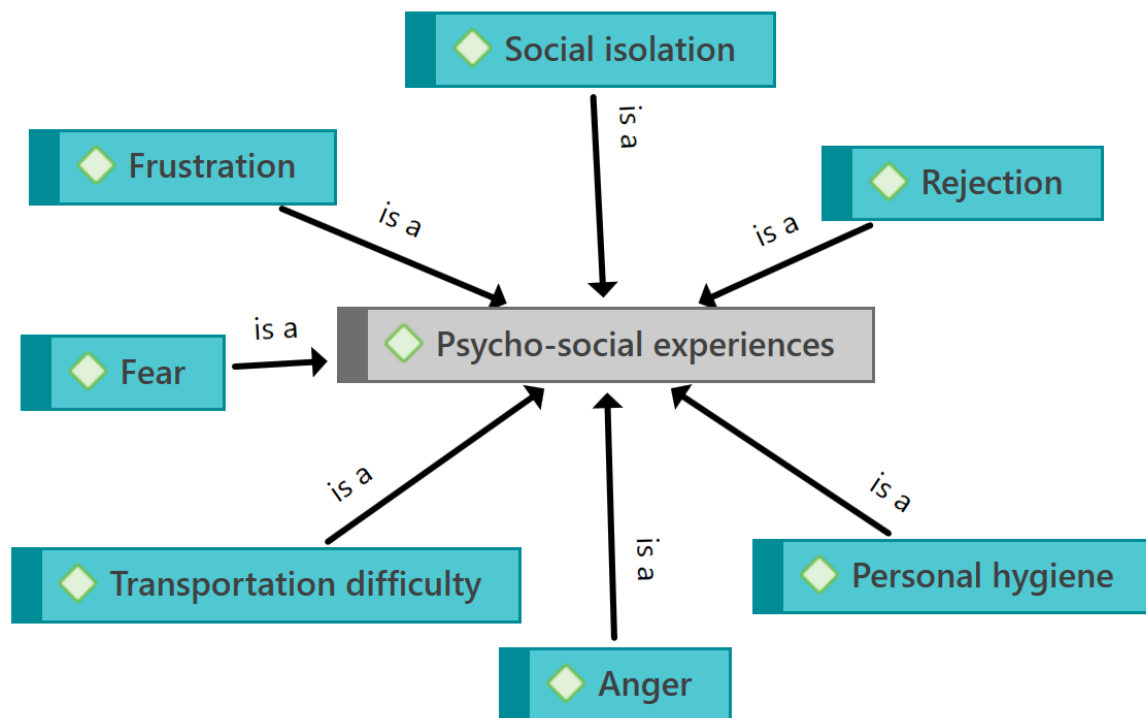


Figure 4.4: Psycho-social experiences

Source: Created by the researcher in Atlas. ti

4.5.2.1 FEAR

Caregivers express how often they get threatened by the mentally ill individual which always includes running away from home and sometimes swearing at the caregiver. This behaviour causes them concern and makes it difficult for them to live with the family member with mental illness. However, they still care for that person and do not want to lose him or her. Those who suffer from dementia require constant monitoring otherwise they stay away from home, consume dangerous substances, or have injuries without reporting them as they struggle with memory loss and require constant supervision. Participant six (6) also mentioned a concerning incident where her sister had an abscess that went unnoticed. The sisters' behaviour and speech had also become erratic and confusing, which was quite concerning to her. Participants are dealing with the constant fear of leaving their family members with mental illness unmonitored for long periods of time and sometimes extreme behaviours from their family members with mental illness shocks them to the point that it evokes feelings of fear.

Below are participants' words:

...The reason I want to speak to the doctor today is because I am very concerned with my second sister's health (SA1, P5)

...It is difficult to care for a person who has dementia because you always have to check on her 24/7. She is more like a baby that is still crawling. I am even afraid to leave her alone in the house because I don't know what she will get up to. Even when she goes to the bathroom I have to check on her (SA1, P6)

...She scared me a lot because this was something she has never done before. I have eight siblings and not even one on us has ever been beaten by my mother before. Seeing that was very painful for me. It was like she is in her own world. She spoke to herself and it was things we never understood that made no sense (SA1, P8).

Fear was expressed by the caregivers subsequent to different kinds of disruptive behaviours possessed by family members with mental illness which were directly/indirectly projected towards them. Cormican et al. (2022) support that fear, uncertainty, and loss can be associated with long-term caregiving.

4.5.2.2 FRUSTRATION

Caregivers expressed their frustrations in caring for the mentally ill individuals, they mentioned their frustration in their inability to have control over their disruptive behaviour, child-like mannerism in elderly people and behaviours such as bedwetting and having to guide them in everything. They also expressed frustration, sadness, and worry about their children's futures. Additionally, they discussed challenges related to mental health, including schizophrenia and dementia, and the difficulties they face in finding appropriate care and support. Participant twelve (12) highlighted the fact that she still has to teach her child how to bath at 14 years old and has now accepted the challenges that come with her condition.

Below are the participants' words:

...I'm also getting confused. Okay. Because most of the time he will be quiet and when you ask him something, that's when he gets space to talk a little. So you don't know whether he doesn't want to talk or not. Whether he's complaining or what (SA1, P1)

It is very hard to care for a person that has mental illness because you speak to him now and the next thing he forgets. I do not even know what kind of mental illness he has because he has been diagnosed many times by doctors (SA1, P2)

She used to be normal before but she then changed and became crazy. Things were really bad. She became violent towards people and beat them up. She would just spill a bucket full of water in the house without any valid reason. This started four years ago. For the first two years, we didn't know that she has mental illness...It was tough and I remember during those years, I was staying and working in Johannesburg (SA1, P8).

He was diagnosed with too many things. He has ADHD. I cannot remember some of them. there is this one where he gets afraid to go to people. It is a type of anxiety. He has a detachment syndrome. He is detached to people and reality. He is living in a world that I cannot explain. Caring for him is a living nightmare ...He behaves like he owns the world and I don't have a say in his life. He doesn't have any sense of reality. My husband and I cannot deal with this anymore. My husband is about to be admitted to a psychiatric hospital for evaluation for three weeks. This whole this is affecting my marriage and my whole life (SA1, P11)

Frustration was expressed by the caregivers, subsequent to different kinds of disruptive behaviours possessed by family members with mental illness which were directly/indirectly projected towards them. Cormican et al. (2022) support that uncertainty/frustration can be associated with long-term caregiving. This can be caused by the confusion that comes with handling the mental illness.

4.5.2.3 ANGER

Caregivers have expressed feelings of anger because of the mentally ill individual's behaviour. These behavioural problems include the mentally ill cursing the caregiver and not following instructions. As a result, caregivers are left upset, sometimes violent, regretful and in a state of denial/ confusion that their care recipients are mentally ill or not.

Below are the participants' words:

Sometimes you don't understand a person who's schizophrenic. Because sometimes he speaks alone. And when you ask him, what did he say? He doesn't answer back. And recently what I encountered, I even thought that this person is not sick. And I was angry. like, he uses swear words on me. Like what I mean by saying he's normal is because everything that he is going to do is everything that is happening in the house in our lives. So I was really upset with that and I thought, this person is not sick. So sometimes you, you don't know how to react. Yeah. You understand? (SA1, P1)

...Sometimes I find myself being angry at him and beating him when he gets up to mischief and I then find myself and draw myself back (SA1, P9).

Anger was expressed by the caregivers, subsequent to different kinds of disruptive behaviours possessed by family members with mental illness which were directly/indirectly projected towards them. this is confirmed by Cormican et al. (2022), it has been found that one of the factors related to the psychosocial vulnerability of caregivers of people with chronic illness is that they tend to struggle emotionally (e.g. anger, frustration).

4.5.2.4 REJECTION

Caregivers explained how their family members with mental illness are facing rejection at school, with their friends and the welfare system. Participant nine (9) explained that her son's teachers do not understand him as a child with ADHD and often complain about his behavioural problems. Caregivers also described how their children are often suspended from school due to behaviours relating to constant breaking of rules. Participant eleven (11) expressed how no one wants to take care of his son when she is away because his conduct seems to be severe as he is a compulsive liar and he steals.

Below are the participants' words:

... He was even suspended at school and I only found out after three days. I had to go to his school and negotiate his return to school on his behalf (SA1, P9)

...He is in the process of being removed from me to Boys town which is a children's home and a school for children like him. His social workers are currently busy with his paperwork. He is suspended from school every two weeks...It affects me to a very big extent. There was a time when my husband was on camp and I was away for work. I had to ask somebody to take care of him. No one wants to take care of him. Not even my friends. Not even the welfare wants to care for him (SA1, P11)

Rejection was expressed by caregivers subsequent to the condition of the person living with mental illness. This is confirmed by findings in Marimbe et al. (2016) indicating that participants reported rejection from other family members as a result of the care-recipient's mental illness. Furthermore, they reported being ostracised, for example, women in the community reported being blamed for the mental illness of their children, one of the participants mentioned that "this is from your family because in my family we never encounter such things, and it's you who brought it to the family" (Marimbe et al., 2016). Most caregivers reported non-disclosure of their relative's mental health status, to avoid discrimination (Shilubane & Mazibuko, 2020).

4.5.2.5 SOCIAL ISOLATION

Caregivers evidently have to deal with a person living with mental illness who does not relate to societal norms. Participant eleven (11) explained how the family member with mental illness behaves like he is living in his own world. Introversion/isolation/antisocial behaviour seems to be one of the most prevalent characteristics in persons with mental illness according to the participants.

Below are the participants' words:

...He is living with me now. He behaves like he owns the world and I don't have a say in his life. He doesn't have any sense of reality (SA1, P11)

...Raising her was very hard. she used to be very quiet before. She would not respond when you speak to her. She is getting better now that she is attending a special school and can now interact with my other grandchildren (SA1, P12)

Social isolation was expressed by caregivers as a character trait of the person living with mental illness. This is confirmed by Shilubane and Mazibuko (2020) postulating negative habits such as social isolation possessed by the person living with mental illness. This behaviour has a profound effect on the caregiver.

4.5.2.6 PERSONAL HYGIENE

Caregivers must ensure that they guide the person living with mental illness to care for themselves as one caregiver described how they lack a sense of personal care. Following instructions from the caregiver to personally care for themselves is also the greatest challenge. Participant one (1) continued to mention that the care recipient does not want to change clothes after bathing.

Below are the participant's words

Hygienically, my brother does not fully care for himself because he does not want to change clothes after bathing, so I have to tell him to change. I have to fight with him to change clothes (SA1, P1)

Care-recipients lacking personal hygiene have a profound effect on caregivers. Riegel, Dunbar, Fitzsimons, Freeland, Lee, Middleton, Stromberg, Vellone, Webber, and Jaarsma (2019) explained how patients with specific mental illnesses might have symptoms of lack of personal hygiene by confirming that mental illness may have an effect on self-care or personal hygiene. Mental illnesses such as Major Depressive Disorder and Schizophrenia increase functional impairment in patients.

4.5.2.7 TRANSPORTATION DIFFICULTIES

Most of the participants from this research study live in low-income households. Therefore, as an old-age grant recipient it is not easy as a caregiver to provide for every expense in the household which includes the needs of the family member with mental illness. Caregivers must

use transport to accompany their family members to clinics and hospitals for psychiatric assistance. Hence, having reliable access to transport to fulfil this role is a challenge to them. Below are the participant's words:

Okay. I came to Johan Heyns Community Health Centre. They gave us antibiotics. I was then given a referral letter to Sebokeng Hospital where they gave us dressing and they made her take a biopsy and mammogram. They didn't give us any medication at Sebokeng hospital. The wound was still oozing. In December I took her to a private clinic. A private doctor referred us to Chris Hani Baragwanath academic hospital a week ago. They took a biopsy and x-rays of her. I used a meter taxi. To go to Baragwanath hospital I have to ask my daughter for transport money because it is quite expensive. Even to go to Sebokeng Hospital it's about R150 a single trip and I am only relying on state pension so it is a lot (SA1, P5)

Cormican et al. (2022) allude that most caregivers are disadvantaged by caregiving, and a few are supported by the society and that overcoming barriers to accessing resources is crucial to some caregivers. Hence, access to transportation to accompany the family member with mental illness to mental health institutions was reported as a challenge.

4.5.3 BEHAVIOUR AND EMOTIONS

Henriques and Michalski (2020) allude to the fact that behaviour is acting in one fashion or another. Dess (2010) explains that emotion has no specific definition, however, it is a relatively brief episode of synchronised evaluative biological and physiological responses. In this analysis, Behaviour and Emotions refers to the effect that the behaviour and emotions of the person living with mental illness has on the caregiver's well-being and the effect that the behaviour and emotions of others have on the person living with mental illness which counter-affect the caregiver's well-being. Behaviour and emotions consist of the following categories: developmental delays, bullying, mental illness behavioural manifestation, and communication difficulties.

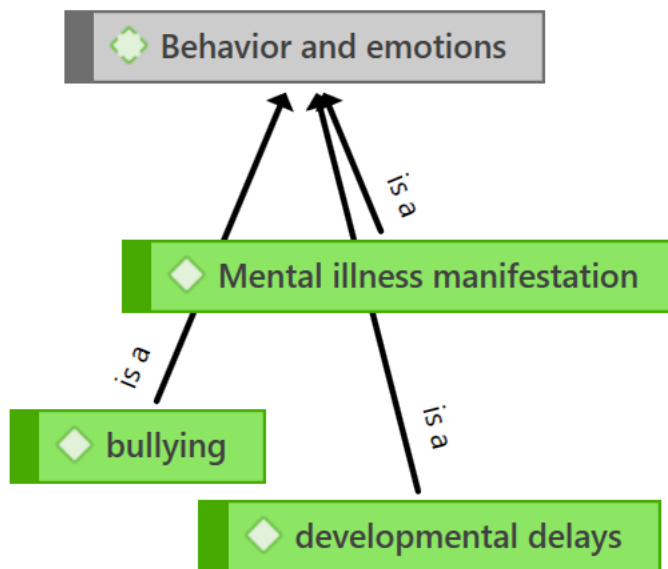


Figure 4.5: Behaviour and Emotions

4.5.3.1 DEVELOPMENTAL DELAYS

These development delays that children with mental illness experience contribute to caregivers' objective burden which evokes feelings of worry and stress. Participant twelve (12) mentioned that her child is attending a school for children with mental disabilities because she is very slow to learn basic educational tasks, and she further expressed that it is very difficult to raise her as a child with mild-intellectual disabilities. The same participant mentioned that her child gets aggressive whenever she teaches her how to write her name which frustrates her.

Below are the participants' words:

He is 15 years old. He was born with intellectual disability. He has ADHD also. Doctors found out that he was born that way because his mother used to drink alcohol a lot when she was pregnant with him. Attending support groups for caregivers here has made me understand his mental condition. He is very hyperactive and does not listen when I speak to him (SA1, P9)

...She is still struggling to write her name. When I try to help her, she sometimes gets aggressive. I really don't know why her previous school kept on promoting her to other grades even though they were aware that she is very

slow. She was diagnosed at a clinic in Bophelong with mild intellectual disability and another mental illness, I don't know what it is. Her teachers at her previous school mentioned that she is a slow learner. Now, she is attending a special school. it is a school for children with physical and mental disabilities. Raising her was very hard (SA1, P12)

Dealing with children with mental illness who show behavioural patterns of delayed cognition, hyperactivity, incapacity to perform tasks and following simple instructions seems to be prevalent in caregivers of children with ADHD and other related types of mental illness. Therefore, caregivers are faced with the responsibility to help. The spirit of helping others stems from fulfilling self-actualisation needs so that those receiving assistance live up to their full potential (Hopper, 2020). This is explained by caregivers offering themselves to continue helping their family members with mental illness despite the challenges experienced.

4.5.3.2 BULLYING

Caregivers described instances of physical and verbal abuse, as well as destructive behaviour exhibited by people they are caring for. Participant eight (8) expressed how her daughter is being beaten constantly and she is unable to prevent such an act at times.

Below are the participants' words:

He hits me, shouts at me, breaks stuff. He also hits other children at school (SA1, P3)

...She used to beat my daughter up and that really did not sit well with me. Things were really bad. She became violent towards people and beat them up. She would just spill a bucket full of water in the house without any valid reason (SA1, P8)

Marimbe et al. (2016) in a study about Perceived burden of care and reported coping strategies and needs for family caregivers of people with mental disorders in Zimbabwe indicated that participants reported that care recipients experienced bullying as a result of the mental illness. Mokgothu (2012) also described that caregivers of people with mental illness experience the objective burden of violence at the hands of the mentally ill individual. It is further stipulated that the person living with mental illness can dominate the entire family through control,

resulting in helplessness in caregivers. The findings in Ndeti et al. (2009) reveal that wandering, verbal aggression, disturbance of family at night, substance dependence, physical aggression, refusal to go to the mental health centre, and unreliability were the behaviours that caused a lot of effect on caregivers of people with mental illness.

4.5.3.3 MENTAL ILLNESS BEHAVIOURAL MANIFESTATION

Caregivers stated that the person with mental illness has a pattern of leaving home and coming back which causes them to become unsettled whenever they are outside, as there is fear that they might leave forever. They even forget things and ideas of places to the extent that they get lost. Participant two (2) mentioned that his son hallucinates and started to speak alone which resulted in him being taken to see a psychologist because he smokes marijuana also. Participant one (5) explained how her sister forgets things and accuses her of stealing her things, which confused her at first because she did not know that she has Alzheimer's. Participant ten (10) mentioned that her daughter locked herself in her room and physically harmed herself. Due to the illness, caregivers reported that individuals will lie and steal. Participant one (1) mentioned that the mentally ill person goes through sleep disturbances. It was also reported by participant three (3) that his son does not relate to societal norms and has a lot of temper.

Below are the participants' words:

At first, he started seeing things we don't see and hearing things. He then escalated to speaking alone. I then thought that he is taking alcohol, but he does not drink. I took him to a psychologist and psychiatrist at the hospital (SA1, P2)

She was diagnosed with depression. She started taking her treatment in February 2022. She used to lock herself in her room. She was always angry and harmed herself. She would cut her wrists at times (SA1, P10).

He sleeps for like maybe a week and then if it's before a week before we come to the clinic he doesn't sleep (SA1, P1).

He has a lot of temper. I didn't understand why he gets so angry. It's like he doesn't have a sense of reality because when I talk to him, everything goes away (SA1, P3)

People living with mental illness showed signs of deceit towards their caregivers. In addition, caregivers witnessed care recipients indulging in risky behaviours. The findings in Ndeti et al. (2009) reveal that wandering, verbal aggression, disturbance of family at night, substance dependence, physical aggression, refusal to go to the mental health centre, and unreliability were the behaviours that caused a lot of effect on caregivers of people with mental illness.

4.5.3.4 COMMUNICATION DIFFICULTIES

Findings suggest that there are experiences from the side effects of medications used by mentally ill people on their communication ability. Communication was a challenge because they seldom respond to questions when asked. They only stare at people. Even when asked whether they need food, they just keep quiet. Also, caregivers mentioned and noticed that the medications slow down their movements, or else give the constant urge to move, and they also struggle with basic body function controls like keeping their mouths closed.

Below are the participants' words:

...I have done research on the medication that she is taking and I have discovered that with her using antipsychotics for a long time causes certain side effects. So, um, and even her mouth, we noticed with the jaw mouth, she can't keep the mouth closed. To such an extent that she starts drooling. So that's a concern for me. (SA1, P5).

She was diagnosed at a clinic in Bophelong with mild intellectual disability and another mental illness, ...She would not respond when you speak to her. She is getting better now that she is attending a special school and can now interact with my other grandchildren. Communication was a challenge because she would not respond to questions when asked. She would just look at me. Sometimes, when I ask if she is hungry. She would not reply. Therefore, I don't know how she feels or what she wants. I have decided to just give her things and not ask if she wants them or not. (SA1, P12).

Communication seem to be a challenge between the caregivers and the care recipients as patterns of hallucination and oral dysfunction were reported to be prevalent. Communication influences a range of negative developmental outcomes in care-recipients with mental illness

when misunderstood by caregivers (Liddle et al., 2011). Therefore, there is a need for caregivers of people with mental illness to educate themselves about the type of mental illness possessed by the care-recipient from a young age.

4.5.4 CHALLENGES

The second theme “challenges” consist of the following sub-themes: emotional struggles, health, finances, and family conflicts. The next section detail each of these sub-themes.

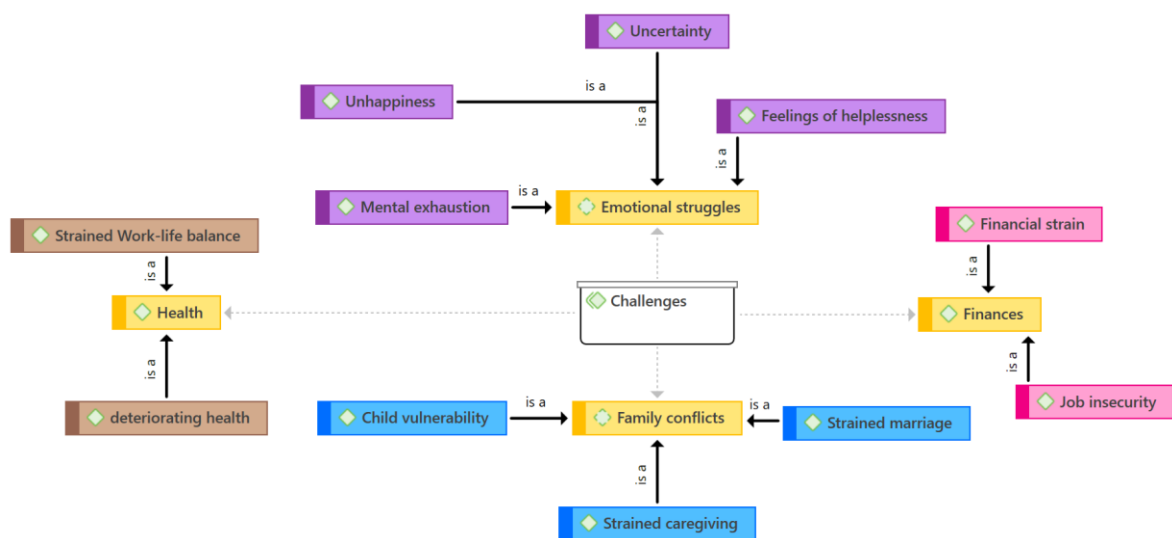


Figure 4.6: Challenges

4.5.4.1 EMOTIONAL STRUGGLES

Zafar and Mubashir (2012) define emotional struggle/distress as feelings of anxiety, anger, and depression. This sub-theme is categorised into the following: feelings of helplessness, uncertainty, mental exhaustion, and unhappiness.

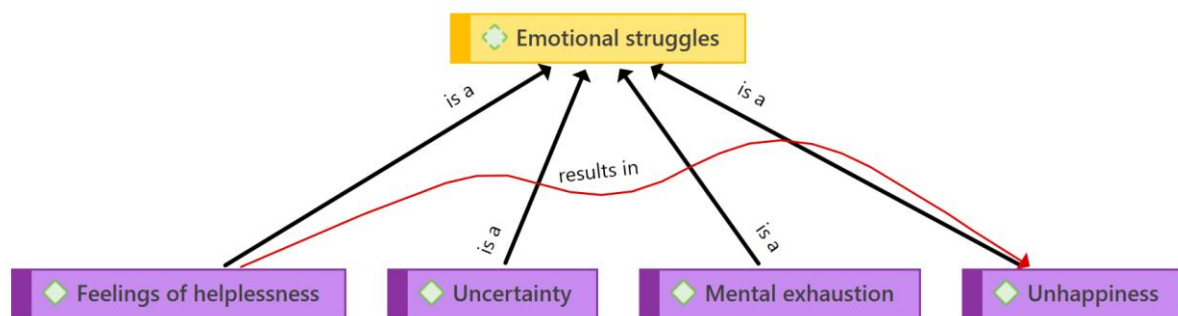


Figure 4.7: Emotional struggles

4.5.4.2 FEELINGS OF HELPLESSNESS

The findings explain the level of confusion that comes with understanding the mentally ill family member. The mentally ill individuals are described as difficult, harsh, and mischievous. Their behaviour is described as complicated. Verbal abuse towards the caregiver was also reported. Regardless of this, participant one (1) felt the need to care for her brother who has mental illness because she feels that she is the one who can do that better. Participant three (3) described how she stops herself from getting angry at her son for his disruptive behaviour because she now understands his illness.

Below are the participants' words:

He's a very difficult person. Maybe you leave him in the morning and think that when you arrive from work, he's the same person but he's not. He's very complicated. I don't want to lie (SA2, P1)

...I even felt like, you know what? I can't. I can't stay with him. I can't. I can't. This is heavy for me. Okay. I can't stay with somebody who can swear at me. (SA2, P1)

...Sometime he doesn't do what I tell him to do, he would sometimes put a whole toilet roll in the toilet, but I would try not to get angry with him because it is not his fault that he is like this (SA2, P3)

It is confirmed by Ntsayagae (2019) that caregivers experience feelings of helplessness when they cannot do something about the patient's condition and when they are fearful of his/her aggressive behaviour. Furthermore, caregivers in this study experienced feelings of powerlessness, they reported thoughts related to lack of self-worth and hopelessness.

4.5.4.3 UNCERTAINTY

Caregivers expressed worry, fear and uncertainty when the mentally ill individual threatens them. Their behaviours of absconding causes caregivers to become unsettled when they are not closer to the mentally ill family member. the behaviour of hallucinating also confuses the caregivers because they wish to understand what their family members are saying. Participant one (1) got confused to the point whereby she thought that her brother's behaviour is learned and not caused by the illness. It was also reported that teachers at school also find it hard to constantly guide the child with mental illness in some respects. This happens more especially in cases where a child with mental illness is not enrolled in a special school. Participant three (3) continued to mention that it is difficult for her to be settled at home when her son is at school due to this situation.

Below are the participants' words:

He can stay alone, but I get worried sometimes. Especially when he's angry. You get scared. sometimes he even mentioned that 'I will go', like he threatens. He once stayed with my mother in Free State and he threatened to take hikes and leave. So sometimes when you're at work, you just like jumpy, because he's always threatening to run away from home. The most confusing part about him is when he talks alone. So you don't know what he is saying. Does he think of leaving? Sometimes he swears at me. When he goes to my younger sister's house, maybe there's something that they talk to him about that I don't know of that makes him threatens to leave (SA2, P1).

...Teachers also have to constantly tell him to do his school work. It is sometimes hard for me when he is at school misbehaving because I am not around him (SA2, P3)

Caregivers reached a point where they question the nature of the illness and get confused by the behaviour of the mentally ill individuals. It has been indicated in the findings of Kamal (2013) that the behaviour of the mentally ill person caused emotional discomfort in their caregivers. This was common in the early stages of the illness, when there was a great deal of uncertainty and suffering since the caregivers lacked knowledge of the type mental illness.

4.5.4.4 MENTAL EXHAUSTION

Depression was reported as one of the psychological issues encountered by the caregiver. This is caused by the pain of seeing their children different and wanting only the best for their children. Participant three (3) mentioned that she fails to understand how something simple as personal care cannot be easy to someone with mental illness even when they are taught.

Below are the participants' words:

It is painful to raise a child that has mental illness because he was not born like that. He was born to have a good future. I went to schools to have a good life and healthy children. Now I am also depressed (SA2, P2)

I have to constantly tell him to brush his teeth, eat, and get dressed and it is not like he doesn't know how to do it. Sometimes I would not understand like why everything doesn't go to his head. I do the same thing every day (SA2, P3)

Caring for a person with mental illness results in caregivers feeling psychologically strained. Care recipients' extreme behaviours exhibited at the caregivers mentally exhausts them. Arevalo-Flechas et al. (2013) found that caregivers of people with dementia (mental illness) encounter role limitations due to emotional problems and psychological distress.

4.5.4.5 UNHAPPINESS

Caring for a person with mental illness on a full-time basis deprives caregivers from having a fun social life of their own where they can distress and interact with others. Lack of social interactions is a common contributor to loneliness and unhappiness in later stages of life. Participant three (3) explicitly expressed her feelings of sadness. Participant two (2) has gotten used to being isolated from everyone and caring for his son to the point that she feels overwhelmed to interact with people. Hurtful words from the person with mental illness directed at caregivers negatively affect their emotions. Participant three (3) continued to mention that when her child is sick, she also feels unwell.

Below are participants' words:

I do not have a life of my own. I cannot even go out for a long time and have fun with colleagues because I have a child that is fully dependant on me. I am unhappy and always sad. I am unable to socialise with people either in person or on the phone. I spend time alone. I feel easily irritated by some of my friends whom I used to spend time with before. I don't want to spend time with them (SA2, P2).

Not really, but my son is missing out on a lot of his school work because he has to come to the clinic to see the doctor every second month. When your child is sick, it throws 10 times at you. Sometimes, I cry a lot. the words he says to me hurts. Like, "I wish you were not my mother, or I don't want to stay with you", or "I'd rather go stay with this person", but I know he doesn't mean everything he says it's because he is just angry and he's going through his own emotions (SA2, P3).

It shows that caregivers are at the risk of developing mental illness themselves due to caring for the mentally ill. Caregivers are at the risk of depression and anxiety. Monteiro et al. (2017) confirms that patients with mental disorder's behaviour leads to burden which increase caregiver depression and anxiety.

4.5.5 HEALTH

The accepted definition of health proposed by World Health Organisation allude "health is a state of overall physical, mental, and social well-being and not merely the absence of disease or infirmity" (Masic, 2015). Health is categorised into strained work-life balance and deteriorating health.

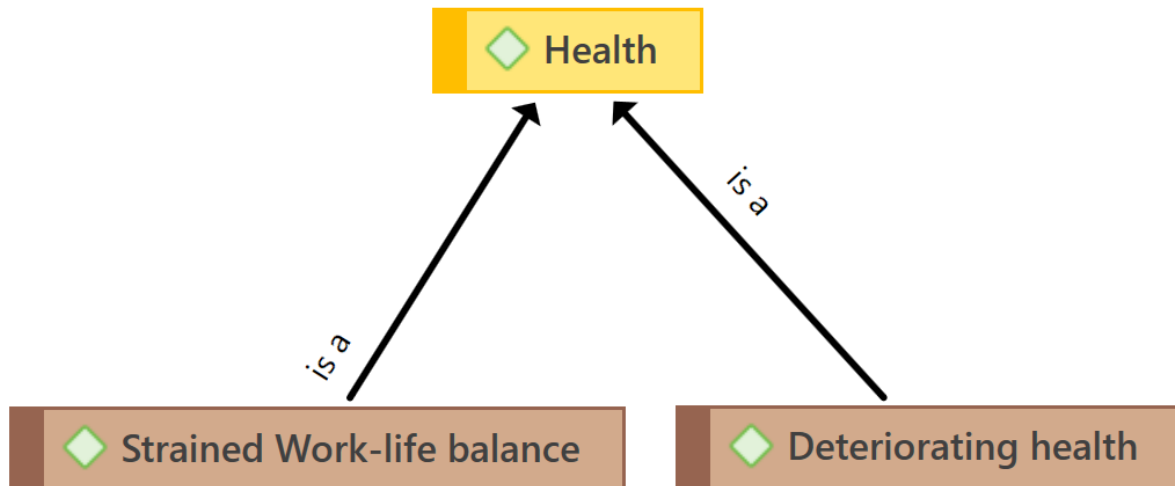


Figure 4.8: Health

4.5.5.1 STRAINED WORK-LIFE BALANCE

Unemployment seems to be common among caregivers of people with mental illness because the role of caregiving is demanding. As a result, caregivers give up their work to assume this role. Participant three (3) mentioned that she had to do her son's schools work because he was falling behind. The child was falling behind with his schoolwork because he has a short attention span and he is hyperactive due to his mental illness. Participant four (4) mentioned that he cares for two people which is highly demanding and difficult.

Below are the participants' words:

...He is too busy for himself at school and sometimes distracts the whole class. Teachers do not understand him as much as I do. As a result, I used to be absent a lot at work because I had to always be there for him as there were complaints about him at school...The teachers had to give me his schoolwork to help him because he was really falling behind (SA2, P3).

...It's a very huge responsibility to care for someone that has mental illness. So, caring for two people is more like caring for twelve people. It is a job on its own. It has challenges but you get used to it with time (SA1, P4).

The responsibility of caregiving is demanding to the point whereby caregivers are unable to live a life outside of caregiving. Most caregivers are unable to keep a balance between their

work and personal life. Ntsayagae (2019) also stipulates that caregiving requires sacrifices about social and occupational life, as caregivers find themselves isolated and unemployed.

4.5.5.2 DETERIORATING HEALTH

As a caregiver with her own health issue, the responsibility of caregiving for two people with mental illness increases the chances of health complications to worsen. Caregivers are struggling to care for themselves as they are always caring for the care recipients. As a result, they feel physically exhausted and are on chronic medication.

Below are the participants' words:

From the past few months, I have now taken a lot of responsibility as my sister with dementia used to bath herself. But now because she has also weakened. Now I have taken over that responsibility to bath both of them. And it's not like they are lightweight. They are big and heavy. I also have my own health issue. ...I have low thyroid. It causes me to feel tired all the time. I also deal with blood pressure issues. I'm on blood pressure medication. So, self-care is a challenge because you are with that person 24/7 (SA2, P5)

Despite caregivers adapting to care for their families with mental illness, their health is at risk. Other caregivers suffer from chronic physical exhaustion because of full-time caregiving. Terzungwe & Ph (2016) indicated that caregivers of individuals with mental illness are vulnerable to illnesses as they have a weaker immune system more often than those who are non-caregivers because they feel overwhelmed by the burden to providing constant care.

4.5.6 FINANCES

Stamenkovski (2018) defines finance as the art and science of managing money. The sub-theme “finances” is categorised into the following: financial strain and job insecurity.

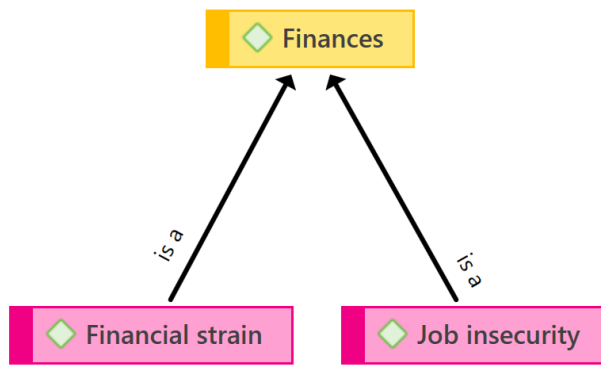


Figure 4.9: Finance

4.5.6.1 JOB INSECURITY

Participant three (3) expressed how she was always late or absent at work and that resulted in her losing her job because she had to fully care for her son who gives her a difficult time when it comes to preparing for school in the morning. There were always complaints from school about her son's behaviour so she was always at school meetings instead of being present at work.

Below are the participant's words:

Losing my job was also another challenge I faced (SA2, P3)

Caregivers cease employment due to the caregiver burden. As a result, their socio-economic condition becomes negatively affected. Anhang et al. (2016) found that caregivers experienced financial difficulties in caring for people with mental illness. Most participants from this research study come from low-income households. Government grants received by people with mental illness is not enough and caregivers ceased employment due to the demand of caregiving.

4.5.6.2 FINANCIAL STRAIN

Lack of finances to cater for all the needs of more than one care recipients is shown to be experienced by caregivers. Participants four (4) and eight (8) mentioned that they do not earn

much at work and sometimes struggle to provide for the individuals with mental illness to a full extent.

Below are the participants' words:

I am not fully financially stable to care for both of them. My company is not doing that good. They require special need. They need a lot of food because they eat a lot. I also feel that their pension grant is not enough for the both of them to be sustained for the whole month (SA2, P4)

...However, I have financial problems because I do not earn much, therefore some of the things she needs I cannot provide for her but I am really trying (SA2, P8)

Most caregivers from this research study come from low-income households. It makes sense that they are unable to financially provide for their family members with mental illness at times. Findings in Maribe et al. (2016) show that financial burden was expressed by many caregivers. For example, it was experienced because of the caregivers leaving their jobs in order to take on the role of caregiving.

4.5.7 FAMILY CONFLICTS

Family conflict is more than just a disagreement emanating from family members, it is a situation in which one or more parties perceive a threat (Aye et al., 2016). The sub-theme “family conflict” is divided into the following categories: strained marriage, strained caregiving, and child vulnerability.

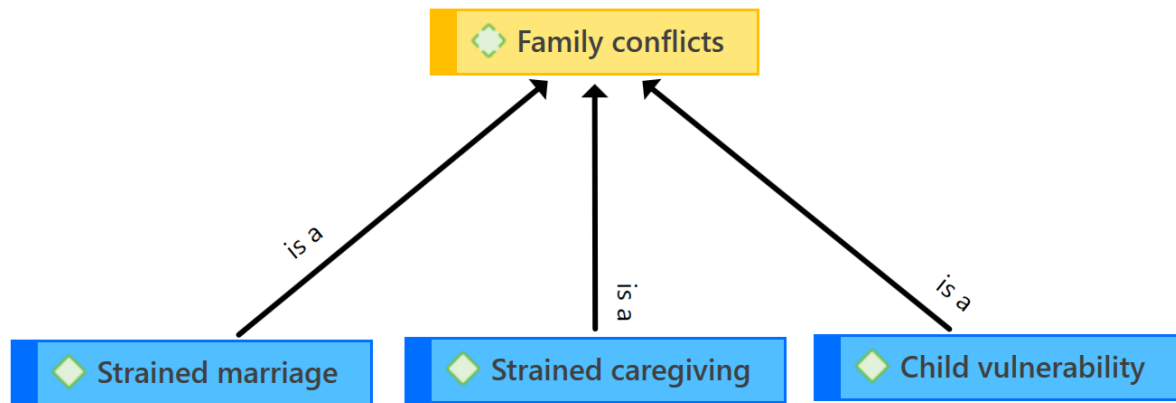


Figure 4.10: family conflicts

4.5.7.1 STRAINED MARRIAGE

The disruptive behaviour exhibited by the person with mental illness within the families causes misunderstanding and conflict between spouses and siblings. In this case, participant five (5) is divorced because of these issues and participant twelve (12) is at the stage of separating with her husband. This might be caused by the lack of knowledge about mental illness and lack of tolerance for people with mental illness.

Below are the participants' words:

...That's the reason why I sold my house. I got divorced. It's now two years that we are in Vanderbijlpark. I am the only one that constantly must bring them to the clinic (SA2, P5)

...It affects me a lot as a mother. Now it is a decision between my biological children, my marriage and me. I need to let go of him. He needs to be taken back to the system. I am on a brim of a divorce because of this. (SA2, P12).

Misunderstandings about the mental illness within the family results in conflict and separation among family members. Ntsayagae (2019) makes a similar report that caregiving requires sacrifices about social life, as caregivers find themselves isolated.

4.5.7.2 STRAINED CAREGIVING

The relationship between the caregiver and the person living with mental illness is also strained due to their behaviour. The family members living with mental illness exhibit tantrums, deceit, isolation, deviance and inadequacy of medication intake.

Below are the participants' words:

...Sometimes he gets late for school because of his morning tantrums, he cries a lot, screams, and shouts. I then take a video of him and show it to the teacher because she told me she is not happy with his late coming, so that I can show her that I am trying my best with him. They cannot handle him at school. He is very active at school, and he can even take an hour to write one sentence. Teachers are not patient with him, I always tell them that he is too busy, they need to make him do tasks at school to keep busy (SA2, P3)

...She hides her own things in the house. She even takes off her clothes from the washing line when they are washed and hides them. She has always hated it when people touch her things. When I am doing laundry outside I have to lock her in the house so that she does not get out and take her clothes from the washing line. I also have to ensure that the gate is always closed because when she goes outside the yard she goes missing. She has been staying with me for three years now but she still wants to go live alone in her house (SA2, P6).

...I always have to remind him to take a bath because he would start to smell bad. He is very lazy. He lives alone in his own house but my wife and I are his caregivers. We make sure that we call him every day but sometimes he switches his phone off. We prepare food for him as well and take the food to his house. We invite him to come during the week and sleep with us in our house and sometimes he refuses to come and says that he does not want to be bothered...At times, I would take him out for shopping or just to go around and think that maybe he will feel better but sometimes he refuses to go out with me and my wife. He prefers being in the house the whole time. He would shout at me at times. He used to physically fight me and my wife sometimes. (SA2, P7)

Caregiver-care-recipient relationship also becomes strained as a result of the disruptive behaviour exhibited by the person living with mental illness. Bom et al. (2019) confirms that informal caregiving can be very demanding and might lead to physical and emotional strain.

4.5.7.3 CHILD VULNERABILITY

Children with mental illness were reported to have experienced sexual abuse. In most cases this happens because their biological, mental and social well-being is taken advantage of, which is a pandemic. Participant ten (10) and twelve (12) reported that their female children were raped which really affected them in a negative way.

Below are the participants' words:

...The rape issue has really affected her and us a lot. Her father is mostly affected because he doesn't want us to talk about it in the house, it is more like taboo (SA2, P10).

When she was 12 years old, she was raped. That really affected me a lot emotionally. I took my retirement package early and resigned from my job because I felt that she was not safe. She was taken advantage of because she does not have the mental capacity to stand up for herself and because she is a child ...What affects me is the fact that she cannot stand up for herself and she is too vulnerable and that stresses me sometimes. That happened when she was away from home and I always feel that I need to protect her at all times (SA2, P12)

Children with mental illness are at risk of being abused due to their vulnerability. As a result, caregivers are emotionally and psychologically counter-affected by the abuse projected to their children. Findings in Marimbe et al. (2016) indicate that caregivers reported rejection from other family members as a result of the care-recipient's mental illness. In addition, they reported being ostracised. Furthermore, Mkabile (2019:5) established in a study conducted in Khayelitsha, Cape Town, that caregivers of children living with mental illness reported that

these children were stigmatized, had no friends, experienced both physical and sexual abuse, and some were neglected and excluded from community activities.

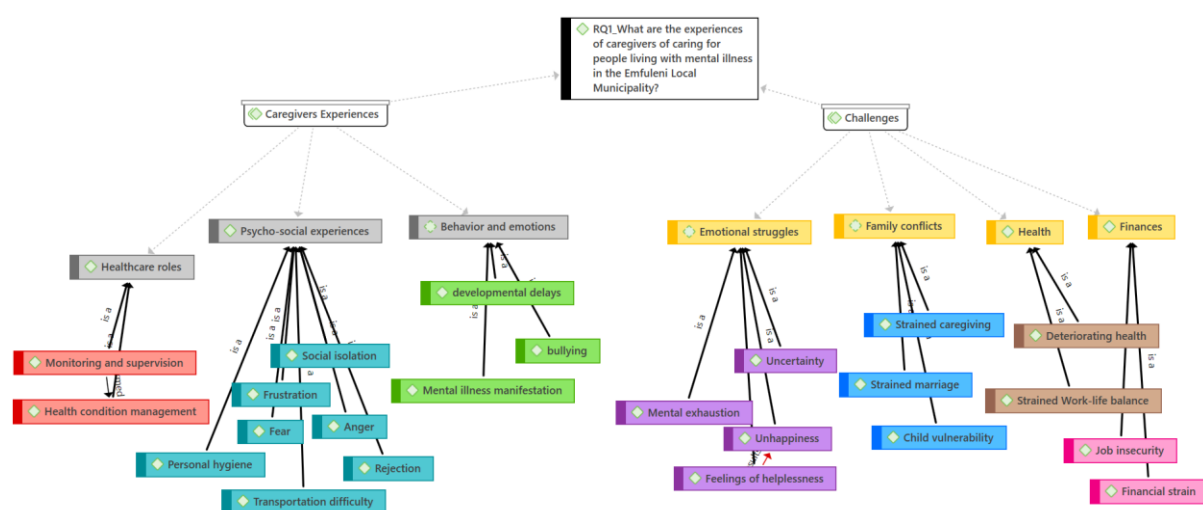


Figure 4.11: Overview of RQ1 and its themes

Research Question 2: What are the coping strategies of caregivers of caring for people living with mental illness in the Emfuleni Local Municipality?

Table 4.4: Themes of the study

THEMES	SUB-THEMES
Coping Strategies	• Social support and networking • Spirituality and Religion • Emotional self-regulation • Counselling & Intervention services • Creativity • Distraction
Support systems	• Family support • Partner support • Health professional support
Caregiver motivation	• Attachment & Commitment

	• Love • Safety & security
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Note: SB, means section B of the transcript document (ANNEXURE C) which is separated into 3 parts (SB1, SB2, and SB3). SB1 addresses statements relating to caregivers' coping strategies, SB2 is concerned with caregivers' statements about their support system, and SB3 is concerned with caregivers' motivation. P1-P12 implies the participants' pseudonyms. As there were 12 participants interviewed. Therefore, as part of establishing the trustworthiness of the study findings for example, a quotation labelled "SB1, P4" means that it can be traced in section B1 of the transcript, and it is the statement of Participant 4.

4.5.8 Coping Strategies

The theme "Coping strategies" is divided into the following sub-themes: Social support and networking, Spirituality and Religion, Emotional self-regulation, Counselling and Intervention services, Creativity, and Distraction.

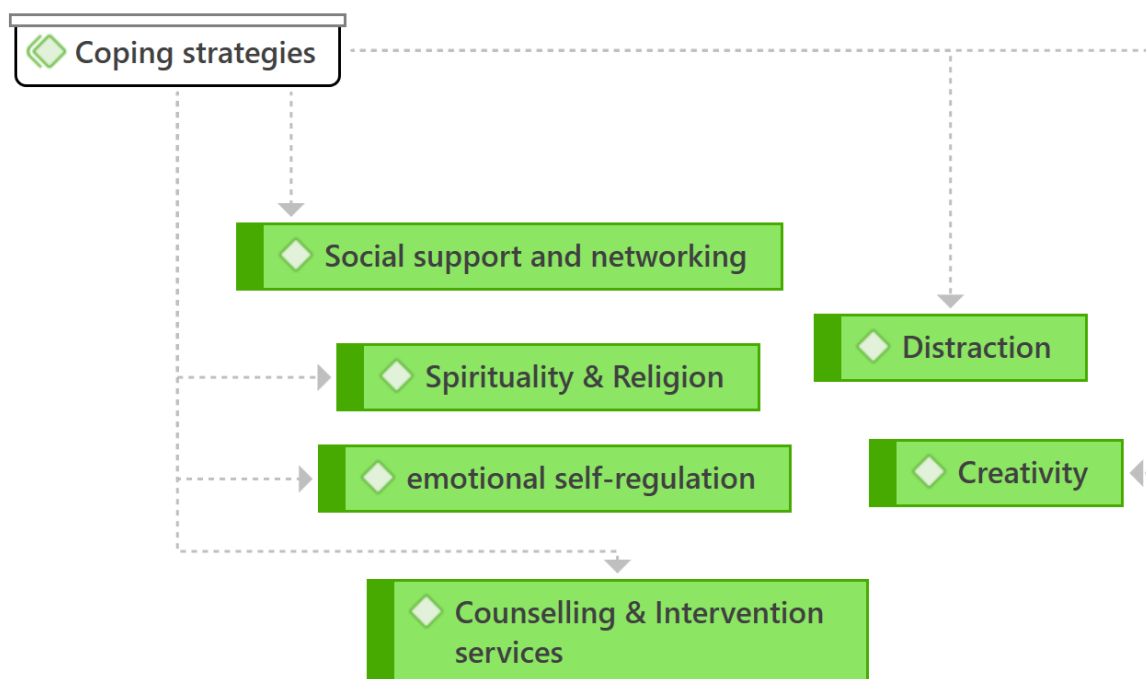


Figure 4.12: Coping strategies

4.5.8.1 SOCIAL SUPPORT AND NETWORKING

Donev and Lijana (2008) define social support as a sense that one is loved and cared for, esteemed and valued and belongs to a network of mutual obligations and communication. Networking is described as person-centred web of social relationships that surround individuals (Donev & Lijana, 2008). Caregivers made reports of attending support groups to gain motional and problem-solving skills in the case of caring for a person with mental illness and networking with people to gain financial skills to be able to provide for the needs of their family members with mental illness. Participant four (4) mentioned that he copes with the burden of caregiving by going to church and being part of the choir. Caregivers visit their loved ones just to have someone to talk to about the emotional burden of caring for a person with mental illness. Online networking was also reported by participant one (1) who listens to podcasts related to caregiving. As a result, she can see and interact with other caregivers online.

Below are the participants' words:

I go out and network with people who might help me gain skills to be financially stable. I attend a church choir to give me that feel good mood. I attend choir practice every Tuesday and Thursday (SB1, P4)

...sometime I visit my daughter in Ennerdail for a week just to have a change of scenery (SB1, P5)

...Support groups from here assist me emotionally and to solve problems as a caregiver of a child with mental illness (SB1, P9)

...I listen to podcasts about families and children with the same problem as me and It helps me to realise that I am not the only one experiencing this (SB1, P1)

To cope with their experiences, caregivers used social support and networking to cope emotionally, psychologically and financially. Caregivers receive this support from their relatives, the community, mental health services, and media. Hsiao, Lu, and Tsai (2020) found that interventions for caregivers of people with mental illness include social support which enhance mutuality and family coping strategies. Additionally, findings in Rahmani et al. (2019)

show that social support focused coping strategies were adaptive among caregivers of patients with mental illness.

4.5.8.2 SPIRITUALITY AND RELIGION

Van Niekerk (2018) defines spirituality and religion as the engagement with the world and nature, and a unified system of beliefs and practices relative to sacred things, which unite into a single moral community called a church. Participants two (2) and ten (10) expressed how much they believe in God and pray to cope with their experiences. Participant two (2) explained that she takes part in religious activities such as reading the bible and listening to pastors preach on radio. Participant ten (10) mentioned that before her daughter saw a psychiatrist, she was assisted by a religious woman who provided pastoral counselling to her and her daughter who has mental illness.

Below are the participants' words:

I just pray. I read the bible and listen to pastors on radio (SB1, P2)

I am Christian. Therefore, I believe so much in God and prayer. There is this woman who used to help me a lot when my step-daughter was sick. This was before she started taking treatment because it took a very long time to get her a psychiatrist. She used a bible way to counsel me and my step daughter (SB1, P10)

I believe in God that's all (SA2, P7)

Religious beliefs such as prayer, seeking pastoral counselling, and having faith in God were expressed as coping strategies used by participants. These findings are confirmed by Raghavan et al. (2023) whereby all participants who were caregivers of mental health service users relied on religious beliefs when explaining how the challenges related to mental illness patients were dealt with and guiding help-seeking behaviour. Findings related to caregivers' spiritual and religious resilience are postulated in Mkabile et al. (2021), Terzungwe & Ph (2016), Sharif et al. (2020), Mahomed & Pretorius (2022), and Grover et al (2017).

4.5.8.3 EMOTIONAL SELF-REGULATION

Emotional self-regulation refers to the complex process of initiating, inhibiting, and modulating the conscious aspects of emotion to effectively achieve one's goals (Sonnentag & Barnett, 2011). Self-care was mentioned by caregivers. Caregivers have learnt emotional intelligence to cope effectively. Engaging in physical fitness was also one of the strategies used by participant four (4).

Below are the participants' words:

I indulge in self-care to cool down. Sometimes when the situation gets out of hand... I am also learning how to regulate my emotions by not getting too angry at him (SB1, P3)

Well, I go and take a lavender bath. I take a bath, put in my lavender. I like lavender (SB1, P5)

I buy a pair of shoes. Retail therapy makes me feel better (SB1, P1)

I take it day by day. We don't live in the yesterdays. Each day by itself (SB1, P11)

...I sometimes go to the gym to help me to be at ease. (SB1, P4)

As explained in Rexhaj, Python, Morin, Bonsack, and Favrod (2013) that Emotional regulation is one of the primary functions of coping for caregivers of individuals with mental illness. Caregivers relate emotions elicited by challenges they are faced with caring for a person with mental illness. Furthermore, given the scarcity of studies to compare to, further studies could be useful to better understand better coping methods that improve emotional regulation. However, a model of self-regulation is recognized as efficient for decreasing caregiver loads.

4.5.8.4 COUNSELLING AND INTERVENTION SERVICES

Intervention services for families of persons with special needs include counselling, social services, family education, skill training and advocacy activities. Therefore, counselling is central to proper life adjustment of an individual (Fareo, 2015). In cases whereby the person living with mental illness was violent or has been violated against, caregivers were assisted by police officers. Educational groups were facilitated by social workers to teach caregivers about mental illness and how to handle their family members with mental illness. Caregivers also

received support from psychologists and social workers who provided counselling to both the caregiver and care recipient.

Below are the participants' words:

...During times when he would be violent, we allowed police to intervene and he was referred to a psychiatric ward in Kopanong hospital (SB1, P7)

Social workers here are educating me on how to handle her and that helps me a lot. I come for support group sessions for us caregivers where we share our stories with other caregivers and the social worker and then come up with solutions.... After her rape incident, she was taken to the clinic and a criminal case was opened. She was then transferred to social workers. These social workers really helped us a lot. They were even able to speed up the process of her receiving grant from the government because she an orphan and counselling (SB1, P12)

...I receive support from the clinic here. I talk to the psychiatrist and psychologist during my son's appointments (SB2, P2)

Intervention services such as social services, psychological services and police services have shown to aid caregivers of people with mental illness. These findings are confirmed by the researcher's findings in the problem statement about her practical experience in 2021 as a student social worker working with caregivers of people with mental illness. Mokgothu (2012) found that most of the caregivers reported using external resources as strengths to support their mentally ill family members. This included the South African Police Service, mostly to assist them apprehend their aggressive and violent mentally ill family members.

4.5.8.5 CREATIVITY

Creativity is an aspect of thinking, as a personality constellation, and as an interaction between thinking, personal properties and motivations (Cropley, 2011). Research, project planning and intervention have been reported to be used by caregivers to get a change of scenery and cope with the psychological effects of caregiving for a person with mental illness. Caregivers who are gifted with creativity use their talents for financial gains which helps to provide for the person with mental illness.

Below are the participants' words:

...Most of the time what I do, I think of a project. What am I going to do? Maybe in the house, like now I'm thinking of doing landscaping. I try new ideas. I Google. Ideas, what am I going to do? So it keeps my mind out of what's going on in my life (SB1, P1)

I am a natural problem solver. So I hustle whenever I have money problems. I am a gifted person, and I can fix things for a living then people pay me, so I do not just sit around. I am creative with my hands (SB1, P8)

In a study about positive aspects of mental illness caregiving, it was established that some caregivers engage in creative outlets and take up new activities to cope with the caregiver burden (Tulloch, Mc Caul, & Scott., 2022). Other findings in Torres-Blasco, Costa-Muniz, Rosario, Porter, Saurez, Pena-Vargas, Toro-Morales, Shen, Breitbart, & Castro-Figueroa (2022) developed a theme called “creative sources of meaning”, this implies that caregivers can actively engage in life through work, deeds, accomplishments, courage, responsibility and commitment to cope with caregiving.

4.5.8.6 DISTRACTION

Traeger (2013) defines distraction as a classification of coping strategy that is employed to divert attention away from a stressor and towards other thoughts or behaviours unrelated to the stressor. Retail therapy, hobby craft, and reading were mentioned to be used as ways to problem shift. Participants one (1) and five (5) referred to buying shoes/dressing up and knitting as a way to distract themselves from their challenges.

Below are the participants' words:

I buy a pair of shoes. Retail therapy makes me feel better. Sometimes even if I feel like, I know, I don't have money to do this, but I end up doing it. My mind shifts from thinking about my problems, sometimes I think that I'm going to dress this shoe with this and this, the feeling is temporary you know, but it helps (SB1, P1)

...I also knit to take my mind off. Okay. And, um, I like reading also but there's not always enough time to read. So, during the times when the one with dementia sleeps through at least it helps (SA1, P5)

Despite caregivers not having enough time to distract themselves and feeling that doing something else evokes temporary feelings, they continue to care for themselves. Traeger (2013) postulates that distraction has been considered a type of emotion focused coping, which involves minimizing the emotional distress related to a stressor. It has also been categorised as passive coping (associated with helplessness and avoidance).

4.5.9 SUPPORT SYSTEMS

The theme “support system is divided into the following sub-themes: Family support, Partner support and Health professional support.

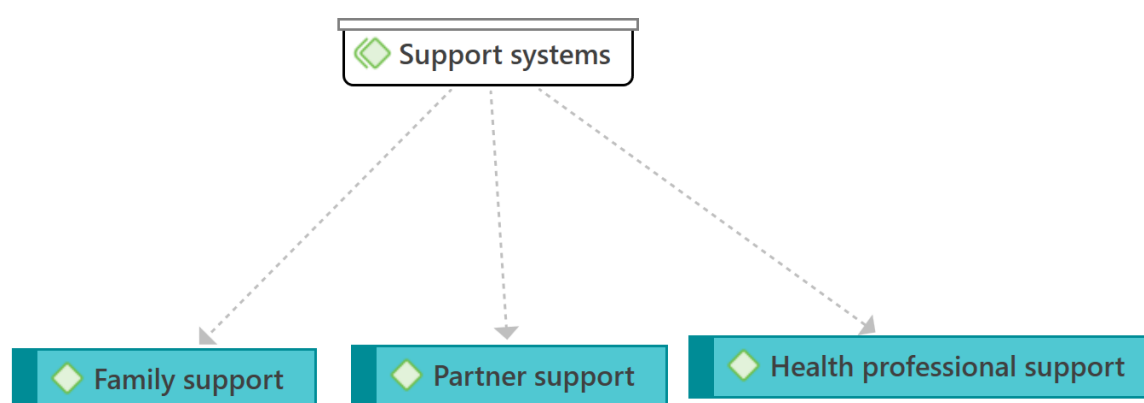


Figure 4.13: Support systems

4.5.9.1 FAMILY SUPPORT

Caregivers perceived support from family to be encouraging, helpful and providing happiness. The support offered as explained by caregivers includes financial assistance, domestic support, counter-caregiving, and emotional support. However, participant one (1) mentioned that she does not have a support system and does everything on her own to support her brother.

Below are the participants' words:

I'm the eldest of my siblings, I have a younger sister but we do not get along. I do not have a support system I do everything on my own to support my brother (SB2, P1)

My family is my support system. My sister and brother. They are the only people I live with. We talk and they provide emotional support. My brother takes care of my son when I am at work like I have mentioned before (SB2, P2)
...They sometimes buy food for our parents and bring to my house, when they have money... It encourages me not to give up on our parents (SB2, P4).

Well, my support system is my daughter. Okay. My son is also there by the bulk caring but I'm the one that's mostly taking care of them... Well, she sometimes helps them bath. She irons. She cooks, so we take turns to do those things. She financially helps me sometimes... I feel relieved sometimes that I am not the only one carrying all of this burden (SB2, P5)

...More especially my brother who takes care of my son when I am at work. It is satisfying to know that my siblings are there for me (SB2, P2).

... And daughter are my support system. They sometimes bring my mother in law to the clinic or assist me in taking care of her when I am away sometimes ... and "It makes me feel relieved. I become happy (SB2, P6).

Receiving support from the family reduces the burden that comes with caregiving. Caregivers feel relieved and satisfied that support is received. These findings are confirmed by Hogan & John-Langba (2016:620) about coping strategies of caregivers of people diagnosed with severe mental illness in South Africa, it has been found that the positive social coping strategies used by caregivers of people with mental illness included support from close friends and families.

4.5.9.2 PARTNER SUPPORT

It was only participant eleven (11) who initially said that support system was unavailable and did explain that the mentally ill person was avoided due to his disruptive nature. Participant six (6), however, confirmed receiving some support from her busy partner. What came out strong from the participants is that all caregivers receive some support from significant persons. This support comes emotionally, physically, and financially.

Below are the participants' words:

I don't have a support system anymore due to the fact that he disrupts everything ... My husband is trying to support but he works a lot... He is emotionally there for me (SB2, P11)"

My husband is my support system... They sometimes bring my mother in law to the clinic or assist me in taking care of her when I am away sometimes. My husband drives us to the clinic most times (SB2, P6)

My fiancé supports me. He supports me financially. Emotionally, he is a father to my son. he's gentle with him. He doesn't scream and shout. Even if he gets angry he goes and sits outside. We have that thing. We don't fight. We just give each other space to avoid saying things to each other we can't tolerate (SB2, P3)

My wife and I support each other in taking care of him because we are capable of providing the support... My wife makes food for him and I take the food to his house (SB2, P7)

My husband supports me. He encourages me to be a better parent and stay calm...He also encourages me to go out and take a break from caregiving (SB2, P9)

My husband...support me... Guide and educate her... Patient with her. (SB2, P12)

When caregivers receive support whether from partners or any other source, they feel very good as they are also able to see improvement in the people they offer care to. The findings in this study (Shilubane & Mazibuko, 2020:416-417) indicated that a strong support system is an important part of the coping milieu.

4.5.9.3 HEALTH PROFESSIONAL SUPPORT

Caregivers referred to receiving support from a psychologist, psychiatrist, social worker and occupational therapist at the clinic or privately. This support comes in the form of individual or group therapy and educational programmes in terms of caring for the person with mental illness.

Below are the participants' words:

.... I receive support from the clinic (SB2, P1), Sometimes as caregivers we get booked for a psychiatrist to evaluate how the behaviour of the patient affects us, but I have a private psychiatrist that I also see as I was diagnosed with mild bipolar disorder. I am also going to see my psychiatrist next week (SB2, P1)

...I receive support from the clinic here. I talk to the psychiatrist and psychologist during my son's appointments (SB2, P2).

...I also receive support from the occupational therapist here at the clinic. He gives me advice on how to handle him. He told me to give him chores or toys to keep him busy. I have done that, and I see a big improvement. He also taught me how to deal with his temper. He told me to put him in a corner, to let him calm down. The psychiatrist is also helping me with him by giving him medication which calms him down (SB2, P3)

...Social workers from here should continue doing these support groups for us because they really help us a lot. I also feel that if he becomes a better child, I will also have peace (SB3, P9)

Findings in Narayanan (2021:91) confirm that caregivers receive support from mental health professionals, the study mentions that caregivers reported anticipating needs for hospitalisation, medication, and planning by seeking advice from primary health professionals in their caregiving duties.

4.5.10 CAREGIVER MOTIVATION

The theme “caregiver motivation” is made of the following sub-themes: Attachment and Commitment, Love, Safety and security.

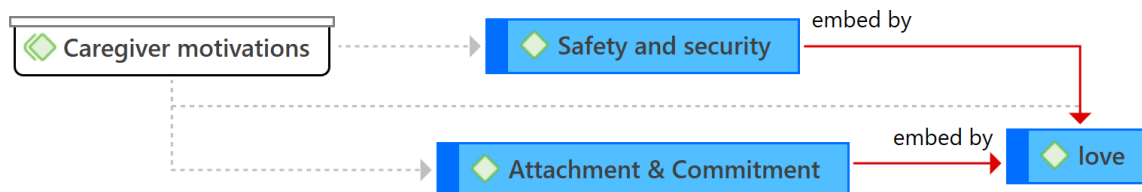


Figure 4.14: Caregiver Motivation

4.5.10.1 ATTACHMENT AND COMMITMENT

The attachment theory was aimed to address the development of human personality and the ethological systems, which extend from the relationship between parents and offspring to the affectional bonds throughout the life course (Carpinelli, Savarese, Rosso, Stornaiuolo, Luisi, Pellegrino, Mollo, & Pellicchia., 2023). In this research study, findings show that caregivers have either an anxious or secure attachment with their care recipients. Participant one (1) suffered from separation anxiety when separated from her care recipient. Other caregivers are secure with their responsibility to take care of their family members with mental illness.

Below are the participants' words:

...If I can let him stay with my younger sister, she won't take care of him the way I do. I feel like he's the person that I want to see every day, like he's okay. So if he's far from me, I don't think I'll be okay. When he's far from me, to be honest, I even cry about it. I will not cope if he's not with me (SB3, P1)

He is my burden. If I don't care for him who will? God has trusted me with him. I brought him to this world and I have the capability to take care of him. I am the only one responsible for him because they do not have a father (SB3, P2)

...I will not give up on her even though she makes me angry sometimes and it causes me to lose myself. I always tell myself that she is sick and needs my help no matter what she does to me. She would insult me at times and say I am evil and trash (SB3, P6)

I would never forsake her because other family members do not care. When her father died, I had to take full responsibility (SB3, P12)

Carpinelli et al. (2023) reported that adult attachment systems were found as frequently tied to one's health by regulating emotions, relationships and behaviour. In addition, findings reflect that caregivers with anxious attachment style, reflect a constructive and indirect form of care-seeking; it is focused on positive problem-solving and it includes help-seeking behaviour that is passive or unclear to the caregiver. However, the anxiety attachment of caregivers was negatively tied to a greater degree of resolution. Furthermore, data from the scientific field suggest that a secure caregiver can be seen as being able not only to make use of existing social supports but also cope with and integrate the emotions concerning his or her relative with health issues, being more emotionally available and decreasing the subjective feeling of the burden that the illness entails.

4.5.10.2 LOVE

Hopper (2020) stated that Maslow's hierarchy of need of love and belonging includes both romantic partners and ties to family members. It includes our need to feel that we belong. Most caregivers explicitly expressed love for their family members with mental illness. This love and family bond has provided them with the motivation to continue caring for them. Caregivers mentioned that they feel responsible for their care recipients and will continue to love them despite challenges. Participant six (6) expressed how she is passionate about helping people, which motivated her to fulfil the caregiving role. Empathy was also reported as one of the strengths which motivated caregivers to care for the person with mental illness.

Below are the participants' words:

There is no one who will take care of him and I feel a sense of responsibility towards him (SB3, P1)

I have to fight for him. He's my baby. Yeah. I love him to bits and pieces. There's nothing I won't do for him. We'll fight like mother and son, but we will make up before we go to sleep. If I'm not going to do it, who else is going to do it? Because he is all I've got. Even if he's like drunk in the street, I will go miles away for him. I will find him. I will

make sure he's fine. It's my blood of course and he knows that too (SB3, P3)

My love for them drove me to continue being there for them. I started caring for them from 2017 until now, and I am doing a great job with them. Despite my financial setbacks sometimes, I continue to care for them (SB3, P4)

I love people so much and I am passionate about helping them. She is my mother-in-law after all and nobody wants to take care of her, even her own biological daughters. I decided to take care of her because I am still alive and I have the capability to do so (SB3, P6)

I empathise with him because nobody was willing to take care of him after his mother died because of his behaviour. I then took him as my child. I love him and want him to succeed and have a bright future. I have hope that he will be a better child one day (SB3, P9)

Caregiving not only involves feeling burdened but having the motivation to fulfil the caregiving role because caregivers love, care and feel responsible for their family members with mental illness. Findings in Coetzee (2016) confirm that caregivers have reported that their relationship with their relatives were not only characterised by challenges, but also love, commitment, and joy.

4.5.10.3 SAFETY AND SECURITY

Hopper (2020) stated that Maslow's hierarchy of safety needs include the need for safe and predictable environments. Findings show that there is a desire for the mentally ill to be in a secure space where they can indulge in activities instead of wandering. A caregiver expressed how she has to ensure that her place is locked so that her sisters with mental illness can be safe. Below are the participants' words:

...If there could be a facility where they can go during the day, where they can get helped. Do crafts and things like that. That would be great. We don't have a lot of those. We don't have at all. You see people with mental illness walking around, wandering around. I keep my gate

locked because the one with dementia, even if I bring her to the clinic, sometimes my daughter must come with me because she will just wander around...There must always be someone to make sure that she must behave. (SB3, P5)

Lack of safety results in caregivers feeling anxious that their family members with mental illness might get lost. Findings in Stajduhar, Giesbrecht, Mollison, Dosani, & McNeil (2020) confirm that there was great worry over the safety of care recipients when caregivers are away from them. Thus, caregivers shaped themselves to provide care in environments that the person with mental illness may feel comfortable, secure, and safe.

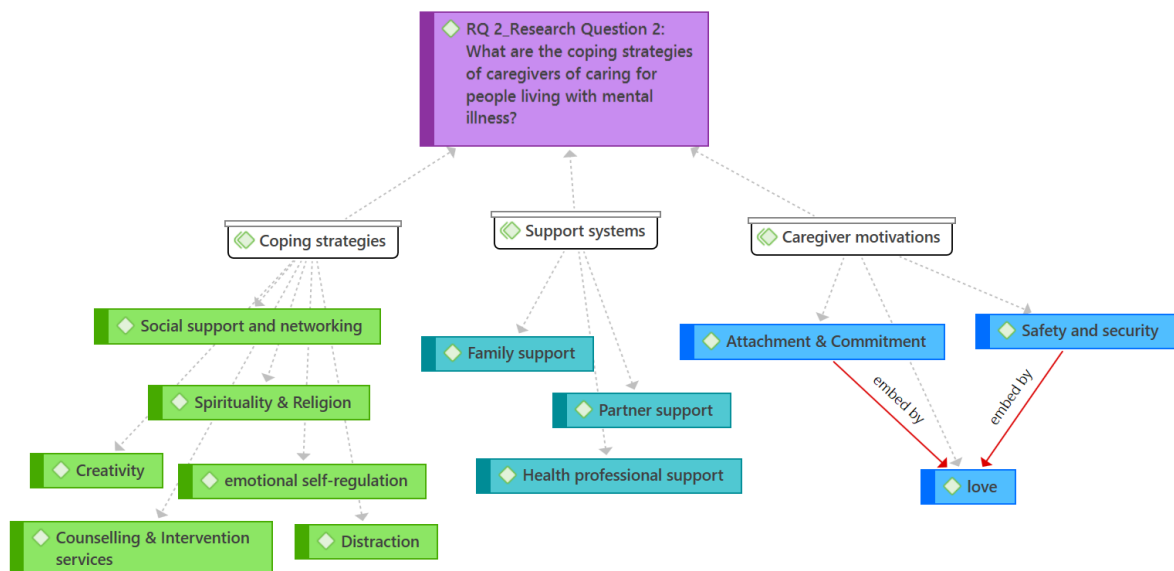


Figure 4.15: Overview of RQ2 and its themes

4.6 SUMMARY OF THE CHAPTER

This chapter presented the process of data analysis, the coding method, demographic information of participants, and findings related to research questions through Atlas. ti Version 23. The virtual presentation of Atlas. ti. was of great assistance in presenting participants' experiences and coping strategies with caregiving for a person with mental illness. The findings revealed that the experiences and challenges of caregivers included: healthcare roles, psycho-

social experiences, behaviour and emotions, finances, and family conflicts while coping strategies included: social networking and support, spirituality and religion, emotional self-regulation, counselling and intervention services, creativity, distraction, social support, attachment and commitment, love, and safety and security.

CHAPTER FIVE

FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter presents a discussion on the research findings in relation to the literature. The findings also relate to the experiences and coping strategies of caregivers of people with mental illness. The findings are organised in accordance with research objectives. Each objective is discussed. Following the discussion, this chapter also presents the conclusions from the study and lastly the recommendations related to future studies.

5.2 Findings as per the objectives of the study

Below is the presentation of the findings as per objectives of the study.

5.2.1 To describe the experiences of caregivers of people living with mental illness in Emfuleni Local Municipality

Emerging from the qualitative data on experiences of caregivers of people living with mental illness, data revealed that all 12 participants had similar or slightly different experiences and coping strategies when it comes to caring for a person with mental illness. In this study, the results showed that caregivers assumed healthcare roles. Participants ensured that their family members with mental illness are well supervised and monitored. Participants had to go to mental health care institutions to collect medication on behalf of the person with mental illness. It also showed that participants communicate constantly with mental health professionals such as psychiatrists, psychologists, nurses, and social workers in managing the mental illness. The findings about healthcare roles is consistent with that of Gloria et al. (2018), who concluded that caregivers need to constantly be on guard due to the inclination of mental illness patients who show signs of behavioural problems and experienced a treatment related burden which is to ensure that medication is taken and psychiatric centres are accessed. Furthermore, participants ensured that their family members with mental illness are well fed and bathed.

Emotions such as anger, fear, and frustration were expressed by the caregivers in response to the disruptive behaviour of the person with mental illness. Cormican et al. (2022) confirmed the same research study's findings that fear, uncertainty, and loss can be associated with long-term caregiving. Access to transportation to visit mental health centres was also reported as a challenge by caregivers.

In this study, it became clear that the disruptive behaviour of the mentally ill person had a negative effect on their caregivers. Participants reported being abused by their family members with mental illness who exhibit control. People with mental illness showed signs of deceitfulness towards their caregivers. Participants were left in a state of helplessness, shame, and confusion due to the behaviour of the person with mental illness. People with mental illness were reported to be discriminated against and this evoked hurt and humiliation in caregivers. Communication was also a challenge between caregivers and care recipients as patterns of hallucination were reported to be prevalent in the person with mental illness. The findings in Ndeti et al. (2009) reveal that disruptive behaviours by people with mental illness caused a lot of effect on their caregivers, it found that wandering, aggression, disturbance, substance dependence, refusal to adhere to medical treatment, and unreliability were behaviours exhibited by people with mental illness which negatively impacted caregivers.

Despite caregivers adjusting to their role of caring for their family members with mental illness, they experienced various challenges. This study established that participants experienced emotional struggles. Emotional struggles were prevalent at the onset of the mental illness as confusion and hurt emerged in caregivers. Caring for a person with mental illness resulted in caregivers feeling emotionally strained/exhausted. Participants were at the risk of developing mental illness themselves due to the caregiver burden. In support, Mointeiro et al. (2017) found that the behaviour of patients with mental disorders lead to depression and anxiety in caregivers.

The health of participants was found to be at risk in this study. Other participants already suffer from chronic illnesses and physical exhaustion because of caregiving. The responsibility of caregiving is demanding to the point whereby caregivers are unable to live a life outside of caregiving. This is confirmed by Anhang et al. (2016) who indicated that caregivers of individuals with mental illness are vulnerable to illness as they have a weaker immune system more than those who are non-caregivers because they feel overwhelmed by the burden of providing constant care.

Anhang et al. 2016) found that participants experienced financial difficulties in caring for people with mental illness. Most participants from this research study come from low-income

households. Government grants received by people with mental illness is not enough and caregivers ceased employment due to the demand of caregiving. This agrees with Marimbe et al. (2016), which shows that financial burden was expressed by caregivers due to them leaving their jobs to take on the role of caregiving.

Family conflicts were found to be a challenge experienced by participants in this research study. Caregiving for a person with mental illness resulted in caregivers being isolated from their families and the society. Misunderstandings about the mental illness within families resulted in conflict and separation. The relationship between the caregiver and the person with mental illness was also strained due to disruptive behaviour. Children with mental illness are at risk of being abused due to their vulnerability. Furthermore, participants are left emotionally and psychologically strained by the abused projected to their children with mental illness. Findings in Marimbe et al. (2016) confirm these findings by reporting that caregivers reported being rejected and ostracised from other family members and the society because of the person with mental illness.

5.2.2 To ascertain the coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality

The qualitative data revealed several coping strategies employed by caregivers of people living with mental illness. To cope with their experiences, participants used social support and networking as a coping strategy to cope emotionally, psychologically and financially. Participants received this support from their relatives, the community, mental health services, and media. Hsiao et al. (2020) also found that interventions for caregivers of people with mental illness include social support to enhance mutuality and family coping strategies. This study found that receiving support from family reduced the caregiver burden and resulted in participants feeling relieved and satisfied. In addition, participants reported that receiving support from their partners made them feel good and that contributes to their improvement in caregiving. It was also found that participants receive support from mental health professionals. These findings about the support system of caregivers of people with mental illness is supported by findings in Hogan & John-Langba (2016), Shilubane and Mazibuko (2020), and Narayanan (2021).

Religious practices such as prayer, seeking pastoral counselling, and having faith in God were expressed as a coping strategy used by participants. These findings are confirmed by Raghavan

et al. (2023) whereby all participants were caregivers of mental health service users relied on religious beliefs to deal with their challenges.

Findings in this study showed that counselling and intervention services such as psychological, social, and police services provided services to participants. These findings align with Mokgothu (2012), who found that most of the caregivers reported using external services to support the person with mental illness. This included the South African Police Services, mostly to assist in apprehending violence projected by the person with mental illness.

Creativity was reported as a coping strategy used by participants to cope with the emotional and psychological burden of caregiving. A study by Blasco et al. (2022) also found that caregivers actively engaged in caregiving through creativity to find meaning. This included work, deeds, accomplishments, responsibility and commitment to cope with caregiving.

Furthermore, participants used distraction as a coping strategy. Distraction has been categorised as passive coping associated with helplessness and avoidance (Traeger, 2013).

This study found that caregiver motivation such as attachment, love, and sense of responsibility (safety and security) prompted caregivers to cope with caregiving.

In this research study, findings showed that participants have an anxious or secure attachment with their care recipients. Carpinelli (2023) found that adult attachment systems were tied to one's health. Furthermore, findings reflect those caregivers with an anxious attachment style, have an indirect constructive and help-seeking role; it is focused on positive problem-solving. However, the anxiety attachment of caregivers was negatively tied to a greater degree of resolution. Furthermore, the data from the scientific field suggest that a secure caregiver can be seen as being able not only to make use of existing social supports but also cope with and integrate the emotions concerning his or her relative with health issues, being more emotionally available and decreasing the subjective feeling of the burden that the illness entails.

Love, care and responsibility have shown to have motivated participants to cope with caregiving in this research study. Findings in Coetzee (2016) confirm that caregivers have reported that their relationship with their family members with mental illness were not only characterised by challenges, but also love, commitment, and joy.

Findings showed that there is a desire for the mentally ill to be in a secure environment. Participants expressed feelings of anxiety whenever the person with mental illness is not in a safe space. Findings in in Stajduhar et al. (2020) confirm that there was great worry over the safety of the person with mental illness when caregivers are away from them. Thus, caregivers shaped themselves to provide care in environments that the care recipients may feel safe.

5.3 Conclusions

The findings as debated in this chapter were constructed on the data collected by means of semi-structured interviews with 12 caregivers of people living with mental illness. The study made several conclusions.

The following conclusions were reached, based on the analysis of the data:

- Caregivers of people with mental illness in Emfuleni Local Municipality assumed healthcare roles.
- Caregivers expressed feelings of anger, fear and frustration.
- Caregivers felt helpless and confused by the disruptive behaviour of the person with mental illness. In addition, they felt emotionally strained and mentally exhausted.
- Caregivers' health was more at risk.
- Caregivers experienced financial difficulties and family conflicts.
- Caregivers used social support, religious practices, counselling and intervention services, creativity, distraction, and motivation as coping strategies.

5.4 Recommendations of the study

The study arrived at the following recommendations:

- More NPO's or NGO's and private entities should be created to provide psychosocial services to caregivers of people living with mental illness.
- Mental health care centres should work more on integrating mental health care user services with caregiver services simultaneously.
- Social Workers, psychologists, nurses and other mental health professionals should create counselling support networks or groups for caregivers of people living with mental illness when offering services to people living with mental illness.
- Government should create adult day care centres for people living with mental illness for working caregivers.

5.5 Recommendations for future research

Based on the findings of this study, it was apparent that there were several issues that could be investigated further.

- Given the scarcity of studies on the emotional regulation as a coping strategy of caregivers of people living with mental illness to compare to, further studies could be useful to better understand effective coping methods that improve emotional regulation.
- The role of private and public mental health care centres in South Africa could be researched further to explore how they support and plan to support caregivers of people with mental illness.
- There is a need to create a coping strategy model for caregivers of people living with mental illness that address all aspects of challenges and intervention plans.

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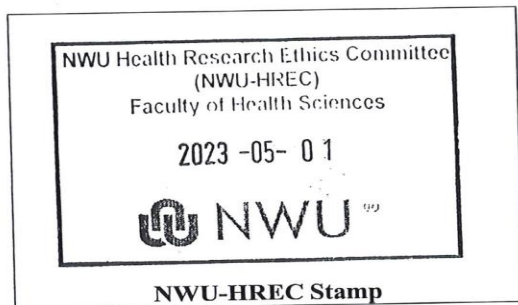
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ANNEXTURE A- SESOTHO INFORMED CONSENT



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TOKOMANE E TSEBISENG EA TUMELO EA BAHLOKOMI BA BATHO BA PHELANG LE LE MAFULE A KELELLO MMASIPENG WA LEHAE LA EMFULENI

SEHLOOHO SA THUTO EA LIPATLISISO: Liphihlelo le mekhoha ea ho sebetsana le boemo ba bahlokomeli ba batho ba phelang le mafu a kelello Masepaleng oa Lehae oa Emfuleni.

LITŠOANTŠISO TŠEPANE: NWU-00181-22-A1

MOHLOMI MOHLOMI: Prof N.H Ntombela

POST MOTHUTO: Ntseteni NA

AKHESE: 6042 Lakeside Extension 2, Orange Farm

KOPO NOMELO: 0711048070

U memeloa ho nka karolo phuputsong ea lipatlisiso e etsang karolo ea litlhoko tsa lengolo la ka la Maseterata Univesithing ea Leboea Bophirima (khamphaseng ea Vanderbijlpark), Afrika Boroa. Ka kopo, ipha nako ea ho bala lintlha tse fanoeng mona, tse tla hlalosa lintlha tsa thuto ena. Ka kopo botsa motho ea u hlalosesang lipatlisiso lipotso leha e le life mabapi le karolo efe kapa efe ea phuputso ena eo u sa e utloisiseng ka botlalo. Ho bohlokoa haholo hore u khotsofale ka botlalo hore u utloisisa hantle hore na patlisiso ena e bua ka eng le hore na u ka ameha joang. Hape, ho nka karolo ha hau ke boithaopo 'me u lokolohile ho hana ho nka karolo. Haeba u re che, sena se ke ke sa u ama hampe ka tsela efe kapa efe. Hape o lokolohile ho ikhula thutong ka nako efe kapa efe, leha o dumela ho nka karolo hona jwale.

Boithuto bona bo mabapi le eng?

- Phuputso ena e tla etsoa ka Vaal Mental Health Organisation, Johan Heyns, le Levai Mbatha Community Health Centers Emfuleni Local Municipality, Profinseng ea Gauteng. Lipatlisiso li hlaloba liphihlelo le mekhoha ea ho sebetsana le bahlokomeli ba batho ba phelang le lefu la kelello. Ho kenya letsoho ha hao morerong ona ho tla fana ka boitsebiso bo molemo tabeng ena. O na le tokelo ya ho nka karolo ha o dula Masepaleng wa Lehae

wa Emfuleni, o pakeng tsa dilemo tse 18-70, o fumana ditshebeletso ho tswa ho Vaal Mental Health Organisation, Levai Mbatha le Johan Heyns Community Health Centers mme o kgona ho buisana ka Sesotho le Senyesemane. U tla botsoa lipotso tse tla u nka metsotso e ka bang 45 ho isa ho hora.

- Lipuisano tse tebileng li tla etsoa le ho rekotoa, 'me li tla tsamaisoa ka boikemelo ke mofuputsi ka phaposing e ikemetseng ea Vaal Mental Health Organisation, Johan Heyns le Levai Mbatha Community Health Centres.
- Sepheo se seholo sa phuputso ena ke ho hlaloba hore na bahlokomeli ba na le phihlelo ea ho hlokomela motho ea nang le lefu la kekello le hore na ba sebetsana joang le liphihlelo tsa bona. Ka hona, thuto ena e leka ka matla ho tsebisa litsebi tsa bophelo bo botle ba kekello ka liphihlelo tsa bahlokomeli ba batho ba phelang le lefu la kekello e le hore ba hlalise merero ea ho kenella ho tšehetsa bahlokomeli.

Ke hobane'ng ha u memetsoe ho nka karolo?

- O kopana le ditekanyetso tsa ho kenyeletswa ha datha
Ho nka karolo phuputsong ena:
 - Barupeluo e lokela ho ba batho ba baholo, ba pakeng tsa lilemo tse 18 le 70.
 - Ba tlang ho nka karolo e lokela ho ba batho ka bomong bao e leng baahi ba Masepala oa Lehae oa Emfuleni.
 - Barupeluo e lokela ho ba bahlokomeli ba batho ba nang le mafu a kekello 'me ba fumane litšhebeletso ho tsoa ho mokhatlo oa Vaal mental Health, Johan Heyns le Levai Mbatha Community Health Centres.
 - Barupeluo ba lokela ho tseba Sesotho le Senyesemane hantle.
 Ka tlhaloso, haeba motho a sa ikamahanye le mokhoa oa ho kenyeletsa, o tla behelloa ka thoko
Mekhahlelo ea ho khaolla e behiloe ka tsela e latelang:
 - Barupeluo ba nang le mathata a kekello a liehang ho utloisisa puo.
 - Barupeluo ba nang le mathata a kekello a liehang ho utloisisa puo.
- U memetsoe ho ba karolo ea lipatlisiso tsena hobane u na le tokelo ea ho ba karolo ea sechaba sa phuputso ea lipatlisiso e batlang ho fuputsa liphihlelo le mekhoea ea ho sebetsana le boemo ba bahlokomeli ba batho ba nang le lefu la kekello. U tla ba le tlhaiso-leseling e lekaneng le boiphihlelo mabapi le taba eo ho buuoang ka eona kaha ke uena sehlopha se shebiloeng. Bonyane palo ea barupeluo ba 12 e tla hlokoa ho phethahatsa sepheo sa phuputso ena.
- Hape u tla tsoanela lipatlisiso hobane ho kenya letsoho ha hao morerong ona ho tla fana ka tlhahisoleseding e molemo mabapi le nts'etsopele ea litšhebeletso tsa tšebetso bakeng sa bahlokomeli ba batho ba phelang le lefu la kekello ke litsebi tsa bophelo bo botle ba kekello.

Ho tla lebelloa eng ho uena?

- U tla lebelloa hore u arabe lipotso tse tebileng tsa lipuisano bakeng sa metsotso e 45 'me li tla thetsoa ka molumo. Mofuputsi o tla botsa letoto la lipotso, a hlalobe likarabo ebe a etsa liqeto. O tla lebelloa ho araba lipotso tse 5 tsa palo ea batho tse fanang ka temohisiso mabapi le semelo sa hau, lipotso tse 6 le lipotso tse 2 tse amanang le thuto. Melao ea COVID-19 etla lateloa di puisanong. Lipotso ke tse latelang:

KAROLO A: TSEBISO EA DEMOGRAPHIC

U lilemo li kae?

Ke batho ba bakae ba phelang le lefu la kelello, bao u ba hlokomelang?

Kamano ea hau ke efe le motho ea phelang le lefu la kelello?

Boemo ba hau ba thuto ke bofe?

Mohloli oa hau oa chelete ke ofe?

KAROLO YA B: PUISANO HO BAHLOKOMI

Ke liphihlelo life tseo u bileng le tsona mabapi le ho hlokomela motho ea phelang le bokooa ba kelello?

Ke mathata afe ao u thulanang le 'ona ka lebaka la ho hlokomela motho ea nang le lefu la kelello?

Ho hlokomela motho ea nang le lefu la kelello ho u ama joang joaloka mohlomeli?

O arabetse joang mathateng kapa liphephetsong tseo u li boletseng?

Ts'ehetso ea hau ke mang, 'me ba u thusitse joang hore u sebetsane le mathata a bakoang ke ho hlokomela motho ea nang le lefu la kelello?

- Ba ile ba etsa'ng ho thusa?

- Seo se ile sa etsa hore u ikutloe joang?

Ke'ng e ileng ea u susumelletsa hore u tsoele pele ho phetha boikarabelo ba hao ba ho ba mohlomeli ho sa tsotellehe mathata ao u a boletseng?

(Mofuputsi o tla etsa lipatlisiso bakeng sa lintlha tse ling)

Na e tla ba melemo e tobileng ho uena ka ho nka karolo lipatlisisong tsee?

- Ha ho na ho ba le melemo e tobileng ea ho nka karolo thutong ena. Lefapheng la saense la tsebo, thuto e tla fana ka tsebo mabapi le liphihlelo le mekhoa ea ho sebetsana ka katleho le bahlokomeli ba batho ba nang le lefu la kelello le ho thusa basebeletsi ba sechaba ba bophelo bo botle ba kelello ho hlalisa mehato e eketsehileng ho tšehetsa malapa a batho ba nang le lefu la kelello ka mefuta e mengata le e akaretsang. Mohlala, nts'etsopele ea lihlopha tsa ts'ehetso bakeng sa bahlokomeli ba batho ba nang le lefu la kelello li ka tsamaisoa ho fana ka tlhabollo le bokena-lipakeng.
- Leha ho le joalo, barupeluo ba tla fuoa lijo nakong ea lipuisano le ka mor'a tsona. Haeba morupeluo a se na chelete ea sepalangoang, o tla fuoa litšenyehelo tsa sepalangoang kaha lipuisano li tla tsoareloa litsing tse amehang.

Na ho na le likotsi tse amehang ha u nka karolo lipatlisisong tsee le hore na ho tla etsoa eng ho li thibela?

- *Ka lebaka la mofuta oa lipuisano tse tebileng, puisano e tla nka metsotso e ka bang 45- hora e le 'ngoe. Tafole e latelang ke kotsi e ka bang teng eo u ka bang le eona le mehato e tla nkuoa ho hlokomela kotsi.*

Kotsi	Phokotso e sisintsweng
1. Kotsi ea ho tsieleha nakong ea lipuisano tse tebileng le ho senola tlhahisoleseding e ka bakang tsietsi ea kelello.	Kotsi ea ho sithabela maikutlong e ka etsahala ha re nahana hore bao e tlang ho ba barupeluo ke bahlokomeli ba batho ba nang le lefu la kelello e leng boikarabelo bo boima haholo. Mosebeletsi oa boiketlo ba sechaba o tla kopuo ho fana ka tlhabollo haeba barupeluo ba ka ba le tsietsi e joalo ea kelello.
2. Kotsi e amanang le tsoaetso ea COVID-19.	Kotsi ea ho tsoaroa ke COVID-19 e ka etsahala kaha ho na le motho ea fumanoeng a e-na le kokoana-hloko nakong ea pokello ea lintlha. Mehato eohle ea Afrika Boroa ea COVID-19 e tla nkuoa nakong ea pokello ea lintlha ho fokotsa kotsi ena. Barupeluo ba tla kopuo ho hloekisa matsoho a bona, ho boloka sebaka sa sechaba sa limithara tse 1,5 le ho roala limaske.
3. Tlhokomelo ea motho ea phelang le lefu la kelello e tla ba kotsing haeba motho a se na tlhokomelo lapeng nakong ea pokello ea lintlha, kaha lipuisano le bahlokomeli li tla tsoareloa mokhatlong le litsing tsa bophelo tsa sechaba.	Ba bang ba batho ba phelang le mafu a kelello ba hlokometsoeng, ke bana ba kenang likolo tse khethehileng 'me ba bang ke batho ba baholo ba kenang lithupelo litsing tse itseng tsa litsebo 'me ha ba eo hae ka nako eohle. Leha ho le joalo, haeba mofuputsi a kopana le boemo boo ho bona motho ea phelang le lefu la kelello a leng lapeng ka nako eohle, nakong ea data, mofuputsi o tla kopa mohlomeli hore a kope setho se seng sa lelapa kapa motsoalle ho hlokomela motho ea nang le lefu la kelello. Haeba ho se na phokotso tabeng ena,

	polokeho ea motho ea phelang le lefu la kelello e tla ba kotsing haeba e sa hlokomeloe.
--	---

Re tla sireletsa lekunutu la hau joang mme ke mang ea tla bona seo u se fumaneng?

- Ha ho mabitso a barupeluo a tla senoloa.
- Ke mofuputsi feela ea tla khona ho sheba liphetho tsa hau.
- Tšebeliso ea molumo o rekotiloeng e tla sebelisoa feela ka tumello ea bankakarolo.
- Lekunutu le tla tiisetsoa ka ho sireletsa lintlha tse ka har'a sesebelisoa se sirelelitsoeng sa mofuputsi le khabinete e sireletsehileng.
- Liphuputso li tla etsoa ka mokhoa o tšepahalang, o bulehileng le o pepeneneng ka moo ho ka khonehang.

Ho tla etsahala'ng ka liphetho kapa lisampole?

- Liphuputso tsa phuputso ena li tla sebelisoa feela bakeng sa ho kenella ho eketsehileng ke litsebi tsa bophelo bo botle ba kelello ho theha mananeo a ho thusa bahlokomeli ba batho ba nang le lefu la kelello.
- Lintlha li tla bolokoa ka har'a khabinete e sireletsehileng le ka har'a komporo e sirelelitsoeng ka password bakeng sa lilemo tse 5, ebe li tla senngoa.

U tla tseba joang ka liphetho tsa lipatlisiso tsee?

- Mmatlisisi o tla etsa khopi ea summary report e akaretsang mme a o romele yona kapa o tla tla howena a hohlosetse hore liphetho tsa lipatlisiso litsamaile joang.

Na u tla lefshoa ho nka karolo phuputsong ee 'me na ho na le litšenyehelo bakeng sa hau?

U ke ke ua lefshoa ho nka karolo phuputsong ea lipatlisiso. Ka hona ho ke ke ha ba le litšenyehelo tse amehang bakeng sa hau, haeba u nka karolo thutong ena.

Litšenyehelo tsa lipalangoang li tla lefuoa haeba monkakaro a hloka.

Na ho na le ntho e 'ngoe eo u lokelang ho e tseba kapa ho e etsa?

- O ka ikopanya le Ntombizodwa Ntseteni ho 0711048070 haeba o na le dipotso tse ding kapa o e-na le mathata.
- U ka boela ua iteanya le Komiti ea Boitšoarō ea Lipatlisiso tsa Bophelo bo Botle ea YBB ka Mof Carolien van Zyl ho 018 299 1206 kapa carolien.vanzyl@nwu.ac.za haeba u na le matshwenyeho afe kapa afe a sa kang a arajoa mabapi le lipatlisiso kapa haeba u na le litšenyehelo mabapi le thuto.
- U tla fumana kopi e thata ea tlhahisoleseling le foromo ea tumello molemong oa hau.

Phatlalatso ka monkakarolo

Ka ho saena ka tlase, ke ho nka karolo phuputsong e nang le sehlooho se reng: Liphihlelo le mekhoha ea ho sebetsana le boemo ba bahlokomeli ba batho ba phelang le mafu a kelello Masepaleng oa Lehae oa Emfuleni.

Ke bolela hore:

- Morero le sebopeho sa phuputso ke hlalositsoe.
- Ke kenya letsoho ka boithaopo.
- Ke fana ka tumello ea hore puisano ea ka le NA Ntseteni e ngoloe.
- Ke utloisisa hore nka ikhula phuputsong efe kapa efe.
- Ke utloisisa hore lebitso la ka le tla netefatsoa ka ho pata boitsebiso ba ka.

E saenetsoe (sebakeng)..... ka (letsatsi)

.....
Tshaeno ea monkakarolo

.....
Tshaeno ya bopaki

.....
(linomoro tsa mohala)

.....
(e-mail)

Phatlalatso ka motho ea fumanang tumello

Nna (lebitso) ke bolela hore:

- I clearly and in detail explained the information in this document to

-
- Ke sebelitse/ha kea sebelisa toloko.
 - Ke ile ka mo khothaletsa ho botsa lipotso mme ka nka nako e lekaneng ho li araba.
 - Ke khotsofetse hore o utloisisa lintlha tsohle tsa lipatlisiso, joalo ka ha ho boletsoe ka holimo.
 - Ke ile ka mo fa nako ea ho buisana le ba bang haeba.

E saenetsoe (sebakeng) ka (letsatsi)

.....
Tshaeno ya motho ea fumanang tumello

.....
Tshaeno ya bopaki

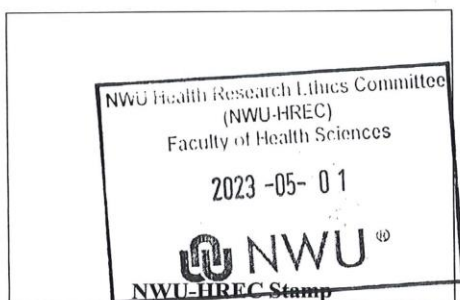
Phatlalatso ka mofuputsi

Nna (Lebitso)..... ke bolela hore:	
• Ke hlalositse lintlha tse tokomaneng ena ho..... • Ke sebelitse/ha kea sebelisa mofetoleli. • Ke ile ka mo khotlaetsa ho botsa lipotso 'me ka ipha nako e lekaneng ho li araba. • Ke khotsofetse hore o utloisisa lintlha tsohle tsa lipatlisiso ka nepo, joalo ka ha ho hlalositsoe ka holimo. • Ke khotsofetse hore o bile le nako ea ho buisana le ba bang haeba a ne a lakatsa ho etsa joalo.	
E saenetswe (sebakeng)..... ka (letsatsi) 20....	
..... Tshaeno ya mofuputsi	 tshaeno ya bopaki

ANNEXTURE B: ENGLISH INFORMED CONSENT



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INFORMED CONSENT DOCUMENTATION FOR CAREGIVERS OF PEOPLE LIVING WITH MENTAL ILLNESS IN EMFULENI LOCAL MUNICIPALITY

TITLE OF THE RESEARCH STUDY: Experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality.
ETHICS REFERENCE NUMBERS: NWU-00181-22-A1

PRINCIPAL INVESTIGATOR: Prof N.H Ntombela

POST GRADUATE STUDENT: Ntseteni NA

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You are being invited to take part in a **research study** that forms part of the requirements for my Master's degree at the North West University (Vanderbijlpark campus), South Africa. Please take some time to read the information presented here, which will explain the details of this study. Please ask person explaining the research to you any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you might be involved. Also, your participation is **entirely voluntary** and you are free to say no to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part now.

What is this research study all about?

- This study will be conducted in Vaal Mental Health Organisation, Johan Heyns, and Levai Mbatha Community Health Centres in Emfuleni Local Municipality, In Gauteng province. The research describe the experiences and coping strategies of caregivers of people living

with mental illness. Your participation in this project will provide useful information on this topic. You will be asked questions that will take you about 45 minutes to an hour.

- Semi-structured interviews will be conducted and audio recorded and will be independently facilitated by the researcher in a private room in Vaal Mental Health Organisation, Johan Heyns and Levai Mbatha Community Health Centres.
- The ultimate goal of this research is to describe how caregivers experience caring for a person living with mental illness and how they cope with their experiences. Therefore, this study strives to inform mental health professionals on the experiences of caregivers of people living with mental illness in order to develop intervention plans to support the caregivers.

Why have you been invited to participate?

- You meet the inclusion criteria of the data.
To take part in this study:
 - Participants should be adults, between the age of 18 and 70.
 - Prospective partakers should be individuals who are residents of Emfuleni Local Municipality.
 - Participants should be caregivers of people living with mental illness and receive services from Vaal mental Health organisation, Johan Heyns and Levai Mbatha Community Health Centres.
 - Participants should be proficient in Sesotho and English.By definition, if a person does not adhere to an inclusion criterion, they will be excluded. Exclusion Criteria are set out as follows:
 - Participants who have mental difficulties that delay comprehension of speech.
 - Participants who are visually impaired and deaf.
- You have been invited to be part of this research because you qualify to be part of the population of the research study which seeks to describe the experiences and coping strategies of caregivers of people living with mental illness. You will have adequate information and experiences about the subject matter as you are the target group. A minimum number of 12 participants will be required to fulfil the aim of this study.
- You will also fit the research because your participation in this project will provide useful information on the development of support services for caregivers of people living with mental illness by mental health professionals.

What will be expected of you?

- You will be expected to answer in-depth interview questions for 45 minutes and they will be audio taped. The researcher will ask a series of questions, evaluate the answers and then draw conclusions. You will be expected to answer 5 demographic questions which gives an insight into your background, 6 questions and 2 sub-questions related to the study. During interviews, all COVID-19 protocols will be followed. The questions are as follows:

SECTION A: DEMOGRAPHIC INFORMATION

How old are you?

How many people living with mental illness, do you care for?

What is your relationship with the person living with a mental illness?

What is your level of education?

What is your source of income?

SECTION B: SEMI-STRUCTURED INTERVIEW GUIDE FOR CAREGIVERS

What experiences have you encountered with caring for a person living with mental illness?

What challenges do you experience as a result of caring for a person living with a mental illness?

How is caring for a person living with mental illness personally affect you as a caregiver?

What coping strategies have you used to deal with the challenges that you have mentioned?

Who is your support system and how have they helped you to cope with problems resulting from caring for a person living with mental illness?

- What did they do to help?
- How did that make you feel?

What motivated you to continue fulfilling your role as a caregiver despite the challenges you have mentioned?

(The researcher will probe for more information)

Will there be direct benefits for you from taking part in this research?

- There will be no direct benefits for taking part in this study. In the scientific field of knowledge, the study will provide knowledge on the experiences and coping strategies of caregivers of persons with mental illness and assist social workers in mental health to develop further interventions to support families of persons with a mental illness in a multidimensional and holistic manner as the focus has always been on the person affected by the illness in previous interventions. For instance, the development of support groups for caregivers of persons with mental illness can be administered to provide counselling and mediation.
- However, participants will be provided with refreshments during and after the interview session. If a participant does not have transport money, he or she will be provided with the transport cost since interviews will be held at the respective institutions.

Are there risks involved in you taking part in this research and what will be done to prevent them?

- *Due to the nature of the interview being in-depth, the interview will take approximately 45 minutes- 1 hour. The following table is a possible risk that you may experience and the measures that will be taken to take care of the risk.*

Risk	Proposed mitigation
1. The risk of being traumatised during in-depth interviews and revealing information that could trigger psychological trauma.	The risk for psychological trauma is possible given that the prospective participants are caregivers of people living with mental illness which is quite an overwhelming responsibility. A social worker will be requested to provide counselling should participants experience such psychological trauma.
2. The risk associated with COVID-19 infections.	The risk of contracting COVID-19 is possible given that there is a person who tested positive for the virus during data collection. All South African COVID 19 measures will be undertaken during data collection to mitigate this risk. Participants will be required to sanitise their hands, maintain 1,5 metre social distancing and wear masks.
3. The care of the person living with mental illness will be at risk if the person is without care at home during the time of data collection, as interviews with caregivers will be conducted at the organisation and community health centres.	Some of the people living with mental illness who are being cared for, are children who attend special schools and some are adults who attend trainings at specific skill centres and they are not at home on a full-time basis. However, if a researcher encounters a situation whereby the person living with mental illness is at home on a full-time basis, during data, the researcher will ask the caregiver to request for another family member or friend to look after the person with mental illness for that 45-60 minutes at home. If there is no mitigation in this regard, the safety of the person living with mental illness will be at risk if left uncared for.

How will we protect your confidentiality and who will see your findings?

- No identities of participants will be revealed.
- Only the researcher will be able to look at your findings. Your feedback will go into a tool of data and will not be traced back to you.
- The use of the audio recording will only be used with the consent of the participants
- Confidentiality will further be assured by protecting the data in the researcher's private protected device and secure cabinet.
- The research will be conducted in an honest, open and transparent manner as far as it is possible.

What will happen with the findings or samples?

- The findings of this study will only be used for further intervention by mental health professionals to develop intervention programs to support caregivers of people living with mental illness.
- The data will be kept in a secure cabinet and on password protected computer for 5 years and will then be destroyed.

How will you know about the results of this research?

- The researcher will make a copy of a summary report of the study and send it to you or come back and show results to you in person which will be more effective.

Will you be paid to take part in this study and are there any costs for you?

You will not be paid to take part in the research study.

There will thus be no costs involved for you, if you do take part in this study.

Transport costs will be paid if the participant is in need.

Is there anything else that you should know or do?

- You can contact Ntombizodwa Ntseteni at 0711048070 if you have any further questions or have any problems.
- You can also contact the NWU-Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 1206 or carolien.vanzyl@nwu.ac.za if you have any concerns that were not answered about the research or if you have complaints about the research.
- You will receive a hard copy of this information and consent form for your own purposes.

Declaration by participant

By signing below, I agree to take part in the research study titled: Experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality.

I declare that:

- The purpose and nature of the research study has been explained to me.
- I am participating voluntarily.
- I give permission for my interview with NA Ntseteni to be recorded
- I understand that I can withdraw from the study at any time, before it starts or while participating and will not be handled in a negative way if I do so.
- I understand that anonymity will be ensured in the right-up by hiding my identity.

Signed at (*place*) on (*date*)

.....
Signature of participant

.....
Signature of witness

.....
(contact details)

.....
(e-mail)

Declaration by person obtaining consent

I (*name*) declare that:

- I clearly and in detail explained the information in this document to
.....

- I did/did not use an interpreter.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I gave him/her time to discuss it with others if he/she wished to do so.

Signed at (*place*) on (*date*)

.....
Signature of person obtaining consent

.....
Signature of witness

Declaration by researcher

I (*name*) declare that:

- I explained the information in this document to
- I did/did not use an interpreter
- I encouraged him/her to ask questions and took adequate time to answer them
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

Signed at (*place*) on (*date*)

.....
Signature of researcher

.....
Signature of witness

ANNEXTURE C: INTERVIEW TRANSCRIPT

Interview Transcript: Experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality.

Analysis: Atlas. Ti

Participants: 12

P: Stands for participants (pseudonyms)

Location of Interview: Emfuleni Local Municipality (Vaal Mental Health Organisation, Levai Mbatha CHC, and Johan Heyns CHC).

SECTION A1

Research Question 1: What are the experiences of caregivers of caring for people living with mental illness in the Emfuleni Local Municipality?

Interview Question 6: What experiences have you encountered with caring for a person living with mental illness? (the researcher probed/sought clarification to clarify what the participant is saying and to avoid unclear responses)

Participant 1

P1: Sometimes you don't understand a person who's schizophrenic. Because sometimes he speaks alone. And when you ask him, what did he say? He doesn't answer back. And recently what I encountered, I even thought that this person is not sick. And I was angry. like, he uses swear words on me. Like what I mean by saying he's normal is because everything that he is going to do is everything that is happening in the house in our lives. So I was really upset with that and I thought, this person is not sick. So sometimes you, you don't know how to react. Yeah. You understand?

Researcher: Yes, you are saying that he threatens to do things and ends up doing them, he swears at you and at times you feel like he is not sick, and he's doing everything on purpose, is that correct?

P1: Yes.

Researcher: So how do you deal with that situation? When you feel as if he is not sick?

P1: Sometimes I feel like I don't know how I should take care of him.

Researcher: Do you know what schizophrenia is or have you been informed here at the clinic on what it entails?

P1: Yeah we have been told what it is and I thought I knew what schizophrenia is, but for now, to be honest, uh, I think I need to get more information on schizophrenia, because like, um, I'm also getting confused. Okay. Because most of the time he will be quiet and when you ask him something, that's when he gets space to talk a little. So you don't know whether he doesn't want to talk or not. Whether he's complaining or what?

Researcher: I also agree with you on learning more about schizophrenia, however, having hallucinations and delusions is most common in schizophrenic patients, and you can also ask your brother's psychiatrist here at the clinic if you get confused. Anything you'd like to add on your experiences?

P1: Hygienically, my brother does not fully care for himself because he does not want to change clothes after bathing, so I have to tell him to change. I have to fight with him to change clothes. He was once lost for quite some time, we didn't know where he was and I found him in Johannesburg. He's the one who saw me and he called me, and then I was like, "we've been looking for you". And then he was at home, let me put it in that way.

Researcher: For how long was he lost for?

P1: It was for a long time, because he will come and disappear just like that. He will come and disappear until I say to my mom, "I think maybe he's got a mental illness". and then that's when she started to take him to Baragwanath academic hospital, and then that's when he also started to take medication, like the injection, He sleeps for like maybe a week and then if it's before a week before we come to the clinic he doesn't sleep. He talks too much alone, that's what I notice. Maybe that injection is getting out of the system. When he says thing like "I'm coming". So I have to make sure that he comes back, and I also ask where is he going? And sometimes you want to give him that independence, but sometimes you get scared.

Researcher: Has he gotten into any trouble while away from home, besides getting lost?

P1: No, he hasn't.

Participant 2

P2: It is very hard to care for a person that has mental illness because you speak to him now and the next thing he forgets. I do not even know what kind of mental illness he has because

he has been diagnosed many times by doctors. He used to go for treatment at Kopanong hospital. He was first diagnosed with bipolar disorder, then schizophrenia, but I did my own research to search for symptoms which align with his behaviour then I realised that he might have both the disorders. He is epileptic and the doctors told me that there is an over secretion of a certain chemical in his brain causing an imbalance. He was affected while doing matric and was diagnosed with major depression at that time. I even thought that it is the school workload that caused him to be like that. As parents we have expectations for our children to meet a certain standard of education without realising the kind of pressure they are under at school. I am a single parent and a very strict parent, so I think that might have caused him not to come and speak to me about his problems and also because he is a boy child. I don't see any change with him, even if he takes treatment. His epilepsy is getting worse. He is also taking marijuana and that affects him a lot. At first he started seeing things we don't see and hearing things we don't see. He then escalated to speaking alone. I then thought that he is taking alcohol, but he does not drink. I took him to a psychologist and psychiatrist at the hospital.

Participant 3

P3: My son is diagnosed with ADHD, so he is very hyperactive. He has a lack of concentration.

Researcher: How is it like to care for a child with ADHD as a parent?

P3: At first, I didn't understand what ADHD was about.

Researcher: So, do you now understand what ADHD entails?

P3: Yes, now I do, the psychiatrist explained it very thoroughly to me.

Researcher: Okay, what other experience do you have with caring for your son?

P3: He has a lot of temper. I didn't understand why he gets so angry. It's like he doesn't have a sense of reality because when I talk to him, everything goes away.

Researcher: How is he like when he has a lot of temper?

P3: He hits me, shouts at me, breaks stuff. He also hits other children at school.

Participant 4

P4: I see them as people who need to be cared for. I have to make sure that they eat on time and bath. I supervise their medication. If I see any odd change in them, I make sure that I inform the psychiatrist here at the clinic. It's a very huge responsibility to care for someone that has mental illness. So caring for two people is more like caring for twelve people. It is a job on its own. It has challenges but you get used to it with time.

Participant 5

P5: My elder sister was diagnosed with Alzheimer's and the middle one was diagnosed with dementia. She had a few silent strokes. With my elder sister it's difficult because she's forgetful. It's like she has a short-term memory. You can tell her "the sugar is in the cup". Then maybe five minutes later, she doesn't remember what you said. She's always looking for things. The constant supervision you know, to make sure that she's doing the right thing. And it's come to that point like right now she had abscess under her breast, it is a swelling under her breast and I only picked up on it when I saw there was blood coming from her pyjamas. At that time, she could still bath herself. But my thinking is, did she not see or did she not feel? so, I don't know if her feeling is gone that she does not see that she has a wound under her breast.

Researcher: do you think she has lost her sense of pain?

P5: Yes, that wound is now 7 months old. She's 74 years old. It's seven months since I've discovered that. I've been trying to get the help for it.

Researcher: So how did you get help.

P5: Okay. I came to Johan Heyns Community Health Centre. They gave us antibiotics. I was then given a referral letter to Sebokeng Hospital where they gave us dressing and they made her take a biopsy and mammogram. They didn't give us any medication at Sebokeng hospital. The wound was still oozing. In December I took her to a private clinic. A private doctor referred us to Chris Hani Baragwanath academic hospital a week ago. They took a biopsy and x-rays of her.

Researcher: So when you're taking her to these hospitals and clinics, what transport do you use?

P5: I used a meter taxi. To go to Baragwanath hospital I have to ask my daughter for transport money because it is quite expensive. Even to go to Sebokeng Hospital it's about R150 a single trip and I am only relying on state pension so it is a lot.

Researcher: Yes, that is quite expensive, I hear you say that you always take your elder sister to her hospital appointments, you use your state pension to transport her and your daughter sometimes helps you with transportation. Any other experience that you have with your elder sister?

P5: Because of her wound, I have to assist her with bathing and eating now. At one stage she took the wrong medication. She has lost that ability. I have to supervise everything she does. I must clarify something. The two of them used to live together in their own house. So, we moved from Ennerdail to Vanderbijlpark. Yeah. So when my second sister was diagnosed with dementia. She was the one that took care of her but there was a time my elder sister, the one with Alzheimer's took the medication of my second sister who has dementia and I think that is how she became forgetful.

Researcher: Wasn't she forgetful before you suspected that she was taking dementia medication?

P5: I cannot really tell when she started forgetting things. I was married at that time and I had my own responsibilities. I had to go to their house to make sure that it is clean, the laundry is done you know and groceries is done. When my elder sister gets into that episode of hers, I don't want to say aggressive but she would accuse me of stealing her stuff. At that time, I didn't know that she had Alzheimer's. I would take her for blood pressure treatment at Baragwanath hospital. It was then discovered that she has Alzheimer's.

Researcher: And how is your experience with caring for the second sister that has dementia?

P5: At 5 am in the morning, she would go to Shoprite in Ennerdail and beg people for money. This happened on pension day. Around 5am it is still dark in the morning and people told me and my son about this thing. She would ask for 50 cents and 10cents. When I actually intervened, she would come to our house and lie about our elder sister borrowing money then I told her that we would rather call my elder sister and ask her if she wanted something. When my daughters found her at Shoprite begging for money they took her and brought her home. She used to smoke cigarettes with that money. I then took her to Lenasia South clinic, then to Jabulani hospital and Baragwanath hospital. They did a scan, then they found that she had dementia. Her behaviour changed. She used to like expensive things and took care of herself really well before. Her behaviour was now out of the normal person that we know.

That is how I have experienced their behaviour. The reason I want to speak to the doctor today is because I am very concerned with my second sister's health. She is going through phases where she just wants to sleep all that time. I must make sure that she eats so that she can take her medication. I also have to help her to bath and get dressed. I cannot bring her to clinic appointment anymore because she just wants to sleep all the time. I have done research on the medication that she is taking and I have discovered that with her using antipsychotics for a long time causes certain side effects. Like now with her, she moves very slowly. And she has this constant urge to move. She can't sit still. Even when we eat. She will take the plate and she would walk and she would eat. You know, she doesn't still at all. So, um, and even her mouth, we noticed with the jaw, she can't keep the mouth closed. To such an extent that she starts drooling. So that's a concern for me. She doesn't really watch television but when she is watching she would watch with a specific weird angle.

Participant 6

P6: It is difficult to care for a person who has dementia because you always have to check on her 24/7. She is more like a baby that is still crawling. I am even afraid to leave her alone in the house because I don't know what she will get up to. Even when she goes to the bathroom I have to check on her. She messes up the bathroom and also pees and poops herself but I understand because she is also an elderly person. Before taking treatment, she used to not sleep. Now, she does sleep for a short period but it's better than before but overall caring for a person with mental illness is difficult. It is my responsibility to make sure that she eats and is taken to the clinic to get medication. When I discover something odd about his behaviour I tell the psychiatrist about it.

Participant 7

P7: He does not take his medication properly. We have to convince him to take his medication properly. He became aggressive and I took him to Kopanong Hospital where he was given injection. It helped him to stay a bit calm for a while. However, he has this problem of staying in bed the whole day sleeping. He does not want to do anything or exercise. He became down and down every time due to the fact that he did not want to take the medication.

Researcher: Is he taking his medication now?

P7: He started last week to take his medication properly. We only found out a week ago. He told me that taking medication is not necessary. We even begged him to take his medication. I

reminded him that he needs to take medication because when he was young he was taken to a specialist who prescribed him eltroxin because his thyroid is not working properly. He does not take medication for his physical and mental health. I have to inform the doctor to give him the eltroxin medication for his thyroid because he becomes very down if he does not take it. I have also discovered changes in his health, he becomes fat and dumb. Therefore, he should take all of his medication.

Participant 8

P8: Living with my mother has always been wonderful but ever since she was diagnosed with a mental illness. She takes pills from the psychiatrist here at the clinic but I do not know what kind of mental illness she has. She used to be normal before but she then changed and became crazy.

Researcher: May you please explain to me what you mean by “crazy”?

P8: Things were really bad. She became violent towards people and beat them up. She would just spill a bucket full of water in the house without any valid reason. This started four years ago. For the first two years, we didn't know that she has mental illness. So as black people, we took her to a traditional healer. It was a waste of time taking her to the traditional healer because they were making reference to witchcraft and also the medication did not help. It was tough and I remember during those years, I was staying and working in Johannesburg. I had to move from Johannesburg and come here to my mother because she was sick and was also living with my daughter. She used to beat my daughter up and that really did not sit well with me. She scared me a lot because this was something she has never done before. I have eight siblings and not even one on us has ever been beaten by my mother before. Seeing that was very painful for me. It was like she is in her own world. She spoke to herself and it was things we never understood that made no sense. Moving here was also tough for me as I had to start from scratch and find a job. It was traumatising for me. However, after receiving mental health support from Kopanong hospital and Johan Heyns CHC, she changed for the better. I can now leave her in the house when I go to work. She is able to clean and cook now.

Participant 9

P9: He is 15 years old. He was born with intellectual disability. He has ADHD also. Doctors found out that he was born that way because his mother used to drink alcohol a lot when he was pregnant with him. Attending support groups for caregivers here has made me understand

his mental condition. He is very hyperactive and does not listen when I speak to him. It takes time for him to comprehend information. I am not yet fully experienced on how I should handle her but I was told by mental health professionals and that his mind is slow to comprehend things so I need to be patient with him. He has a mind of an 8 years' old. Sometimes I find myself being angry at him and beating him when he gets up to mischief and I then find myself and draw myself back. I would even regret beating him up because he does not know how to be angry with me. Right now he is attending a normal school with children who have no mental disabilities, he needs to be taken to a special school for children like him. There's lot of complaints about him from school. He cannot concentrate for more than 10 minutes. He leaves class while there's a teacher giving a lesson and plays outside. He used to sell things at schools and that was not allowed. He was even suspended at school and I only found out after three days. I had to go to his school and negotiate his return to school on his behalf. He likes to draw a lot and prefers to draw on his books than write up what he is being taught. Therefore, social workers here are helping him find a special school to cater for his needs as a mentally slow child. Some of the parents of other children from our community complain about him misusing things which belong to their children and bullying them. I haven't done research about ADHD so I do not know much about it.

Researcher: How do you handle him when he acts like that?

P9: I make sure that he takes his medication. I take him for treatment. The pills calm him down because he is too hyperactive.

Participant 10

P10: She was diagnosed with depression. She started taking her treatment in February 2022. She used to lock herself in her room. She was always angry and harmed herself. She would cut her wrists at times. The treatment she took seem to be helping her because the psychiatrist mentioned that in six months she can stop taking the medication. She used to live with her mother before in Soweto when she was young. Her problem started when she was living with her mother. She was referred to Chris Hani Baragwanath Hospital and then to Kopanong Hospital for an evaluation. She started living with me when she was 11 years old and attending school this side. From Kopanong hospital, she was then transferred here for her treatment. I collect medication on her behalf because she goes to school unless when it is her date to see her psychiatrist for her session, she then skips school for that day. In December 2021, she was

raped on the 31st. it was found that she has always been depressed and the rape case triggered everything. This is what they told me at Baragwanath hospital.

Participant 11

P11: He was diagnosed with too many things. He has ADHD. I cannot remember some of them. there is this one where he gets afraid to go to people. It is a type of anxiety. He has a detachment syndrome. He is detached to people and reality. He is living in a world that I cannot explain. Caring for him is a living nightmare. He is in the process of being removed from me to Boys town which is a children's home and a school for children like him. His social workers are currently busy with his paper work. He is suspended from school every two weeks. He is literally living in a world we can't get in. He is in total denial, he is a compulsive liar and he steals. He stole like a R100 from me and my phone. He is living with me now. He behaves like he owns the world and I don't have a say in his life. He doesn't have any sense of reality. My husband and I cannot deal with this anymore. My husband is about to be admitted to a psychiatric hospital for evaluation for three weeks. This whole this is affecting my marriage and my whole life.

Researcher: May you please describe what you mean by "it affects your whole life"?

P11: It affects me to a very big extent. There was a time when my husband was on camp and I was away for work. I had to ask somebody to take care of him. No one wants to take care of him. Not even my friends. Not even the welfare wants to care for him.

Participant 12

P12: She was diagnosed at a clinic in Bophelong with mild intellectual disability and another mental illness, I don't know what it is. Her teachers at her previous school mentioned that she is a slow learner. Now, she is attending a special school. it is a school for children with physical and mental disabilities. Raising her was very hard. she used to be very quiet before. She would not respond when you speak to her. She is getting better now that she is attending a special school and can now interact with my other grandchildren. I raised her when she was still very young, from when I was still working. When I was at work, I would leave her with my daughter. She is 14 years old now. I am still guiding her on how to bath and take care of herself because she is very slow. I have to guide everything that she does. I have even accepted that she pees her blankets and that is something I really have no control over. I make sure I supervise her when it comes to cleaning after herself and washing her clothes and blankets. She is still

struggling to write her name. When I try to help her, she sometimes gets aggressive. I really don't know why her previous school kept on promoting her to other grades even though they were aware that she is very slow. She is doing better now at her previous school. another thing, it seems like she is unable to relate to people on an emotional level because her father was sick and died she did not seem to show any emotion, but I understand that she is still a child and she has a mental illness.

SECTION A2

Interview Question 7: What challenges do you experience as a result of caring for a person living with mental illness? (the researcher probed/ sought clarification to clarify what the participant is saying and to avoid unclear responses)

Participant 1

P1: He's a very difficult person. Maybe you leave him in the morning and think that when you arrive from work, he's the same person but he's not. He's very complicated. I don't want to lie.

Researcher: Can he manage being left alone in the house?

P1: He can stay alone, but I get worried sometimes. Especially when he's angry. You get scared. sometimes he even mentioned that "I will go", like he threatens. He once stayed with my mother in Free state and he threatened to take hikes and leave. So sometimes when you're at work, you just like jumpy, because he's always threatening to run away from home. The most confusing part about him is when he talks alone. So you don't know what he is saying. Does he think of leaving? Sometimes he swears at me. When he goes to my younger sister's house, maybe there's something that they talk to him about that I don't know of that makes him threatens to leave. I even felt like, you know what? I can't. I can't stay with him. I can't. I can't. This is heavy for me. Okay. I can't stay with somebody who can swear at me. Nevertheless, I make sure that I take care of him wholeheartedly. I mean, he's my brother and I also don't want to lose him. I don't want him to be away from me. I think I'm doing my best with him. When my mom passed away, I had to stay with him after that.

Participant 2

P2: I do not have a life of my own. I cannot even go out for a long time and have fun with colleagues because I have a child that is fully dependant on me. He is very restless. He even

knows the time when I come back from work and is always expecting me. He doesn't feel safe when I am at work or when he is left with his other caregiver at home.

Researcher: Who is the person that you leave him with, when you go to work?

P2: I leave him with my brother and he is used to him. I think he is also affected my son's mental illness because he looks depressed.

Researcher: any other challenges?

P2: It is painful to raise a child that has mental illness because he was not born like that. He was born to have a good future. I went to schools to have a good life and healthy children. Now I am also depressed.

Researcher: How do you know that you are depressed?

P2: I am unhappy and always sad. I am unable to socialise with people either in person or on the phone. I spend time alone. The only time where I spend time with my sister, but only after church on a Sunday. I feel easily irritated by some of my friends whom I used to spend time with before. I don't want to spend time with them.

Participant 3

P3: Every day is a new challenge.

Researcher: Please explain to me what the challenges are?

P3: I have to constantly tell him to brush his teeth, eat, and get dressed and it is not like he doesn't know how to do it. Sometimes I would not understand like why everything doesn't go to his head. I do the same thing every day. Sometime he doesn't do what I tell him to do, he would sometimes put a whole toilet roll in the toilet, but I would try not to get angry with him because it is not his fault that he is like this. Teachers also have to constantly tell him to do his school work. It is sometimes hard for me when he is at school misbehaving because I am not around him. He is too busy for himself at school and sometimes distracts the whole class. Teachers do not understand him as much as I do. As a result, I used to be absent a lot at work because I had to always be there for him as there were complaints about him at school. The

teachers had to give me his schools work to help him because he was really falling behind. Losing my job was also another challenge I faced. Another thing, he is very energetic, he can play the whole day and does not get tired. Sometimes he only sleeps two to three hours at night. It's like his mind doesn't shut down. Sometimes he gets late for school because of his morning tantrums, he cries a lot, screams, and shouts. I then take a video of him and show it to the teacher because she told me she is not happy with his late coming, so that I can show her that I am trying my best with him. They cannot handle him at school. He is very active at school and he can even take an hour to write one sentence. Teachers are not patient with him, I always tell them that he is too busy, they need to make him do tasks at school to keep busy.

Researcher: I am sorry about losing your job. Is your son attending a special school or a normal school?

P3: A normal school.

Researcher: Any other challenge that you might experience with caring for him?

P3: Not really, but my son is missing out on a lot of his school work because he has to come to the clinic to see the doctor every second month. When your child is sick, it throws 10 times at you. Sometimes, I cry a lot. the words he says to me hurts. Like, "I wish you were not my mother, or I don't want to stay with you", or "I'd rather go stay with this person", but I know he doesn't mean everything he says it's because he is just angry and he's going through his own emotions.

Participant 4

P4: I am not fully financially stable to care for the both of them. My company is not doing that good. They require special needs and it is emotionally draining for me to care for two elderly people with schizophrenia, even though they are not severe but it is not easy. They need a lot of food because they eat a lot. I also feel that their pension grant is not enough for the both of them to be sustained for the whole month.

Participant 5

P5: From the past few months, I have now taken a lot of responsibility as my sister with dementia used to bath herself. But now because she has also weakened. Now I have taken over that responsibility to bath both of them. And it's not like they are lightweight. They are big and heavy. I also have my own health issues. I come to Johan Heyns Community Health Centre for my Thyroid. I have low thyroid. It causes me to feel tired all the time. I also deal with blood pressure issues. I'm on blood pressure medication. So self-care is a challenge because you are with that person 24/7. That's the reason why I sold my house. I got divorced. It's now two years that we are in Vanderbijlpark. I am the only one that constantly have to bring them to the clinic.

Participant 6

P6: I experience a lot of challenges. Her sickness is a challenge on its own. She hides her own things in the house. She even takes off her clothes from the washing line when they are washed and hides them. She has always hated it when people touch her things. When I am doing laundry outside I have to lock her in the house so that she does not get out and take her clothes from the washing line. I also have to ensure that the gate is always closed because when she goes outside the yard she goes missing. She has been staying with me for three years now but she still wants to go live alone in her house.

Researcher: Have you ever experienced a case whereby you lost track of her movement in the yard and she went missing?

P6: Yes, she was once lost for a day and we found her.

Researcher: Okay, any other challenge that you might experience?

P6: Ensuring that she always has an adult diaper on at all times is a huge task but I don't mind doing it.

Participant 7

P7: My wife and I took care of him from a very young age. He was diagnosed with this illness from a very young age. I always have to remind him to take a bath because he would start to smell bad. He is very lazy. He lives alone in his own house but my wife and I are his caregivers. We make sure that we call him every day but sometimes he switches his phone off. We prepare food for him as well and take the food to his house. We invite him to come during the week and sleep with us in our house and sometimes he refuses to come and says that he does not

want to be bothered. At times, I would take him out for shopping or just to go around and think that maybe he will feel better but sometimes he refuses to go out with me and my wife. He prefers being in the house the whole time. He would shout at me at times. He used to physically fight me and my wife sometimes.

Participant 8

P8: Now that she is much better, I feel that it is my responsibility to look after her because she raised me and I also feel that It is my turn to now look after her. However, I have financial problems because I do not earn much, therefore some of the things she needs I cannot provide for her but I am really trying.

Participant 9

P9: Before I knew that there were support groups for us caregivers of children with mental illness, I didn't know what was wrong with my nephew. I didn't know how to handle him. Being with him 24/7 is also a challenge because I am always reprimanding and talking. I prefer him being at school and I see him after school. Sometimes I feel like locking him in the yard but then I realise that he is still a child and he needs to play with other children. Parents of these children that he plays with, do not understand him. I really feel for him. It doesn't sit well with me that he is not attending a school which is meant for people like him, I am still waiting for social workers to assist me in finding a special school. However, I heard from one of the social worker that his school is responsible for transferring him to a special school. I also feel that his school is taking His condition lightly because they only realised last year that he needs to be transferred to a special school.

Participant 10

P10: A case was opened. Sometimes she doesn't want to take her medication. She complains that the medication makes her tired and sleepy. It is not a good thing for her not to take her medication knowing very well that she needs it. I always have to supervise her medication intake.

Researcher: Okay. What is your response when she doesn't want to take medication?

P10: I have to beg her to take it. We get along very well, so she listens to me when I advise her to take her medication. She does not get along well with her biological mother. She does not have a good relationship with her mother. It is a challenge on its own to raise a child with

depression because as a parent you expect good things to happen to your child and for your child to be healthy. The rape issue has really affected her and us a lot. Her father is mostly affected because he doesn't want us to talk about it in the house, it is more like taboo.

Researcher: I really understand, any other challenge?

P10: I feel like I am the only one who is emotionally there for my step-daughter. My husband doesn't like to address things so that causes him to ignore talking to her daughter. That is a lot for me because I have to encourage him to speak to his daughter all the time and not wait for something bad to happen before he can respond to her behaviour.

Participant 11

P11: That is one of them. He misbehaves when we are out in town to such an extent that we had to put him in a car and go back home. I don't have friendships anymore. I try to discipline him by putting him in a corner or give him a hiding, then he would start breaking things in the house. He does not care about his hygiene. He would wear his underwear for like three days unwashed. He does not have a sense of cleanliness. I have to supervise everything he does before he gets to school or else he would look like he hasn't bathed for like three weeks. Sometimes people think that I am not a good mother to him because I do not buy him sweets and all those nice things. They do not understand that the medication he is on does not allow him to eat sweets. He is so severe. I make sure that I limit his sugar intake. My own children feel like I have neglected them because he is not a child you can easily guide. He has an attitude. He is a 28 hours' child and not even 24 hours. I have this whole gap between myself and my own biological children. I cannot go out because I do not have any one else to take care of him.

Participant 12

P12: Communication was a challenge because she would not respond to questions when asked. She would just look at me. Sometimes, when I ask if she is hungry. She would not reply. Therefore, I don't know how she feels or what she wants. I have decided to just give her things and not ask if she wants them or not. She gets angry when I guide her to do things for herself and that drains me. When her father, who is my son, was still alive, he never took care of her. He did not maintain her while he knew that my granddaughter does not receive any form of financial aid. I had to be the responsible one but he has passed now and may his soul rest in peace.

SECTION A3

Interview Question 8: How does caring for a person living with mental illness personally affect you as a caregiver? (the researcher probed/sought clarification to clarify what the participant is saying and to avoid unclear responses)

Participant 1

P1: Even now, like emotionally, I'm exhausted. and physically, I feel like my body is tired. Yesterday, that's when I felt like I'm not myself. Energy wise, I don't have energy. I'm this person who don't want to be pressured in the corner. Like now he wanted some sneakers and every time he was talking about sneakers. So I don't want to be pressured. That's me. I want to do something if I want to. I know he does need those. It's not a question of need because I buy him almost everything that he wants. Yes, I'm exhausted. I don't want to lie to you. That's why when I think about him, sometimes I cry. Last week, I cried too much and when you look at him, he's like, "everything is normal". My mind is exhausted. Even physically, I just feel like I can just close my eyes and sleep.

Participant 2

P2: My concentration levels have decreased. I cannot even focus when I am watching television. I just look at it. I am always sick and my health has deteriorated. I easily get flu and I was never like that before. My heart is always painful. Sometimes I would sit and have thoughts but I cannot find answers.

Participant 3

P3: Losing my job affected me financially and emotionally because they always thought that I was unprofessional as I was always late for work, but I will get another job I am positive.

Participant 4

P4: It does not personally affect me a lot. I am passionate about caring for them even though it might be hard sometimes but it does not get harder to an extent where I find myself wanting to quit. I love them so much and I am strong enough to be able to be there for them.

Participant 5

P5: Oh, like now I feel overwhelmed. Overwhelming. That I can tell you. Um, Because it's a lot. I don't have a helper. My daughter helps me however she can. She lives with me. She helps me now and then. I don't want to do this. You have to make sure that they clean. They have clean clothes. They have food to eat. So now, it's only me and my daughter who do the washing. I mean cleaning, knowing your normal house stuff where, you know, sometimes you have to do spring cleaning and you still have to take care of them, so my daughter cares. There's no time for self-care really, because I would like to go on holiday. I can't go. Even putting them in a mental health care facility is not possible.

Researcher: How is it not possible to put them in a mental health care facility?

P5: Okay. The three of us are on state pension. So there's no other income. I cannot say, I can call on family and friends to put them in a facility because the facilities are expensive. It's very expensive. The cheapest one that I found out about was about 3000 per month. So for the both of them, it's out of the question. So now I have to do the care-work by myself. I am exhausted. Like I can give you one experience, on Monday evening, we went to bed early, the one with dementia was up. From 9pm. She didn't sleep at all. We have to resort to like locking our bedroom doors and switching off the lights because she wakes up at night and she switches on the lights. Then she's up and down. She doesn't sleep.

Researcher: So what do you do in that situation?

P5: Well, we had to put all the light switches off so that if she puts on the switches in the passage, it doesn't go on. We can't leave food stuff in the kitchen alone because she can eat anything and everything that she sees. So we locked the kitchen door. When she's outside, we allow her to walk around outside, but not for long periods. She's at that stage now where she doesn't want to eat. Even the elder one. She went through a period last year where she didn't want to eat.

Researcher: For how long was she not eating?

P5: It was about two months. So we had to like get replacement meals, you know. Things like that to make sure that she eats at least to get some nutrition. You know, she also got a stunt now, say January, February, when she doesn't want to eat. The one with dementia, she eats up porridge in the morning. Then it's a mission on lunchtime to get her to eat. In the evening we have to give her now a replacement meal. So that she at least has something. Yeah. So you know it's always something with them.

Participant 6

P6: Like I have mentioned before that I am a business person. My business is suffering a lot because I cannot move most of the time and sometimes my children do not want to assist in looking after their grandmother. They are not patient like I am. I feel like my life is boxed. She has boxed me. I don't have me time.

Researcher: How is your business suffering?

P6: My business involves selling meat and other products. I have to deliver these products to clients when they request for a delivery. I do not get enough chance to deliver to my clients as I have to wait for my children to come back from school sometimes. With that little chance, I would then be able to deliver to my clients. Three years ago, before I took care of her, I used to make deliveries from morning. I would then make a lot of deliveries per day. Fewer deliveries negatively affect my profit right now. Another thing bothering me is coming to the clinic from 06:30 in the morning only to wait for the longest time before my mother in law can receive her medication. It hits me but I then remind myself that one day I will also be this old and sick and my children will have the responsibility to take care of me as well.

Participant 7

P7: To be honest with you, my wife cries too much about that. We suffered too much. We want to do more for him but we cannot. Last week, we asked him to come and drive with us around and he refused to come with us because he wants to sleep. My wife is very emotional so when she cries it also affects me emotionally.

Participant 8

P8: It affected me a lot because a lot of things changed. I remember that time I had to separate with my wife because we did not understand each other. She felt like I was more attentive to my mother than to her as my mother was sick. It was difficult. The divorce even caused me high blood pressure.

Participant 9

P9: It doesn't sit well with me. It hurts me because I want him to succeed but there is no progress with him but I understand because he was born sick. At the end of the day I will be okay.

Participant 10

P10: Sometimes I feel like her biological mother should take over because she doesn't care about her child. She does not have contact with her child.

Participant 11

P11: It affects me a lot as a mother. Now it is a decision between my biological children, my marriage and me. I need to let go of him. He needs to be taken back to the system. I am on a brim of a divorce because of this. I am no longer focused at work and my manger even complained. On the other hand, and in my heart, how do you just give away a child? I still feel for him. His own parents failed and at this point I am about to fail him as well but I need to make a choice.

Participant 12

P12: When she was 12 years old, she was raped. That really affected me a lot emotionally. I took my retirement package early and resigned from my job because I felt that she was not safe. She was taken advantage of because she does not have the mental capacity to stand up for herself and because she is a child. What affects me is the fact that she cannot stand up for herself and she is too vulnerable and that stresses me sometimes. That happened when she was away from home and I always feel that I need to protect her at all times.

Research Question 2: What are the coping strategies of caregivers of caring for people living with mental illness in the Emfuleni Local Municipality?

SECTION B1

Interview Question 9: What coping strategies have you used to deal with the challenges that you have mentioned? (the researcher probed/sought clarification to clarify what the participant is saying and to avoid unclear responses)

Participant 1

P1: I buy a pair of shoes. Retail therapy makes me feel better. Sometimes even if I feel like, I know, I don't have money to do this, but I end up doing it. My mind shifts from thinking about

my problems, sometimes I think that I'm going to dress this shoe with this and this, the feeling is temporary you know, but it helps. Most of the time what I do, I think of a project. What am I going to do? Maybe in the house, like now I'm thinking of doing landscaping. I try new ideas. I Google. Ideas, what am I going to do? So it keeps my mind out of what's going on in my life.

Researcher: So those are the only things you do in order to cope with your challenges?

P1: Yes.

Participant 2

P2: I just pray. I read the bible and listen to pastors on radio. I listen to podcasts about families and children with the same problem as me and It helps me to realise that I am not the only one experiencing this.

Participant 3

P3: I indulge in self-care to cool down. Sometimes when the situation gets out of hand, I ask my fiancé to intervene in that situation by talking to him and explaining to him that he has to follow the rules and listen. I am also learning how to regulate my emotions by not getting too angry at him.

Participant 4

P4: I go out and network with people who might help me gain skills to be financially stable. I attend a church choir to give me that feel good mood. I attend choir practice every Tuesday and Thursday. It really keeps my mind off a lot of things. I sometimes go to the gym to help me to be at ease.

Participant 5

P5: Well, I go and take a lavender bath. I take a bath, put in my lavender. I like lavender. I also knit to take my mind off. Okay. And, um, I like reading also but there's not always enough time to read. So, during the times when the one with dementia sleeps through at least it helps. Then I can get some sleep. Sometimes she sleeps during the day. I don't know if she confuses time that during the day it's evening, I don't know.

Researcher: Anything else that you do to cope?

P5: Well, as I said, I haven't been able to go anywhere for the past two years but sometime I visit my daughter in Ennerdail for a week just to have a change of scenery.

Participant 6

P6: To cope emotionally, I talk about what is bothering me to my loved ones and it helps me sometimes.

Participant 7

P7: I believe in God that's all. During times when he would be violent, we allowed police to intervene and he was referred to a psychiatric ward in Kopanong hospital.

Participant 8

P8: I am a natural problem solver. So I hustle whenever I have money problems. I am a gifted person and I can fix things for a living then people pay me, so I do not just sit around. I am creative with my hands.

Participant 9

P9: When I have problems I cry and pray about it afterwards. I find healing in that. Support groups from here assist me emotionally and to solve problems as a caregiver of a child with mental illness.

Participant 10

P10: I am Christian. Therefore, I believe so much in God and prayer. There is this woman who used to help me a lot when my step-daughter was sick. This was before she started taking treatment because it took a very long time to get her a psychiatrist. She used a bible way to counsel me and my step daughter. I communicate every time when I am not happy about something and that helps me a lot.

Participant 11

P11: I take it day by day. We don't live in the yesterdays. Each day by itself.

Participant 12

P12: Social workers here are educating me on how to handle her and that helps me a lot. I come for support group sessions for us caregivers where we share our stories with other caregivers and the social worker and then come up with solutions. After her rape incident, she was taken

to the clinic and a criminal case was opened. She was then transferred to social workers. These social workers really helped us a lot. They were even able to speed up the process of her receiving grant from the government because she an orphan and counselling

SECTION B2

Interview Question 10: Who is your support system and how have they helped you to cope with problems resulting from caring for a person living with mental illness? (the researcher probed/sought clarification to clarify what the participant is saying and to avoid unclear responses)

Participant 1

P1: I'm the eldest of my siblings, I have a younger sister but we do not get along. I do not have a support system I do everything on my own to support my brother. However, I receive support from the clinic.

Researcher: How do you receive support at the clinic?

P1: Sometimes as caregivers we get booked for a psychiatrist to evaluate how the behaviour of the patient affects us, but I have a private psychiatrist that I also see as I was diagnosed with mild bipolar disorder. I am also going to see my psychiatrist next week.

Researcher: How does it make you feel to receive support from a psychiatrist here at the clinic and privately?

P1: Sometimes you may feel as if you are okay meanwhile you are not and when you are alone, that is when you feel that everything is too much. Talking to my psychiatrist is nice because I do not feel judged. I like that a lot. Talking to a normal person is not easy because they do not understand and they'll ask questions which you do not want to be asked.

Participant 2

P2: My family is my support system. My sister and brother. They are the only people I live with. We talk and they provide emotional support. My brother takes care of my son when I am at work like I have mentioned before. I receive support from the clinic here. I talk to the psychiatrist and psychologist during my son's appointments.

Researcher: How does receiving support make you feel?

P2: It helps a lot. More especially my brother who takes care of my son when I am at work. It is satisfying to know that my siblings are there for me.

Participant 3

P3: My fiancé supports me.

Researcher: What does he do in terms of supporting you?

P3: He supports me financially. Emotionally, he is a father to my son. he's gentle with him. He doesn't scream and shout. Even if he gets angry he goes and sits outside. We have that thing. We don't fight. We just give each other space to avoid saying things to each other we can't tolerate. I also receive support from the occupational therapist here at the clinic. He gives me advice on how to handle him. He told me to give him chores or toys to keep him busy. I have done that, and I see a big improvement. He also taught me how to deal with his temper. He told me to put him in a corner, to let him calm down. The psychiatrist is also helping me with him by giving him medication which calms him down.

Researcher: How does it make you feel to receive support from your fiancé and here at the clinic?

P3: My son has improved a lot and that makes me feels good. Even though at his school, he is still misunderstood, and they think that I am doing everything on purpose and I am actually not.

Participant 4

P4: My family is not financially stable so they do not assist me a lot. I understand their situation. My wife emotionally supports me and helps me to care for my parents. I talk to my siblings about my issues and I often get advices from them. They sometimes buy food for our parents and bring to my house, when they have money.

Researcher: How does it make you feel to receive support from your family?

P4: It encourages me not to give up on our parents.

Participant 5

P5: Well, my support system is my daughter. Okay. My son is also there by the bulk caring but I'm the one that's mostly taking care of them.

Researcher: What does your daughter do when she's helping?

P5: Well, she sometimes helps them bath. She irons. She cooks, so we take turns to do those things. She financially helps me sometimes.

Researcher: How does it make you feel to receive help from your children with caring for your sisters?

P5: I feel relieved sometimes that I am not the only one carrying all of this burden.

Participant 6

P6: My husband and daughter are my support system. They sometimes bring my mother in law to the clinic or assist me in taking care of her when I am away sometimes. My husband drives us to the clinic most times.

Researcher: How does it make you feel to receive support?

P6: It makes me feel relieved. I become happy.

Participant 7

P7: My wife and I support each other in taking care of him because we are capable of providing the support. Even though my pension fund is not enough to care for him but I do my best. My wife makes food for him and I take the food to his house. The clinic helped him to get disability grant from the government.

Researcher: How does it make you feel to have received support from the people you have mentioned?

P7: I feel that it is my wife and I's obligation to care for him because we are his parents. We want him to improve.

Participant 8

P8: I do not have any support system but my father does assist me sometimes with caring for my mother. He brings her to clinic appointments at times. He is working at a farm, so he financially supports the family whenever he can.

Researcher: How does receiving support from your father make you feel?

P8: It feels better to have someone to assist you in taking care of someone who is sick because I cannot always be with my mother as I have to work also.

Participant 9

P9: My husband supports me. He encourages me to be a better parent and stay calm. When he is not at work he assists me with taking care of him. He also encourages me to go out and take a break from caregiving.

Researcher: How does it make you feel to know that your husband supports you?

P9: It makes me happy as his wife.

Participant 10

P10: My husband supports us financially. He provides for his family. I sometimes speak to her psychiatrist when she does something wrong. It helps to have someone to talk to.

Researcher: How does that make you feel to receive support?

P10: It makes me realise that I am not alone in this and I have people who care about me.

Participant 11

P11: I don't have a support system anymore due to the fact that he disrupts everything. No one wants him to come over to their places because he is breaking everything. I don't know if I should mention Christianity or not. It is a sad thing. There is no place to go to with places like those. I have tried taking him to a normal Sunday school at church and they told me that he disrupts the church so it would be better if he comes back to church when he is much older or has manners. I thought that taking him to churches would make him feel accepted but it didn't work because I was told that he disrupts the church. When he is in church he fights with other children. It frustrates me a lot that people do not understand him, I feel that there is not enough education about children with special needs out there. People judge very quickly to such an extent that my co-worker who was like a best friend and a brother to me stopped being friends with me because his wife who doesn't have any children of her own who judges him for

supporting me and threatens him. However, I have friend who is pastor and has a daughter who is also like my foster son so he understands me. My husband is trying to support but he works a lot. He is emotionally there for me. We are still staying together even though we are still in the process of divorce. We are trying to keep things civil. Yesterday I wasn't feeling well and I had to take one tablet to make me calm. I even told my husband that he should take him with wherever he is going for that day because I was very emotional. He even understands that he has to take full custody for our biological children when we divorce because I work night shifts and I won't be able to take care of them.

Researcher: How does it make you feel to receive support?

P11: I am happy that my husband understands the custody situation. In terms of helping me with our foster son, I appreciate it.

Participant 12

P12: My husband and daughter support me. They guide and educate her. They are patient with her. My daughter financially supports us because she is working.

Researcher: How does that make you feel?

P12: Knowing that they can also assist makes things better.

SECTION B3

Interview Question 11: What motivated you to continue fulfilling your role as a caregiver despite the challenges you have mentioned? (the researcher probed/sought clarification to clarify what the participant is saying and to avoid unclear responses)

P1: There is no one who will take care of him and I feel a sense of responsibility towards him. If I can let him stay with my younger sister, she won't take care of him the way I do. I feel like he's the person that I want to see every day, like he's okay. So if he's far from me, I don't think I'll be okay. When he's far from me, to be honest, I even cry about it. I will not cope if he's not with me.

Researcher: You must really love him a lot, I can tell.

P1: I do and I wish he can also see that. sometimes he doesn't eat and then I will ask what do you want? Like maybe some biscuits, whatever, you know, just to make him eat because sometimes he doesn't eat.

Researcher: How long can he go without food?

P1: Sometimes he doesn't eat for the whole day. He will eat at night. So I have to buy things like fruits and then if you say this is yours, that's when he will eat.

Researcher: So if you do not mention that the food is his, what happens?

P1: He won't eat, it's like now he's going back to being a child. You have to give him food to eat.

Researcher: How old is he?

P1: He is 55 years old. It's better now because I can send him to the shops to buy something and he would be able to bring back the change.

Researcher: That's incredible, at least there is something he can do on his own despite all the other challenges. Is there something else that you'd like to add?

P1: Taking care of someone with mental illness is tough, it is not easy. Even if you try to live a normal life it hits you. I feel like schizophrenia is more severe than the others and it's complicated. You cannot confirm the person. He is like this today and he is like that tomorrow.

Participant 2

P2: He is my burden. If I don't care for him who will? God has trusted me with him. I brought him to this world and I have the capability to take care of him. I am the only one responsible for him because they do not have a father.

Researcher: I hear you. Is there anything you might like to add before we adjourn our session?

P2: South Africa has a very huge problem with the youth using drugs. As parents we are affected by that. It takes a village to raise a child. It hurts me when I saw my son smoking marijuana. As a community we need to do something about that. I feel so irritated. Everything irritates me. My other youngest child is diabetic and I am really worried about him. I also suspect that he is taking drugs. He doesn't want to do anything with his life.

Researcher: It must be really heavy on you to care for two children with medical conditions. I can imagine.

P2: My son, the one who has a mental illness. He was once lost for 24hours. He was so messed up, but he was taken for counselling after that.

Researcher: You made a wise decision by taking him to a mental health professional. Thank you for answering all my questions and opening up. We are done. Have a nice day.

Participant 3

P3: I have to fight for him. He's my baby. Yeah. I love him to bits and pieces. There's nothing I won't do for him. We'll fight like mother and son, but we will make up before we go to sleep. If I'm not going to do it, who else is going to do it? Because he is all I've got. Even if he's like drunk in the street, I will go miles away for him. I will find him. I will make sure he's fine. It's my blood of course and he knows that too. Well, when he has done something wrong, he comes to me like, mommy, I'm sorry, but this is what I did. And I'm like, why did you do that? the other day he broke the house key. Then I told him that he must not do that ever again.

Researcher: Do you have anything else you would like to add?

P3: I am very happy, and like I said that my therapist is really helping me and I learn something new every time. I really appreciate that therapist. She is very friendly and nice.

Participant 4

P4: My love for them drove me to continue being there for them. I started caring for them from 2017 until now, and I am doing a great job with them. Despite my financial setbacks sometimes, I continue to care for them.

Participant 5

P5: Okay, for me, it is because they are my sisters, they were never married. They don't have children, so I'm the only one left. I'm the youngest one to take care of them. I also read about mental health state facilities. I don't want them to be abused, neglected, not being taken care of. So that is why I'm still taking care of them, to make sure that they are taken care of. It's the only reason.

Researcher: That is understandable, is there anything that you'd like to add regarding your experiences and coping strategies?

P5: You know what I was thinking about, if it was possible, if I had the money, I would open up a facility. Like, take care of people with mental illness where the caregiver drops-off the person and come take them back. They mustn't be frail. Because now with my sisters, I cannot keep them busy. I have tried with colouring books, reading. They don't want to do anything. So if there could be a facility where they can go during the day, where they can get helped. Do crafts and things like that. That would be great. We don't have a lot of those. We don't have at all. You see people with mental illness walking around, wandering around. I keep my gate locked because the one with dementia, even if I bring her to the clinic, sometimes my daughter must come with me because she will just wander around. I mean it's dangerous for them. It's not like it used to be before where people say, okay, "this person doesn't look right, let me take this person to the police station". Other than that, you find opportunists. The one with dementia, from the moment she's awake. You call her name constantly and the constant talking. You can't live her alone. There must always be someone to make sure that she must behave. That's what I can say, because like now we have to close the toilet. She will just flush for the sake of it. She will take the aerosol spray and spray it just for the sake of it.

Researcher: It sounds like now she has gone back to behaving like a child. I can imagine.

P5: We have to put everything out of her way. At one time, we brought the grandchildren. You know these toys that look like food?

Researcher: Yes.

P5: She ate the doughnut and I was wondering what she was chewing. I thought she was eating a marsh-mellow. I had to like literally take it out of her mouth because she was eating the doughnut. She thought it was a real doughnut. Things like that. The constant supervision, the constant talking. My elder sister would want to help sometimes, but it's difficult because it's like I have to help her in order for her to help me. I don't know of any support group for caregivers around here you know.

Researcher: I used to intern at Vaal Mental Health as a student social worker and they do have support groups facilitated by social workers for caregivers of people with mental illness. Do you know where it is located?

P5: No, I don't know it.

Researcher: It's in Sebokeng. You can also search for it on the internet.

P5: I also emailed Alzheimer's South Africa to ask about the kind support they give to caregivers of people with Alzheimer's. I also asked for monetary assistance from them because I use my own money to care for them but they told me that I have to be registered as a formal caregiver first.

Participant 6

P6: I love people so much and I am passionate about helping them. She is my mother in law after all and nobody wants to take care of her, even her own biological daughters. I decided to take care of her because I am still alive and I have the capability to do so. I will not give up on her even though she makes me angry sometimes and it causes me to lose myself. I always tell myself that she is sick and needs my help no matter what she does to me. She would insult me at times and say I am evil and trash.

Researcher: I can imagine, is there something else that you wish to add before you leave?

P6: During the time when I brought my mother in law here at the clinic, I actually wanted for her to go to a home for people with her condition. Then I found a home for the elderly people with dementia. However, the home requested a referral letter from a mental health clinic. The mental health clinic then told me that they do not work with homes which accommodate elderly people with dementia and I should look for a private one. It was very painful for me to hear that because I am not financially stable in that kind of way. It's been over a year now trying to place her at a home.

Researcher: You can do your own research to find homes around the Vaal which accommodate elderly people with dementia. I am sure you will find a public one.

P6: I will most definitely do that.

Participant 7

P7: What motivates me is the fact that I was born from a poor family and I started working very young. I live quite well now so I do not want my son to suffer. He is my son he is our blood. Everything that I have, I try to give to him.

Participant 8

P8: I am the first born, my siblings are young. As the older one I feel responsible for my mother.

Participant 9

P9: I empathise with him because nobody was willing to take care of him after his mother died because of his behaviour. I then took him as my child. I love him and want him to succeed and have a bright future. I have hope that he will be a better child one day.

Researcher: That is good, anything you might like to add?

P9: I just want my niece to be a better child and be successful one day. Social workers from here should continue doing these support groups for us because they really help us a lot. I also feel that if he becomes a better child I will also have peace.

Participant 10

P10: As a Christian. I believe that God wants us to do the right thing despite the circumstances. I play my part as a mother until she is independent. I want to push for her to further her dreams and succeed.

Researcher: That sounds good to hear, any other thing you might want to add?

P10: I am honestly doing good right now. The beginning of the year I felt really sick and I didn't want to go to the doctor. I then decided to seek medical attention and get tested for every disease. Fortunately, I am healthy.

Participant 11

P11: First of all, I chose to be his foster mother. Not everybody qualifies to be a foster mother, I feel that I am going to fail him as that one person who was supposed to be there for him. Unfortunately, doctors have explained to me that his frontal lobe has problems. Both of his biological parents are drug abusers. Therefore, he has a very big problem. No matter what anybody does for him, he will not change because he does not feel anything. He has no compassion. He is a very angry child.

Participant 12

P12: I would never forsake her because other family members do not care. When her father died I had to take full responsibility.

Researcher: I hear you, anything you might like to add?

P12: Not really, my granddaughter just needs love, protection and guidance that is all. I am also not perfect. I am still learning every day on how to handle her.

ANNEXTURE D: PROOF OF ETHICS TRAINING





Zertifikat Certificat

Certificado Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that



Ntombizodwa Ntseteni

a complété avec succès - has successfully completed

Research Ethics Evaluation

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

Release Date: 2022/03/25

CID : n333xat0v4

Professeur Dominique Sprumont
Coordonateur TRREE Coordinator



Programme de formation continue (2 crédits)
Continuing Education Program (2 credits)

Federatio
Pharmaceutica
Helvetica

FPH

Programme de formation continue
Continuing Education Program
Programmes de formation
postgraduate continue

Ce programme est soutenu par - This program is supported by :

European and Developing Countries Clinical Trials Partnership (EDCTP) (www.edctp.org) - Swiss National Science Foundation (www.snf.ch) - Canadian Institutes of Health Research (<http://www.cihr-irsc.gc.ca/e/2091.html>) -
Swiss Academy of Medical Sciences (SAMS/ASSM/SANW) (www.sams.ch) - Commission for Research Partnerships with Developing Countries (www.fph.ch)

(R3V : 20220217)



Zertifikat Certificat

Certificado Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that



Ntombizodwa Ntseteni

a complété avec succès - has successfully completed

Introduction to Research Ethics

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

Release Date: 2022/03/25
CID : 7pF0KshyQb

Professeur Dominique Sprumont
Coordinateur TRREE Coordinator



Programme de formation continue (2 crédits)
Continuing Education Program (2 credits)

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Pharmaceutica
Helvetica

FPH

Programme de formation continue
Continuing Education Programme
Programmes de formation
postgraduate continue

Ce programme est soutenu par - This program is supported by :

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(R3V : 20220217)



Zertifikat Certificat

Certificado Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that

Ntombizodwa Ntseteni

a complété avec succès - has successfully completed

Informed Consent

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation



Release Date: 2022/03/25
CID : C17258Cultus

Professeur Dominique Sprumont
Coordonnateur TRREE Coordinator



Programme de formation continue (2 crédits)
Continuing Education Program (2 credits)

Federatio
Pharmaceutica
Helvetica

FPH

Programme de formation continue
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Swiss Academy of Medical Sciences (SAMS/ASSM/SANW) (www.sams.ch) - Commission for Research Partnerships with Developing Countries (www.fph.ch)

(R10V : 20220217)

ANNEXTURE E: PERMISSION LETTERS TO CONDUCT THE STUDY



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Sedibeng District Health Services
Enquiries: Ms. N. Tuswa
Tel: 016 950 6255
Email: Nomonde.Tuswa@gauteng.gov.za

Date: 12 December 2022

Ms. Ntombizodwa Ntseteni
North-West University
6042 Lakeside Extension
Orange Farm
1841

Dear Ms. Ntseteni

RE: EXPERIENCES AND COPING STRATEGIES OF CAREGIVERS OF PEOPLE LIVING WITH MENTAL ILLNESS IN EMFULENI LOCAL MUNICIPALITY

Kindly be informed that permission has been granted for you to carry out the above-mentioned research at Johan Heyns CHC in Sedibeng District Health. It is noted that you have already obtained Provincial Ethics Committee as well as Research Ethics Clearance from North-West University.

Kindly note that a copy of the report on the findings (especially) that concerns Sedibeng District Health Services should be submitted to the Chief Director's office at the completion of the study.

This permission is also subject to the conditions stated in the protocol and any change in design and methodology must be communicated to the Chief Director.

We wish you success in your research endeavours.

☒ Recommended / ☐ Not recommended / ☐ Recommended as amended


Prof. OB Omole
Chairperson: Sedibeng Research Committee
Date: 12/12/2022

☒ Approved / ☐ Not approved / ☐ Approved as amended


Mr. MT Magoro
Acting Chief Director: Sedibeng District Health Services
Gauteng Health Department
Date: 12/12/2022

RESEARCH PROPOSAL DETAILS: GP_202211_034

Sedibeng DHS, Cnr Frikkie Meyer & Pasteur Blvd, Private Bag X 023, Vanderbijlpark



GAUTENG PROVINCE
SOCIAL DEVELOPMENT
REPUBLIC OF SOUTH AFRICA

Enquiries: Dr. Sello Mokoena
Tel: 082 331 0786
File no.: 02/10/22

Dear N Ntseteni

RE: APPLICATION TO CONDUCT RESEARCH IN THE GAUTENG DEPARTMENT OF SOCIAL DEVELOPMENT

Thank you for your application to conduct research within the Gauteng Department of Social Development.

Your application to conduct research on **"Experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality"** as approved by North West University has been considered and approved for support by the Department as it was found to be beneficial to the Department's vision and mission. The approval is subject to the Department's terms and conditions as stated on the GDSD application form.

You have permission to interview officials and beneficiaries within facilities regulated by the department, conduct observations and access relevant documents where necessary.

May I take this opportunity to wish you well on the journey you are about to embark on.

We look forward to a value adding research and a fruitful co-operation.

With thanks


Dr. Sello Mokoena
Director: Research and Policy Coordination
Date: 31/10/2022



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Mrs I.A Mokone

 071 686 9892

 (016) 950 6015

Email: Itumeleng.Mokone@gauteng.gov.za

Ntombizodwa Ntseteni
North-West University
Student Number - 30109019

TO: Ntombizodwa Ntseteni
FROM: Mrs I.A Mokone – Facility Manager Johan Heyns CHC
DATE: 09 May 2023
SUBJECT: RESEARCH PERMISSION AT JOHAN HEYNS CHC

Permission is hereby granted to the above mentioned to conduct research on experiences and coping strategies of caregivers of people living with mental health illness

Regards



Mrs I.A Mokone
Facility Manager – Johan Heyns CHC
Date: 2023/05/09



GAUTENG PROVINCE

HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: N Ramohloki

TEL: 071 686 9903

TO: NTOMBIZODWA NTSETENI

FROM: N RAMOHLOKI

DATE: 12 MAY 2023

SUBJECT: RESEARCH PERMISSION AT LEVAI MBATHA

Permission is hereby granted to Ntombizodwa Ntseteni to do research on the experiences and coping strategies of caregivers of people with mental illness at Levai Mbatha community health Centre

Regards

N. Ramohloki

Facility manager

pp Rampha

date 12/05/2023



Vaal Mental Health

PO Box 1180
Vanderbijlpark
1900

Vanderbijlpark Office
(016) 931-2910 / 1
mentalhealth@iantic.net
10 Daudet Street
Vanderbijlpark
1911

Sebokeng Office
(016) 100 0334 or (016) 100 0337
sebokeng.vaalmentalhealth@gmail.com
Stand 57
Industria
Zone 10
Sebokeng

Services rendered in a professional and transparent way in a spirit of caring, honesty and dignity

04-05-2023

NWU

Ethics approval letter of study

Student: NA Ntseteni - 30109019

We approve that Me Ntseteni conduct her research at Vaal Mental Health.
It is an honour for us to support her in her studies.

Kind regards

Yvonne Coertze
Director



ANNEXTURE F: CODE OF CONDUCT FOR RESEARCHERS

CODE OF CONDUCT FOR RESEARCHERS

This code of conduct is applicable to all NWU researchers.

As a researcher of the North-West University (NWU), I subscribe to the rules of the NWU Institutional Research Ethics Regulatory Committee (IRERC), all applicable policies of the NWU as well as all national and international laws and regulations applicable to my field of study. Furthermore, I commit myself to abide by the ethical principles and responsibilities as set out in the Singapore statement on Research Integrity (22 September 2010), in any and all research endeavours that I undertake as a researcher of the NWU.

The four major principles of research integrity to which I will adhere and that will guide my research are:

- Honesty in all aspects of research
- Accountability in the conduct of research
- Professional courtesy and fairness in working with others
- Good stewardship of research on behalf of others

Consequently I will also adhere to the following ethical responsibilities:

1. I will take responsibility for the originality and trustworthiness of my research.
2. I will stay abreast of and adhere to all institutional, national, and international laws, regulations, and policies applicable and related to my research.
3. I will at all times employ appropriate research methods, base my conclusions on critical analysis of the evidence and report my findings and interpretations fully and objectively.
4. I will keep clear and accurate records of all research that I have conducted in a manner that will allow verification and replication of my work by others, if applicable.
5. I will, where applicable, share my data and findings openly and promptly, in line with external funding rules. This will be done as soon as possible after I have had an opportunity to establish priority and ownership claims.
6. I will take responsibility for my own contributions to publications, funding applications, reports and other representations of my research. I will also and only include authors who meet valid authorship criteria.
7. I will acknowledge the names and roles of those who made significant contributions to my research in publications, including writers, funders, sponsors, and others, but do not meet authorship criteria.
8. In my peer reviews, I will provide fair, prompt and rigorous evaluations and I will respect confidentiality when I review others' work.
9. I will disclose all conflicts of interest (financial and other) that could compromise the trustworthiness of my work in research proposals, publications, public communications, and in review activities.
10. When I publically address a community in the spirit of academic freedom, I will in all stages base my professional comments on research findings (if applicable) and my expertise. I will distinguish between professional comments and opinions based on personal views.
11. Should any irresponsible research practices and/or research misconduct become known to me or brought under my attention, I will report such irresponsible research activities to the appropriate authorities.
12. I will respond to irresponsible research practices or conduct, by taking prompt actions as set out in the procedures of the university. I will also protect those who report misconduct in good faith, to the best of my abilities.
13. I will endeavour to create and sustain an environment that encourage research integrity through education of students, research teams and peers, as well as abide by policies, and reasonable standards for advancement.
14. I will at all times weigh societal benefits against the risks inherent in my work.

Name: Ntombizodwa Ntseteni
Date: 2022/09/05

Signature:



CODE OF CONDUCT FOR RESEARCHERS

This code of conduct is applicable to all NWU researchers.

As a researcher of the North-West University (NWU), I subscribe to the rules of the NWU Institutional Research Ethics Regulatory Committee (IRERC), all applicable policies of the NWU as well as all national and international laws and regulations applicable to my field of study. Furthermore, I commit myself to abide by the ethical principles and responsibilities as set out in the Singapore statement on Research Integrity (22 September 2010), in any and all research endeavours that I undertake as a researcher of the NWU.

The four major principles of research integrity to which I will adhere and that will guide my research are:

- Honesty in all aspects of research
- Accountability in the conduct of research
- Professional courtesy and fairness in working with others
- Good stewardship of research on behalf of others

Consequently I will also adhere to the following ethical responsibilities:

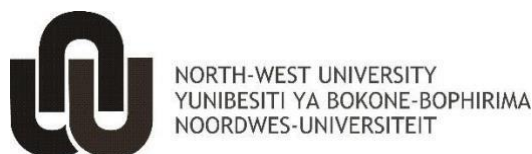
1. I will take responsibility for the originality and trustworthiness of my research.
2. I will stay abreast of and adhere to all institutional, national, and international laws, regulations, and policies applicable and related to my research.
3. I will at all times employ appropriate research methods, base my conclusions on critical analysis of the evidence and report my findings and interpretations fully and objectively.
4. I will keep clear and accurate records of all research that I have conducted in a manner that will allow verification and replication of my work by others, if applicable.
5. I will, where applicable, share my data and findings openly and promptly, in line with external funding rules. This will be done as soon as possible after I have had an opportunity to establish priority and ownership claims.
6. I will take responsibility for my own contributions to publications, funding applications, reports and other representations of my research. I will also and only include authors who meet valid authorship criteria.
7. I will acknowledge the names and roles of those who made significant contributions to my research in publications, including writers, funders, sponsors, and others, but do not meet authorship criteria.
8. In my peer reviews, I will provide fair, prompt and rigorous evaluations and I will respect confidentiality when I review others' work.
9. I will disclose all conflicts of interest (financial and other) that could compromise the trustworthiness of my work in research proposals, publications, public communications, and in review activities.
10. When I publically address a community in the spirit of academic freedom, I will in all stages base my professional comments on research findings (if applicable) and my expertise. I will distinguish between professional comments and opinions based on personal views.
11. Should any irresponsible research practices and/or research misconduct become known to me or brought under my attention, I will report such irresponsible research activities to the appropriate authorities.
12. I will respond to irresponsible research practices or conduct, by taking prompt actions as set out in the procedures of the university. I will also protect those who report misconduct in good faith, to the best of my abilities.
13. I will endeavour to create and sustain an environment that encourage research integrity through education of students, research teams and peers, as well as abide by policies, and reasonable standards for advancement.
14. I will at all times weigh societal benefits against the risks inherent in my work.

Name: Prof Ngenisiwe Ntombela

Signature: _____

Date: 2022/09/05

ANNEXTURE G: CONFIDENTIALITY UNDERTAKING



CONFIDENTIALITY UNDERTAKING entered into between:

I, the undersigned

Prof/ Dr / Mr / Ms Ntombizodwa Ntseteni

Identity Number 0004080537089

Address House No: 6042 Lakeside Ext 2

hereby undertake in favor of the **NORTH-WEST UNIVERSITY**, a public higher education institution established in terms of the Higher Education Act No. 101 of 1997

Address: Office of the Institutional Registrar, Building C1, 53 Borchard Street, Potchefstroom, 2520
(hereinafter the “NWU”)

Interpretation and definitions

1.1. In this undertaking, unless inconsistent with, or otherwise indicated by the context:

1.1.1. “Confidential Information” shall include all information that is confidential in its nature or marked as confidential and shall include any existing and new information obtained by me after the Commencement Date, including but not be limited in its interpretation to, research data, information concerning research participants, all secret knowledge, technical information and specifications, manufacturing techniques, designs, diagrams, instruction manuals, blueprints, electronic artwork, samples, devices, demonstrations, formulae, know-how, intellectual property, information concerning materials, marketing and business information generally, financial information that may include remuneration detail, pay slips, information relating to human capital and employment contract, employment conditions, ledgers, income and expenditures and other materials of whatever description in which the NWU has an interest in being kept confidential; and

1.1.2. Commencement Date” means the date of signature of this undertaking by myself.

1.2. The headings of clauses are intended for convenience only and shall not affect the interpretation of this undertaking.

Preamble

2.1. In performing certain duties requested by the NWU, I will have access to certain Confidential Information provided by the NWU in order to perform the said duties and I agree that it must be kept confidential.

2.2. The NWU has agreed to disclose certain of this Confidential Information and other information to me subject to me agreeing to the terms of confidentiality set out herein.

Title to the Confidential Information

I hereby acknowledge that all right, title and interest in and to the Confidential Information vests in the NWU and that I will have no claim of any nature in and to the Confidential Information.

Period of confidentiality

The provisions of this undertaking shall begin on the Commencement Date and remain in force indefinitely.

Non-disclosure and undertakings

I undertake:

5.1. to maintain the confidentiality of any Confidential Information to which I shall be allowed access by the NWU, whether before or after the Commencement Date of this undertaking. I will not divulge or permit to be divulged to any person any aspect of such Confidential Information otherwise than may be allowed in terms of this undertaking;

5.2. to take all such steps as may be necessary to prevent the Confidential Information falling into the hands of an unauthorised third party;

5.3. not to make use of any of the Confidential Information in the development, manufacture, marketing and/or sale of any goods;

5.4. not to use any research data for publication purposes;

5.5. not to use or disclose or attempt to use or disclose the Confidential Information for any purpose other than performing research purposes only and includes questionnaires, interviews with participants, data gathering, data analysis and personal information of participants/research subjects;

5.6. not to use or attempt to use the Confidential Information in any manner which will cause or be likely to cause injury or loss to a research participant or the NWU; and

5.7. that all documentation furnished to me by the NWU pursuant to this undertaking will remain the property of the NWU and upon the request of the NWU will be returned to the NWU. I shall not make copies of any such documentation without the prior written consent of the NWU.

Exception

The above undertakings by myself shall not apply to Confidential Information which I am compelled to disclose in terms of a court order.

Jurisdiction

This undertaking shall be governed by South African law be subject to the jurisdiction of South African courts in respect of any dispute flowing from this undertaking.

Whole agreement

8.1. This document constitutes the whole of this undertaking to the exclusion of all else.

8.2. No amendment, alteration, addition, variation or consensual cancellation of this undertaking will be valid unless in writing and signed by me and the NWU.

Signed at Lakeside on this date 05 September 2022

Witnesses:

1. Elme Coetzee

(Signatures of witnesses):

A handwritten signature in cursive script, appearing to read 'Coetzee', is written in black ink on a light-colored background.

ANNEXTURE H: ETHICS APPROVAL LETTER TO CONDUCT THE STUDY



Private Bag X1290, Potchefstroom
South Africa 2520

Tel: 086 016 9698
Web: <http://www.nwu.ac.za/>

North-West University Health Research Ethics
Committee (NWU-HREC)

Tel: 018 299-1206
Email: Ethics-HREC@nwu.ac.za (for human
studies)

1 May 2023

ETHICS APPROVAL LETTER OF STUDY

Based on approval by the North-West University Health Research Ethics Committee (NWU-HREC) on 01/05/2023, the NWU-HREC hereby approves your study as indicated below. This implies that the NWU-HREC grants its permission that, provided the general and specific conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

Study title: Experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality																												
Principal Investigator/Study Supervisor/Researcher: Prof NH Ntombela																												
Student: NA Ntseteni - 30109019																												
Ethics number:	<table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>0</td><td>0</td><td>1</td><td>8</td><td>1</td><td>-</td><td>2</td><td>2</td><td>-</td><td>A</td><td>1</td></tr><tr><td colspan="3">Institution</td><td colspan="3">Study Number</td><td colspan="3">Year</td><td colspan="3">Status</td></tr></table>	N	W	U	-	0	0	1	8	1	-	2	2	-	A	1	Institution			Study Number			Year			Status		
N	W	U	-	0	0	1	8	1	-	2	2	-	A	1														
Institution			Study Number			Year			Status																			
Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation																												
Application Type: Single study	Risk: <table border="1"><tr><td>Medium</td></tr></table>	Medium																										
Medium																												
Commencement date: 01/05/2023																												
Expiry date: 30/05/2024																												
Approval of the study is provided for a year, after which continuation of the study is dependent on receipt and review of a six-monthly monitoring report and the concomitant issuing of a letter of continuation. Monitoring reports are due at the end of November and May annually until completion of the study.																												

General conditions:
While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, the following general terms and conditions will apply: • The principal investigator/study supervisor/researcher must report in the prescribed format to the NWU-HREC: - six-monthly on the monitoring of the study, whereby a letter of continuation will be provided annually, and upon completion of the study; and - without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study. • The approval applies strictly to the proposal as stipulated in the application form. Should any amendments to the proposal be deemed necessary during the course of the study, the principal investigator/study supervisor/researcher must apply for approval of these amendments at the NWU-HREC, prior to implementation. Should there be any deviations from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited. • Annually a number of studies may be randomly selected for active monitoring. • The date of approval indicates the first date that the study may be started. • In the interest of ethical responsibility, the NWU-HREC reserves the right to:



Prof NH Ntombela
Social work
COMPRES

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Health Sciences Ethics Office for Research,
Training and Support

North-West University Health Research Ethics
Committee (NWU-HREC)

Tel: 018-299 2092
Email: wayne.towers@nwu.ac.za

30 May 2023

Dear Prof Ntombela

APPROVAL OF DOCUMENTS SUBMITTED DURING THE PROGRESS OF THE STUDY

Ethics number: NWU-00181-22-A1

Kindly use the ethics reference number provided above in all future correspondence or documents submitted to the administrative assistant of the North-West University Health Research Ethics Committee (NWU-HREC).

Study title: Experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality

Study leader: Prof NH Ntombela

Student: NA Ntseteni – 30109019

Application type: Single study

Risk level: Medium

You are kindly informed that the documentation related to the in-process requirement (as indicated below), as was submitted to the NWU-HREC, was reviewed by the designated reviewers:

- a. Copies of the goodwill permission letters from the managers or Chief Executive Officers (CEOs) of the Vaal Mental Health organisation, as well as the Johan Heyns and Levai Mbatha Community Health Centres, granting access to these facilities.

The reviewers have indicated that the submitted documents are acceptable and that you as the researcher can proceed with implementing the aforementioned documentation in your approved project. Please note that there is no further documentation outstanding.

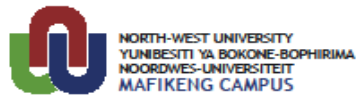
We wish you the best as you conduct your research. If you have any questions or need further assistance, please contact the Faculty of Health Sciences Ethics Office for Research, Training and Support at Ethics-HRECAppl@nwu.ac.za.

Yours sincerely

Head of Health Sciences Ethics Office for Research, Training and Support

Current details: (23239522) G:\My Drive\6. Research and Postgraduate Education\9.1.5.3 Letters Templates\9.1.5.4.1 In-Progress_Approval_Jetter_HREC.docm
30 April 2018
File reference: 9.1.5.4.1

ANNEXTURE I: CERTIFICATE OF LANGUAGE EDITING



ALDE UNIT BASE BUILDING G83 (Department of Academic Literacy)
RS NGUBANE (28383095) ext 892109, Cell 0828178046

24 October 2023

CERTIFICATE OF EDITING A DISSERTATION

To whom it may concern

This confirms that I have proofread and edited the dissertation by **NA Ntseteni, orcid.org 0000-0002-3849-251X**, titled **'Experiences and coping strategies of caregivers of people living with mental illness in Emfuleni Local Municipality.'**

The candidate corrected the language errors identified. The document is now of an acceptable linguistic standard.

I thank you

A handwritten signature in black ink, appearing to read 'RS Ngubane'.

.....
RS NGUBANE (Ms)