# CHALLENGES FACED BY FAMILY CAREGIVERS OF MENTAL HEALTH CARE USERS IN THULAMELA MUNICIPALITY, LIMPOPO PROVINCE

**by**

**Raluthaga Mutshotshomi Nelson**

**Student number: 17023734**

**Dissertation submitted in fulfilment of requirements for the degree**

**Master of Nursing**

**in the**

**Department of Advanced Nursing Science**

**School of Health Sciences**

**at the**

**University of Venda**

**Supervisor**: Prof N.H. Shilubane

**Co-supervisor:** DR S.A. Mulondo

**FEBRUARY 2021**

# DECLARATION

I, Raluthaga Mutshotshomi Nelson, hereby declare that the dissertation, ***Challenges faced by family caregivers of Mental Health Care Users in Thulamela Municipality, Limpopo Province*** submitted by me, has not been submitted previously for a degree at this or any other university, that it is my own work in design and execution, and that all reference material contained therein has been duly acknowledged.

28/02/2021

……………………… ……………………..

M N Raluthaga Date

# DEDICATION

This dissertation is dedicated to my loving wife, Tubake, sons, Pfunzo, Uhone and all family caregivers of mental health care users in Thulamela Municipality.

# ACKNOWLEDGEMENT

To God, Jireh, my provider, thank you very much for giving me the strength to succeed. To God be the glory.

My supervisor, Professor N.H. Shilubane. I do not have sufficient words to thank you. Thank you very much for your patience, guidance and dedication throughout the study. You motivated me to work hard regardless of the challenges I encountered. Indeed hard work does not kill.

Dr S.A. Mulondo, my co-supervisor, your inputs and feedback are much appreciated, thank you very much.

Tubake, my loving wife and pillar of strength, thank you ngwana le kgowa for understanding when I stole your time to focus on my study.

Mihloti Mabasa, thank you very much for encouraging me to pursue my studies. You saw the unpolished diamond in me.

Dr R.F. Mathevula, thank you very much for believing and guiding me on the study.

Mrs T.E. Mbedzi, you were there to listen, guide and encourage me when the going got tough. Thank you for being my home librarian.

Ms S. Hlabangwane, the librarian, thank you very much for your assistance with the literature search.

Marion Pfeiffer, the language editor, thank you very much for giving my dissertation a professional touch, and

Special thank you to all family caregivers who participated in the study; you made this study a reality.

# LIST OF ACRONYMS AND ABBREVIATIONS

| | |
|---|---|
| AIDS | Acquired Immunodeficiency Syndrome |
| CHW | Community Health Workers |
| DEM | District Executive Manager |
| HIV | Human Immunodeficiency Virus |
| MHCU | Mental Health Care User |
| NGO | Non-Governmental Organisation |
| OPD | Out-Patients Department |
| PHC | Primary Health Care |
| SA | South Africa |
| SASSA | South African Social Security Agency |
| UK | United Kingdom |
| USA | United States of America |

# ABSTRACT

**Background:** The government of South Africa changed from a hospital-based to a community-based mental health care system for mental health care users. The intention was to allow the mental health care users to be cared for in a home setting, in familiar surroundings with family support. Consequently, family members became mental health care user's caregivers. However, despite the government's effort, some family caregivers still report being unable to care for their mental health care users. The study aimed to investigate the challenges faced by family caregivers of mental health care users.

**Methods:** The study was conducted using qualitative, exploratory, descriptive and contextual research design. The population was family caregivers of mental health care users. Non-probability, purposive sampling was used to select a sample of ten participants. Data collection was done through semi-structured interviews, each lasting 30-45 minutes. The study sought to explore the challenges family caregivers faced when caring for mental health care users and the support they received from health care professionals to assist them in caring for these individuals. Probing was done as interviews progressed, guided by the responses of the participants. Data were analysed using Tech's open-coding method. Measures to ensure trustworthiness were applied and ethical considerations were adhered to.

**Results:** The study showed that family caregivers experience challenges regarding mental health care users' adherence to medication, disruptive behaviour, interpersonal relationships and lack of support from health care professionals.

**Recommendations:** The study recommended that health care professional give family caregivers professional support to enable them to care for their mental health care users. Health care professionals should educate these patients and their family caregivers about mental illness and the importance of adhering to treatment. Furthermore, family caregivers should be encouraged to seek help from health care professionals as soon as possible when they feel emotionally drained before becoming depressed.

**Key words**: Challenges, family caregivers, mental health care users, mental illness.

# TABLE OF CONTENTS

## LIST OF FIGURES AND TABLES

# CHAPTER 1

## 1.1 Introduction

The introduction focuses on the background, problem statement, significance, purpose and objectives of the study.

## 1.2 Background

Mental illness may affect any person at any stage of one's life span. It is one of the chronic diseases that hamper a person's economic productivity (Janse Van Rensburg & Fourie, 2016:4). According to Grant et al. (2016:133), two-thirds of American mentally ill adults are parents. Therefore, this places the responsibility of caring for them on their children's shoulders and other family members who become caregivers. Some of those caregivers are young adults establishing themselves and their own families socially and economically.

Due to the mental health reforms in developed countries such as America and developing countries, mental health care services have moved from hospital-based to community-based care (Balthazar et al., 2020:957). This means that family members, particularly spouses, siblings and children, are expected to care for their mental health care users (MHCUs), creating challenges for them as they are not trained in their new role. A study conducted in Croatia demonstrated that younger family caregivers experienced burnout, financial problems and poor social support. The low social and economic status of these households further increased their vulnerability to the high burden of care (Franza, 2019:439). Furthermore, in Italy, family caregivers experienced anxiety and depression (Dice & Zoena, 2017:1782). Littlewood and Dein (2016:60) state that family caregivers in London reported being assaulted by the MHCUs for whom they cared.

Most MHCUs depend on their family members for daily living activities like bathing, eating and taking medications due to their mental illness and caring for them frequently adversely affects the family's functioning, as it consumes most of their time. Some family caregivers develop feelings such as anger, shame, guilt and despair (Ata & Dogan, 2018:114). Chinese family caregivers experienced burnout symptoms, high burden of care and low quality of life (Balthazar et al., 2020:957). Batra et al. (2018: 59) found that in India, family caregivers faced the disruption of their lives and emotional hardship as they assumed the lifelong care of MHCUs. In Indonesia, family caregivers experienced associative stigma, whereby the stigma of mental illness was attached to the family caregivers because they are related to MHCUs. Consequently, they were socially isolated and discriminated against due to their relative's mental illness (Reong & Astuti, 2019: 86).

The challenges faced by family caregivers in Tanzania include the lack of psychotropic medications, mental health care providers and infrastructure (Iseselo & Ambikile, 2017:6). As a result of the absence of those essential services and supplies, there is a high relapse rate as family caregivers had to buy medications with their own money. Furthermore, family caregivers living a long distance from health care facilities had to travel to get mental health services for their MHCUs, incurring financial losses due to the taxi fares for MHCUs and themselves (Iseselo, Kajula & Yahya-Malima, 2016:5). In Nigeria, some family caregivers were stressed by caring for their MHCUs. A high burden of care was associated with a large family size and the severity of the MHCU’s symptoms (Olagundoye, Akhuemokhan & Alugo, 2017: 153). Thus, family caregivers of psychotic individuals experience a higher burden of care than those taking care of non-psychotic MHCUs.

Also, financial and human resources meant for mental health services have to compete with the needs of physical ailments like the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) in Swaziland and malaria in Mozambique (Janse van Rensburg & Fourie, 2016:6). Few resources are reserved for mental health services and family caregivers have to seek alternative ways to care for their MHCUs. Hender et al. (2016:22) assert that in Zimbabwe, there is no political will to prioritise mental health services due to the stigma attached to it. Therefore, family caregivers have little support from the state institutions to help them care for their MHCUs.

Den Hertog and Gilmoor (2016:539) state that South Africa (SA) has an under-resourced and overburdened Primary Health Care (PHC) system. Lack of services like psychological and rehabilitation services at the community level compounds the challenges of family caregivers as there is little support from PHC services besides supplying medications. In the Northern Cape, some caregivers experience resistance from their MHCUs, who refuse health care, personal and general hygiene. In addition to verbal and physically aggressive behaviour, some refused to change their lifestyles, such as using substances like alcohol and cannabis (den Hertog & Gilmoor, 2016:543). In Limpopo, the aggressive behaviour of MHCUs aggravates the emotional burden placed on the family members (Leech & Dolamo, 2016:726). No known studies have been done in the Vhembe District and Thulamela Municipalities about the challenges faced by family caregivers. Despite the availability of health care institutions in the Thulamela Municipality, family caregivers seem to face challenges in caring for their MHCUs. This study seeks to explore these challenges faced by these family caregivers.

## 1.3 Problem statement

The researcher is a professional nurse working in a mental health care unit. He has observed family caregivers bringing in their MHCUs for admission. Ninety per cent of MHCUs admitted at Tshilidzini Regional Hospital are patients on treatment for years. From February 2018 to July 2018, about 45 per cent of the re-admitted MHCUs were again admitted within two months of being discharged. The researcher also observed that family caregivers do not regularly visit their MHCUs in hospital, and even on discharge, family caregivers appear reluctant to fetch them. Consequently, MHCUs stay for days in the ward after being discharged, while family caregivers live a walking distance from the hospital.

Despite recognising the importance of community-based care in settings with limited resources, few studies have focused on the challenges faced by family caregivers of MHCUs in a rural setting. The statistics of Tshilidzini Hospital from June 2017 to

September 2018 showed that 122 MHCUs were admitted to the psychiatric ward. Twenty-six family caregivers requested institutionalisation of the MHCUs admitted.

### 1.4 Rationale of the study

There are international studies concerning the challenges faced by family caregivers of MHCUs. However, most are undertaken in urban areas, unlike the current study that focuses on rural areas in the Thulamela Municipality. Thulamela Municipality is situated in the Vhembe District in the Limpopo Province, where there has been no research on this subject. Studies focusing on challenges faced by family caregivers of MHCUs in rural settings are limited in the available literature. Therefore, the current study is pivotal as it will capture the challenges these family caregivers face in rural settings.

### 1.5 Significance of the study

The challenges faced by family caregivers of MHCUs identified in the study may be used by health policymakers to develop guidelines that support MHCUs and their family members. The information may also assist in designing programmes to support caregivers in caring for them at home. Also, they may benefit when their relapse rates are reduced because their caregivers receive professional support in caring for them, adding to the number of MHCUs who may be cared for in their home setting, in familiar surroundings. Family caregivers may be able to focus on their lives and economic activities for their families without worrying about relapses of their MHCUs. In addition, communities may benefit because the MHCUs may be mentally stable, pose no risk to their safety and become community members who can contribute to the development of the community. The Department of Health may benefit from reduced overcrowding in hospitals as the relapse rates should decrease, reducing overcrowding in the hospitals. The Department of Social Services may benefit, as some MHCUs can create or seek employment and cease to be financially dependent on the disability grant offered by the South African Social Security Agency (SASSA).

## 1.6 Purpose of the study

- The purpose of the current study is to investigate the challenges faced by family caregivers of MHCUs.

## 1.7 Objectives of the study

The objectives of the current study are:

- To explore the challenges faced by the family caregivers of MHCUs.
- To identify the support given to family caregivers by health care professionals to assist them in caring for their MHCUs.

## 1.8 Definition of terms

Challenges: This refers to situations requiring great mental or physical effort to be successfully (McIntosh, 2017:239). In this study, challenges refer to difficulties or problems faced in caring for MHCUs.

Family Caregiver: Refers to that person who takes care of another individual who cannot look after herself or himself in some or all aspects of daily living in the family environment (McIntosh, 2017:65). In this study, caregiver means a family member over the age of 21 years caring for an MHCU for at least six months.

Mental Illness: According to Townsend (2015:16), mental illness refers to maladaptive responses to internal or external environment manifested by thoughts, feelings and behaviours that are inconsistent with the local cultural norms and values. In this study, mental illness refers to all diagnosed mental disorders that affect the persons socially occupationally and/or physically.

Mental Health Care User: Refers to a person who receives care, treatment and rehabilitation to enhance their mental status (Mental Health Care act 17 of 2002). In this study, MHCU refers to a person living with mental illness and receiving treatment for that condition.

## 1.9 Research methodology

Research methodology involves selecting the research method and design used by the researcher in the study. It includes the population, sampling, same size, data collection and data analysis. Chapter 3 explains more details about research methodology .

## 1.10 Research design

The overall plan of how the study has been conducted is referred to as the research design. It is the architectural backbone of the study (Polit & Beck, 2017:56). A qualitative approach was used for this study. The approach was exploratory, descriptive and contextual in nature. The description of the challenges faced by family caregivers assisted the researcher in obtaining an accurate representation of the difficulties and the support received from health care professionals to assist them in caring for their family members who have a mental illness. In the current study, the researcher explored the challenges family caregivers face and support received from health care professionals. The study's context was in a natural setting; that is, the homes of the participants, as this is the environment where family caregivers living with MHCU face most challenges. The research design is explained in detail in Chapter 3.

## 1.11 Research setting

According to Burns, Grove and Gray (2015:38), a research setting refers to where a study is conducted. The study was conducted at the Thulamela Municipality in the Vhembe District of Limpopo Province, SA. Thulamela Municipality has a population of 618 462. Eighty-five per cent of the population lives in tribal areas. There are three hospitals, Hayani Specialized Psychiatric, Tshilidzini Regional and Donald Fraser District hospitals. In addition, Thulamela has 52 fixed and 14 mobile clinics. Thirty-five per cent of people employed in Thulamela Municipality are employed in the retail industry. Almost 9,934 people, including MHCUs, receive disability grants (Statistics SA, 2016). Chapter 3 describes the research setting of this study in detail.

### 1.12 Population and sampling

The population for this study was composed of family caregivers above the age of 21 who have been caring for MHCUs for at least six months in the Thulamela Municipality. According to De Vos et al. (2011: 223), sampling is a process of taking a portion of a population as representative of the total population. In the current study, the selection of participants was done using the non-probability purposive sampling method. Chapter 3 describes the population and sampling used for this study.

### 1.13 Inclusion criteria

Inclusion criteria refer to those characteristics that are necessary for people to be included in the sampling process (Polit & Beck, 2017:250).

The inclusion criteria for this study were:

- Family caregivers above the age of 21 years who have been caring for MHCU for more than six months.
- Both male and female family caregivers under the age of 65 years were included.
- Participants who agreed to be part of the study.

### 1.14 Data collection tool

The interview guide was used to collect data in the current study. The interview guide supports researchers in considering the aim of the interview and the possible difficulties they may encounter in terms of the wording of questions and sequence. It also helps to generate questions with appropriate content and structure and the themes to be covered (De Vos et al., 2011:352). The measurement instrument used in this study will be explained in detail in Chapter 3.

### 1.15 Pre-test study

In the current study, the pre-test intended to evaluate whether the interview guide questions were clear for the participants to modify vague and ambiguous questions. The other reason for the pre-test was to assess if the time allocated for the interview was sufficient (De Vos et al., 2011:394).

### 1.16 Trustworthiness

Trustworthiness is a method of establishing validity and reliability in qualitative research and achieved when it accurately represents the participant's experience (Polit & Beck, 2017:557). It encompasses four criteria: credibility, dependability, confirmability and transferability, which were ensured in this study and described in Chapter 3.

### 1.17 Data collection

The researcher used semi-structured interviews to collect the data. De Vos et al. (2011:352) define semi-structured interviews as a method of collecting data from the participants through direct interchange with individuals who possess the knowledge sought by the researcher. The interview guide had two questions. The first question was: 'What challenges do you face when caring for your MHCU?' The second question was: 'What kind of support do you receive from health care professionals to help you care for your MHCU?'

### 1.18 Data analysis

Data analysis refers to the process of reducing the volume of raw information into data, removing trivia and constructing a framework for communicating what the data reveals when analysed (De Vos et al., 2011:397). In the current study, data analysis was done immediately after data collection, whereby data was transcribed verbatim and translated into English. Tesch’s open coding method was used. The data analysis process is described in detail in Chapter 3.

### 1.19 Ethical considerations

Ethical consideration refers to the proper care required when doing research. The researcher must respect the rights of individuals and communities taking part in a study. All human beings' rights need to be respected at all times, and any research should avoid doing or exposing harm to their participants (Brink, Van der Walt & Van Rensburg, 2012:32). In the current study, the ethical principles were adhered to, and Chapter 3 discusses these principles.

### 1.20 Limitations of the study

The study was limited to family caregivers caring for MHCUs interested in participating in the study. The sample was purposively selected based on the researcher's judgment, and its findings cannot be attributed to the whole population.

### 1.21 Dissemination and implementation of results

Communicating the research findings is the final step of the research process. The findings are communicated through presentations, publications to audiences of nurses, health care professionals, policymakers and health care consumers (Grove, Burns & Gray, 2013:615). A copy of the published dissertation will be submitted to the Provincial Department of Health in Limpopo. The dissertation will be summarised into an article and sent to peer-reviewed journals for possible publication. Also, the researcher will present the findings at relevant conferences.

### 1.22 Chapter outline

| | |
|---|---|
| Chapter 1: | Overview of the study. |
| Chapter 2: | Literature review. |
| Chapter 3: | Research methodology. |
| Chapter 4: | Data analysis, discussion and literature control. |
| Chapter 5: | Summary, limitations, recommendations and conclusion. |

### 1.23 Summary

Chapter 1 described the orientation of the study and explained the purpose and the objectives of the study and defined the relevant concepts. It introduced the research methodology applied in the study. Trustworthiness and ethical considerations for the study were discussed, and it provided an outline of the chapters of the study. In the next section, Chapter 2 describes the available literature related to the challenges faced by family caregivers in caring for MHCUs.

# CHAPTER 2

# LITERATURE REVIEW

## 2.1 Introduction

A literature review is an organised written presentation of what is already known about the selected topic of study. It familiarises the researcher with the existing base of knowledge (Brink et al., 2012:70). In addition, Polit and Beck (2017:88) add that a literature review helps the researcher identify gaps or inconsistencies in the body of research. In order to achieve this the researcher searched a variety of research websites on empirical and grey research literature including Sabinet, Ebsco host, Science Direct, Web of Science and Google scholar. With regard to accessing of the articles the researcher used list of key words relevant to the study topic. Articles that focused on challenges faced by family caregivers in the home setting and not older than five years were included.

## 2.2 Associative stigma

Family caregivers of MHCUs face various challenges, including stigma, which refers to a strong feeling of disapproval felt by many people in society towards something or someone (McIntosh, 2017:1538). Van der Sanden et al. (2017:1235) add that stigma is a negative blemish on the identity and reputation of a person. Associative stigma refers to internalised stigma among family members of stigmatised individuals, including labelling, stereotyping, separation, status loss and discrimination (Zhang et al., 2018:56). Family caregivers felt they were avoided and socially excluded by their community members because they are related to an MHCU. In a study in Indonesia, Holis, Yusuf and Suhardiningsih (2019:2425) found that social stigma affects MHCUs and their family caregivers, causing psychological stress such as depression, frustration and anxiety for the family.

In a study in India, family caregivers reported being socially excluded because of their association with an MHCU leading to negative consequences for the family caregivers in the form of unhappiness and helplessness (Mehra et al., 2020:13). Australian family caregivers had the same experience being discriminated against, avoided and shunned by fellow community members (O'Reilly et al., 2019:561)

Similar to the findings in European and Asian countries, family caregivers in Sub-Saharan Africa had the same experiences. Spittel, Mair and Kraus (2019:111) reported that family caregivers of MHCUs were discriminated against even by educated people in health issues. In Nigeria, family caregivers experienced the associative stigma of mental illness because of caring for, assisting and supporting their MHCUs and were socially isolated in their communities (Olagundoye et al., 2017:149). Furthermore, parents and spouses of these patients experienced more noticeable associative stigma. In Egypt, the parents of MHCUs suffered more from stigma than other relatives as they blamed themselves for the child's mental illness. The MHCU's behaviour worsened this. Family caregivers of MHCUs displaying psychotic features such as aggressive and disinhibited behaviours in public were linked to feeling of shame (Ebrahim et al., 2020:6)

According to Gyamfi, Hegadoren and Park (2018:369), family caregivers in Ghana were also discriminated against simply because they are relatives of MHCUs. A South African study by Nxumalo and Mchunu (2017) reported that community members passed nasty remarks to family caregivers and mocked and ridiculed them. They were isolated from community events and blamed for the actions of their MHCU (Nxumalo & Mchunu, 2017:206). Also, family caregivers felt socially isolated as their social roles and standing in their communities were affected (Ntsayagae, Poggenpoel & Myburgh, 2019:4).

### 2.3 Low quality of life

Quality of life is the overall wellbeing of individuals, including both negative and positive structures of life (Bukhari et al., 2020:567). In a study in Pakistan, family caregivers had low quality of life as they experienced non-satisfactory personal relationship and poor social support from the surrounding communities (Bukhari et al., 2020:567). Chinese family caregivers experienced a low quality of life as they suffered from burn out because of caring for MHCUs. Moreover, family caregivers experienced distress from the financial burden and disruption of family interactions (Balthazar et al., 2020:961). In Indonesia, family caregivers of MHCUs also reported a reduced quality of life as they experienced labelling by community members, which affected their functionality as a family within the community (Fitryasari et al., 2018:258).

Like their Asian counterparts in Indonesian, family caregivers in Malaysia reported that caring for their MHCUs led to an added financial burden and change in social lifestyle (Ivan Vun, Cheah & Helmy, 2019:20). Therefore, the quality of their lives was negatively impacted. In Chile, family caregivers experienced a reduced quality of life, which manifested as physical illness, loss of vitality and depressive disorders (Caqueo-Urizar et al., 2017:3).

Similarly, family caregivers in Ghana reported a lower quality of life due to the financial cost of caregiving (Opoku-Boateng et al., 2017:46). Family caregivers incurred substantial medical and non-medical costs in caring for family members suffering from mental health problems. Ndikuno et al. (2017:2) add that in Uganda, family caregivers experienced reduced productivity at home and in the workplace, resulting in a loss of wages. This created or worsened poverty. Family caregivers in Dar es Salaam, Tanzania, also stated that caring for the MHCUs resulted in the disruption of family functioning and household routine and lack of family harmony (Iseselo et al., 2016:6).

Like studies in Ghana, Uganda and Tanzania, South African family caregivers experienced a reduced quality of life. Lekoadi et al. (2019:6) reported that family caregivers found that caring for MHCUs was exhausting, strenuous and disrupted their routine, leading to strained family relations. In Limpopo, family members who were still attending school reported that they felt the added responsibility of caring for their MHCUs, which negative affected their school performance (Molepo & Mfidi, 2020:4).

### 2.4 Non-adherence to medication

Non-adherence to medication refers to the extent to which a person takes medications according to the recommendations of the health care provider (Chakrabarti, 2016:402).

Non-adherence to medication by MHCUs is a global challenge faced by family caregivers. In the United States of America (USA), Velligan et al. (2017:461) found that MHCUs did not adhere to their medication regime due to poor insight, negative attitudes and side-effects of medication. In addition, family caregivers in Thailand reported that MHCUs were relapsing because they could not follow their medication regimen due to their mental illness (Punsawat, Inchaithep & Lorga, 2017:482).

In the United Kingdom (UK), cannabis use increased the risk of non-adherence to antipsychotic medication because cannabis is the most used illicit drug among MHCUs (Foglia et al., 2017: 1696). In a study in Spain and the USA, De Las Cuevas et al. (2017:682) stated that non-adherence to medication remains a serious challenge in clinical psychiatric practice as it increases relapse and hospitalization rates for MHCUs. Some patients became violent and suicidal. Furthermore, Asalem (2017:9) indicated that in Saudi Arabia, MHCUs did not adhere to medication due to the increased number of medications, side-effects and forgetfulness. However, in Germany, symptom severity, good insight, positive attitude and strong social support by family caregivers showed that better adherence could be achieved (Stentzal et al., 2018:7).

In Ethiopia, MHCUs on antipsychotic medication for five years and longer and those using substances like cannabis and alcohol did not take their medication. Furthermore, those on several antipsychotic medications were not adherent compared to those on a single drug (Tareke et al., 2018:4). In Tanzania, side-effects and inadequate knowledge about the management of these side-effects led to non-adherence (Iseselo & Ambikile, 2017:2). Adeosun (2017:5) reported that in Nigeria, a country with widespread beliefs in spiritual and faith healers, MHCUs defaulted from treatment as they sought alternative healing. Therefore, family caregivers had to be taught about the importance of adherence to medication to reduce relapses. Similarly, in Ghana, pastors believed that mental illness has supernatural origins; therefore, they felt that doctors and prescribed medication were not suitable for treating mental illness (Kpobi & Swartz, 2018:6). Consequently, those MHCUs who went to church seeking healing had to stop taking medication.

According to Sibeko et al. (2017:1), adherence to medication is a major problem in SA. This is associated with poor clinical outcomes and an increased burden of care on family caregivers. Furthermore, Du Plessis (2019:40) adds that family caregivers experienced uncontrolled and disruptive behaviour by MHCUs who were not adhering to medication, with some MHCUs being aggressive towards family members.

## 2.5 Lack of professional support

Family caregivers expect and require professional support from health care professionals to assist them in caring for their MHCUs as they are not trained to provide care. However, in a study in Australia and New Zealand, family caregivers felt that clinicians overlooked them in making decisions regarding the care of MHCUs (Kokanovic et al., 2018:829). One of the roles of health care professionals is to prepare and support family caregivers caring for MHCUs. In a study in Saudi Arabia, the burden of care was higher on family caregivers as they did not receive support (Alzahrain et al., 2017:7).

Although family caregivers in some countries did not get professional support, Niksalehi et al. (2019:3) reported that family caregivers in a study in Iran were supported through family psycho-education therapy. The therapy improved the family caregiver's awareness about mental illness, treatment compliance and relapse prevention strategies. The importance of caring for MHCUs in the community cannot be undermined. Tyler, Wright and Waring (2019:13) reviewed various interventions intended to ensure continuity of care following the discharge of MHCUs to the community. Despite the interventions, the support for and expected by family caregivers was not enough.

In a study done by Ortiz (2019:28), rapid re-admissions of MHCUs, which occurred within 30 days after discharge, were indicators of poor psychiatric care and inadequate linkage with community-based care. Therefore, professional support for family caregivers is crucial. Those MHCUs discharged from the hospital need to continue with care at PHC facilities. However, in Ethiopia, the negative attitude of nurses towards

MHCUs resulted in patients and family caregivers not receiving the anticipated support (Sahile et al., 2019:5). Caregiving is a responsibility that puts a burden on family caregivers; therefore, professional support is crucial. However, despite this much support being considered essential, family caregivers in Nigeria received minimal support from health care professionals in general (Olawande et al., 2019:2011).

Unlike Ethiopia, where nurses had negative attitudes towards MHCUs, nurses in Ghana were supportive of these patients and their family caregivers. However, some MHCUs assaulted and threatened nurses during the home visits, and family caregivers cautioned nurses against coming to their (MHCU's) homes (Opare et al., 2016:11). Therefore, nurses could not provide the necessary professional support as they feared for their lives.

Also, there are not enough mental health care professionals in Ghana compared to the increasing demand for mental health care services. This was due to the ageing workforce and increasing migration of specialists leaving the country (Badu, O'Brien & Mitchell, 2018:10). However, South Africa has introduced a system of treatment partner and family psycho-education strategies to reduce the number of relapses of MHCUs and support family caregivers to reduce the burden of care (Sibeko et al., 2017:5).

Professional support given to family caregivers is essential as it decreases relapse rates among MHCUs. However, factors such as individual vulnerability and service responsiveness play an essential role in the effectiveness of the support given (Sfetcu et al., 2017:6). In addition, the referral of discharged MHCUs to community psychosocial support units lowered the re-admission rates compared to referral to the usual outpatient facility. Moreover, community psychosocial support units offered psychological support to MHCUs. Furthermore, visits at homes of family caregivers by a nurse or social worker were significant in reducing the re-admissions of MHCUs (Sfetcu et al., 2017:7). Those interventions helped stabilise the MHCUs, enabling and assisting the family caregivers in caring for their MHCUs. In Canada, Cheng et al. (2017:697) found that the referral of discharged MHCUs to high-intensity out-patient programmes helped reduce re-admissions. Those programmes were helpful as they helped family caregivers to cope with the burden of caring for MHCUs. Also, in China, psychiatric rehabilitation helped to re-integrate MHCUs back into society. Psychiatric rehabilitation services included cognitive behavioural therapy and family interventions (Luo et al., 2018: 2).

In the US, the implementation of the McFarlane model enabled family caregivers to support one another in times of crisis. The McFarlane model is a professionally facilitated clinical intervention that addresses problem-solving skills, effective communication, illness management, family coping and the development of a supportive network (Labrum et al., 2021:16). Furthermore, in Iran, psychosocial support programmes helped increase the skills of family caregivers in managing the different caregiving situations, and family caregivers’ problem-solving skills improved their anxieties decreased (Hajisadeghian, Ghezelbash & Mehrabi, 2021:48).

Furthermore, in Austria, the provision of psychological services to MHCUs proved beneficial to family caregivers as MHCUs were taught how to prevent relapses. Non-Governmental Organisations (NGOs) in Romania provided home visits to MHCUs, and health care professionals' telephone calls helped to reduce relapse rates (Adnanes et al., 2020:1036). Stabilising the condition of MHCUs alleviated the care burden of the family caregivers, giving them the time to attend to their personal needs. In addition, in China, the availability of community rehabilitation institutions provided relief for family caregivers as they had the opportunity to return to their social lives. Moreover, health care professionals facilitated community health education and support groups for family caregivers, which helped them communicate with others in similar situations and increased their knowledge about mental illness and alleviated their psychological pressure (Chen et al., 2019:6).

In Singapore, family caregivers who received professional support showed high resilience, lower caregiver burdens and positive psychological wellbeing in times of stress (Ong et al., 2018:2). Similarly, professional family interventions like family therapy had improved their quality of life (Caqueo-Urizar et al., 2017:5, Hajisadeghian et al., 2021:48). Therefore, it is evident from the literature that the support of health care professionals assisted the family caregivers in coping with the burden of caring for their MHCUs.

## 2.6 Summary

This chapter described the various challenges experienced by family caregivers globally, as well as in Africa and SA and described the support received by family caregivers of MHCUs from health professionals. It reviewed the literature relevant to the challenges experienced by family caregivers and the support family caregivers received from health professionals. Chapter 3 describes the research methodology of the current study.

# CHAPTER 3

# RESEARCH METHODOLOGY

## 3.1 Introduction

This chapter describes the research design, study setting, population, sample, inclusion criteria, data collection method and pre-test of data collection tools. It also details the steps taken to ensure trustworthiness, how the collected data was analysed and the application of ethical principles in the current study.

## 3.2 Study design

According to Leavy (2017:125), the research design is a blueprint of the study indicating how the study will be conducted and how to maximise relative control over factors that may interfere with the study's outcome. The qualitative approach was used in the current study. Qualitative research utilises an approach whereby the researcher describes the experiences and circumstances of those individuals' perspectives in the situation (Grove & Gray, 2019:59). The researcher chose a qualitative approach that is exploratory, descriptive, and contextual in nature.

### 3.2.1 Qualitative approach

The qualitative research approach allows the researcher to interact with participants in a holistic way to understand the life experiences of the participants and the meaning they attach to those experiences (Grove et al., 2013:23). According to Brink et al. (2011:121), qualitative research helps the researcher explore the in-depth richness of the phenomenon. Grove and Gray (2019:64) add that qualitative research is an interpretive and naturalist approach, where the study is conducted in the natural setting where the phenomenon occurs. In the current study, a qualitative approach allowed the researcher to interact with participants in their homes where they face the challenges in caring for the MHCUs. Participants narrated their life experiences regarding the challenges and support received from health care professionals to assist them in caring for their MHCUs.

### 3.2.2 Exploratory research

Exploratory research aims to gain insight into a situation (De Vos et al., 2011:95). The researcher explored the challenges family caregivers face as they care for MHCUs and identify the support they received from health care professionals to assist them. In this study, questions were asked in face-to-face in-depth interviews with the family caregivers. The family caregivers narrated their lived experiences to the researcher.

### 3.2.3 Descriptive research

Descriptive research aims to obtain complete and accurate information about the phenomenon so that the researcher can provide new information about the phenomenon (Babbie, 2012:96). Also, De Vos et al. (2011:96) add that descriptive research refers to a more intensive examination of a phenomenon and its deeper meaning. In this study, family caregivers described the challenges they faced as they took care of MHCUs at home and the support they received from health care professionals. A detailed and comprehensive description of the challenges assisted the researcher to get an accurate portrayal of the characteristics of those challenges and the support they received from health care professionals.

### 3.2.4 Contextual research

According to Babbie (2012:97), contextual research helps the researcher to understand events, actions and processes in their natural context. In other words, in the natural setting where events or actions happen without any manipulation. Hence, the researcher explored the challenges family caregivers faced caring for MHCUs and identified the support received from health care professionals in their home environments. Therefore, data collection from family caregivers took place in their homes, a natural setting where the phenomenon occurred.

## 3.3 Study setting

**Figure 1: Map of Vhembe District Municipality**

**(Source: Limpopo Province freight Data Bank >authorities>Vhembe, 2019)**

According to Burns et al. (2015:38), a research setting refers to where a study is conducted. The study was conducted at the Thulamela Municipality in the Vhembe District in Limpopo Province, SA. This municipality includes the following local municipalities, namely Collins Chabane, Makhado, Musina and Thulamela, and located in the northern part of the Limpopo Province. It shares borders with Zimbabwe and Botswana in the north-west and Mozambique in the south-east through the Kruger National Park. To the south, it borders Capricorn and to the west with the Mopani District Municipalities.

Thulamela Municipality is the easternmost local municipality in the Vhembe District Municipality. To the east, it shares the border with Kruger National Park and Makhado Municipality to the south-west. To the north, it borders with Musina local municipality and Collins Chabane local municipality to the north-east. Thulamela Municipality has a population of 618 462, with 85 per cent of the population living in tribal areas. It has three hospitals, Hayani Specialized Psychiatric, Tshilidzini Regional and Donald Fraser District hospitals, and 52 fixed and 14 mobile clinics. Thirty-five per cent of people employed in Thulamela Municipality work in the retail industry. Almost 9934 people, including MHCUs, receive disability grants (Statistics SA 2016).

In Thulamela Municipality, these are several villages and two townships, namely, Shayandima and Makwarela. In addition, there are two towns, Thohoyandou, the seat of the municipality and Sibasa. Primarily, MHCUs in the Thulamela Municipality are admitted to the Tshilidzini Regional and Donald Fraser District hospitals. If referred by these two hospitals or courts of law for 30 days' observations for forensic patients, patients are admitted to Hayani Specialized Psychiatric Hospital. The most common languages in Thulamela Municipality are Tshivenda, English, Xitsonga and Sepedi. Data was collected in the villages where family caregivers stayed.

## 3.4 Population and sampling

### 3.4.1 Target population

Population refers to the total aggregation of people or objects in which the researcher is interested. The target population is the number of cases about which the researcher would like to generalise (Polit & Beck, 2017: 249). In the current study, the population was all family caregivers of MHCUs. The target population was family caregivers over the age of 21 who have cared for MHCUs for at least six months and are accessible to the researcher in the Thulamela Municipality.

### 3.4.2 Sample and sampling

A sample is part of a whole selected by the researcher to participate in research with the characteristics of the population. Sampling is the process of selecting the sample from the population in order to obtain information about a phenomenon (Brink et al., 2012:132). According to Babbie (2012: 119), a sample refers to the subset of a population from which the researcher will conduct the study. The researcher used the Tshilidzini Hospital's register for mental health care unit to select the participants for the current study. The register was for the period from January 2019 to December 2019 and had 178 names of MHCUs and the family caregivers who brought them to the hospital. Of these 178 patients, 15 were readmitted twice in a consecutive three-month period. Only ten participants were interviewed due to data saturation. All the family caregivers in the sample were above the age of 21 years and had cared for family health member with mental health problems for more than six months and were willing to participate in the study. The sample size was determined by data saturation, that is, when no new information is obtained from participants during data collection despite increasing the sample size (Burns et al., 2015:274).

Sampling refers to selecting participants for the study to be conducted, and the sample must be representative of the population (Bertram & Christiansen, 2014:59). In the current study, the selection of participants was done using the non-probability purposive sampling method. In non-probability sampling, each unit in the sampling frame does not have the same possibility of being selected for the study. The sample is based on the judgment of the researcher (De Vos et al., 2011:390). Non-probability purposive sampling method was chosen so that the researcher could intentionally select family caregivers who meet the inclusion criteria for this study. Only family caregivers of MHCUs who had been re-admitted twice in a consecutive three-month period were included in the sample. Tshilidzini Regional Hospital was chosen because it admits 59 per cent of MHCUs in the Thulamela Municipality.

### 3.4.3 Inclusion criteria

Inclusion criteria refer to those characteristics a case must possess to be included in the study (Polit & Beck, 2017:250).

The inclusion criteria for this study were:

- Family caregivers of MHCUs who had been re-admitted twice in a consecutive three-month period.
- Family caregivers above the age of 21 years who have been caring for MHCU for more than six months.
- Both male and female family caregivers under the age of 65 years were included.
- Participants who agree to be part of the study.

These criteria were adopted in this study so that only adult family caregivers could take part in the study. Individuals over the age of 21 years are legal adults who can make their own decisions. In order to obtain a rich description of the challenges faced by family caregivers in caring for the MHCUs, the researcher decided to include family caregivers who had cared for these for at least six months. Caring for MHCUs is a long-term responsibility; therefore, six months was the minimum period for inclusion in the study.

### 3.5 Data collection tool

The researcher used a semi-structured interview with the aid of an interview guide to collect data. De Vos et al. (2014:352) define a semi-structured interview as a method of collecting data from the participants through direct interchange with individuals who possess the knowledge researcher seeks. The interview guide had two questions. The first question was: 'What challenges do you face in caring for your MHCU?', and the second, 'What kind of support do you receive from health care professionals to help you care for your MHCU?' Further probing questions were based on the participant’s response. The interview guide was translated into Tshivenda, Xitsonga and Sepedi languages by experts from the University of Venda’s Linguistics Department. All recruited participants were asked to prove that they are above the age of 21 years. Their ages were verified with their identity documents.

The interview guide allows and assists researchers to consider what they want the interview to cover and possible difficulties they may encounter in terms of the wording of questions and sequence. It also helps to generate questions with appropriate content and structure and the themes to be covered (De Vos et al., 2014:352).

The disadvantages of an interview guide are that it may channel the researcher to focus on the written questions and not probe according to the participants' responses. Also, if not used properly, it may distract the researcher because when the participants are responding to a question, the researcher will be reading the next question on the guide (De Vos et al., 2014: 353)

The researcher overcame the disadvantages of the interview guide by listening carefully to the participants' responses and exploring their answers accordingly. This helped the researcher to focus during interviews and not be distracted by looking at the interview guide for the next question.

### 3.6 Pre-test study

The interview guide was pre-tested to evaluate if the interview guide’s questions are clear for the participants, with the intent to modify unclear and ambiguous questions. The other reason for the pre-test was to assess if the time allocated for the interview is sufficient (De Vos et al., 2014: 394). The researcher purposefully selected two Tshivenda speaking participants from the accessible population and conducted the interviews using the developed interview guide. During the interviews, both participants had problems understanding the term 'mental health care user' as it was directly translated from English to Tshivenda. Although the participants struggled to understand it, after an additional explanation from the researcher, they could answer with the relevant information. The researcher refined the word 'mental health care user' to 'mentally ill person'. Then, the researcher selected two Tshivenda speaking participants for another pre-test study who both resided in one of the selected villages. Both participants had no problems with the wording of the questions. They understood the expression 'mentally ill person’, and they responded without hesitation. These four interviewed participants were included in the main study.

### 3.7 Trustworthiness

According to Lincoln and Guba (1985) in Polit and Beck (2017:559), trustworthiness refers to the criteria for ensuring rigour in qualitative research. The four criteria for developing trustworthiness are credibility, dependability, confirmability and transferability. These four criteria are parallels to criteria of internal validity, reliability, objectivity and external validity.

### 3.8 Credibility

Credibility refers to having confidence in the accuracy of the data and its interpretation. Researchers should carry out research so that the findings are credible (Polit & Beck, 2017:559).

In the current study, the researcher ensured credibility by the following:

- The researcher had prolonged engagement with the participants during the interview sessions. The researcher first met with the participants to make an appointment and establish rapport and then for interview sessions. The researcher could collect data, and clarifying questions were asked during the interview, and there was no need for follow up sessions.
- The researcher created a trusting relationship with the participants, whereby participants were free to express themselves in their vernacular.
- Probing concerning the main question took place after the responses of participants. Clarity was sought, and participants asked for detailed explanations to exclude any inconsistencies and mistakes.
- A member check was done. This refers to the researcher submitting the transcript or field notes to participants to correct errors (Creswell et al., 2016:125). The member check was done during data collection, where the researcher summarised the interview to ensure the correct interpretation.
- Data collection triangulation was done. This is the use of multiple methods to collect data (Brink et al., 2011:99). The researcher used a voice recorder, observation and field notes to collect data.
- There was a thick description of the challenges faced by family caregivers caring for MHCUs and the support received from health care professionals.

### 3.9 Transferability

Transferability refers to how the findings can be applied in other settings or group (Polit & Beck, 2017:560). In the current study, transferability was achieved through:

- The thick description of research design, participants and the context in which the phenomenon occurred.

- Purposive sampling ensured that the study has the relevant participants who meet the inclusion criteria and the description of the participants' demographics.
- Participants were representative of the population and its characteristics.
- The researcher made connections from the collected data to both local and entire community level behaviour and practice.
- There was a detailed description of results supported by verbatim quotations and supported by a literature control.

### 3.10 Dependability

According to Polit and Beck (2017:559), dependability refers to the stability of data over time and conditions. The researcher should ensure that should the study be repeated with similar participants in a similar context, it can yield similar results. In the current study, dependability was achieved through the following activities:

- Dense description of phenomena being studied that is challenges faced by family caregivers caring for MHCU, and the support they received from health care professionals were well described.
- The researcher used a voice recorder and field notes during data collection to ensure accuracy and kept hard copies of transcripts, observation and field notes to ensure an audit trail.
- Data was back up by relevant literature.

### 3.11 Confirmability

Confirmability captures the concept of objectivity. According to Lincoln and Guba (1999) in De Vos et al. (2014:421), there is a need to ask whether the study's findings could be confirmed by another researcher. The researcher has to provide evidence which corroborates the findings. In the current study, confirmability was ensured through the following activities:

- The researcher ensured that he is neutral in collecting data, analysing and coding it.
- The researcher ensured that he records the true responses of the participants. This was achieved by triangulation using a voice recorder, observation and field notes.

- The researcher avoided bias during the study.
- There was a dense description of the phenomenon under study.

### 3.12 Data collection

Data collection in qualitative research involves attaching meaning to recorded data by perceiving, reacting and reflecting on how they responded to the questions (Grove & Gray, 2019:78).

### 3.12.1 Preparation for data collection

In preparation for data collection, the researcher obtained ethical clearance from the University of Venda Higher Degree Committee and permission letters from the Limpopo Department of Health's research committee and Vhembe District Executive Manager (DEM). He also obtained a permission letter from Tshilidzini Hospital's research committee to enable him to access family caregivers at the hospital and MHCUs' records, where he obtained the contact numbers of interested family caregivers. All the family caregivers in the study resided in villages under the jurisdiction of chiefs. Therefore, the researcher obtained a permission letter from the traditional council to visit the villages. The traditional council is composed of local chiefs and headed by the king, and the consent given covered all visited villages. In addition, before visiting the homes of family caregivers, the researcher obtained permission from the household owners telephonically. Some telephone contact numbers of household owners were asked from family caregivers who had brought MHCUs to the hospital and others taken from their clinical files. Participants were asked to sign consent forms before data was collected. The following methods were used to collect data.

### 3.12.2 In-depth individual interview

According to De Vos et al. (2014: 342), an in-depth individual interview seeks to understand the world from the participant's perspective and describe the meaning of the experience of their lived world. Therefore, the research must avoid any pre-conceived ideas and judgmental attitude. The researcher chose this method as it allowed him to interact with the participants face-to-face at the participants' homes. All interviews were audio-recorded with the permission of the participants. The duration of the interviews did not exceed 45 minutes.

All participants were asked the following questions as per the interview guide: ‘What are the challenges you face as you care for your mentally ill relative’ and ‘What kind of support do you receive from health care professionals to assist you to care for your mentally ill relative’. Those questions were asked individually, and explanations were given for each question.

Although the interview guide was translated into three local languages, as explained above, interviews were conducted in Tshivenda since all the participants were Tshivenda speaking people. Two Xitsonga speaking prospective participants were unwilling to participate in the study; therefore, the study was comprised of Tshivenda speaking participants. The interview guide helps researchers to consider what they want the interview to cover and possible difficulties they may encounter in terms of the wording and sequence of questions. It also helps to generate questions with appropriate content and structure and the themes to be covered (De Vos et al., 2014:352).

In order to enrich the interview, the researcher used the following communication techniques as described by De Vos et al. (2014:345).

- **Paraphrasing:** This was achieved by stating the participant’s words in another form with the same meaning.
- **Clarification:** The researcher got clarity on vague statements.
- **Encouragement:** The researcher encouraged the participants to say more about a specific idea.
- **Minimal verbal response:** The researcher did not interfere when the participant discussed a particular idea. At times he nodded without saying a word.
- **Probing:** The researcher persuaded the participants to give more detailed information by linking the participant’s comment with the information sought by the researcher.

- **Reflective summary:** The researcher summarised the participant’s ideas or feelings to ensure he understood the participant correctly.

### 3.12.3 Observation and field notes

Observation refers to taking note of how the participant acts before, during and after the interview, whereas field notes are the written account of what the researcher hears and sees while collecting data regardless of how insignificant it may seem at that moment. This may include posture, eye contact and facial expression (De Vos et al., 2014:335). The researcher observed the participant's behaviour during interviews in terms of facial expressions and documented these.

## 3.13 Data management and analysis

Data analysis is a process whereby data is organised, given structure and meaning is obtained (Polit & Beck, 2017:530). De Vos et al. (2014:373) add that data analysis in qualitative research involves sorting, organising and reducing data into more manageable pieces and exploring ways to reassemble them. In the current study, data was transcribed immediately verbatim and translated into English. The translated interviews were analysed using Tesch’s analysis technique as described in Creswell (2012:191)

- Step 1: Getting a sense of the whole. The researcher read the transcript and wrote down ideas as they came to mind.
- Step 2: Pick-up interview documents. The researcher picked up an interview document and read it, checked the meaning and wrote thoughts that came to mind on the margins.
- Step 3 Make lists of all topics. After all data has been analysed, the researcher made a list of similar topics and grouped them into major, minor or unique topics.
- Step 4: Abbreviate topics as codes. The researcher abbreviated topics into codes, wrote them next to each segment and reviewed them to check if new codes emerged.

- Step 5: Find the most descriptive wording. The researcher found the most descriptive wording for the identified topics and turned them into categories while grouping the related topics and indicating their interrelationship.
- Step 6: Making a decision. The researcher made a final decision regarding the abbreviation for each category and arranged them alphabetically.
- Step 7: Assemble similar categories of data. All data material belonging to one category were placed together, and preliminary analysis done.
- Step 8: Recoding of data. The recoding of existing data was done by the researcher.

### 3.14 Ethical considerations

Ethical consideration refers to the care which needs to be followed when undertaking research. The researcher must respect the rights of individuals and communities participating in a study. Human beings' rights need to be respected at all times, and research should avoid any harm to their participants (Brink et al., 2012:32). In the current study, the following principles were observed:

#### 3.14.1 Permission to conduct study

After choosing the topic of interest to be studied, he wrote and presented the research proposal to the Department of Advanced Nursing Sciences of the University of Venda for corrections and recommendations. This ensured that the research proposal was of the required standard and adhered to the University of Venda's ethical standards for research. After attending to the Department's corrections and recommendations, the researcher presented his research proposal to the School of Health Sciences' Higher Degree Committee for further corrections and recommendations. With the approval of the School of Health Sciences Higher Degrees Committee, the researcher sent the research proposal to the Executive School Higher Degrees Committee for consent. Once this consent had been obtained, the research proposal was sent to the Research Ethics Committee for approval.

The Research Ethical Committee granted the researcher approval to conduct the study. The researcher applied for permission to conduct the study from the Limpopo Department of Health, and permission was granted. Also, agreement to conduct the study was applied for at the Vhembe District Municipality's health department and approved. The researcher applied for permission to conduct the study at the Tshilidzini Hospital, and it was granted by the institution's research committee. As the participants resided in villages under traditional authority jurisdiction, the researcher applied for permission from the traditional council of local chiefs and headed by the king. Consent was given by the Tshivhase Traditional Council that has jurisdiction over all the included villages. Before conducting the interviews were conducted, permission was sought from each household owner, where the participant was not the owner.

### 3.14.2 Informed consent

Brink et al. (2012:38) explain that informed consent means that the individual agrees to participate in the study. Polit and Beck (2017:731) add that informed consent is an ethical principle that dictates that researchers obtain the respondents agreement to voluntarily participate in the study after informing them about possible benefits and risks. No individual must be forced into participation. All participants were informed about the benefits of being in a study and that no risks were involved. The participants were aware that they could withdraw from the study at any time without penalties (see attached consent form). All the participants signed the consent forms.

### 3.14.3 Anonymity

Anonymity refers to the participant remaining anonymous when the final report is produced (Burns et al., 2015:106). In the current study, the researcher excluded the names of participants during the interviews, and in the report, the participants were identified by numbers, for example, P1 meant participant number one. Numbers were allocated according to the sequence in which the interviews were conducted.

### 3.14.4 Confidentiality

According to Grove et al. (2013:106), confidentiality refers to the researcher's management of private information shared by the participants. In this study, confidentiality was maintained by keeping the participants' details anonymous. No information was attributed or attached to any of the participants.

### 3.14.5 Care of vulnerable group

A vulnerable group refers to a group of people who have diminished or mental incompetence to give informed consent (Burns et al., 2015:101). In the current study, people in vulnerable groups did not take part in this study, for example, mental health care users and minors.

### 3.14.6 Right to self-determination

The right to self-determination refers to the right to choose how to live one's life without external controls (Grove et al., 2013:101). In the current study, the participants voluntarily agreed to participate in the study. They were informed that they have the right to withdraw at any time without penalties.

### 3.14.7 Right to privacy

Grove et al. (2013:105) assert that the right to privacy refers to the freedom of individuals to determine the time, extent and circumstances in which private information can be shared with or withheld from others. That information may include beliefs, attitudes, behaviours, opinions and records. The researcher did not share the information received from participants without their consent. The consent forms signed by the participants agreed to share the information with the research team.

### 3.14.8 Right to protection from harm

According to Grove et al. (2013:108), the right to protection from harm emanates from the principle of beneficence which advocates for one to do good and to do no harm. In the current study, the researcher ensured no harm to the participants by not pressuring them to answer questions that made them uncomfortable. No participant cried or became emotional during the interviews, and there was no need for any referral to a psychologist.

### 3.15 Limitations of the study

The study was limited to family caregivers caring for MHCU who were interested in participating in the study. The sample was purposively selected based on the judgment of the researcher, and its findings cannot be attributed to the whole population. Recommendations were based on the findings of the current study.

### 3.16 Dissemination and implementation of results

Communicating research findings is the final step of the research process. The findings are communicated through presentations, publications to audiences of nurses, health care professionals, policymakers and health care consumers (Grove et al., 2013:615). A copy of the dissertation will be submitted to the Provincial Department of Health in Limpopo. The dissertation will be summarised into articles and sent to peer-reviewed journals for possible publication. The researcher will also present the findings at relevant conferences.

### 3.17 Summary

This chapter described the research design, setting, population, sampling, trustworthiness, data collection and analysis. It also described the ethical considerations applied to the study, discussed the limitations and dissemination of the results of the study. Chapter 4 describes data analysis and literature control.

# CHAPTER 4

# DATA ANALYSIS, DISCUSSION AND LITERATURE CONTROL

## 4.1 Introduction

Data analysis in qualitative research is a process whereby the researcher combines the data, making the invisible obvious, linking and attributing consequences to antecedents. This process involves scrutinising the data carefully and searching for meaning and understanding (Polit & Beck, 2017:531). This chapter covers the analysis and discussion of the research findings. Firstly, the biographical details of the participants are presented, followed by the findings of the semi-structured interviews. The themes are summarised, and subthemes discussed. The findings are considered and integrated with the relevant literature where applicable.

The interview guide was used during the data collection process. The two questions in the interview guide were as follows:

- What are the challenges you face when caring for your mentally ill relative?
- What support do you receive from health care workers as you care for your mentally ill relative?

The researcher used in-depth one-to-one interviews and field notes to collect data. The interviews were conducted in Tshivenda, as all the participants were Tshivenda speaking people. They were transcribed and translated into English. Data analysis in qualitative research is done simultaneously with data collection (Creswell & Creswell, 2017:192). This process enables the researcher to thoroughly analyse data as it still vivid in his mind. Data analysis in the current study was done using Tesch's analysis technique.

- Step 1: Getting a sense of the whole. The researcher read the transcript and wrote down ideas as they came to mind.

- Step 2: Examined the interview documents. The researcher selected an interview document and read it, checked the meaning and wrote down the thoughts that came to mind on the margins.
- Step 3: Make lists of all topics. After all data has been analysed, the researcher made a list of similar topics and clustered them together as a major, minor or unique topic.
- Step 4: Abbreviate topics as codes. The researcher abbreviated topics as codes, wrote them next to each section and reviewed them to check if new codes emerged.
- Steps 5: Find the most descriptive wording. The researcher found the most descriptive wording for the identified topics and created categories while grouping the related topics and indicating their interrelationship.
- Step 6: Making decisions. The researcher made a final decision regarding the abbreviation for each category and arranged them alphabetically.
- Step 7: Assemble similar categories of data. All data material in each category were placed together, and preliminary analysis done.
- Step 8: Recoding of data. The researcher recoded the existing data.

### 4.2 Demographic profile of participants

Ten participants from different villages in the Thulamela Municipality participated in the current study. Participants' biographical information includes their age, gender, marital status, employment, relationship with the MHCUs and number of years as caregivers.

**Table 4.1 Demographic profile of participants.**

| Participants | Age | Gender | Marital status | Employment status | Relationship | Number of years |
|---|---|---|---|---|---|---|
| 1 | 59 | Female | Married | Unemployed | Wife | 39 |
| 2 | 59 | Female | Married | Unemployed | Mother | 15 |
| 3 | 38 | Female | Single | Unemployed | Niece | 7 |
| 4 | 61 | Female | Single | Pensioner | Sister | 30 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 5 | 47 | Female | Married | Unemployed | Wife | 8 |
| 6 | 53 | Female | Divorced | Unemployed | Mother | 10 |
| 7 | 48 | Female | Single | Unemployed | Sister | 6 |
| 8 | 60 | Female | Widow | Pensioner | Mother | 14 |
| 9 | 49 | Male | Married | Employed | Brother | 12 |
| 10 | 63 | Female | Widow | Pensioner | Mother | 18 |

### 4.2.1 Age of the participants

The participants' ages in this study are as follows: 01 is between the age of 30–39 years, 02 between the age of 40–49 years, 03 between the age of 50–59 years and 03 above the age of 60 years.

### 4.2.2 Gender of the participants

According to Opoku-Boateng et al. (2017:46), caregiving roles are primarily undertaken by female family members. Females are mostly associated with caring. Similarly, in the current study, 90 per cent of the participants were females. Several studies found that women globally are mostly family caregivers (Inogbo et al., 2017:3, Mohammed & Ghaith 2018:274, Zhang et al., 2018:56, Nayak et al., 2020:98). In the Mediterranean culture, specifically the Calatan culture, the responsibility of caring for a family falls on women. Caring for family members is regarded as a moral obligation within the patriarchal society (Amell et al., 2018:2). Therefore, there are social and cultural demands on women to adopt the role of the family caregiver. Family caregiving remains a feminine activity irrespective of changing social structures and norms (Sharma, Chakrabarti & Grover, 2016:7). Neong and Rashid (2018:16) add that women have been linked with the higher burden of care in Africa and India.

### 4.2.3 Marital status

In the current study, four participants are married, three are single, two are widows, and one is divorced. The marital status of participants is significant as it plays a role in caring for MHCUs. It is a full-time and long-term responsibility, caregivers who are not married to MHCUs find it challenging to care for the MHCUs as they have their own spouses and families. However, widows and unmarried family caregivers experience emotional distress as they do not have spouses who could offer support in time of distress when taking care of MHCUs (Jeyagurunathan et al., 2017:7).

### 4.2.4 Employment status

Six of the ten participants are unemployed; one is employed, and three are pensioners. Unemployment amongst family caregivers of MHCUs is a common phenomenon as most caregivers cannot seek employment while caring for MHCUs. Azman, Singh and Sulaiman (2017:2) concur with this finding. They stated that caring for MHCU disrupts caregiver's daily activities, social life, financial and employment opportunities.

### 4.2.5 Relationship of MHCU with the participant

All participants are immediate family members of MHCUs. Two participants are wives of MHCUs, two are sisters to the MHCUs, one is a brother, one is a niece, and four are the female parents of MHCUs. In Malaysia, like in most countries globally, family members are encouraged to look after their mentally ill loved ones at home after discharge from the hospital (Azman et al., 2017:3). According to Sharma and colleagues (2016:259), most family caregivers are parents, followed by spouses and siblings of the MHCU, usually the sisters (Sharma et al., 2016:259).

### 4.2.6 Number of years caring for MHCU

The minimum years the participants cared for their MHCUs is six years. One participant has been caring for the MHCU for 39 years. Previous studies have shown that it is not unusual for family caregivers to care for MHCUs for years. Furthermore, Mulud and McCarthy (2017: 24), Ramezani et al. (2018:3) indicated that caring for MHCUs is a long-term responsibility.

## 4.3 Presentation of findings

In the current study, the researcher explored the challenges faced by family caregivers of MHCUs and their support from health care professionals. Four themes, namely non-adherence to medication, disruptive behaviour, emotional turmoil and poor interpersonal relations, emerged as the subthemes from the first question on the interview guide which dealt with challenges family caregivers faced when caring for MHCUs. One theme and subthemes emerged from the second question on the interview guide, which asked about the support family caregivers received from health care professionals. The themes and subthemes are presented in Table 4.2

**Table 4.2: Themes and subthemes**

| **Themes** | **Subthemes** |
|---|---|
| • Non-adherence to medication | 1.1 Poor insight into mental condition<br>1.2 Changes in medication.<br>1.3 Lack of transport to collect medication.<br>1.4 Inadequate supervision.<br>1.5 Substance use. |
| • Disruptive behaviour | 2.1 Destruction of property<br>2.2 Assaulting people.<br>2.3 Disruption of family functioning. |
| • Emotional turmoil | 3.1 Feeling emotionally drained and hopeless. |
| • Interpersonal relations | 4.1 Poor relations with family members.<br>4.2 Involvement in arguments and physical fights. |
| • Support system | 5.1 Poor support from health care professionals.<br>5.2 Poor family support. |

### 4.3.1 Theme 1: Non-adherence to medication

Non-adherence indicates not following the given rules or instructions (McIntosh, 2017:1041). In terms of medication, non-adherence to treatment refers to when a patient does not take medicine as prescribed by the doctor. The MHCU may decide to stop taking antipsychotic treatment for various reasons (Velligan et al., 2017:450). Subthemes that emerged from this theme are described below.

*4.3.1.1 Poor insight into mental condition*

Most participants mentioned that MHCUs do not adhere to medication regimes and frequently blatantly refuse to take medication. They attributed this behaviour to poor insight by the MHCUs. Some believe that they are not supposed to take medication because they are not mentally ill. This is what the participants said:

> *He does not take his medication. I do not know if I can get people who can talk to him about medication so that he can understand that he must take medication. We always talk to him about medication, but he undermines us, he says I must tell my husband take his medication not him (P2, 59).*
>
> *My eldest son urged him to take his medication so that he could stop disturbing them while they are studying as he was in grade 12 and his younger brother in grade 11. He refused to take his medication. He (the son) even tried to put his (father's) medication in the tea and food. But his father would see it and throw it away (P5, 47).*
>
> *The problem is that he does not think that he needs the medication. He thinks that he is not mentally ill. We always force him to take the tablets by threatening to have his disability grant terminated. He does not like the medication. He needs to be taught about his mental illness (P3, 38).*
>
> *It is always a struggle to make him take his medication. I do not know what we must do to make him understand that he is mentally ill. The other time he threw the tablets in the pit toilet. His cousin tried to talk to him about the importance of the medication, but it did not help. He still says he is not ill (P6, 53).*

From these quotes it is evident that family caregivers find themselves in a difficult situation when providing care for MHCUs. Hence, insight into a patient's mental condition is essential to ensure compliance with medication. The poor insight of MHCUs aggravates the challenges faced by family caregivers, such as the refusal to take medication and uncooperative behaviour. Hence some family members try to administer medication in food or drinks. Furthermore, the family caregivers tried to convince them to take their medication by giving health education to the MHCU to understand the need to take it. However, it was difficult for family members to live peacefully with an MHCU who refuses medication as they would relapse. The findings agree with Hernandez and Barrio (2017:16), who found that family members often struggle to persuade MHCUs to take treatment as they have difficulty acknowledging that they are mentally ill.

Mahesh et al. (2018:1453) argue that non-adherence to medication can also be due to wilful refusal by the MHCU to take medication, especially tablets, which in turn increases the aggressive behaviours. Despite the refusal, family caregivers try their best to persuade the MHCU to adhere to medication. However, when their efforts are fruitless, they become frustrated (Ntsayagae et al., 2019:4).

### *4.3.1.2 Changes in medication*

Some participants reported that the non-adherence to medication by the MHCUs was related to changes made by doctors to their medications. Mental illness is a chronic disease, and patients are on treatment for life. As a result, MHCUs get used to their medications, for instance, the number and colours of the tablets. Changes in medication's type and packaging had led to non-compliance by the MHCUs. Regarding changes in medications, participants said the following:

> *They changed his injection from one injection to a different one and also added tablets. Since he was put on the new injection, his re-admissions are frequent. When he was on the previous one, he used to stay for a year without re-admission. He was used to it (P1, 59).*
>
> *The tablets he used to take last year are different from the current ones. Even the containers are not the same. They used to give him white tablets, but now they gave him yellow ones. The problem is that doctors are not consistent; they change tablets frequently. It is a pity some good tablets are no longer available (P4, 61).*
>
> *I wish the injection can be given as it was before, being full not reduced as it is the case now. Because when it is reduced, he stops taking the tablets. This causes his relapses to be frequent, unlike when the injection is full (P5, 47).*
>
> *She used to take the pink tablets for almost three years now. The problem started when the hospital ran out of pink tablets. They gave her white tablets in a box, unlike the previous one, which was in sachets. Those tablets work the same way, but she says hers are pink not white. She believes they gave her wrong tablets, and she does not take them (P8, 60).*

These quotes show that changes in the medication of MHCUs contribute to their non-adherence to medication. Things like colour and container play a crucial role in medication adherence by MHCUs despite their having the same effects. Any change of container or package and colour of tablets should be communicated to the MHCUs to minimise non-compliance. Some participants revealed that adjusting the dosage of injection led to MHCU defaulting oral treatment. However, Tiihonen et al. (2017:691) reported that combining oral and long-acting injectable antipsychotics effectively reduced the non-adherence to medication, which eventually led to re-hospitalization of MHCUs. Moreover, changes in antipsychotics could be due to either switching from one drug to the other or increasing the current prescription when mental illness is unresponsive (Mohammed et al., 2017: 132).

Therefore, it is not uncommon to have mental disorders which are not responsive to treatment. In their study, Brain et al. (2018:2) asserted that the management of treatment-resistant schizophrenia dictated a change in the treatment approach. Treatment-resistant schizophrenia is a type of mental disorder that is not responsive to atypical or typical antipsychotics. Inevitably, MHCUs' treatment will change as doctors seek alternative antipsychotic drug to stop schizophrenia's symptoms. Furthermore, Jawad et al. (2018:353) add that changes in medication's type, dosage and frequency may affect adherence. A once-a-day dosage of antipsychotic drugs had a higher adherence compared to three times a day dosage. However, in Nigeria, the use of two or more antipsychotic drugs was associated with non-adherence (Tareke et al., 2017:5). Additional medication may be perceived with scepticism and seen as unnecessary by MHCUs, leading to non-adherence (Las Cuevas et al., 2018:307). Consequently, regardless of the reason for medication changes, in the current study, the relapse rate increased, and MHCUs were difficult to handle at home.

Inevitably, MHCUs associate package and colour to efficacy. If the tablets in a package and colour are changed, MHCUs assume they are of low efficacy and therefore do not take them. In Iran, the wrong mindset about the effectiveness of medication led to non-adherence (Mehralian, Sharif & Abbasian, 2019:350). When changes were made frequently to the medication of MHCUs, especially tablets, the adherence was reduced. There are two main routes for administering antipsychotic medications, namely oral (tablets) and intramuscular routes. Intramuscular medications are long acting and recommended for those who do not adhere to oral medications. Those MHCUs who default on oral medication can benefit when they are on intramuscular medications. The intramuscular medication improves treatment adherence, reduces rates of re-hospitalization and risk of violent behaviour of MHCUs. Intramuscular medications also improve the management of difficult and problematic MHCUs (Mohr et al., 2017:5).

#### *4.3.1.3 Lack of transport fare to collect medication*

Like all people on chronic medication, MHCUs have to go to the hospital to be reviewed by the doctors and/or collect their monthly medication packages. However, the hospital is far from the MHCUs' home, and therefore they need to use transport to reach it. The lack of money for transport becomes a challenge for MHCUs and the relatives who have to accompany them. Of the participants, one is employed, three receives age-old grants, and the rest are unemployed. The unemployed participants depend financially on the MHCUs' disability grants. Regarding lack of transport fare to collect medication, participants said the following:

> *He spends all his money on alcohol. He says he does not want to be controlled with his money. I have asked him several times to give me some money to keep so that we can use it to go to the hospital for his check-up, but he refused. We ended up not going because of lack of taxi fare (P1, 59).*
>
> *It is the same story every month: no money for transport to hospital. When I do not accompany him, he does not go to fetch treatment on his own. So I have to pay for both of us, so that he can get his treatment and I cannot do this every month. In fact, he is not serious about his health (P3, 38).*
>
> *I wish he can stop smoking dagga because he spends his grant on it. He uses his money to an extent of not having taxi fare to collect treatment at the hospital. I receive a child grant for my youngest child, but it is not enough to help him with money for transport (P7, 48).*
>
> *This month she claimed to have no money for transport, and we did not go for her check-up. Last month her younger sister gave us money to go to hospital. This month she said she must pay for our trip to the hospital because she does not help us to buy food with her grant. I cannot buy food and pay for her transport while she misuses her grant (P10, 63).*

It is evident that lack of transport fare contributes to non-adherence to medication. Although the government made financial provision for MHCUs to receive disability grants through SASSA, the grants are misused by some MHCUs. They do not help their family caregivers to buy food and keep some money for their transportation for follow up days. They use their grants to buy substances like alcohol and dagga, which exacerbates the non-adherence to medication, a challenge experienced by family caregivers. When it is time for follow up visits, MHCUs expect their caregivers to pay their taxi fares to the hospital. Most caregivers depend on the MHCUs' disability grant for transportation to the hospital. However, when the family caregivers realized that MHCUs have no taxi fare, they would not accompany the MHCUs. This led to MHCUs not going for their monthly follow-ups, and consequently, they defaulted on their medication. Iseselo et al. (2016:6) also reported similar findings where caregivers experienced financial constraints regarding transport fare to the hospitals to collect medication. There is a need for MHCUs and family caregivers to work together, especially on finance and educated about the expected financial contributions towards their health.

Although some of the participants in the current study do receive an old age grant, it is not sufficient to cover all the expenses at home. This finding is similar to one in Malaysia, where caregivers had budgets inadequate to cover their living expenses like buying groceries and electricity (Azman et al., 2017). Therefore, little money remained for the transportation of MHCUs to the hospitals and clinics.

In South Africa, like other countries in the world, health care facilities like hospitals and clinics can be far away. MHCUs and their family members must travel long distances to get health services. Therefore, caregivers must spend money on transportation of MHCUs hospitals for check-up visits and collection of medication (Gloria et al., 2018; Nenobais, Jatimi & Jufriyanto, 2019:32). In Ghana, family caregivers also faced the challenge of travelling long distances to health care facilities for the collection of medications.

#### *4.3.1.4 Inadequate supervision*

In most instances, MHCUs need someone to remind them to take their medication. It is usually the responsibility of a close relative, especially the mother, sister or. The problem arises when that particular family member is absent and leaves the responsibility of taking the treatment to the MHCU. The findings of the current study reveal that MHCUs were not taking the treatment as expected by the family caregivers because there was no one to supervise them when taking treatment. This was expressed in the following quotes:

> *Whenever I have piece jobs, I leave early before he wakes up and just leave the treatment on the table so that he can take it by himself. I trusted him, but I had realized that he does not take tablets. I cannot stay at home without doing piece jobs, we need money to meet our needs (P5, 47).*

> *I am scared to remind him to take his medication because he gets angry and become verbally aggressive whenever I remind him. He swears at me, saying why I treat him like a child. So I let him keep his medication, I am sure he does not take it the way they told us at the hospital. His behaviour has changed (P3, 38).*
>
> *He does not want us to get involved in his medication. He locks his room and fights with us when we ask if he took his medication. I think he undermines me because I am a woman. Sometimes he looks well but sometimes looks like he has relapsed. I wish I had a male person in the house who would force him to take treatment (P6, 53).*
>
> *I think the problem is that I am employed and cannot supervise him taking treatment every day. He needs someone to remind him, but unfortunately, he does not like my wife. She would be the one to supervise him as she is always at home, but he resents her (P9, 49).*

The findings reveal that MHCUs needs consistent supervision and need someone to remind them to take their medication. However, it is not always possible. The family caregivers need to assign that responsibility to another close relative so that in their absence, they can take over and supervise the MHCU. However, sometimes the aggressive behaviour of MHCUs makes family caregivers reluctant to remind them about treatment as they are scared of the MHCU. Most of MHCUs who stay alone have a challenge adhering to medication. Therefore, it is critical that MHCUs do not to stay alone because they need supervision regarding the taking of medication. In their study, Hernandez and Barrio (2017:02) found that MHCUs who live with or receive support from family members tend to have better medication adherence compared to those who do not. Thus, family involvement in medication use may be a protective factor for medication adherence. Family caregivers who are personally involved in the administration and monitoring of MHCUs' medication reported improved adherence. MHCUs need close supervision to prevent relapses. In addition, the psychological preparedness of the family caregivers to supervise MHCUs to adhere to medication is of great importance (Kretchy et al., 2018:292). Therefore, a prepared and willing family caregiver can provide adequate supervision.

#### *4.3.1.5. Substance use*

The findings of this study indicate that MHCUs do use substances. Substance use was indicated as a cause of non-adherence to medication by the participants. It was revealed during the interviews that family caregivers wished that their MHCUs would not use substances as it significantly impaired their judgments. The commonly reported used substances are alcohol and dagga. Alcohol included beers and home-brewed liquor. Those substances were prone to use because of their affordability, easy accessibility and availability in the community. Once MHCUs are intoxicated, they defaulted treatment and were difficult. This is what the participants had to say about substance use:

> *He drinks alcohol and sometimes smokes dagga. It does not help to drink alcohol while one is on treatment because that alcohol dilutes the tablets. Sometimes he comes home late at night and drunk. I cannot force him to take medication (P1, 59).*
>
> *Tablets are good if he takes them every day, but he does not. He wakes up early in the morning and goes to his friends. They are the ones who give him dagga. They smoke dagga the whole day. Once he is intoxicated with dagga, he does not listen to anybody (P5, 47).*
>
> *I hate alcohol from the bottom of my heart; it makes my son a monster in the house. It makes him forget his treatment. If you dare tell him about medication, he will swear at you with vulgar words. He takes treatment whenever he likes. I just keep quiet and let him do as he pleases (P6, 53).*
>
> *I do not know what we can do to make him take his treatment because that is the only thing which can make him stable. If he can stop drinking this 'mahafhe' (home-brewed liquor) thing, everything would be fine. Liquor is the main problem (P9, 49).*

Most family caregivers have accepted that their family members are mentally ill, however, the fact that some of the MHCUs use substances like alcohol and dagga, concerns them. According to Gloria et al. (2018:818), family caregivers in Ghana felt that the MHCUs had aggravated their mental conditions by continued substance use. Due to mental illness, some MHCUs under-estimate the dangers of using substances on their mental health. In addition, non-adherence to medication in most MHCUs is related to factors such as substance abuse. Similar to the current study, previous studies found that MHCUs have an inclination to use substances (Rababa'h, Yousef & Al-Omari, 2017:73). Consequently, substance use harmed treatment adherence by MHCUs. There is a higher association between treatment non-adherence and substance abuse as substances destabilise the mental state of MHCUs (Salloum & Brown, 2017:1, Jawad et al., 2018:351)

### 4.3.2 Theme 2: Disruptive behaviour

There are different ways in which MHCUs behave to show their emotions. One is destructive behaviour when MHCUs display physical aggression towards a property with the intention to damage or destroy (Hodgins & Klein, 2017:87). This may be due to anger, frustrations and anxiety.

### *4.3.2.1 Destruction of property*

The destruction of property by MHCUs is a challenge faced by participants as they care for their MHCUs. It is a behaviour that is common when the MHCU has relapsed and leads to family caregivers seeking admission for the MHCU. Participants revealed the following during interviews:

> *He breaks windows (panes) here at home, he is not cooperative. The problem is that he does not take treatment and does not listen to anybody. When he has relapsed, he is violent (P1, 59).*
>
> *We also have a challenge with accommodation. The room he sleeps in is not suitable for anyone to sleep in. He made holes on the wall and broke wall robes in there. Nothing is useful in that room, everything is in pieces (P4, 61).*
>
> *He is problematic, destroys property, bang and breaks windowpanes. He is also verbally aggressive. He broke chairs, the plastic ones. We tried to have him arrested but it did not work out (P7, 48).*
>
> *We are tired of replacing his room's windowpanes, every time he relapses he breaks them. We were forced to replace the wooden door with the steel one because he used to bang it until it split. Every time he loses the key, he would bang it until it became loose (P9, 49).*

From the above quotes, it is evident that relapsed MHCUs pose a challenge to family caregivers. Due to poor medication adherence, MHCUs could not control their emotions, especially anger; hence they became destructive. Destructive behaviour costs family caregivers money in repairs of damaged items. It was reported as one of the sources of interpersonal conflicts between MHCUs and family caregivers (Walke, Chandrasekaran & Mayya, 2018:183). Gloria et al. (2018:818), in their study, found that there was an inclination to damage property by MHCUs. The behaviour was common when the MHCU has relapsed due to non-adherence to medication. According to Lippi (2016:3), MHCU's hostility, aggression, disruptive symptoms and property damage increased the burden experienced by family caregivers. Destruction of property disrupted family life and impacted negatively on the economic status of the family.

### *4.3.2.2 Assaulting people*

Like destructive behaviour, MHCUs often express their emotions by assaulting people. It is unacceptable, but it happens. Markiewicz, Pilszyk and Kudlak (2020:2) describe assault as an impulsive and harmful action towards other people by MHCUs. Family caregivers indicated that MHCUs assaulted family members without provocation, especially when they have relapsed. This caused emotional distress to caregivers as MHCUs' behaviours were unpredictable, and they lived in fear of being assaulted or harmed. The following quotes of participants revealed their experiences:

> *One day he came into the house and asked if I know about his keys. I did not know where they were, he beat and kicked me, saying, go back to your family, I will kill you, and I will kill you. I escaped through the window (P2, 59).*
>
> *When he has relapsed he swears at everyone in the house without provocation and I am his target. He beats me up and swears at me. When that happens, I run to the children's room and hide there (P1, 59).*
>
> *He is verbally aggressive. He also assaulted my mother, bite her leg and hit my child with a hammer. He carries knives and machete around and threatening people. Even his uncle, who used to calm him down, now is scared of him as he also assaulted him (P3, 38).*
>
> *When he has relapsed, he does not want people to come into our home. He chases people away and pelted them with stones. He assaulted his youngest son for no reason. When I confronted him he showed no remorse and he threatened to assault me with a stick (P5, 47).*

These quotes reveal the problematic situations the family caregivers endure in their homes. MHCUs assaulted family caregivers without provocation who live in fear as they were scared of the MHCUs. Some family caregivers opened assault cases with the police but later withdrew the case as they felt that he had relapsed when he assaulted them. They fear judgment from other family members who do not live with the MHCU. Some family caregivers were accused of hating the MHCUs when they opened police cases against them. Caregivers showed fear of weapons carried by MHCUs and were scared to confront the MHCUs about their unacceptable behaviours as they feared for their lives. One MHCU even threatened the family caregivers following what had happened in the neighbouring village whereby a father killed his two children with a machete knife.

Family caregivers are the support system of MHCUs; even though their service is free, it is not appreciated (Batra et al., 2018:60). When MHCUs become aggressive, both physical and verbal, it tends to frustrate family caregivers. This is common when the MHCU has relapsed and psychotic (Marimbe & al., 2016:3). Family caregivers are always fearful and stressed about MHCU's behaviour. Riley-McHugh, Brown and Lindo (2016:99) add that family caregivers were angry and frustrated by the MHCU's aggressive behaviour towards them.

The unpredictable, aggressive behaviour of the MHCU towards family caregivers make them live in fear. The inability of the caregivers to cope with inappropriate and violent behaviour of the MHCU led to reduced social interactions in the family (Akbari et al., 2018:332). Family caregivers expressed concern about handling the MHCU's unpredictable behaviour, and most were frightened of being attacked by the MHCU and safety of the users themselves. Also, as in most cases, family caregivers are females, and they struggle to cope with such situations. These behaviours warrant hospitalization (Souza et al., 2017:7). However, family caregivers are compelled to control, manage or tolerate such behaviours, exposing themselves to risks of being assaulted and attacked by MHCUs. This is a daunting task for most caregivers.

#### *4.3.2.3 Disruption of family functioning*

The disruption of family functioning when caring for MHCUs has a negative impact on their lives to such an extent that it interferes with their daily activities. Family caregivers put the MHCUs interest ahead of their own (Fekadu et al., 2019:4). Families are the support systems of MHCUs, and how they behave has an impact on family functioning. The participants indicated that the MHCUs behaved in a manner that negatively disturbed the family. This is what the participants said:

> *Once we hear him swearing whenever he comes home, we lock ourselves in the room because we know that he is angry. He comes home and bangs windows, shouting at everyone for no apparent reason. We are scared even to watch television (P3, 38).*
>
> *Our children are unable to study well or write their homework with peace. He roams around, playing music loudly late in the evening. His behaviour disturbs even our neighbours. He does not care about other people. He does whatever he wants regardless of how others feel about it (P5, 47).*
>
> *He has a separate room in the yard, but he comes to my house and demand things like money and food. My wife will give him food but when she says that she does not have money, he gets angry and swears at her. My children are scared of him when he has relapsed (P9, 49).*
>
> *When her father was still alive, she did not behave like this. Nowadays she drinks alcohol and verbally abuses her younger sister's children. She causes chaos in the house; at*

> *times she talks until the early hours of the morning. I wish her father was still alive (P10, 63).*

From the above quotes, it is evident that the behaviour of MHCUs in a family is crucial to how the family function. Regardless of their mental illness, MHCUs still have the responsibility to behave in a manner in which there will be harmony at home, so they must remain compliant to treatment so that they remain stable for the emotional wellbeing of the whole family. Caregiving is a long-term responsibility that demands time and attention and MHCUs need full support from family caregivers. According to Leng et al. (2019:26), family caregivers have little time for their own entertainment and social activities because they spent their time caring for MHCUs. Hence, family caregivers sacrifice their social time for the MHCUs, and consequently, they do not have time to rest and interact with others (Nenobais et al., 2019:30).

Family caregivers do their best to provide support to the MHCUs. They provide for the day-to-day needs of the MHCUs, including providing meals, monitoring their medication as well as their behaviour to detect signs of relapse (Ntsayagae et al., 2019:5). In this study, family caregivers revealed that relapsed MHCUs sometimes do not sleep at night. They were noisy and roamed around the house, disturbing others and making it uncomfortable for other family members. Due to the unpredictable behaviour of MHCUs, family caregivers must constantly be vigilant. They are always on standby for any emergencies caused by MHCUs (Brain et al., 2018:5). This interferes with their ability to focus on other essentials, such as seeking employment. Family caregivers must plan their life activities around the MHCUs' needs.

### 4.3.3 Theme 3: Emotional turmoil

McIntosh (2017:1692) defines turmoil as a state of uncertainty. Therefore, emotional turmoil causes family caregivers to be unsure of how they can emotionally handle a situation regarding the care of MHCUs. Moreover, Fekadu et al. (2019:3) add that caring for MHCUs takes an emotional, psychological and physical toll on family caregivers.

#### *4.3.3.1 Being emotionally drained*

Taking care of MHCUs takes its toll on the emotional aspect of family caregivers. They feel exhausted, having no energy to carry on with caring. The feeling is exacerbated because other family members do not support them and feel neglected and abandoned by family members. The caregivers must be supported, and their emotional wellbeing taken care of by family members. The following quotes revealed the experiences of participants:

> *I am tired, not that I don't want to take care of my brother, but I feel that I do not have energy anymore. I wish there was someone to assist me in taking care of my brother (P4, 61).*
>
> *To tell you the truth sir, my spirit is down, I am exhausted with the behaviour of my son. He exhausted any energy in me. No matter how much we talk to him, he does not change (P6, 53).*
>
> *I am exhausted, I tried everything to make her a good person, but I failed. I do not have any energy to fight with her. I want her to do as she wishes but one day she will remember me when I am no longer here for her (P8, 60).*
>
> *Daughters are supposed to take care of their mothers, but my case is different. In fact, she is my headache. I am tired. At my age, I cannot control her. I don't have the energy to chase her around, forcing her to take her medication. It would be better if she was taking her treatment, maybe she would behave better (P10, 63).*

The above quotes demonstrate that family caregivers often feel they do not have the energy to continue providing care to MHCUs. They need both physical assistance as well as emotional support in order to continue with the caring role. The support would greatly assist in preventing their emotional exhaustion. Emotionally drained family caregivers cannot to provide adequate care to MHCUs. Therefore, steady family caregivers are the foundation for stable MHCUs. Members of the multi-disciplinary team could be called on to attend to the emotional needs of family caregivers. Caregiving is a full-time responsibility that family caregivers undertake for most of their lifespan; consequently, their quality of life may decrease (Walke et al., 2018:182). They feel emotionally drained and have no desire to continue with caregiving.

Mental illness is a chronic condition that only stabilises when MHCUs are on treatment. However, when they default on treatment and relapse, it aggravates the depleted emotional state of family caregivers. They feel that MHCUs are defaulting treatment intentionally. The lack of effort by MHCUs to adhere to treatment, volatile behaviour and no signs of recovery makes family caregivers feel emotionally exhausted (Fitryasari et al., 2018:259). Taking breaks and support from family members would help family caregivers rejuvenate their strength to continue caregiving. However, family support was not forthcoming to the detriment of the caregiver, so the emotional exhaustion continued unabated. Caring for MHCUs brought dissatisfaction for the family and relatives. This finding is consistent with the findings of the current study.

#### *4.3.3.2 Feeling hopeless*

McIntosh (2017:751) defines hopeless as a state of being without hope, a feeling that something will not happen or when a person feels that the possible means to solve a problem has been exhausted. Caring for MHCUs challenges family caregivers as they feel that nothing will alleviate the burden they carry. Therefore, they look at their challenges and feel overwhelmed, with no sign of assistance coming their way. The following quotes elaborate on the participants' views:

> *I do not know what else can we do as a family to make him responsible for his own health. He knows that he is mentally ill but does not behave accordingly. Why must he stop his medication if he wants to be well like other people? I am tired of talking to him (P1, 59).*
>
> *He is our uncle; we cannot disown him, but he makes our lives difficult. I wish I knew what to do or where I can take him to. We always live in fear; we do not know what will happen next. You cannot predict his behaviour (P3, 38).*
>
> *I am old and I cannot manage him when he becomes violent. There is nowhere I can run to as I am unable to walk. I have tried to get people around here, to assist me by taking him to the clinic or hospital but sometimes they refuse as they are afraid of him. They are not his relatives; therefore, they are not much concerned about him. What more can I do at my age? Whatever happens is fine (P6, 53).*
>
> *Life was good when she was taking her treatment. She used to cook and wash clothes for us. She was fine; some people did not know that she is mentally ill. Recently she has changed, she is unmanageable and stubborn. I do not know what went wrong. Life is tough (P10, 63).*

Family caregivers provide crucial support to MHCUs and are their advocates acting in their best interests at all times. Therefore, their emotional state is of paramount importance if quality care is to be provided to the MHCUs. The above quotes reveal that family caregivers felt hopeless. Health care professionals will need to play a critical role in restoring family caregivers' hope if quality caregiving is to be achieved.

The behaviours of MHCUs exacerbated the feeling of hopelessness among the family caregivers. In the present study, they reported feeling hopeless that the conditions of their MHCUs will change as they have tried to cope with the psychotic behaviours of their MHCUs. This finding is consistent with the findings of Souza et al. (2017:7), who found that MHCUs who exhibited psychotic symptoms that warranted institutionalisation aggravated the family caregivers' despair. The study by Nenobais et al. (2019:42) also reported feelings of sadness, shame and losing hope among family caregivers due to uncontrolled behaviours of MHCUs. Furthermore, they felt powerless as they could not control the future of MHCUs and feared that MHCUs might endanger the lives of the community members. (Nenobais et al, 2019:42).

Due to their mental illness, MHCUs do not realize the emotional strain they put on their caregivers through their behaviour. According to Ntsayagae et al. (2019:4), family caregivers became emotionally and physically exhausted when the MHCUs became aggressive as there was nothing they could do about the situation. They felt helpless and fearful. Caregiving demands emotional energy from the caregiver, especially in chronic conditions like mental illness. According to Kretchy et al. (2018:292), mental distress is common among family caregivers because they are at high risk of experiencing depression and anxiety. They become exhausted and have no energy to carry on with caregiving. An emotionally drained and exhausted family caregiver will give suboptimal care to the MHCUs. Therefore, they must receive all the support possible to prevent the state of emotional exhaustion.

In the current study, family caregivers reported feeling hopeless and overwhelmed. In Sharma et al. (2017:261), family caregivers were severely stressed and depressed. This was related to the long duration of care they have provided to MHCUs. Therefore, family caregivers must be encouraged to request family members to assist them with care so that they have time to attend to their mental and physical health needs to improve their quality of life. Family caregivers with low quality of life displayed negative emotions such as social isolation, self-harm and suicide (Leng et al., 2019:26). The state of emotional exhaustion should be avoided if possible for the sake of the MHCUs and other family members.

### 4.3.4 Theme 4: Poor interpersonal relations

The interaction of human beings creates relationships. However, disorganised internal and external relations give rise to mixed feelings, which are contradictory and sometimes unbearable (Souza et al., 2017:7). Conflicting feelings between individuals give rise to poor interpersonal relations.

#### 4.3.4.1 Poor relations with family members

One of the challenges experienced by family caregivers were the poor relations between the MHCUs and family members. Family members felt alienated by MHCUs' behaviour, and despite their efforts to support the MHCUs, the relations remain strained. Poor interactions negatively impacted the teamwork attitude which families were expected to foster towards caring for the MHCUs. The feelings of the participants were expressed as follows:

> *Our relationship with him is not good because of his aggression. We are always scared of him. His uncle and aunt have also distanced themselves from him. My children are scared of him. Now it is us who are to tolerate him because he stays with us. Anyway he is our uncle, what can we do? (P3, 38).*
>
> *I wish his relationship with his father was good. Yes, my husband is mentally ill, but he is his father. He must respect him and obey him. What kind of example is he setting for his younger brother? I wish we can have peace in our family. We need one another, no one can live alone (P2, 59).*
>
> *We come a long way as a family. Our sons love their father, but he is the one who causes conflict here. He disrupts their studies at home and makes threats. The older one at least tries to understand him, but the young one is too young to understand his father's illness (P5, 47) said:*
>
> *Before I die, I want my daughter to have good relations with her younger sister and her children. They are the family I have; my heart is sore when I see my children not getting well with each other. I feel like I am a failure. It is painful (P8, 60).*
>
> *The only problem is his poor communication with my wife. He swears at her when she does not give him what he wants. The way he talks to her, it creates tension between them, and our children are scared. I try my best to talk to him about his behaviour, but he does not change (P9, 49).*

Good relations between family caregivers, family members and MHCUs are imperative in caring for MHCUs. A family is a fundamental support system for MHCUs. Therefore, family cohesion needs to be encouraged as much as possible. MHCUs should be involved in building family relations because they are part of families. Family caregivers said that when MHCUs have relapsed, they make demands which family caregivers cannot meet. At times MHCUs become uncooperative, hostile, verbal and physically aggressive, which create a poor relationship between the MHCU and family members. According to Fitryasari et al. (2018:259), volatile behaviour and few signs of recovery causes tension in the family. Jenkins and Schumacher (2018:33) also indicated that female caregivers reported a high degree of conflict and stress in managing male MHCUs in the home setting. This is related to the degree of aggression male MHCUs display compared to their female counterparts, often resulting in a constrained relationship between the MHCU and family members. They are anxious about caring for him due to his unpredictable and possibly dangerous behaviour. Similarly, Chen et al. (2019:7) indicated that MHCUs had exhibited threatening behaviours to others' property and personal security. In this research, violence was one of the main concerns of family caregivers.

#### *4.3.4.2 Involvement in arguments and physical fights*

MHCUs are part of the community; therefore, their interaction within the community is of paramount importance. However, their behaviour towards community members made people apprehensive. This made family caregivers anxious about the MHCUs when they are not at home. The following quotes reveal the feelings of the participants.

> *When he is drunk he gets into fights with people in the community. I am afraid that one day he will get hurt because he is old. I do not know what they fight for, but it has occurred several times (P1, 59).*
>
> *He likes to make threats to people for no reason. People do not like him because he carries a knife. People are scared of him, the other day he disrupted a neighbour's funeral (P3, 38).*
>
> *My brother does not respect anyone, even some community members. We talk to him about his behaviour, but he ignores our advice. We are uneasy when he goes to community gatherings because he is irritable and argumentative. Some people do not like him (P7, 48).*

Communities are the support systems of families, and the relationships of families within the community are important. The behaviour of MHCUs were a concern to family caregivers who expected MHCUs to behave in a manner that will foster good relations with community members. Family caregivers revealed that members of the community are afraid of some MHCUs due to their aggressive behaviour. According to Hodgins and Klein (2017:87), the high risk of aggression by MHCUs has been strongly established, and a factor found to contribute to the aggressive behaviour of MHCUs is non-adherence to medication, which is the case in the current study.

Non-adherence to medication was associated with increased hostility, which negatively impacted family caregivers, health and social systems (Mohr et al. 2017:2). In the current study, family caregivers reported that MHCUs were aggressive and hostile towards community members. This was consistent with findings in study by Wu et al. (2018:4040), whereby MHCUs exercised physical force, hostile attitudes, verbal and physical aggression. According to Roberts et al. (2018:3), some MHCUs displayed signs of agitation, including inner tension, uncooperativeness, anxiety, excessive motor activity and inappropriateness. These behaviours are sometimes frightening to community members resulting in poor relationships with community members who felt threatened by the MHCUs' behaviour and were uneasy in their company.

### 4.3.5 Theme 5: support system

Support means to give someone the encouragement to succeed (McIntosh, 2017:1581). Family caregivers, at times, feel exhausted with no desire to continue caring for their MHCUs; therefore, encouragement from health care professionals and family members is of paramount importance. Poor support aggravates the situations in which family caregivers find themselves. The subthemes that emerged from this theme are presented below.

#### *4.3.5.1 Poor support from health care professionals*

Mental illness is a chronic medical condition that is managed by different members of the multi-disciplinary team. Multi-disciplinary team members include doctors, nurses, social workers and psychologists. They have a crucial role in treating MHCUs and supporting family caregivers who expect health care professionals to support them as they care for their MHCUs. Often they lack knowledge and skills on how to resolve challenges which they come across. Participants in the current study became frustrated when the support they expected from the health care professionals was not forthcoming. This is evident from the following quotes:

> *The problem is that my son's disability grant was terminated; we went to the social workers who gave us a letter to take to SASSA. At SASSA, they gave him a six months grant instead of a permanent one. His treating doctors were supposed to have motivated for a permanent grant (P2, 59.)*
>
> *We told the home-based care workers about our uncle's behaviour of threatening us with a machete. They told the social workers about it, social workers came to talk to him. He convinced them that he would change, and they believed him, but they did not make follow up on whether he changed or not (P3, 38).*
>
> *What aggravates his behaviour is that he does not go for check-ups at the hospital. I wish nurses can come and inject him at home as they used to do previously. At that time, he used not to be admitted frequently compared to now. Nurses used to go to homes of mentally ill patients with medication (P5, 47).*

Participants revealed they do not receive sufficient support from health care professionals. When the care of MHCUs moved from the institution to home care, the responsibility to ensure that MHCUs adhere to medication and attend follow up visits at health care facilities fell to the caregivers. Family caregivers provided personal care and emotional support to the MHCUs (Neong & Rashid, 2018:12). However, family caregivers are untrained in health care matters, including caring for MHCUs and need support from health care professionals to help them care for their MHCUs.

Health care professionals should support family caregivers and provide them with information related to mental illness and how to resolve conflicts between them and MHCUs (Batra et al., 2018:60). In the current study, most family caregivers reported that health care professionals, especially nurses, do not support them. Nurses are essential members of a multi-disciplinary team. According to Delaney (2017:952), nurses are direct health care providers and constitute the largest share of the total accessible primary care workforce. Nurses provide both general and mental health care in rural and underserviced areas.

Furthermore, nurses are likely to work in more rural areas compared to other health care professionals (Chapman et al., 2018:44). Nurses are typically the first health care professionals MHCUs and family caregivers would meet. Harms et al. (2017:102) add that nurses see the MHCUs first and refer them to other health care professionals like the doctor, social worker and psychologists, among others.

Participants reported that previously, nurses used to go to the villages with mobile clinics. Those MHCUs who did not attend the mobile clinic were followed up at their homes, and treatment was given. This reduced re-hospitalisation rates and family caregivers felt supported by health care professionals. This finding is consistent with a study by Cheng et al. (2018:614), which found that home visits improve treatment adherence and reduce re-hospitalisation rates of MHCUs from 42,1 per cent to 11,6 per cent in Taiwan. However, nurses who were doing home visits experienced safety issues; they were harassed, verbally and physically abused by MHCUs. MHCUs homes are unpredictable and uncertain environment (Kim, Choi & Yoon 2020:3).

Family caregivers need support from health care providers on how family members can convince their MHCUs to adhere to follow-up visits. If MHCUs make consistent follow-up visits to the clinic and OPD, aggressive behaviour and re-hospitalisation rates will decrease. However, due to the lack of teamwork between health care professionals and family caregivers, they cannot share their frustrations and challenges in caring for their MHCUs. Similarly, family caregivers in Australia received less support from health care professionals to help their MHCUs change their unacceptable behaviours (Bailey et al., 2018:8).

#### *4.3.5.2 Poor support from family members*

Caring for MHCUs is a long-term responsibility. In most families, not all family members are directly involved in caring for the MHCU, and there is a particular family member, for example, the wife, mother or sister of the MHCU, who bears that responsibility. That family caregiver often feels emotionally exhausted and expects other family members to assist in the caring duties. However, their expectations are not met. This was evident in the following quotes:

> *He undermines us, especially his father who is also mentally ill. He says I must tell my husband to take his medication not him. If we had other family members staying with us,*

> *I think we would be able to manage him. Our families do not support us and we need them (P2, 59).*
>
> *We used to rely on our uncle, who used to come and calm him down. But since he assaulted him too, he is reluctant to help us. His aunt also does not want to be involved any more since he accused her of killing her husband. We have no one to assist us when he becomes aggressive (P3, 38).*
>
> *We stay being two, my younger brother died in 2015. My nephew is in Gauteng and married there. Around here, we have our aunt, but she is too old to help me. I have no one to assist me to look after my brother. I do everything for him (P4, 61).*
>
> *We are the only surviving siblings. Our parents, elder brother and younger sister have died. Because he fights with my wife, I am the only one who is responsible for his wellbeing. What can I do? I cannot abandon him; he is my blood. Our parents are watching everything I do. He is my responsibility (P9, 49).*
>
> *I stay with her and her younger sister's children. All my children are married they have their own homes. I try to talk to her, but she does not listen to me. Her brothers do not want to get involved anymore. They are tired of her behaviour. It is my responsibility, I too I am tired. At my age, I have no strength anymore (P10, 63).*

Family caregivers feel overwhelmed by the responsibility of caring for MHCUs alone in the family and need support from other family members. Teamwork in a family of caregivers can alleviate the burden carried by one caregiver. According to Caqueo-Urizar et al. (2017:3), having an MHCU in the family disrupts normal family dynamics with every family member affected in some way or the other. The family caregiver of the MHCU needs support to help with caring for the MHCU. In the current study, family caregivers did not receive support from other family members who did not want to be involved to assist or relieve the caregiver of some responsibilities. If family caregivers are not assisted, they will become stressed and possibly suffer from depression. It should be noted that in this study, some caregivers were elderly people who were more prone to physical and emotional exhaustion. In Malaysia, family caregivers of advanced age who had cared for the MHCUs for longer duration suffered from higher stress levels (Neong & Rashid, 2018:13).

In Singapore, single or widowed family caregivers faced more challenges due to the absence of a spouse who could offer support and share some of the distress. Spouses caring for a spouse who was an MHCU reported more psychological stress as they felt that they had lost a confidant, household co-manager and child-rearing assistant (Jeyagurunathan et al., 2017:7). It could be a similar situation in the current study since most family caregivers are single due to divorce, death of a spouse or never married Family cohesion is essential, especially to the family caregivers, as they would not bear the caring role alone. Support from within the family is crucial as caregivers can share their challenges without fear of being judged. However, in other families, there was a detachment of family members due to the existence of mental disorder within the family (Caqueo-Urizar et al., 2017:3). Furthermore, support from family members is an important element in the family's relationships. However, some family members looked down on family caregivers of MHCUs and did not visit them or express concern for them (Azman et al., 2017:6). Similarly, in this study, participants reported that they are not supported by their fellow family members in caring for the MHCUs in the family.

## 4.4 Summary

This chapter discussed data findings supported by literature control. Four themes emerged from the data analysis of the first question on the interview guide: non-adherence to medication, disruptive behaviour, emotional turmoil and interpersonal relations. One theme emerged from the second question, namely, poor support. Chapter 5 describes the summary, recommendations, conclusions and limitation of the study.

# CHAPTER 5

# SUMMARY, RECOMMENDATIONS, CONCLUSIONS AND LIMITATIONS

## 5.1 Introduction

The previous chapter discussed data analysis and literature control conducted. This chapter aims to provide a summary, recommendations, conclusions and limitations of the study.

## 5.2 Summary of the study

The study identified challenges faced by family caregivers of MHCUs and the support received from health care professionals in Thulamela Municipality, Limpopo Province.

## 5.3 Summary of chapters

### 5.3.1 Chapter 1

Chapter 1 introduced the study, including the background, problem statement, significance, purpose and objectives of the study. The study aimed to investigate the challenges faced by family caregivers of MHCUs, explore the challenges and identify the support given by health care professionals to family caregivers to assist them in caring for their MHCUs.

### 5.3.2 Chapter 2

Chapter 2 of this study described the details of the reviewed literature relevant to the study. The literature supported the background of the study regarding the challenges faced by family caregivers of MHCU's globally and the support they received from health care professionals.

### 5.3.3 Chapter 3

Chapter 3 described the research methodology used in this study. The qualitative approach, which is exploratory, descriptive and contextual in nature used in the current study, was described. The setting was Thulamela Municipality in Limpopo Province. The study population included ten family caregivers over 21 years of age caring for MHCUs for more than six months. The non-probability, purposive sampling method used to sample the study population was described. The data collection method used, which included individual face-to-face, in-depth interviews, and the measures taken to ensure trustworthiness and ethical aspects of the study were discussed.

### 5.3.4 Chapter 4

Chapter 4 focused on the research results. The study sought to investigate the challenges faced by family caregivers caring for MHCUs. The objectives of the study were to:

- Explore challenges faced by family caregivers of MHCUs
- Identify the support given to family caregivers by health care professional to assist them in caring for their MHCUs

The objectives of the study were met during data collection, which was conducted through in-depth face-to-face interviews. All the objectives of the study were achieved. Four themes with subthemes emerged as challenges faced by caregivers of MHCUs, namely, non-adherence to medication, disruptive behaviour, emotional turmoil and poor interpersonal relations. One theme and subthemes regarding the support family caregivers received from health care professionals also emerged.

### 5.3.5 Chapter 5

Chapter 5 focuses on the summary, recommendations and limitations of the study and conclusion. The recommendations regarding the alleviation of family caregivers' challenges caring for MHCUs and the support they need from health care professionals are described.

## 5.4 Themes and subthemes

The following themes and subthemes emerged as challenges faced by the caregivers of MHCUs and the support they received from health care professionals.

**Table 5.1: Themes and subthemes.**

| **Themes** | **Subthemes** |
|---|---|
| • Non-adherence to medication | 1.1 Poor insight into mental condition<br>1.2 Changes in medication.<br>1.3 Lack of transport to collect medication.<br>1.4 Inadequate supervision.<br>1.5 Substance use. |
| • Disruptive behaviour | 2.1 Destruction of property<br>2.2 Assaulting people.<br>2.3 Disruption of family functioning. |
| • Emotional turmoil | 3.1 Feeling emotionally drained and hopeless. |
| • Interpersonal relations | 4.1 Poor relations with family members.<br>4.2 Involvement in arguments and physical fights. |
| • Support system | 5.1 Poor support from health care professionals.<br>5.2 Poor family support. |

## 5.5 Recommendations

### 5.5.1 Recommendations for the nursing practice

The findings of the current study were that family caregivers were not receiving adequate support from health care professionals, including nurses. Of all health care professionals, nurses are the first ones the MHCUs and family caregivers will meet. Nurses are mostly accessible to MHCUs and their family caregivers on a frequent basis, whether in a hospital or local clinics. Therefore, based on the findings of the current study regarding the challenges faced by family caregivers caring for MHCUs, the following recommendations are made:

- Health care professionals should educate MHCUs and their family caregivers about mental illness and the importance of adhering to treatment.
- Health care professionals should inform MHCUs about the dangers of using substances like dagga and alcohol as they interfere with the therapeutic actions of treatment.
- Health care professionals to effectively communicate any changes made to the treatment regimen with the MHCUs and family caregivers to prevent non-compliance to medication.
- Nurses to advocate for MHCUs by encouraging doctors at local hospitals to refer treatment compliant MHCUs to local clinics to minimise non-compliance due to lack of transport fare.
- Family caregivers to be taught how to supervise MHCUs regarding taking treatment effectively. All family members to be encouraged to be part of MHCU’s support system.
- Family caregivers to be encouraged to institute criminal cases against MHCUs who commit criminal acts like damage to property and assault. This will deter MHCUs from using violence to have their demands met.
- Family caregivers to be encouraged to seek help from health care professionals when their mental health is affected by the burden of caring for their MHCUs. When they feel depressed or emotionally drained, they must seek medical help as soon as possible.
- Health care professionals to provide emotional support to family caregivers of MHCU through mental health awareness campaigns for family caregivers, teaching problem-solving and coping skills. MHCUs should not be the only focus for health care professionals during follow-up visits at hospitals and clinics as it is essential that other family members, particularly the caregivers, be given support.
- Nurses to screen family caregivers during follow up visits who need a referral to a psychologist for counselling. A health care professional should conduct family therapy for family caregivers and other family members to enhance cohesion and teamwork.

- Local clinics to initiate community outreach activities regarding mental health matters through the involvement of Community Health Workers (CHW).

### 5.5.2 Recommendation for nursing education

During their training, professional nurses are taught psychiatric nursing science, where they are taught types of mental illnesses, clinical manifestations and management thereof. However, in practice MHCUs and their family caregivers are attended to by all nursing categories, for example, enrolled and assistant nurses. Based on the findings of this study, the following recommendations are made:

- Staff and Assistant nurses to be trained in elementary psychiatric nursing science where they learn the identification of the symptoms of psychosis.
- Staff and Assistant nurses to be involved in family therapy sessions to help them understand the importance of support to family caregivers of MHCUs.

### 5.5.3 Recommendation for further research

Based on the findings of the study, research on the challenges faced by family caregivers of MHCUs can be repeated using a quantitative study involving a larger population in the province. The findings could assist in the development of a model to support family caregivers in caring for MHCUs.

## 5.6 Limitations of the study

The current study was based at Thulamela Municipality, a largely rural area. The study's findings are based on a purposefully selected sample which does not represent the views of all family caregivers. The findings of family caregivers in an urban area may differ from the findings of this study.

## 5.7 Conclusions

The current study revealed the various challenges faced by family caregivers at Thulamela Municipality, Limpopo province. Caring for MHCUs has challenges for family caregivers who are untrained in caring for MHCUs. However, as they are the support system of the MHCUs, they find themselves compelled to play a caring role.

In their efforts, family caregivers need the support of health care providers to enable them to achieve their caring roles. The current study revealed the challenges family caregivers face and how health care providers can support them.

## 5.8 Summary

This chapter summarised the results of the study. It described the recommendations for the nursing practice, education and further research, the limitations of the study and conclusions.

# LIST OF REFERENCES

Adeosun, I. I. (2017) Are depot anti-psychotics associated with longer persistence in treatment compared with oral antipsychotic among patients with Schizophrenia, *Journal of Pharmaceutical Research Internationa*l, 18 (3), 1–8.

Adnanes, M., Creswell-Smith, J., Melby, L., Westerlund, H., Sprah, L., Sfectu, R., Strabmayr, C. & Donisi, V. (2020) Discharge planning, self-management and community support: Strategies to avoid psychiatric re-hospitalization from a service user perspective, *Patient Education and Counselling*, 103, 1033–40.

Akbari, M., Alavi, M., Irajpour, A. & Maghsoudi, J. (2018) Challenges of family Caregivers of Patients with Mental Disorders in Iran: A narrative Review, *Iranian Journal of Nursing and Midwifery Resear*ch, 23(5), 329–37.

Alzahrani, S.H., Fallata, E.O., Alabdulwahab, M.A., Alsafi, W.A. & Bashawri, J. (2017) Assessment of the burden on caregivers of patients with mental disorders in Jeddah, Saudi Arabia, *BMC Psychiatry*, 17, 202.

Amell, R.C., Cobo, J., Castanyeri, M.M. & Gomez, N.G. (2018) Gender and other factors influencing the burden of care in relatives of people diagnosed with schizophrenia spectrum disorders, *International Journal of Culture and Mental Health*, 11(4).

Asalem, M.S. (2017) Psychotropic medication non-adherence among psychiatric patients at King Abdulaziz Hospital-Makkah, *International Neuropsychiatric Disease Journal,* 10(2), 1–11.

Ata, E.E. & Dogan, S. (2018) The effects of brief cognitive behavioural stress management programme on mental status, coping with stress, attitude and caregiver burden while caring for schizophrenic patients, *Archive of Psychiatric Nursing*, 32, 112–19.

Azman, A., Singh, P.S.J. & Sulaiman, J. (2017) The mentally ill and their impact on family caregivers: a qualitative case study, *International Social Work*, 1–11.

Badu, E., O'Brien, A.P. & Mitchell, R. (2018) An integrative review of potential enablers and barriers to accessing mental health services in Ghana, *Health Research policy and systems*, 16, 110.

Bailey, J.M., Hansen, V., Wye, P.M., Wiggers, J.H., Bartlem, K.M. & Bowman, J.A. (2018) Supporting change in chronic disease risk behaviours for people with a mental illness: a qualitative study of the experiences of family carers. *BMC Public Health*, 18, 416.

Balthazar, N., Xiaoming, X., Li, X., Suman, R.K., Edmond, N. & Gaspard, U. (2020) Psychological challenges encounters by family caregivers of psychiatric illness in Chinese Community: A narrative review study, *Mental Health and Family Medicine*, 16, 957–65.

Batra, B.S., Saoji, A.M., Batra, S. & Batra, D.S. (2018) Effects of family psycho education on knowledge, quality of life, expressed emotions, burden of disease and coping among caregivers of patients with schizophrenia, *IOSR Journal of Dental and Medical Sciences*, 17(8), 59–73.

Bertram, C. & Christiansen, I. (2014) *Understanding research: An introduction to reading research*. Hatfield: Van Schaik.

Babbie, E. (2012) *The basics of social research*. 6th ed. Wadsworth: Cengage Learning.

Brain, C., Kymes, S., Dibenedetti, D.B., Brevig, T. & Velligan, D.I. (2018) Experiences, attitude and perceptions of caregivers of individuals with treatment resistant schizophrenia: a qualitative study, *BMC Psychiatry*, 18, 253.

Brink, H., Van der Walt, C. & Van Rensburg, G. (2012) *Fundamentals of Research Methodology for health care professionals*. 3rd ed. Cape Town: Juta

Bukhari, S.R., Abbasi, U.Z., Ghani, M.U., Ashraf, W. & Afzal, A. (2020) Quality of life and caregiver burden among caregivers of patients with psychiatric disorders, *Rawal Medical Journal*, 45(3), 565–68.

Burns, N., Grove, S.K. & Gray, J.R. (2015) Understanding Nursing Research. Building an evidence-based practice.6th ed. Missouri: Elsevier.

Caqueo-Urizar, A., Alessandrini, M., Urzula, A., Zendjidjian, X., Boyer, L. & Williams, D.R. (2017) Caregiver's quality of life and its positive impact on symptomatology and quality of life of patients with schizophrenia, Health and Quality of Life Outcomes, 15, 76.

Caqueo-Urizar, A., Rus-Calafell, M., Craig, T.K.J., Irarrazavali. M., Urzua, A., Boyer, L et al. (2017) Schizophrenia: Impact on Family Dynamics, Current Psychiatry Reports, 19, 2.

Chapman, S.A., Phoenix, B.J., Hahn, T.E. & Strod, D.C. (2018) Utilization and economic contribution of psychiatric mental health nurse practitioners in public behavioural health sciences, *American Journal of Preventative Medicine*, 54(3), 243–49.

Chen, L., Zhao, Y., Tang, J., Jin, G., Liu, Y., Zhao, X., Chen, C. & Lu, X. (2019) The burden support and needs of primary family caregivers of people experiencing schizophrenia in Beijing communities: a qualitative study, BMC Psychiatry, 19, 75.

Cheng, C, Chan, C.W.T, Gula, C.A. & Parker, M.D. (2017) Effects of outpatient aftercare on psychiatric rehospitalisation among children and emerging adults in Alberta, Canada, *Psychiatric Services*, 68, 696–703.

Creswell, J.W. (2012) *Research design: Qualitative, quantitative and mixed methods approaches*. 4th ed. California: Sage.

Creswell, J.W. & Creswell, J.D. (2017) *Research design: Qualitative, quantitative and mixed methods approache*s. 5th ed. Los Angeles: Sage.

Delaney, K.R. (2017) Psychiatric mental health nursing advanced practice workforce: capacity to address shortages of mental health professionals, *Psychiatric Services*, 68(9), 952–54.

De las Cuevas, C., De Leon, J,. Penate, W. & Betancort, M. (2017) Factors influencing adherence to psychopharmacological medications in psychiatric patients: a structural equation modeling approach, *Patient Preference and Adherence*, 11, 681–90.

Den Hertog, T.N. & Gilmoor, A.R. (2016) Informal care for people with chronic psychotic symptoms: Four case studies in a San community in South Africa. *Health and Social Care in the communit*y, 25(2), 538–47.

De Vos, A.S., Strydom, H, Fouche, C.B. & Delport, C.S.L. (2011) *Research at grassroots for the social sciences and humans service professions*. 4th ed. Hatfield: Van Schaik.

Dice, F & Zoena, F. (2017) Loneliness and family burden: An exploratory investigation on the emotional experiences of caregivers of patients with severe mental illness, *The Qualitative Report*, 22(7), 1781–91.

Du Plessis, J. (2019) Family members experience of non-compliance to psychiatric medication by adult females living with depression, unpublished master's thesis, University of Johannesburg.

Ebrahim, O.S., Al-Atta, G.S.T., Gabra, R.H. & Osman, D.M.M. (2020) Stigma and burden of mental illness and their correlates among family caregivers of mental ill patients, *Journal of Egyptian Public Health Association*, 95, 31.

Fekadu, W., Mihiretu, A., Craig, T.K.J. & Fekadu, A. (2019) Multidimensional impact of severe mental illness on family members: systematic review, British Medical Journal Open, 9.

Fitryasari, R., Yusuf, A., Tristiana, R.D., & Nihayati, H.E. (2018) Family members' perspective of family resilience's risk factors in taking care of schizophrenia patients, *International Journal of Nursing Sciences,* 5(3), 255–61.

Foglia, E., Schoeler, T., Klamerus, E., Morgan, K. & Bhattacharyya, S. (2017) Cannabis use and adherence to antipsychotic medication: a systematic review and meta-analysis psychological medicine, *Psychological Medicine*, 47(10), 1691–705.

Franza, F. (2019) The emotional and psychological burden of the ''burnout'' in the families of psychiatric patients, *Psychiatria Danubina*, 31(3), 438–42.

Gloria, O., Osafo, J., Goldmann, E., Parikh, N.S., & Nonvignon, J. & Kretchy, I.M.A. (2018) The experiences of providing caregiving for patients with schizophrenia in Ghanaian context, *Archives of Psychiatric Nursing,* 32, 815–22.

Grant, A., Goodyear, M., Maybery, D. & Reupert, A. (2016). Differences between Irish and Australian Psychiatric Nurses' family-focused practice in adult mental health services, *Archives of Psychiatric Nursing*, 30(2), 132–37.

Grove, S.K., Burns, N. & Gray, J.R. (2013) The practice of nursing research. Appraisal, synthesis and generation of Evidence.7th ed. Missouri: Elsevier.

Grove, S.K., & Gray, J.R. 2019. Understanding nursing research: Building an evidence-based practice.7th ed. Missouri: Elsevier.

Gyamfi, S., Hegadoren, K. & Park, T. (2018) Individuals factors that influence experienc4es and p4erceptions of stigma and discrimination towards people MI in Ghana. *International Journal of Mental Health Nursing*, 427(1), 368–77.

Harms, M., Haas, M., Larew, J., & DeJongh, B. (2017) Impact of a mental health clinical pharmacist on primary care mental health integration team, *Review Health Clinician*, 7(3),101–05.

Hajisadeghian, R., Ghezelbash, S. & Mehrabi, T. (2021) The effects of a psychosocial support on perceived stress of family caregivers of patients with mental disorders, *Iranian Journal of Nursing and Midwifery Research*, 26(1), 47–53.

Hender, R., Kidia, K., Machado, D. & Crooks, M. (2016) 'We are not really marketing mental health': mental health advocacy in Zimbabwe, accessed 10 May 2018 from Journals.plos.org

Hernandez, M., & Barrio, C. (2017) Families and medication use and adherence among Latinos with schizophrenia, *Journal of Mental Health*, 26(1), 14–20.

Hodgins, S., & Klein, S. (2017) New clinically relevant findings about violence by people with schizophrenia, *The Canadian Journal of Psychiatry*, 62(2), 86–93.

Holis, W., Yusuf, A & Suhardiningsih, A.S. (2019) Illness-related stigma of family caregiver living with mental illness in Pamekasan, Indonesia: A qualitative study. 44 *International Journal of Nursing and Health Services*, 3(3), 424–29.

Inogbo, C.F., Olotu, S.O., James, B.O. & Nna, E.O. (2017.)Burden of care amongst caregivers who are first degree relatives of patients with schizophrenia, *Pan African Medical Journal*, 28(1).

Iseselo, M.K. & Ambikile, J.S. (2017) Medication challenges for patients with severe mental illness: experience and views of patients, caregivers and mental health care workers in Dar es Salaam, Tanzania. *International Journal of Mental Health System* 11,17.

IIseselo, M.K., Kajula, L. & Yahya-Malima, K.I. (2016) The psychosocial problems of families caring for relatives with mental illness and their coping strategies: a qualitative urban based study in Dar es Salaam, Tanzania, *BMC Psychiatry*, 16,146.

Ivan Vun, J.S., Cheah, W.L. & Helmy, H. (2019) Mental Health status and its associated factors among caregivers of psychiatric patients in Kuching, Sarawak, Malays Family Physician, 14(2): 18-25.

Janse Van Rensburg, A. & Fourie, P. (2016) Health policy and integrated mental health care in SADC region: strategic clarification using rainbow model, accessed on 10 April 2018 from https://ijmhs.biomedicalcentral.com.

Jawad, I., Watson, S., Haddad, P.M., Talbot, P.S. & McAllister-Williams, R.H. (2018) Medication non-adherence in bipolar disorder: a narrative review, The Therapeutic Advances in Psychopharmacology, 8(12), 349–63.

Jenkins, J.H. & Schumacher, J.G. (2018) Family burden of schizophrenia and depressive illness, *British Journal of Psychiatry*, 174(01), 31–38.

Jeyagurunathan, A., Sagayadevan, V., Abdin, E., Zhang, Y., Chang, S., Shafie, S., Rahman, R.F.A., Vaingankar, M., Chong, S.A. & Subramaniam, M. (2017)

Psychological status and quality of life among primary caregivers of individuals with mental illness, *Health and Quality of Life Outcomes*, 15, 106.

Kokanovic, R., Brophy, L., McSherry, B., Flore, J., Moeller-Satone & Herraman, H. (2018) Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners, *Australian & New Zealand Journal of Psychiatry*, 52(9), 826–33.

Kpobi, L.N.A. & Swartz, L. (2018) 'The threads in his mind have torn': conceptualization and treatment of mental disorders by neo-prophetic Christian healers in Accra, Ghana, *International Journal of Mental Health Systems*, 12, 40

Kretchy, I.A., Osafo, J., Agyemang, S.A., Appiah, B. & Nonvigon, J. (2018) Psychological burden and caregiver-reported non-adherence to psychotropic medication among patients with schizophrenia, *Psychiatric Research*, 259, 289–94.

Labrum, T.L., Zingman, M.A,. Nossel, I. & Dixon, L. (2021) Violence by persons with severe mental illness towards family caregivers and other relatives: A review, *Harvard Review of Psychiatry*, 29(1).

Las Cuevas, C.D., Motuca, M., Baptista, T. & De Leon, J. (2018) Skepticism and pharmacophobia towards medication may negatively impact adherence to psychiatric medication: a comparison amongst Out-Patients samples recruited in Spain, Argentina and Venezuela, *Patient Preference and Adherence*, 12, 301–10.

Leavy, P. (2017) *Research design quantitative, qualitative, mixed methods, art-based and community based participatory research approaches*. New York: The Guilford Press.

Leech, R. & Dolamo, G.K. (2016) Challenges experience by caregivers of family members with mental illness in a rural community, accessed 15 May 2018 from https://nursinglibrary.org

Lekoadi, R.G., Poggenpoel, M., Temane, M.A. & Myburgh, C.P.H. (2019) Lived experiences of family members caring for individuals living with Bipolar disorder, *African Journal of Nursing and Midwifery*, 21(1), 1–9.

Leng, A., Xu, C., Nicholas, S., Nicholas, J. & Wang, J. (2019) Quality of life in caregivers of a family member with serious mental illness: Evidence from China, *Archives of Psychiatric Nursing*, 33, 23–29.

Lippi, G. (2016) Schizophrenia in a member of the family: Burden expressed emotion and addressing the needs of the whole family, South African Journal of Psychiatry, 22(1).

Littlewood, R & Dein, S. (2016) Carers and families: life and suffering amongst Bangladeshi psychiatric patients and their families in London – an interview study. *Anthropology and Medicine Journal* 25(1), 54–70.

Luo, H., McNeil, E.B., Feng, O., Li, H., Chen, Q., Qin, X,. Feng, J. & Assanangkornchai, S. (2018) Utilization of psychiatric rehabilitation services and influencing factors among people with psychotic disorders in rural communities of Guangxi, China, *International Journal of Mental Health Systems*, 12,17.

Mahesh, K.H.D., Weerasundera, R., Morrissey, H., Ball, P.A. & Subasinghe, H.W.A.S. 2018. Comparison of relapse rates of depot and oral antipsychotics in patients with schizophrenia, *International Journal of Current Medical and Pharmaceutical Research* 4(1), 1451–57.

Marimbe, B.D., Cowan, F., Kajawu, L., Muchirahondo, F. & Lund, C. (2016) Perceived burden of care and reported coping strategies and needs for family caregivers of people with mental disorders in Zimbabwe, *African Journal of Disability*, 5(1), 1–9.

Markiewicz, I., Pilszyk, A. & Kudlak, G. 2020. Psychological factors of aggressive behaviour in patients of forensic psychiatry wards with the diagnosis of schizophrenia, *International Journal of Law and Psychiatry*, 72.

McIntosh, C. (Ed.). (2017) Cambridge Advanced Learner's Dictionary. 4th ed. Cambridge: Cambridge: University Press.

Mehra, A., Kumar, A., Grover, S., Charkrabarti, S. & Avasthi, A. (2020) Relationship of stigma with burden for coping among caregivers of patients with severe mental disorders, *Indian Journal of Social Psychiatry*, 36(1), 11–18.

Mehralian, G., Sharif, Z. & Abbasian, G. (2019) Medication adherence in patients with psychotic disorder in Tehran, Journal of pharmaceutical Health Services Research, 10, 347–52.

Mohammed, S.F.M. & Ghaith, R.F.A.M. (2018) Relationship between burden, psychological wellbeing and social support among caregivers of mentally ill patients, *Egyptian Nursing Journal*, 15(3), 268–80.

Mohamed, S., Johnson, G.R., Chen, P., Hicks, P.B., Davis, L.L., Yoon, J., Gleason, T.C., Vertrees, J.E., Weingart, K., Tal, I., Scrymgeour, A., Lawrence, D.D., Planeta, B., Thase, M.E., Huang, G.D. & Zisook, S. (2017) Effect of antidepressant switching vs augmentation on remission among patients with major depressive disorder unresponsive to antidepressants treatment: The VAST-D randomized Clinical Trial, *Journal of American Medical Association*, 318(2), 132–45.

Mohr, P., Knytl, P., Vorackova, V., Bravermanova, A. & Melicher, T. (2017) Long-acting injectables antipsychotics for prevention and management of violent behaviour in psychiatric patients, *International Journal of Clinical Practice*, 71.

Molepo, M.M. & Mfid, F.H. (2020) Lived experiences of young people who live with mental healthcare users in Limpopo, South Africa. *African Journal of Nursing and Midwifery*, 22(2), 1–11.

Mulud, Z.A. & McCarthy, G. (2017) Caregiver burden among caregivers of individuals with severe mental illness: Testing the moderation and mediation models of resilience, *Archives of Psychiatric Nursing*, 31, 24–30.

Nayak, M.R., Mallik, T, Hembram, S. & Dash, M. 2020. Perceived family burden among the male and female caregivers of schizophrenia patients – A comparative study in Eastern India, *International Journal of Research and Review*, 7(1), 93–100.

Ndikuno, C., Namutebi, M., Kuteesa, J., Mukunga, D. & Olwit, C. (2017) Quality of life caregivers of patients diagnosed with severe mental illness at the national referral hospitals in Uganda, *BMC Psychiatry*, 16, 400.

Nenobais, A., Jatimi, A. & Jufriyanto, M.Z. (2019) Family Burden for Caregivers of People with Mental Disorder: A systemic Review. *Journal of Nursing Sciences*, 14(3).

Neong, S.C. & Rashid, A. (2018) Quality of life of caregivers of patients with psychiatric illness in Penang. *Journal of Clinical Psychiatry Cognitive Psychology*, 2(1), 12–18.

Niksalehi, S., Namazi, S., Tashk, M., Bavaghar, S., Adandi, M. & Jamalizadeh, F. (2019) Impact of family psycho-education intervention on relapse prevention in hospitalized psychiatric patients, *Hormozgan Medical Journal*, 23(4).

Ntsayagae, E.I., Poggenpoel, M. & Myburgh, C. (2019) Experiences of family caregivers of persons living with mental illness: A meta-synthesis, *Curationis,* 42(1).

Nxumalo, C.T. & Mchunu, G.G. (2017) Exploring the stigma related experiences of family members of persons with mental illness in a selected community in the iLembe district, KwaZulu-Natal, *Health SA Gesondheid*, 22, 202–12.

Olagundoye, O., Akhuemokhan, V. & Alugo, M. (2017) Towards caring for caregivers: assessing the burden of care and experience of associative stigma among caregivers of patients with chronic mental illness at a mental health care facility in Lagos Metropolis, Nigeria, *Family Medicine & Primary Care Review*, 19(2), 149–55.

Olawande, T.I., Ajayi, M.P., Amoo, E.O. & Iruonagbe, C.T. (2019) Variations in family attitudes towards coping with people living with mental illness, *Macedonian Journal of Medical Sciences*, 7(12), 2010–16.

Ong, H.L., Vaingankar, J.A., Abdin, E., Sambasivam, R., Fauziana, R., Tan, M., Chong, S.A., Goveas, R.R., Chiam, P.C. & Subramaniam, M. (2018) Resilience and burden in caregivers of older adults: moderating and mediating effects of perceived social support. *BMC Psychiatry,* 18, 27.

Opare, F.Y., Adafara, P., Kuug, A., Nyande, F., Apaanye, M.A., Achaliwie, F. & Ninnoni, J.P.K. (2016) As I see it: the cry of the community psychiatric nurse in Ghana, *Pyrex Journal of Nursing and Midwifery*, 2(2), 7–15.

Opoku-Boateng, Y.N., Kretchy, I.A., Aryeetey, G.C., Dwomoh, D., Decker, S., Agyemang, S.A., Tozan, Y., Aikins, M. & Nonvignon, J. (2017) Economic cost and quality of life of family caregivers of schizophrenic patients attending psychiatric hospitals in Ghana, *BMC Health Services Research*, 17(2), 697.

O’Reilly, C.L., Paul, D., McCahon, R., Sharkar, S., Rosen, A. & Ramzy, T. (2019) Stigma and discrimination in individuals with severe and persistent mental illness in an assertive community treatment team: Perceptions of families and health care professionals, International Journal of Social Psychiatry, 65(7-8), 570-579.

Ortiz, G. (2019) Predictors of 30-days post discharge readmission to multistage national sample of state psychiatric hospitals, *Journal for Healthcare Quality,* 41(4): 228–36.

Ozen, M.E., Orum, M.H. & Kalenderoglu, A. (2018) The burden of schizophrenia on caregivers, *Psychiatry and Behavioral Sciences*, 8(3).

Polit, D.F. & Beck, C.T. (2017) Nursing Research: Generating and assessing evidence for nursing practice.10th ed. Philadelphia: Wolters Kluwer.

Punsawat, M., Inchaithep, S. & Lorga, T. (2017) Relating, realizing, repeating and reinventing: Experiences of psychiatric patients and family caregivers in Thai rural community: 2017 ANPOR ANNUAL conference, Thailand, 2017, pp. 481–90.

Rababa’h, S.Y.A.A., Yousef, F.N.M. & Al-Omari, A.A.R. (2017) Predictors of non-adherence in patient taking psychotropic medication and suggestions to improve, *Journal of Health, Medicine and Nursing*, 38, 73–84.

Ramezani, A., Lolaty, H.A., Bastani, F. & Haghani, H. (2018) Family caregivers burden and its related factors among Iranian elderly psychiatric patients’ caregivers, *Iran Journal of Psychiatry Behavioral Sciences*, 12(2).

Reong, A.R. & Astuti, R.P. (2019) Stigma in family patients who have psychiatric disorders: a systematic review, *Journal of Nursing Sciences,* 14(3), 86–90.

Riley-McHugh, D, Brown, C.H. & Lindo, J.L.M. 2016. Schizophrenia: its psychological effects on family caregivers, *International Journal of Advanced Nursing Sciences*, 5(1), 96–101.

Roberts, J., Canales, A., Blanthorn-Hazell, S., Boldeanu, A.C., & Judge, D. (2018) Characterizing the experience of agitation in patient with bipolar disorder and schizophrenia, *BMC Psychiatry*, 18,104.

Sahile, Y., Yitayih, S., Yeshanew, B., Ayelegne, D. & Mihiretu, A. (2019) Primary health care nurses attitude towards people with severe mental disorders in Addis Ababa, Ethiopia: a cross sectional study*, International Journal of Mental Health Systems*, 13, 26.

Salloum, I.M. & Brown, E.S. (2017) Management of comorbid bipolar disorder and substance use disorders, *American Journal of Drug and Alcohol Abuse*, 43(4), 366–76.

Sfetcu, R., Musat, S,. Haaramo, P., Ciutan, M., Scintee, G., Vladescu, C,. Wahlbeck, K. & Katschnig, H. (2017) Overview of post-discharge predictors for psychiatric re-hospitalisations: a systematic review of the literature, *BMC Psychiatry*, 17, 227.

Shamsaei, F., Nazari, F. & Sadeghian, F. (2018) The effects of training intervention of stigma associated with mental illness of family caregivers: a quasi experimental study, *Annals of General Psychiatry,* 17, 48.

Sharma, N., Chakrabarti, S. & Grover, G. (2016) Gender differences in caregiving among family caregivers of people with mental illness, *World Journal of Psychiatry*, 6(1), 7–17.

Sharma, R., Sharma, S.C. & Pradhan, S.N. (2017) Assessing Caregiver Burden in caregivers of patients with Schizophrenia and Bipolar Affective Disorder in Kathmandu Medical College. *Journal of Nepal Health Research Council*, 15(37), 258–63.

Sibeko, G., Temmingh, H., Mall, S., Williams-Ashman, P., Thornicroft, G, Susser, E.S., Lund, C., Stein, D.J. & Milligan, P.D. (2017) Improving adherence in mental health service users with severe mental illness in South Africa: a pilot randomized controlled trial of a treatment partner and text message intervention vs. treatment as usual, *BMC Research Notes*, 10, 584.

South Africa, Republic. 2002. Mental Health Care Act (Act no.17 of 2002). Cape Town: Government printers.

Souza, A.L.R., Guimaraes, R.A., de Araujo Vilela, D., de Assis, R.M., de Almeida Cavalante Oliveira, L.M.A.C., Souza, M.R., et al. (2017) Factors associated with the burden of family caregivers of patients with mental disorders: a cross-sectional study, *BMC Psychiatry*, 17, 353.

Spittelis, Maier, A .& Kraus, E. (2019) Awareness challenges of mental health disorders and dementia facing stigmatization and discrimination: a syst4ematic literature review from sub-Sahara Africa. *Journal of Global Health*, 9(2).

Stentzal, U., Van Den Berg, N., Schulze, L.N., Schwaneberg, T., Radicke, F., Langosch, J.M., Freyberger, H.J., Hoffmann, W. & Grabe, H. (2018) Predictors of medication adherence among patients with severe psychiatric disorders: findings from the baseline assessment of a randomized controlled trial, *BMC Psychiatry*, 18, 155.

Tareke, M., Tesfaye, S., Amare, D., Belete, T. & Abate, A. (2018) Antipsychotic medication non-adherence among schizophrenia patients in central Ethiopia, *South African Journal of Psychiatry*, 24(0).

Tiihonen, J., Mittendorfer-Rutz, E., Majak, M., Mehtala, J., Hoti, F., Jedenius, E., Enkusson, D., Leval, A., Sermon, J., Tanskanen, A. & Taipato, H. (2017) Real-World effectiveness of antipsychotic treatment in a nationwide cohort of 29823 patients with schizophrenia, *Journal of American Medical association*, 74(7): 686–93.

Townsend, M.C. (2015) Psychiatric mental health nursing: concepts of care in Evidence based practice. 8th ed. Philadelphia: F.A. Davis Company.

Tyler, N,. Wright, N. & Waring, J. (2019) Interventions to improve discharge from acute adult mental health impatient care to the community: systematic review and narrative synthesis, *BMC Health Services Research*, 19, 883.

Van der Sanden, R.L.M., Pryor, J.B., Stutterheim, S.E., Kok, G. & Bos, A.E.R. (2017) Stigma by association and family burden among family members of people with mental illness: the mediating role*, Social Psychiatry and Psychiatric Epidemiology* 51(9),1233–45.

Velligan, D.I., Sajatovic, M., Hatch, A., Kramata, P. & Docherty, J.P. (2017) Why do psychiatric patients stop antipsychotic medication? A systematic review of reasons of non-adherence to medication in patients with serious mental illness, *Patient Preference and Adherenc*e, 11, 449–68.

Walke, S.C., Chandrasekaran, V, & Mayya, S.S. (2018) Caregiver burden among caregivers of mentally ill individuals and their coping mechanisms, *Journal of Neurosciences in Rural Practice*, 9(2), 180–85.

Zhang, Y., Subramaniam, M., Lee, S.P., Abdin, E., Sagayadevan, V., Jeyagurunathan, A., Chang, S., Shafie, S.B., Rahman, R.F.A., Vaingankar, J.A. & Chong, S.A. (2018) Affiliate stigma and its association with quality of life among caregivers of relatives with mental illness in Singapore, *Psychiatry Research,* 265, 55–61.

## ANNEXURE A: Data Collection tool (Interview guide)

The data collection tool had two sets of questions namely biographic and study’s objectives questions.

(A) Biographic questions.

- How old are you?
- How long had you cared for your relative with mental illness?

(B) Study’s objectives questions.

- What are the challenges you face in caring for your mental ill relative?

- What kind of support do you receive from health care professionals to assist you in caring for your mental ill relative?

## ANNEXURE B: LETTER OF INFORMATION

**Title of the Study**: Challenges faced by family caregivers of Mental Health Care Users in Thulamela Municipality, Limpopo Province.

**Principal Investigator/s/ researcher** : M.N. Raluthaga

**Supervisor** : Professor N.H. Shilubane
**Co-Supervisor** : Dr S.A. Mulondo

**A brief Introduction and Purpose of the Study:** The South African government, like most governments has adopted community-based care of mental ill people. The responsibility of caring for Mental Health Care User (MHCU) rests with family members including children of the MHCUs. The caregivers are not trained to provide psychiatric care. The purpose of the study is to investigate the challenges faced by family caregivers of MHCUs in the Thulamela Municipality, Limpopo Province, South Africa.

**Outline of the Procedures**: The researcher will make appointments with individual participants in advance to set the date, time and venue for the interview. Prior to the commencement of the interview, the researcher will explain the ethical issues regarding their participation in the research, and then the participants choose to sign or not to sign the consent form. The researcher will also ask the interviewees for permission to record the interview proceedings. Once permission is granted, an audio tape will be used. The researcher will collect data through semi-structured interview. This will give participants an opportunity to narrate and explain the challenges they face in caring for MHCU. An interview guide with two questions will be used for all the participants. Then probing questions will be asked, determined by the response from the participants. An interview session will last for 30-45minutes. This study will focus only on family caregivers who have been caring for MHCUs for at least 6 months.

**Risks or Discomforts to the Participant**: No invasive procedures will be done to the participants.

**Benefits**: MHCU may benefit when their family caregivers improve the manner in which they provide care to them. The relapse rates of MHCU may be reduced and the workload be reduced at local hospitals. Stable MHCUs may contribute positively to the development of their communities. Community members will be safe from relapsed and disruptive MHCUs.

**Reason/s why the Participant May Withdraw from the Study**: The participant has the right to withdraw at any stage of the research if he/she wishes to do so. There is no harm or threats expected in participating or withdrawing from the study.

**Remuneration:** No remunerations will be offered.

**Costs of the Study:** Participants will not be expected to pay anything towards the study.

**Confidentiality:** To ensure confidentiality, the interview will take place in a quiet private place. Your anonymity will also be safeguarded by using pseudo names throughout the study. No information will be linked to your name.

**Research-related Injury**: In case of research related injury, the researcher will withdraw the participant from the study, refer him or her to the nearest clinic, report to my supervisors at Univen and ask for assistance. No compensation is available.

Persons to Contact in the Event of Any Problems or Queries:

Please contact the researcher MN Raluthaga at (079 3088 438) my supervisor Professor N.H. Shilubane at (082 536 7441) or the University Research Ethics Committee Secretariat on 015 962 9058. Complaints can be reported to the Director: Research and Innovation, Prof GE Ekosse on 015 962 8313 or Georges Ivo.Ekosse@univen.ac.za

**CONSENT**

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, MN Raluthaga about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: SHS/19/PDC/43/0811

- I have also received, read and understood the above written information (*Participant Letter of Information*) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis, will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

Full Name of Participant Date Time Signature

**I,…………………………. ……………. ………. …………..**

MN Raluthaga herewith confirm that the above participant has been fully

Informed about the nature, conduct and risks of the above study.

Full Name of Researcher

**…………………….** Date**……………….** Signature**………………**

Full Name of Witness (If applicable)

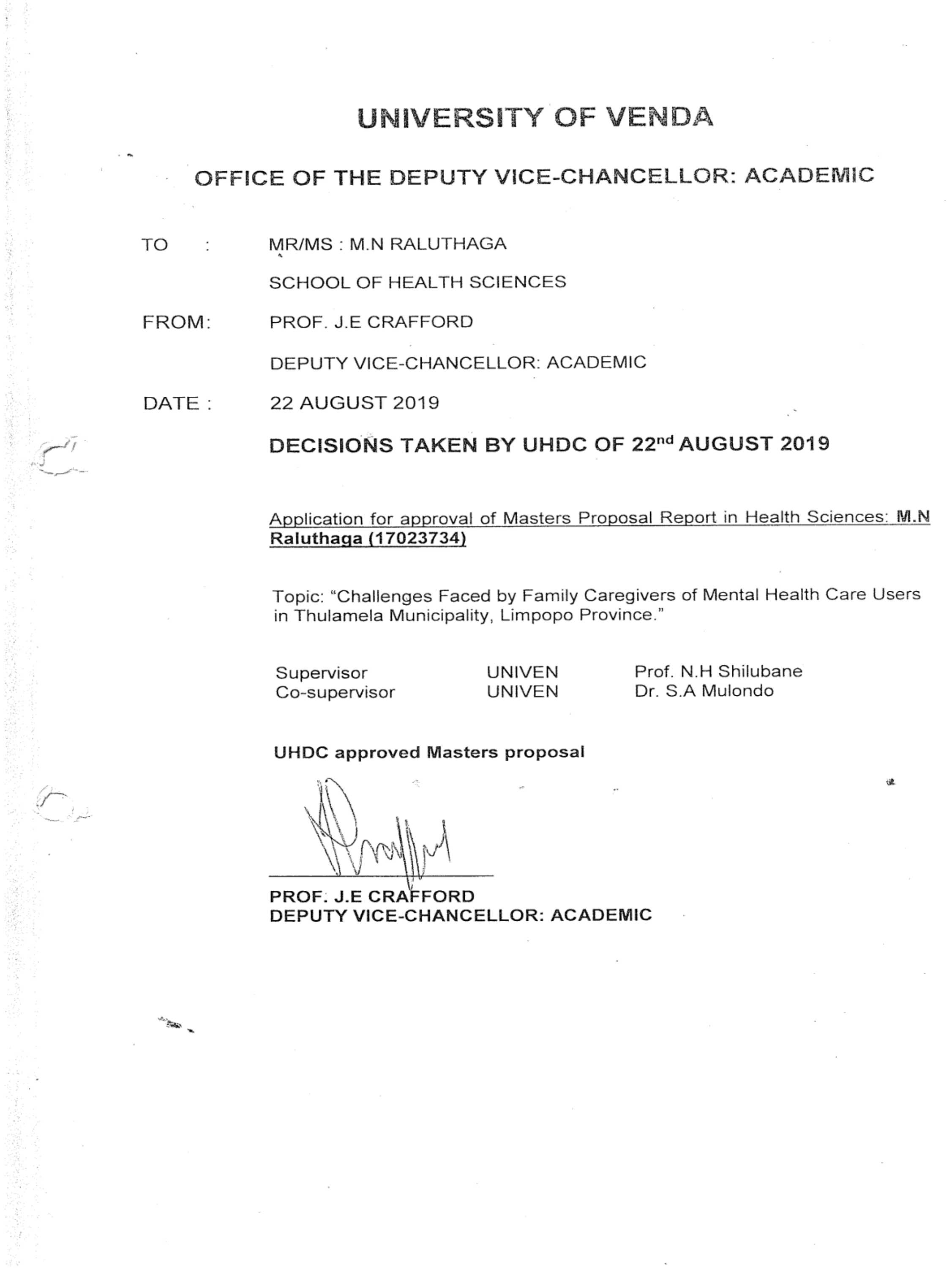
**…………………….** Date **……………….**

Signature**…………………..**

Full Name of Legal Guardian (If applicable)**…………………………………**Date**………………**

Signature**…………………….**

## ANNEXURE C: Approval letter from Univen UHDC



### UNIVERSITY OF VENDA

### OFFICE OF THE DEPUTY VICE-CHANCELLOR: ACADEMIC

TO : MR/MS : M.N RALUTHAGA
SCHOOL OF HEALTH SCIENCES

FROM: PROF. J.E CRAFFORD
DEPUTY VICE-CHANCELLOR: ACADEMIC

DATE : 22 AUGUST 2019

**DECISIONS TAKEN BY UHDC OF 22nd AUGUST 2019**

Application for approval of Masters Proposal Report in Health Sciences: **M.N Raluthaga (17023734)**

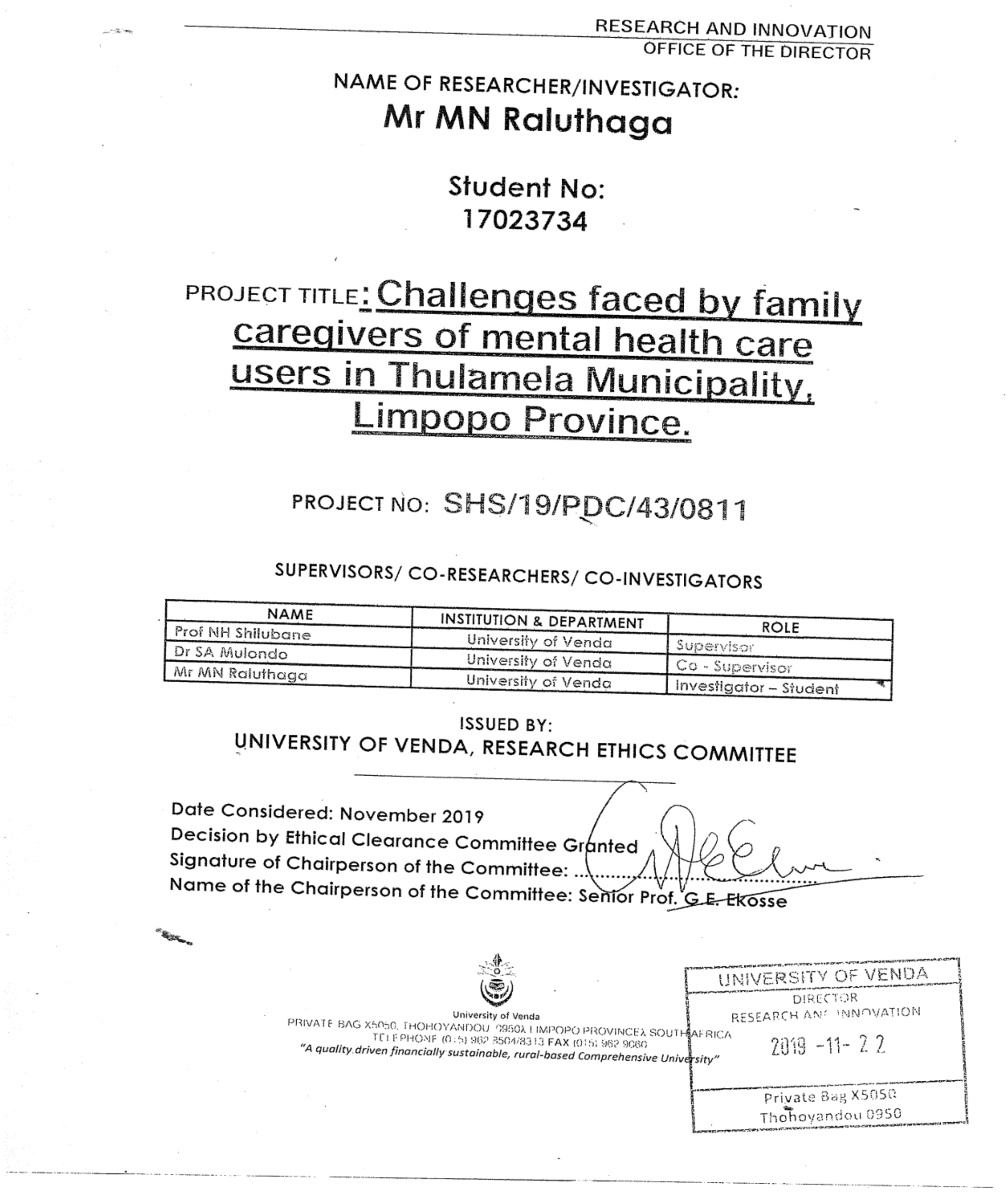
Topic: "Challenges Faced by Family Caregivers of Mental Health Care Users in Thulamela Municipality, Limpopo Province."

| | | |
|---|---|---|
| Supervisor | UNIVEN | Prof. N.H Shilubane |
| Co-supervisor | UNIVEN | Dr. S.A Mulondo |

**UHDC approved Masters proposal**

**PROF. J.E CRAFFORD**
**DEPUTY VICE-CHANCELLOR: ACADEMIC**

## ANNEXURE D: Ethical clearance certificate



RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
**Mr MN Raluthaga**

**Student No:**
**17023734**

PROJECT TITLE: **Challenges faced by family caregivers of mental health care users in Thulamela Municipality, Limpopo Province.**

PROJECT NO: SHS/19/PDC/43/0811

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

| NAME | INSTITUTION & DEPARTMENT | ROLE |
|---|---|---|
| Prof NH Shilubane | University of Venda | Supervisor |
| Dr SA Mulondo | University of Venda | Co - Supervisor |
| Mr MN Raluthaga | University of Venda | Investigator – Student |

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: November 2019
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: ..............................
Name of the Chairperson of the Committee: Senior Prof. G.E. Ekosse

University of Venda
PRIVATE BAG X5050, THOHOYANDOU 0950λ LIMPOPO PROVINCEλ SOUTH AFRICA
TELEPHONE (015) 962 8504/8313 FAX (015) 962 9060
*"A quality driven financially sustainable, rural-based Comprehensive University"*

UNIVERSITY OF VENDA
DIRECTOR
RESEARCH AND INNOVATION
2019 -11- 22
Private Bag X5050
Thohoyandou 0950

### ANNEXURE E: Application to conduct study to the Limpopo Department of Health

P.O. BOX 649
Lwamondo
O985
31 January 2020

Head of Department
Limpopo Department of Health
Private Bag X 9302
Polokwane
0700

Dear Sir/ Madam

Application for permission to conduct research.

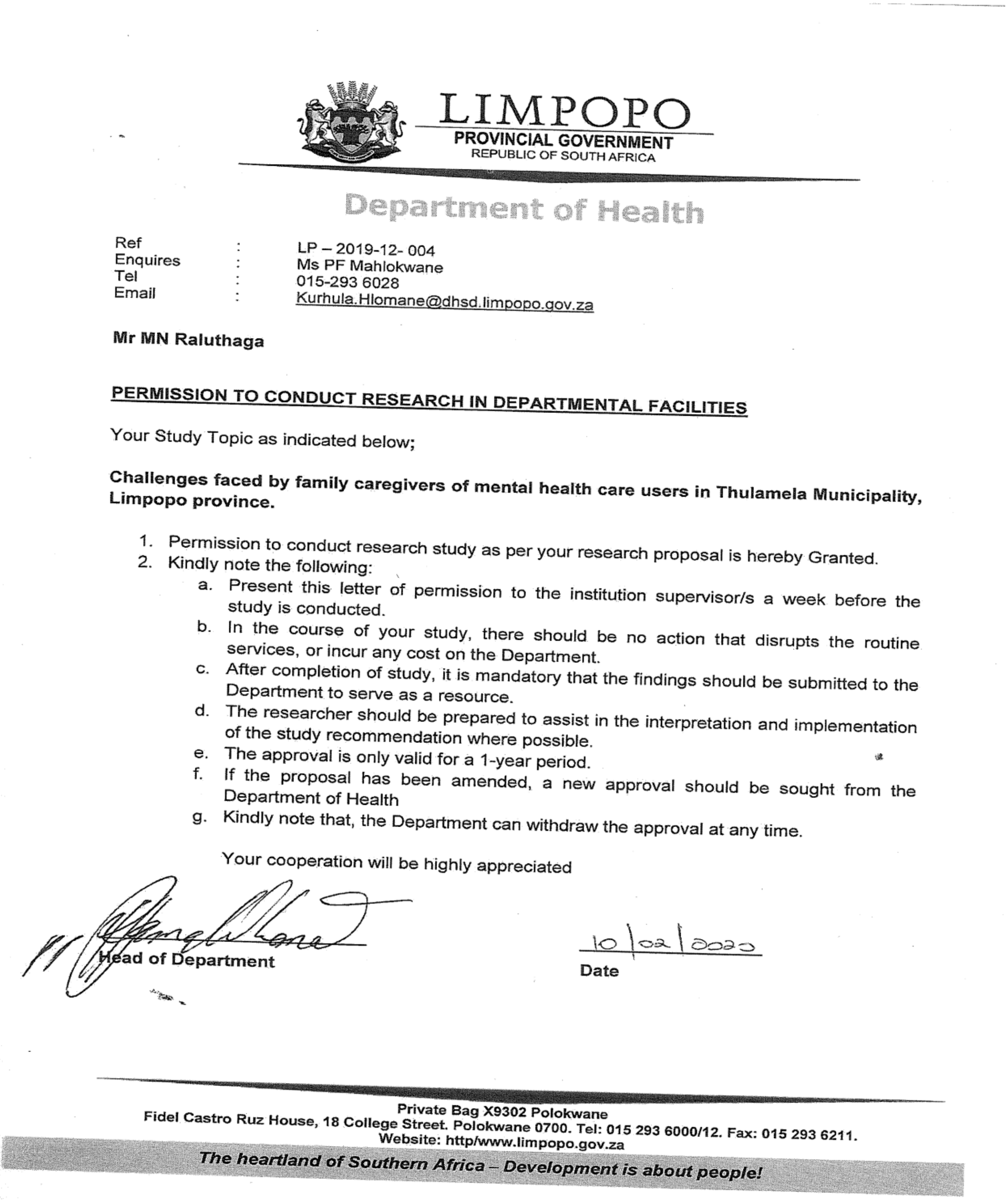
I am currently studying towards Masters in Nursing (M cur) Degree at the University of Venda. The title of my research is ‘’ Challenges faced by family caregivers of Mental Health Care Users (MHCUs) in Thulamela Municipality, Limpopo Province’’ The purpose of this study is to explore the challenges faced by family caregivers caring for MHCUs.

I hereby request your permission to access Limpopo Department of Health’s facilities for making appointments with family caregivers and to access MHCU’s records to obtain family caregivers’ contact numbers. Data collection with family caregivers will be done at their homes.

I will be grateful if the permission is granted.

Yours faithfully
Raluthaga MN (Mr.)

## ANNEXURE F: Permission letter from Limpopo Department of Health



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Department of Health

| | | |
|---|---|---|
| Ref | : | LP – 2019-12- 004 |
| Enquires | : | Ms PF Mahlokwane |
| Tel | : | 015-293 6028 |
| Email | : | Kurhula.Hlomane@dhsd.limpopo.gov.za |

**Mr MN Raluthaga**

**PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES**

Your Study Topic as indicated below;

**Challenges faced by family caregivers of mental health care users in Thulamela Municipality, Limpopo province.**

1. Permission to conduct research study as per your research proposal is hereby Granted.
2. Kindly note the following:
   a. Present this letter of permission to the institution supervisor/s a week before the study is conducted.
   b. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
   c. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   d. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   e. The approval is only valid for a 1-year period.
   f. If the proposal has been amended, a new approval should be sought from the Department of Health
   g. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

Head of Department

10/02/2020
Date

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

*The heartland of Southern Africa – Development is about people!*

## ANNEXURE G: Application letter to Vhembe District Municipality

P.O. BOX 649
Lwamondo
O985
06 March 2020

The District Health Manager
Vhembe District Municipality
Private Bag X 5009
THOHOYANDOU
0950

Dear Sir

Application for permission to conduct research.

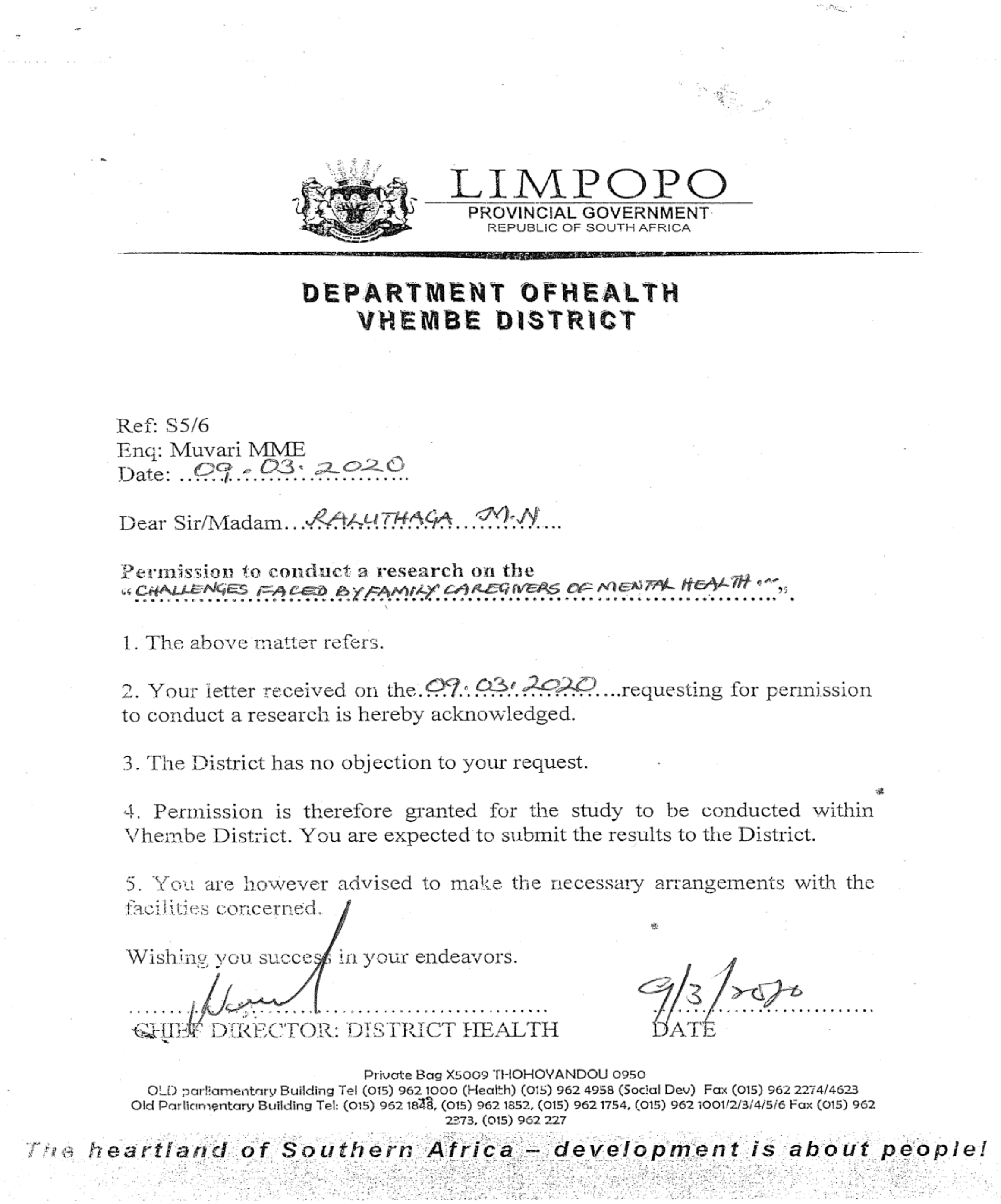
I am currently studying towards Masters in Nursing (M cur) Degree at the University of Venda. The title of my research is ‘’ Challenges faced by family caregivers of Mental Health Care Users (MHCUs) in Thulamela Municipality, Limpopo Province’’ The purpose of this study is to explore the challenges faced by family caregivers caring for MHCUs.

I hereby request your permission to access Tshilidzini Hospital to make appointments with family caregivers and to access MHCU’s records to obtain family caregivers’ contact numbers. Data collection with family caregivers will be done at their homes.

I will be grateful if the permission is granted.

Yours faithfully
Raluthaga MN (Mr.)

## ANNEXURE H: Permission letter from Vhembe District Municipality



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

**DEPARTMENT OFHEALTH**
**VHEMBE DISTRICT**

Ref: S5/6
Enq: Muvari MME
Date: 09. 03. 2020

Dear Sir/Madam RALUTHAGA M.N

Permission to conduct a research on the
"CHALLENGES FACED BY FAMILY CAREGIVERS OF MENTAL HEALTH ..."

1. The above matter refers.

2. Your letter received on the 09. 03. 2020 requesting for permission to conduct a research is hereby acknowledged.

3. The District has no objection to your request.

4. Permission is therefore granted for the study to be conducted within Vhembe District. You are expected to submit the results to the District.

5. You are however advised to make the necessary arrangements with the facilities concerned.

Wishing you success in your endeavors.

CHIEF DIRECTOR: DISTRICT HEALTH

9/3/2020
DATE

Private Bag X5009 THOHOYANDOU 0950
OLD parliamentary Building Tel (015) 962 1000 (Health) (015) 962 4958 (Social Dev) Fax (015) 962 2274/4623
Old Parliamentary Building Tel: (015) 962 1848, (015) 962 1852, (015) 962 1754, (015) 962 1001/2/3/4/5/6 Fax (015) 962 2273, (015) 962 227

*The heartland of Southern Africa – development is about people!*

## ANNEXURE I: Application letter to Tshilidzini Hospital

P.O. BOX 649
Lwamondo
O985
13 March 2020

Chief Executive Officer
Tshilidzini Hospital
Private Bag X 924
SHAYANDIMA
0945

Dear Madam

Application for permission to conduct research.

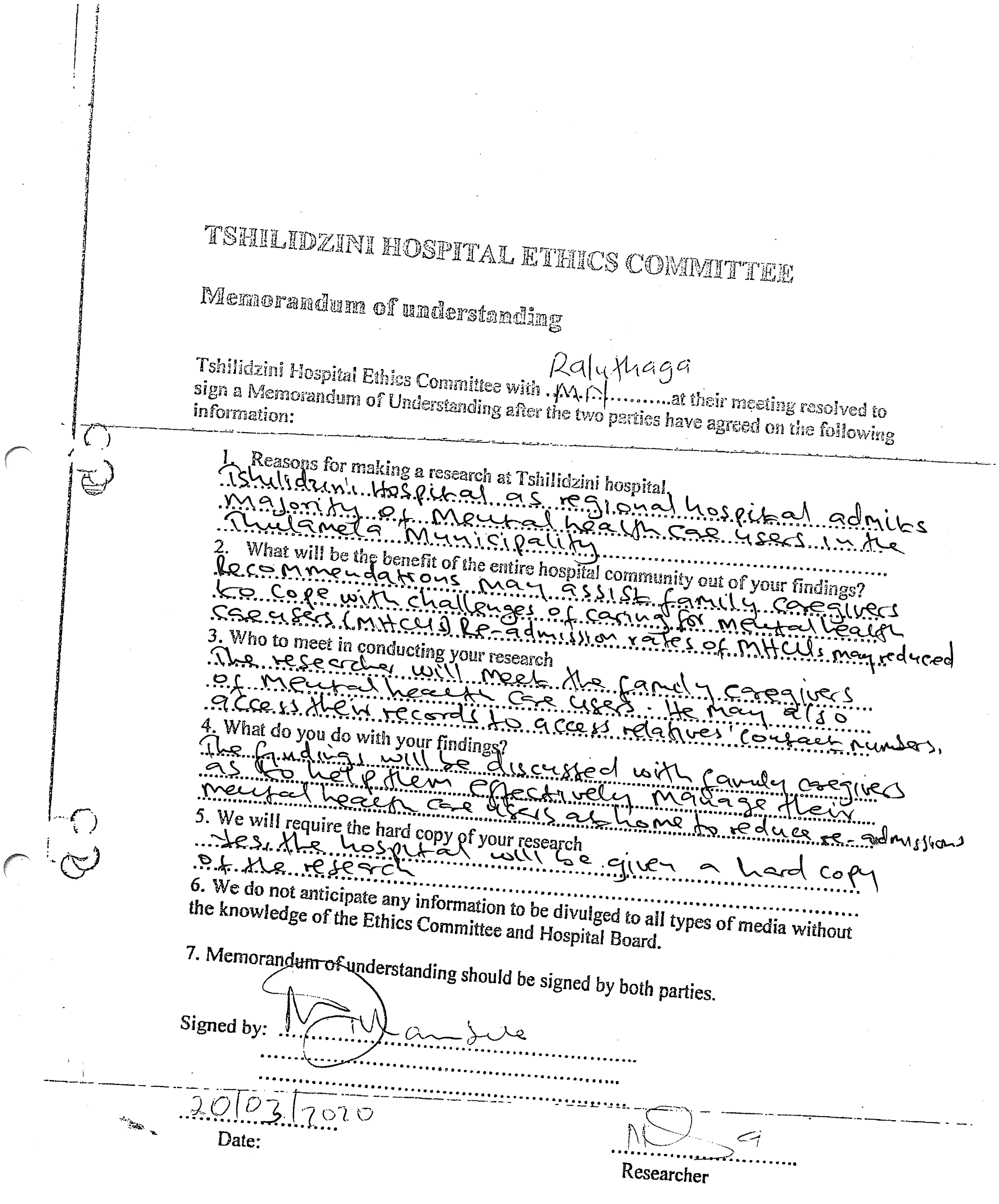
I am currently studying towards Masters in Nursing (M cur) Degree at the University of Venda. The title of my research is ‘’ Challenges faced by family caregivers of Mental Health Care Users (MHCUs) in Thulamela Municipality, Limpopo Province’’ The purpose of this study is to explore the challenges faced by family caregivers caring for MHCUs.

I hereby request your permission to access your institution to make appointments with family caregivers and to access MHCU’s records to obtain family caregivers’ contact numbers. Data collection with family caregivers will be done at their homes.

I will be grateful if the permission is granted.

Yours faithfully
Raluthaga MN (Mr.)

## ANNEXURE J: Permission letter from Tshilidzini Hospital



### TSHILIDZINI HOSPITAL ETHICS COMMITTEE

### Memorandum of understanding

Tshilidzini Hospital Ethics Committee with Raluthaga M.A ..........at their meeting resolved to sign a Memorandum of Understanding after the two parties have agreed on the following information:

1. Reasons for making a research at Tshilidzini hospital.
Tshilidzini Hospital as regional hospital admits
Majority of Mental health care users in the
Thulamela Municipality

2. What will be the benefit of the entire hospital community out of your findings?
Recommendations may assist family caregivers
to cope with challenges of caring for mental health
care users (MHCUs) Re-admission rates of MHCUs may reduced

3. Who to meet in conducting your research
The researcher will meet the family caregivers
of mental health care users. He may also
access their records to access relatives' contact numbers.

4. What do you do with your findings?
The findings will be discussed with family caregivers
as to help them effectively manage their
mental health care users at home to reduce re-admissions

5. We will require the hard copy of your research
Yes, the hospital will be given a hard copy
of the research

6. We do not anticipate any information to be divulged to all types of media without the knowledge of the Ethics Committee and Hospital Board.

7. Memorandum of understanding should be signed by both parties.

Signed by: ..........................................

20/03/2020
Date:

..........................
Researcher

## ANNEXURE K: Application letter to the tribal authority

P.O. BOX 649
Lwamondo
O985
24 March 2020

Tshivhase Traditional Authority
P.O. Box 1093
VHUFULI
0971

Dear Sir

Application for permission to conduct research.

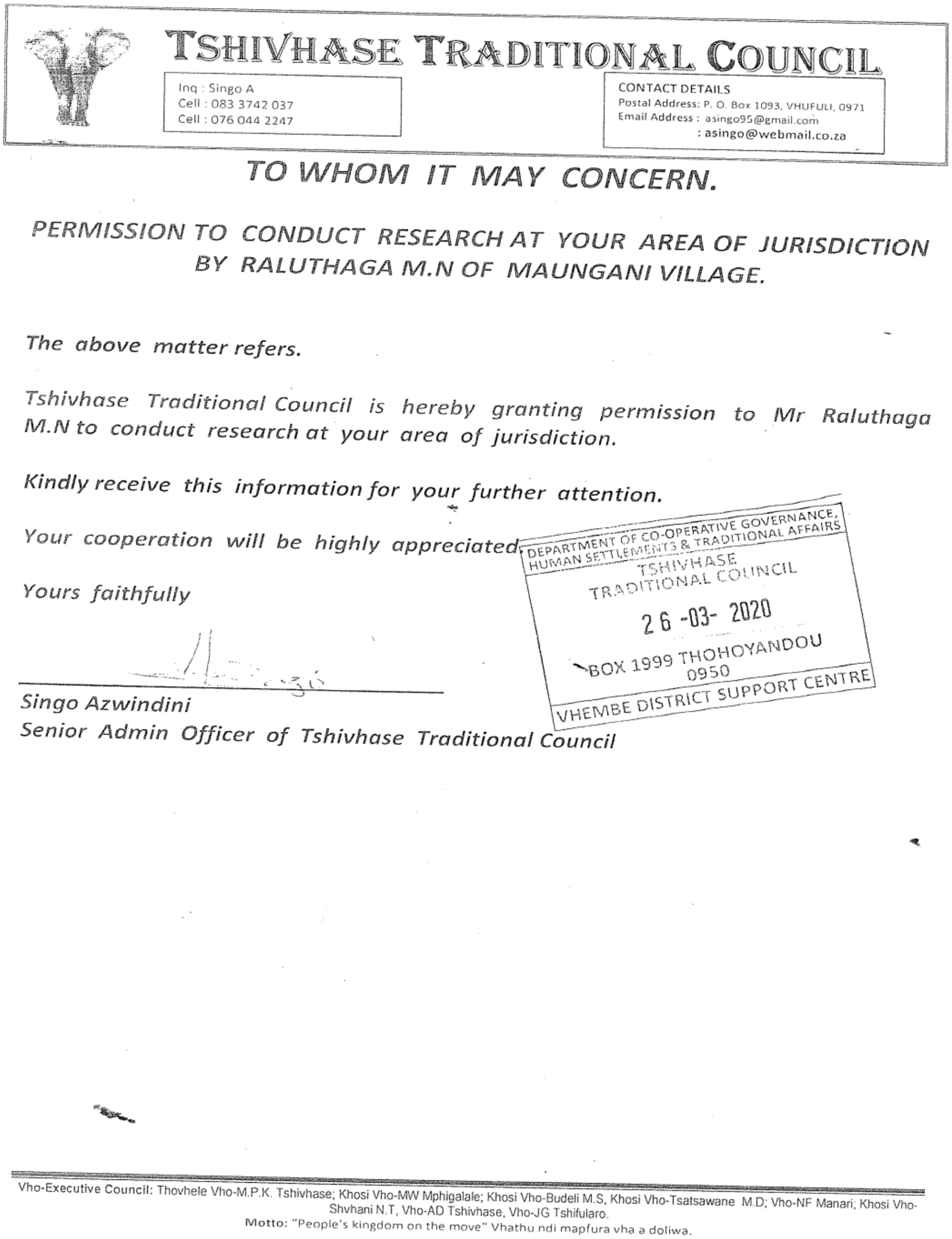
I am currently studying towards Masters in Nursing (M cur) Degree at the University of Venda. The title of my research is ‘’ Challenges faced by family caregivers of Mental Health Care Users (MHCUs) in Thulamela Municipality, Limpopo Province’’ The purpose of this study is to find out the challenges faced by family relatives of mentally ill people.

I hereby request your permission to visit families of relatives of mentally ill people in your villages. Appointments will be done with the relatives themselves and interviews with relatives will be done at their homes.

I will be grateful if the permission is granted.

Yours faithfully
Raluthaga MN (Mr.)

## ANNEXURE L: Permission from Tribal Authority



**TSHIVHASE TRADITIONAL COUNCIL**

Inq : Singo A
Cell : 083 3742 037
Cell : 076 044 2247

CONTACT DETAILS
Postal Address: P. O. Box 1093, VHUFULI, 0971
Email Address : asingo95@gmail.com
: asingo@webmail.co.za

### TO WHOM IT MAY CONCERN.

**PERMISSION TO CONDUCT RESEARCH AT YOUR AREA OF JURISDICTION BY RALUTHAGA M.N OF MAUNGANI VILLAGE.**

The above matter refers.

Tshivhase Traditional Council is hereby granting permission to Mr Raluthaga M.N to conduct research at your area of jurisdiction.

Kindly receive this information for your further attention.

Your cooperation will be highly appreciated.

Yours faithfully

Singo Azwindini
Senior Admin Officer of Tshivhase Traditional Council

DEPARTMENT OF CO-OPERATIVE GOVERNANCE, HUMAN SETTLEMENTS & TRADITIONAL AFFAIRS
TSHIVHASE TRADITIONAL COUNCIL
26 -03- 2020
BOX 1999 THOHOYANDOU
0950
VHEMBE DISTRICT SUPPORT CENTRE

Vho-Executive Council: Thovhele Vho-M.P.K. Tshivhase; Khosi Vho-MW Mphigalale; Khosi Vho-Budeli M.S, Khosi Vho-Tsatsawane M.D; Vho-NF Manari; Khosi Vho-Shvhani N.T, Vho-AD Tshivhase, Vho-JG Tshifularo.
Motto: "People's kingdom on the move" Vhathu ndi mapfura vha a doliwa.

## ANNEXURE M: Interview transcript

### Participant 1

**Key : R – Researcher**

**P- Participant**

R : Good day, how are you?

P : I am fine and how are you?

R : I am fine.

R. : What are the challenges you face caring for your uncle who is a mentally ill person?

P : He is a problem. He is troublesome.

R : What do you mean when you say he is problem and troublesome?

P : He destroys property.

R : According to you, what make him destroy property?

P. : I don't know exactly the cause, but most of the time he is angry. He does not sleep at night, he is verbally aggressive. He assaulted my mother, bit her leg and hit my child with hammer. He carries knives and machete around and threatening people. Even his uncle, who used to calm him down, now is scared of him as he also assaulted him. We opened a case against him, but we withdraw it because he is our family member.

R : Hmm, does he take his treatment?

P : (Sigh) No, the problem is that he does not think that he needs the medication. He thinks is not mentally ill. We always force him to take the tablets by threatening to have his disability grant terminated. He does not like medication. He needs to be taught about his mental illness.

R : How do you feel about him not taking medication? You seem tired about his behaviour.

P : I am very tired of my uncle. I am scared to remind him to take his medication because he gets angry and become verbally aggressive. He swears at me, saying why I treat him like a child. So I let him keep his medication. I am sure he does not take it the way they told us at the hospital. His behaviour has changed.

R : Does he say what makes him to stop taking treatment?

P : He does not tell us, he does not want us near him. He spends his grant money with loose girls. He does not contribute to the wellbeing of the family.

R : So he does not buy food for the family?

P : He does not contribute, he buys food for himself, locks himself in the house and cooks for himself but when he relapses he buys sex from those loose girls.

R : But does he ask for food from you as family?

P : No, he does not eat at home, he roams around.

R. : Does this occur every month when he gets paid disability grant?

P : Yes. It is a daily story. I am tired of him.

R : Does he go for check up at the hospital?

P : Yes only when I force him to go.

R : So you have to force him to go for his check?

P : Yes

P : Yes, it is the same story every month, no money for transport to hospital. When I do not accompany him, he does not go to fetch treatment on his own. So I have to pay for both of us, so that he can get his treatment and I cannot do this every month. In fact, he is not serious about his health.

R : How do you feel about his behaviour?

P : We feel scared because he walks around threatening to damage neighbour's care and saying he will kill someone, he will be arrested for murder.

P : What is that made to make such a threat?

P : To tell you the truth, I do not know what had happened. But such behaviour is common when he is relapsing. He talks things which we do not understand, call people's name and make accusations. My uncle is a problem

R : Hmm, so you feel scared?

P : Yes, very scared.

R : Regarding medication, does he take them regularly?

R : I hear you. So his compliance is poor?

P : Yes, not good at all. He selects tablets; he will tell you that he will not take this or that tablet because it makes him feel weak. He knows his tablets very well. He knows what each tablet does to him. He chooses what he thinks is good for him. The ones he does not like he throws them away.

R : So he is selecting and throwing other tablets away?

P : Yes, he knows them very well

R : How do you feel about him choosing which tablet to drink and throwing others?

P : I personally, I feel depressed but there is nothing I can do, I am scared of him.

R : Okay. Does he use any substances like alcohol or dagga?

P : No, he does not drink nor smoke. He is a church goer when he is stable. But once he relapses, he changes and becomes another person.

R : How is your relationship with him when he is stable? I mean when he has not relapsed.

P : When he is stable his behaviour is okay but once he relapses, he is verbally aggressive and threatening us.

R. : So you are saying once he relapses he is verbally aggressive and that makes you live with fear that he will hurt you?

P : Yes, he threatens to assault us with a machete. We always scared because there is nowhere we can escape to. We have difficult times caring for him.

R : So in other words you live with fear because of his behaviour?

P : Yes, that is why we feel relieved when he is admitted at the hospital because we don't know what we can do with him. Once we hear him swearing whenever he comes home, we lock ourselves in the room because we know that he is angry. He comes home and bangs windows, shouting at everyone for no apparent reason. We are scared even to watch television. When we call the police they don't come to help us to take him to hospital, they say we must take him there ourselves. We cannot handle him because he had weapons like knife and machete with him. He is also strong.

R : Hmmm.

P : We would be safe if he can be admitted at any hospital at least for a year. We would be very much relieved. We love him, but our lives are in danger. He is our uncle, we cannot disown him, but he makes our lives difficult. I wish I knew what to do or where I can take him to. We always live in fear; we do not know what will happen next. You cannot predict his behaviour.

R : Who are other family members who assist you to take care of your uncle?

P : We used to rely on our uncle, who used to calm him down. But since he assaulted him, he is reluctant to help us. His aunt also does not want to get involve any more. He accused her of killing her husband. We have no one to assist us when he becomes aggressive.

R : Hmm, it is tough. What about your mother, why does she not intervene?

P : My mother works in Johannesburg, she comes home every second month. So we have no one around here to help us. Even our neighbours do not want to get involve anymore. He makes threats to people for no reason. People do not like him because he carries a knife. People are scared of him, the other day he disrupted a neighbour's funeral.

R : What happened there?

P : He went there singing. When they tried to call him to order, he did not listen. He roamed around the cars parked on the along the road making hand gestures. At least he did not damage the cars, but his behaviour was annoying.

R : That was not good at all. Then what happened?

P : We were so embarrassed. My mother later went to our neighbour to apologize, at least they understood because they know that he is on tablets.

R : What support did you can get from health care professionals to assist you care for your mental health care user?

P : We told the home-based care workers about our uncle's behaviour of threatening us with machete. They told the social workers about it, social workers came to talk with to him. He convinced them that he will change and they believed him, but they did not make follow up on whether he changed or not. So they didn't assist us. It just ended up like that. We did not know where else can we go to get help.

R : Why did you not make follow with the social workers to find out how far are they with your uncle's matter?

P : Firstly, one thing which made me specifically not to make follow up is that I knew they would resolve it because it was not for the first time we told them about it. The last time we told them they said there is nothing they can do as my uncle did no hurt anyone that time. Secondly, the way the asked my uncle about his behaviour did not bode well with me. They mentioned me as if I am the only one in the family who is worried about his behaviour. Instead of saying the family says, they said she says you are not taking your medication.

R : Tell me more about that?

P : From there my relationship with my uncle become strained worse. He says I think I am clever. He says who am I to report him to social workers. He says if I was clever I was supposed to have my own stand, own husband and children of the same father.

R : Okay, I hear you. Did you tell the nurses or doctors about the challenges you have with your uncle when you went for check visit?

P : I did but the nurses said I must tell the doctors. His doctor said unfortunately at Hayani Hospital there is no vacancy, so we have to make sure he drinks his tablets at all times. He advised that should he relapse and we need to bring him to hospital, we must call the police to assist us.

R : Do you think health care professionals gave you support?

P : No because our problem remains. My uncle does not drink all his medication, we are still living in fear. Our problem would have been resolved if they admitted him for at least a year. For that period of time we would rest a bit.

R. : In summary, your uncle is verbally aggressive towards you as family He does not drink all his medication, he selects some tablets and throws others away. So you consulted the social workers, and you did not get any assistance as your uncle convinced them that there is nothing wrong with his behaviour. Nurses and doctors did not provide any support to you and your family regarding your uncle.

P : Yes.

R : Do you want to add something, or something you feel I left out?

P : You said everything I said.

R : Thank you very much for your time

P : Thank you

## Annexure N: Declaration of Professional Editing

Marion Pfeiffer
11 Heron Way
Eastford Glen
Knysna 6571
Tel: 083 590 6762
imarion100@gmail.com

24 February 2021

### DECLARATION OF PROFESSIONAL EDIT

**CHALLENGES FACED BY FAMILY CAREGIVERS OF MENTAL HEALTH CARE USERS IN THULAMELA MUNICIPALITY, LIMPOPO PROVINCE**

I declare that I have edited and proofread this document. My involvement was restricted to language usage and spelling, completeness and consistency, referencing style and formatting of headings, captions and Tables of Contents. I did no structural re-writing of the content.

Sincerely,

M Pfeiffer

Marion Pfeiffer

Freelance Copy-editor and Proofreader
Intermediate Member, CIEP UK
Full member, Professional Editors Group and SAFREA

Professional
EDITORS
Group