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DEVELOPMENT OF A PSYCHOEDUCATIONAL PROGRAM FOR FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS IN VHEMBE DISTRICT IN LIMPOPO PROVINCE

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DEDICATION

- First and foremost, I would like to dedicate this thesis to the Almighty God, my Creator, my strong pillar, my source of inspiration, wisdom, knowledge and understanding. God has been the source of my strength throughout this study when I felt exhausted He kept on renewing my strength. It is for this reason that I can say “Ebenezer, which means thus far the Lord has been with me” I Samuel 7:12
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DECLARATION

I, the undersigned, Takalani Ellen Mbedzi (19399864) hereby declare that **"DEVELOPMENT OF A PSYCHOEDUCATIONAL PROGRAM FOR FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS IN VHEMBE DISTRICT IN LIMPOPO PROVINCE"** is my own original work and has never been submitted before for any degree or examination at any other institution. All the sources that I used or quoted have been indicated and acknowledged by means of complete references.

Signature: Date: 06/06/2023

ABSTRACT

Introduction: The prevalence of mental illness is rising in all regions of the world. There is an increased need for family caregiving in South Africa due to deinstitutionalization that leads to a reduction of in-patient psychiatric beds. This means a shift of responsibility from clinicians to families, who may not have the knowledge and psychological skills to undertake this role. The lack of family support programs in the community compromises the well-being of family members. It is in this context that this study seeks to develop a psychoeducational program to support family members caring for mental health care users in the Vhembe district of Limpopo province in South Africa.

Aim: The overall aim of this study was to develop a psychoeducational program to support family members caring for mental health care users.

Objectives: The first objective was to explore and describe the needs of family members caring for MHCUs, the second objective was to develop a psychoeducational program, and the third objective was to refine and validate the program to support family members caring for MHCUs in Vhembe district, Limpopo province, South Africa.

Research design: This study used a multi method design to develop a psychoeducational program to support family members caring for mental health care users in the Vhembe District of Limpopo Province.

Methods: The study was done in the eight healthcare centers of the Vhembe district in Limpopo province. The study followed a pragmatist approach in three phases. Phase 1: A qualitative, explorative, descriptive, and contextual approach was used to explore the psychosocial support needs of family members, using one-to-one semi-structured interviews. Braun and Clark's thematic data analysis was employed to analyze qualitative data. Phase 2: A one-day nominal group technique workshop with stakeholders with experience of working with mental health care users and their family members was conducted to develop a psychoeducational program which was guided by the results of phase 1. Thematic data analysis was used to analyze qualitative data and identify themes. Statistical analyses (computing averages) was used to analyze quantitative data. Phase 3: An e-Delphi technique was adopted to refine the psychoeducational program. A questionnaire was developed to gather data from a purposively selected panel of experts in mental health. Consensus was obtained using a Likert scale to evaluate and refine the draft program based on expert panelists' recommendations in each e-Delphi round.

Findings: The findings indicated that family members caring for the MHCUs had many healthcare needs namely, physical, psychological, social, educational and information, financial and spiritual needs. They also indicated their expectations from the healthcare system.

Conclusion: The findings of the study could assist healthcare providers in addressing the healthcare needs of family members caring for mental healthcare users in order to reduce the burden of care placed on them. The refined psychoeducational program could make a valuable contribution to the well-being of family members and improve their quality of life. The health care providers may incorporate interventions for families in the management protocol. It is recommended that quantitative research be done to determine the healthcare needs of family members caring for MHCUs in bigger populations.

Keywords: caring, community health center, family member, mental health care user,
mental illness, psychoeducation program.

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ABBREVIATION	MEANING
CHC	Community health centres
MHCU	MHCU: Mental health care user
NGT	Nominal group technique
np	no page number
SA	South Africa
WHO	World Health Organization
SANC	South African Nursing Council

CHAPTER 1
ORIENTATION TO THE STUDY

1.1 INTRODUCTION

There is an increased need for family care giving in South Africa due to global deinstitutionalization, the discharge of persons with mental illness from psychiatric hospitals to community settings (Parker 2014:76). This means a shift in responsibility from healthcare professionals to families, who may not be psychologically prepared to undertake this role owing to lack of knowledge and skills to manage the mental health care users (MHCUs). Most of the MHCUs in South Africa reside in rural areas and the majority live with their family members (Mokwena, Madiba & Mokoena-Molepo 2014:374). Despite numerous challenges experienced by family caregivers, there are also advantages for example, family caregiving brings the family together, helps the family to accept the condition of mental illness, and creates love and respect for MHCUs (Seloilwe 2006:246; Modise, Mokgaola & Sehularo 2021:4). Caregiving by family members is perceived to be more a more rewarding experience that fosters meaning, resilience and it leads to personal growth (Phillips, Durkin, Engward, Cable & Lancu 2022:17). Fewer relapses, reduced number of admissions and earlier detection of warning sign of recurrence of mental disorders were reported by Ong, Fernadez and Lim (2021:214). African families are traditionally entrusted to take care of members with mental illness. Family members accept the caring of MHCUs as their obligation or moral duty, despite the challenges related to caregiving. When feeling that they have no choice, the caregiving becomes an emotional burden (Mokwena & Ngoveni 2020:5). For example, a study in Dar es Salaam, Tanzania found that families suffered from the burden of care which negatively affected their physical and mental wellbeing (Iseselo, Kajula & Yahya-Malima 2016:11).

Mental health is defined as a state of well-being in which individuals realise their own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and are able to contribute to their communities (WHO 2022:8). Mental illness refers to all the diagnosable mental disorders which are characterised by abnormalities in thinking, feelings or behaviours. Mental illness is closely related to vulnerability, in its causes and in its effects (WHO 2022:8).

In 2012, the World Health Organization (WHO) outlined the main vulnerabilities and risk factors related to mental illness that should be considered when developing and implementing appropriate health and social policies or strategies (WHO 2012:1). In 2017, the WHO reported that globally, 14% of the burden of disease is attributed to mental illness, which includes a broad spectrum from common mental illnesses, like anxiety and substance abuse, to severe illness like psychosis (WHO 2017:5). In 2019, 301 million people globally were living with anxiety disorders; and 280 million were living with depressive disorders (WHO 2022:40). The prevalence of these common mental disorders is increasing, particularly in low- and middle-income countries where mental illness is underreported due to the stigma (Liu, He, Yang, Feng, Zhao & Lyu 2020135; WHO 2022:44).

In many countries, such as China and India, the burden of mental illness contributes to premature mortality, high morbidity and loss of economic productivity (Charlson, Baxter, Cheng, Shidaye & Whiteford 2016:378). Mental, neurological and substance use disorders take a high toll on health outcomes, particularly in low- and middle-income countries, and there is an increasing global suicide rate among individuals with physical and mental conditions (Baumann 2018:1425). In 2002, mental disorders accounted for 5% of the total burden of disease and 19% of all disability in Africa (Amuyunzu-Myamongo 2013:59). Consequently, mental illness is a major cause of morbidity and a burden to the patients, their families and society. In addition, the high prevalence of communicable diseases, including tuberculosis and HIV/AIDS, is closely associated with mental illness. Social stigma has meant that in much of Africa, mental illness is a hidden issue equated to a silent epidemic. In many African countries the social environment does not nurture good mental health due to war and major disasters (Amuyunzu-Nyamongo 2013:59). In 2013, psychiatric disorders were ranked third in their contribution to the overall burden of disease in South Africa, after HIV and AIDS and other infectious diseases (Department of Health [DOH] 2013). With the exception of sub-Saharan Africa, neuropsychiatric disorders are the leading contributor to years lived with disability in all regions of the world. Unipolar depression is a major contributor to disease burden in high- middle- and low-income countries and is expected to become a leading cause of disease burden globally by 2030 (Baumann 2015:13). Mental health problems appear to be increasing in importance in Africa. Between 2000 and 2015 the continent’s population grew by 49%, yet the number of years lost to disability as a result of mental and substance use disorders increased by 52%. In 2015, 17·9 million years were lost to disability as a consequence of mental health problems. Such disorders were almost as important a cause of years lost to disability as were infectious and parasitic diseases, which accounted for 18·5 million years lost to disability (WHO 2016:1)

In Vhembe district, Limpopo Province, the mental health caseload increased to 21% in 2013 (Health Systems Trust 2015:21). Mental health caseload refers to all youth with an identified mental health disorder, including those who have a psychiatric disorder, including but not limited to psychoses, schizophrenia, bipolar with psychotic features, depression with psychotic features, severe post-traumatic stress disorder, schizoaffective disorders and those who, consistent with reasonable professional judgment require psychiatric or psychological care.

A study on the burden of untreated mental disorders in KwaZulu-Natal in 2014 found a treatment gap of approximately 80% for those in need of acute mental healthcare services (Burns 2014:9). South Africa has a supportive legislative and policy environment, but meeting the goals of the South African mental health policy and commitments, remains a challenge. There are inefficiencies in the system for the delivery of critical mental health services within an integrated primary care model. A lack of community structures for MHCUs left families without any option but to mend the shortage of services and provide care for family members (Docrat, Besada, Cleary, Daviaud & Lund 2019:718; Petersen & Lund 2011:751). This background motivated the researcher to develop a psychoeducational program to support the families caring for MHCUs in a rural community in South Africa.

1.2 BACKGROUND AND RATIONALE FOR THE STUDY

This section discusses the background and rationale for the study according to mental health system legislation and policy; the role of the family caring for a family member with mental illness; families' experiences of care-giving burden, responses of families towards MHCUs, and family psychoeducational interventions. The different aspects are discussed with reference to the literature reviewed.

1.2.1 Mental health system legislation and policy

Global deinstitutionalization led to a reduction in in-patient psychiatric care and beds. The aim of deinstitutionalization was to change the focus of care from the hospital to the community, shifting long-term caregiving responsibility from the mental healthcare professionals to the family members (Anokye 2018:323; Middleton 2020:16). In-patient care has been the main form of care during the institutional era, comprising 86% of the cost of mental health care, which reflects a historical legacy focused on curative in-patient care. To increase accessibility to healthcare for MHCUs, the Mental Health Care Act, 17 of 2002 designated some regional and district public hospitals in South Africa to admit MHCUs for 72-hour assessment and observations (South Africa 2002:19).

Legislation prior to 2002 reinforced the alienation, stigmatization and disempowerment of MHCUs in South Africa. In line with international developments in mental health legislation, the Government promulgated the Mental Health Care Act, 17 of 2002. The Act makes provision for users' human rights; decentralization and integration of mental health care at primary, secondary and tertiary levels of care, and a focus on care, treatment and rehabilitation. However, various challenges at community and regional hospitals, such as lack of infrastructure, inadequate skills and poor support and training of healthcare providers, undermine successful implementation (Burns 2008:46). Some progress in decentralization of mental health services in South Africa has been made, but insufficient resources resulted in a "revolving door" phenomenon, namely readmissions (Petersen & Lund 2011:751).

In line with the values and principles of the Alma Ata Declaration, 1978, on primary health care (PHC), mental health is an integral element of health and improved mental health is fundamental to achieving the South African government's goal of a "long and healthy life for all South Africans" (Naledi, Barron & Schneider 2011:23). The primary healthcare re-engineering strategy aims to strengthen the delivery of PHC services as the backbone of health service delivery in the context of the National Health Insurance system (Naledi et al 2011:18). It repositions a curative, individually oriented system towards a proactive, integrated and population-based approach to service delivery, based on municipal ward-based primary healthcare outreach teams. In rural areas, these teams walk to the villages to do home visits. The Department of Health's *National Mental Health Policy Framework and Strategic Plan 2013-2020* was an important milestone in the ongoing efforts to transform mental health in South Africa. The policy framework is in line with the broader health sector transformation, including the re-engineering of the PHC system. Limited resources contribute to inability to make follow-up services for MHCUs and conduct home visits. Community health workers are often used to do home visits due to shortages of health care professionals but their effectiveness in the mental health field has not been established (Middleton 2020:255). Similarly, during an informal meeting in April 2020, home-based workers told the researcher that they only referred MHCUs who had relapsed or were neglected to the primary healthcare nurses and social workers stationed at the community health centres.

1.2.2 Role of the family caring for a family member with mental illness

Family caregivers of MHCUs are their main source of emotional and physical support, and usually have to bear the financial costs associated with mental health treatment and care. In 2014, over four million families in the United States of America (USA) lived with MHCUs (Kneisl & Trigoboff 2013:633). In South Africa, over 70% of out-patients live with their families. Families taking care of a family member with a mental disorder perceive caregiving as their duty about which they have no choice. This is also associated with the cultural practice of taking care of each other prompted by emotional bonds between family members (Middleton 2020:86).

Long-term caregiving leads to significant stress, which is referred to as family burden or caregiving burden. Ayalew, Workicho, Tesfaye, Hailesilasie and Abera (2019:10) describe family burden as any undesirable or negative consequences experienced by caregivers as a result of taking care of a family member suffering from mental illness. It can be either objective burden, such as family disruption, financial crisis, limitations on activities of daily living and social interactions, or subjective burden, which is a perceived feeling of being overwhelmed by daily care provision (Ayalew et al 2019:10).

Family members monitor adherence to medication and follow-up appointments. The family plays a crucial role by making sure that the medication is taken every day which is a difficult task as some MHCUs are reluctant to be supervised. In addition, they also observe and report the side effects of the medication to healthcare professionals. Families take the caregiver role in provision of the basic care, such as ensuring hygiene and nutrition for the MHCU (Chadda 2014:221).

A study in the North-West Province of South Africa found that families designed their own strategies to calm or contain MHCUs who appeared to be physically or verbally aggressive (Mokgothu, du Plessis & Koen 2015:7). The families coped by using kind words to persuade the MHCU talk politely and respectfully or asked their next-door neighbours, friends or pastors to pray for them. If they suspected that the MHCU had omitted a dose of medication, they would give it immediately. They tried to protect the family member from any form of abuse to which they were vulnerable and ensured safety and security at all costs, including providing shelter. The MHCUs were also protected from negative outside influences. As an African cultural practice, families often consulted traditional healers (*sangomas)* and faith healers, who might prescribe rituals to be performed, which were costly, but the families felt obliged to conduct them. If there was no improvement in the mental condition, western medical doctors were consulted (Mokgothu et al 2015:7).

1.2.3 Families’ experience of the caregiving burden

Caring for an MHCU can have significant physical, emotional and social impacts on the family’s well-being (Hercelinskyj & Alexander 2022:438). A study in India assessed the impact of mental illness based on the form of burden, caregiving experience, and psychiatric or psychological morbidity (Avasthi 2010:113). Studies differentiate between the objective and subjective burden with regard to the impact of mental illness. The objective burden refers to the observable, tangible cost (eg time and finances) caused by the MHCUs’ illness to the caregiver, while the subjective burden refers to the personal perception and personal evaluation of the extent of caregiving burden (Flyckt, Fatouros-Bergman, & Koernig

2015:684). Kneisl and Trigoboff (2014:633) define family burden as the difficulties and responsibilities of a family who assume a caretaking function for an MHCU, and contend that caregiving for MHCUs is a stressful, time-consuming, and lifelong task which is largely underappreciated and stigmatized.

In a study in Letaba, Limpopo Province, most of the participating families reported inadequate informational support, lack of knowledge and skills needed to help the family member and failing to understand the illness and behaviour displayed by the MHCU (Banyini 2012:78). A study among families in rural communities of Limpopo Province found that family members indicated that it was difficult to care for a family member with mental illness (Mabunda, Mangena-Netshikweta, Lebese & Olaniyi 2022:6). The caregivers were over-burdened and socially isolated, and experienced feelings of hopelessness, financial and emotional strain and a lack of professional, social and community support (Mabunda et al 2022:6). Family burdens reported most often included financial strain, exposure to violence, reduction in the physical and mental health of family caregivers, concern about the future, and the impact of stigma. Families sometimes experienced the mental health system as a stressor and felt overwhelmed, accompanied by an inability to cope with the MHCU (Monyaluoe, Mvandaba, du Plessis & Koen 2014:134; Ayalew et al 2019:14).

In Tehran, Iran, Von Kardorff, Soltaninejad, Kamali and Shahrbabaki (2016:248) found that family members caring for MHCUs with schizophrenia and affective disorders experienced uncertainty and ambivalence due to the unpredictable nature of mental illness. The caregivers experienced emotional, financial and physical burdens, stigma and blame, restrictions and disruptions in routines, dissatisfaction with their families, relatives and friends, troubles with patients' adherence to medication, and problems with health services and governmental support. Von Kardorff et al (2015:254) recommended that the authorities should provide adequate financial, educational, and psychosocial support for caregivers of patients with mental illnesses. A study in Brazil examined the emotional and family burden in relatives of patients in first-episode psychosis and found that the majority of the participants experienced severe caregiving burden (Zanetti, de Souza, de Souza Tressoldi, de Azevedo-Marques et al 2018:394). In Pakistan, Siddiqui and Khalid (2019:1332) found that over time, caregiving for family members with serious mental illness compromised the well-being of the caregivers. The caregivers in rural areas were found to be at risk due to lack of community resources to engage in problem-solving skills. A study in China found that family caregivers received little social support (Leng, Nicholas, Nicholas & Wang 2019:23).

In Ghana, Kretchy, Osafo, Agyemang, Appiah and Nonvignon (2018:293) found that caregivers experienced a heavy psychological burden and a lack of support from mental health care systems and reported poor adherence among outpatients with schizophrenia. In iLembe district, Kwazulu-Natal, Nxumalo and Mchunu (2017:206) found that family members experienced stigma from the community in the form of isolation, blame and exploitation. The community blamed the family members because they were perceived as the cause of the mental illness and not taking good care of the MHCU. A study in Vhembe District of Limpopo Province found that family members experienced burnout associated with caregiving to MHCUs. Families wished their loved ones to remain in long-term institutions for the rest of their life (Matambela, 2019:13). In Vhembe district, Nemathaga (2018:55) found that families experienced psychological and social burdens, financial problems, fear, isolation, and disrupted family life.

1.2.4 Families' response to mental health care users

Families respond in different ways to the MHCUs. They search for relief from symptoms and treatment options, they struggle to accept the reality, and to support and advocate for the MHCU and attempt to find equilibrium (Engelman 2020:iv). A strong relationship was found between elevated expressed emotions and relapses in patients during the first episode of psychotic symptoms. Families with elevated expressed emotions presented with higher scores of family burden (Zanetti et al 2018:394). The findings concurred with Wang, Chen and Yang's (2017:1508) findings that the emotional expression of primary caregivers was a predictor of rehospitalisation rates in patients with schizophrenia and the primary caregivers experienced an obvious burden of care. Families with low expressed emotions believe that the illness is caused by external forces, such as witchcraft, which are beyond the MHCU's control therefore the MHCU is not expected to behave normally. In these families, the MHCU is allowed to make decisions but is held accountable for those decisions. This provides room for personal management and growth. The caregivers with low expressed emotion had a low score in burden of care compared to those with high expressed emotions (Wang et al 2017:1508).

1.2.5 Family psychoeducation

This section describes family psychoeducational interventions, the benefits, and challenges of family psychoeducation.

Family psychoeducation is defined as an intervention with systematic, structured, and didactic knowledge transfer for an illness and its treatment, integrating emotional and motivational aspects to enable families to cope with illness to improve treatment, adherence and efficacy (Ekhtiari, Rezapour, Aupperle, & Paulus 2017:239-264). Family psychoeducation aims to provide psychosocial support, information and education to families aimed at building capacity of carers to improve their caring skills. Psychoeducation is delivered via individual or group programs and involves mental health clinicians providing information to family caregivers and patients (Sin, Gillard, Spain, Cornelius, Chen & Henderson 2017:13).

The goals of psychoeducation include improving communication within the family, teaching the family to recognize early warning signs and symptoms of relapse and how to respond to these warning signs, and education regarding medication adherence. The content of psychoeducation includes communication and problem-solving skills training, lifestyle and stress management, and the importance of family involvement as primary care providers (Tsui & Tsang 2017:76; Motlova, Balon, Beresin, Brenner, Coverdale, Guerrero, Louie & Roberts 2017:449). Psychoeducation may be done with one family, referred to as single-family psychoeducation, or in multiple family groups. It may vary in length and number of sessions, and settings can be different, including clinics, hospitals, or family homes. Psychoeducation programs may vary in how much they emphasize behavioural, cognitive, informational, clinical, rehabilitative, and family theory and techniques, problem solving, communication and consultative therapeutic aspects (McFarlane 2016:462).

For nurses to address the needs of families effectively, nurses must learn to hear the voices of the families with whom they work, try to understand the experiences and meaning that chronic illness has for the individual family (Hercelinskyj & Alexander 2022:441). While different mental health care professionals can be the initiators or facilitators of family psychoeducation programs, nurses are in a unique position to provide support to the family. They are the majority in the provision of primary health care (PHC) services and often the first point of contact. At the same time, it is a problem to expect PHC nurses in rural communities to conduct family psychoeducation if they struggle with time constraints and limited resources. The shortage of staff has been found to be a disadvantage of referral of MHCUs from mental hospital service to PHC clinics in Gauteng province (Hattingh & Joubert 2019:1218).

1.2.5.1 Benefits of psychoeducation

Psychoeducation is beneficial for enhancing caregivers' knowledge about mental health, and to provide emotional support. A better understanding of treatment mediators and moderators may inform the optimal design of psychoeducational interventions, targeting both MHCUs' and caregivers’ outcomes. While improving caregiving capacity is pivotal for MHCUs' outcomes, families' needs in terms of their own health and wellbeing should be better understood and addressed (Sin, Gillard, Spain, Cornelius, Chen & Henderson 2017:14).

Group psychoeducation for the families of MHCUs can be effective in changing their attitudes towards mental illness (Rahmani, Ranjbar, Ebrahimi & Hosseinzadeh 2015:245). Psychoeducation has been found a major therapeutic tool to enable families to manage the day-to-day stress triggered by a family member's mental disorder. Psychoeducation yields positive outcomes, such as fewer relapses, spending less time in in-patient mental health care units, decreased sense of stigma, better compliance with psychotropic drugs, better social and problem-solving skills, improved global level of functioning, less occurrence of depression and anxiety among caregivers (Srivastava & Panday 2016:129).

A review of the feasibility and acceptability of psychoeducation and psychosocial interventions for schizophrenia in low- and middle-income countries revealed positive outcomes in improved knowledge of mental illness and adherence, personal hygiene, self-esteem, psychosomatic symptoms, self-isolation from others associated with stigma and discrimination of people living with mental illness and their caregivers. The MHCUs affirmed improvement after attending psychoeducation with their family members which led to improved family-user relationships (Brooke-Sumner, Petersen, Asher, Mall, Egbe & Lund 2015:12). In low- and middle-income countries barriers to optimal use of family psychoeducation included low levels of education, low economic status, limited human and other resources and regular follow-up of medications at PHC facilities.

1.2.5.2 Challenges of psychoeducation

In Sweden, Ingvarsdotter, Persson, Hjarthag and Ostman (2016:484) examined the views of professionals regarding a multifamily psychoeducational model and reported two challenges namely, a defensive culture and unsuitable model. Resistance to introducing the new intervention was found on multiple levels. The model proposed was considered too rigid for both the target group and the organizations because it could not be adjusted to the needs of patients, families, or facilitators.

In Italy, Fiorillo, Del Vecchio, Luciano, Sampogna, Sbordone, Catapano, De Rosa, Malangone, Tortorella, Veltro and Nicolò (2016:657) investigated the feasibility of a psychoeducational family intervention for people with bipolar I disorder and their relatives. The findings highlighted high levels of organizational difficulties related to the need to integrate psychoeducation with other work routines to counteract the shortage of health care professionals. The study revealed a lack of time to carry out the interventions, but the retention rate of families receiving the intervention was good (Fiorillo et al 2016:661).

In Canada, Selick, Durbin, Vu, O'Connor Volpe and Lin (2017:371) examined the barriers and facilitators to implementing family support and education in early psychosis intervention programs. The interest of the family, readiness to participate; unique family support needs/preferences, and timing, length and content of the intervention were important facilitators. The ability to access support, staff training and availability of resources were barriers. Selick et al (2017:371) recommended a flexible, tiered approach to care to meet family needs and increase rates of uptake of family support.

Although the importance of psychoeducation is clear, the implementation may pose challenges. Chongwe-Sungani (2013:650) indicated that many nurses in Malawi lacked the knowledge and skills to deal with mental health problems. Similarly, Thupayagale-Tshweagae and Ganga–Limando (2014:981) found that nurses lacked basic skills; some were not trained in the management of MHCUs, while others considered themselves incompetent to provide quality care for the MHCUs and their families. In 2019, the South African Human Rights Commission (SAHRC) reported that the situation was exacerbated by poor mental health literacy among South African communities with little information provided in pamphlets and written in English only (SAHRC 2019:28). Moreover, nurses experience challenges such as staff shortages, a lack of caring ethos, declining interest and disjuncture between the needs of communities and nurses' perceptions (Gray & Vawda 2015:18). In Vhembe district, the shortage of professional and support staff compromised quality of primary mental health care services (Vhembe District Municipality 2019/2020 IDP Review:106). There is a need in South Africa to develop community-based family care, in keeping with international best practice and to strengthen primary mental healthcare services (Docrat, Besad & Lund 2019:12).

Currently there is no family psychoeducational intervention program in South Africa for families caring for MHCUs in rural communities. Therefore, the researcher wished to develop a psychoeducational program to support families caring for MHCUs in Vhembe District, Limpopo Province in order to help them cope and reduce the burden associated with caregiving.

1.3 PROBLEM STATEMENT

The researcher is a clinical facilitator with advanced mental health nursing experience, working at a higher education institution and has 24 years of clinical experience in acute mental health care units. During student clinical accompaniment the researcher observed that many MHCUs admitted in mental healthcare units of the general hospital in Vhembe district are well known to the service. When interacting with the family members they expressed feelings of anger, frustration, loss, grief, and being powerless, indicating that they are "lost and left out" by the mental health system. They experienced stress of caring for the MHCUs, lack of support from mental health providers, and inability to cope with their relatives' mental illness.

In South Africa, the Mental Health Care Act, 17 of 2002 makes provision for families to be empowered to ensure that they play an active role in the treatment of MHCUs. The National Mental Health Policy Framework and Strategic Plan 2013-2020 (Department of Health [DOH], 2013) emphasizes the need for family support and psychoeducational programs to decrease relapse and reduce the burden of care. Nurses are in a position to provide psychoeducation as they are the frontline of health care systems and have frequent contact with family members. The South African Nursing Council's (SANC, 2005) scope of practice requires professional nurses to empower healthcare users to enhance active participation in health care.

Lack of family support negatively affects the physical and mental well-being of family caregivers. This is supported by the findings of the study done in Zimbabwe by Marimbe, Cowan, Kajawu, Muchirahondo and Lund (2016:76) who found that caregivers of MHCUs experienced physical, psychological, emotional, social and financial burdens. In India, the caregiver burden led to reduced productivity at home and work, loss of income and employment, disrupted family and social networks, stigma, discrimination, rejection, marginalization and decreased quality of life (Chadda 2014:223). In Tanzania, family caregivers found that a lack of education on the nature of mental illness was a problem (Iseselo et al 2016:7). In Iran, family caregivers' burden included burnout, lower quality of life, uncertainty, grief, depression, fear, lack of energy and sleeping disturbances (Akbari, Alavi, Iralpour & Maghsoudi 2018:335; Von Kardorff et al 2015:250).

In South Africa, current interventions to support family members such as awareness campaigns and family day events do not meet the specific psychosocial needs of the families. Mental health education is not well structured and is usually done informally. Shilubane and Khoza (2014:384) found that primary healthcare workers in Vhembe District, Limpopo Province, highlighted inadequate opportunities to provide mental health education. Families were largely ill equipped to manage MHCUs and reported negative experiences related to caregiving for MHCUs at home (Lippi 2015:922; Monyaluoe et al 2014:4).

In Vhembe District Mbedzi (2018:96) found that family members reported lack of knowledge, ineffective involvement in the care of MHCUs, and financial and emotional distress. The families felt that healthcare professionals were not supportive enough because they were not given information about the MHCU's condition and treatment program and were treated like outsiders.

The researcher found several studies on the experiences of family members caring for MHCUs, and little or no research on programs to support families in rural areas in South Africa. This prompted the researcher to develop a psychoeducational program applicable to the rural context of SA in order to assist family members caring for MHCUs and minimize their caregiving burden.

1.4 RESEARCH QUESTION AIM AND OBJECTIVES OF THE STUDY

The study wished to answer the following research questions:

How can a psychoeducational program be developed to support family members caring for MHCUs in Vhembe District, Limpopo province?

What should a psychoeducational program to support family members caring for MHCUs in Vhembe District, Limpopo province look like?

The aim and objectives of the study are outlined in Table 1.1.

Table 1.1 Research aim and objectives

Research aim	The aim of the study was to develop a psychoeducational program to support family members caring for MHCUs in Vhembe District, Limpopo Province.
Phase 1	
Objective 1	To explore and describe the needs of family members caring for MHCUs in Vhembe district, Limpopo province.
Phase 2	
Objective 2	To develop a psychoeducational program to support family members caring for MHCUs in Vhembe district, Limpopo province using a nominal group technique
Phase 3	
Objective 3	To refine a psychoeducational program to support family members caring for MHCUs in Vhembe district, Limpopo province using an e-Delphi technique

1.5 PARADIGM AND THEORETICAL FRAMEWORK

The paradigm and theoretical framework of the study are briefly described next.

1.5.1 Paradigm

A paradigm is a worldview that encompasses a set of philosophical assumption that guides the study towards an appropriate research approach (Polit & Beck 2017:738). The researcher selected pragmatism as paradigm for the study (see chapter 3 for full discussion).

1.5.2 Theoretical framework

The researcher used the theory for health promotion in nursing (THPN) (University of Johannesburg 2017:4-7) as the theoretical framework for the study. The goal and emphasis of this theory is the promotion of health of the individual, family, group and community. The theory is applicable within psychiatric nursing science as the patient is viewed holistically in interaction with his/her environment. The psychiatric nurse, as a sensitive therapeutic agent, implements the nursing process as a resource in the promotion of mental health of the MHCU and the family. The meta-theoretical and theoretical assumptions of THPN (University of Johannesburg 2017:4) are discussed and applied in chapter 2.

1.6 STUDY SETTING

The study setting refers to the location where the study is conducted (Gray, Grove & Sutherland 2017:353). The study was conducted in the community health centres of Vhembe District. Vhembe district is one of the five districts in Limpopo Province and is located in the northern part of the province. The district comprises four local municipalities, namely Musina, Collins Chabane, Thulamela and Makhado.

Health care services in Vhembe District are provided by 112 clinics, eight community health centres (CHCs), 39 mobile services, six district hospitals, one regional hospital and one specialised mental hospital. Three of the general hospitals do not have mental healthcare units but admit MHCUs for 72-hour assessments and observation in general units. Out of 160 primary healthcare professional nurses, 66 are trained in mental health, and one nurse with an advanced psychiatric nursing qualification is allocated to the mobile clinic. The district has a functional mental health review board and one advanced psychiatric nurse practitioner acting as district manager who coordinates mental health services. There is one psychiatrist for the whole district stationed at a psychiatric hospital (see chapter 2 for a detailed discussion of the study context).

1.7 RESEARCH DESIGN AND METHODOLOGY

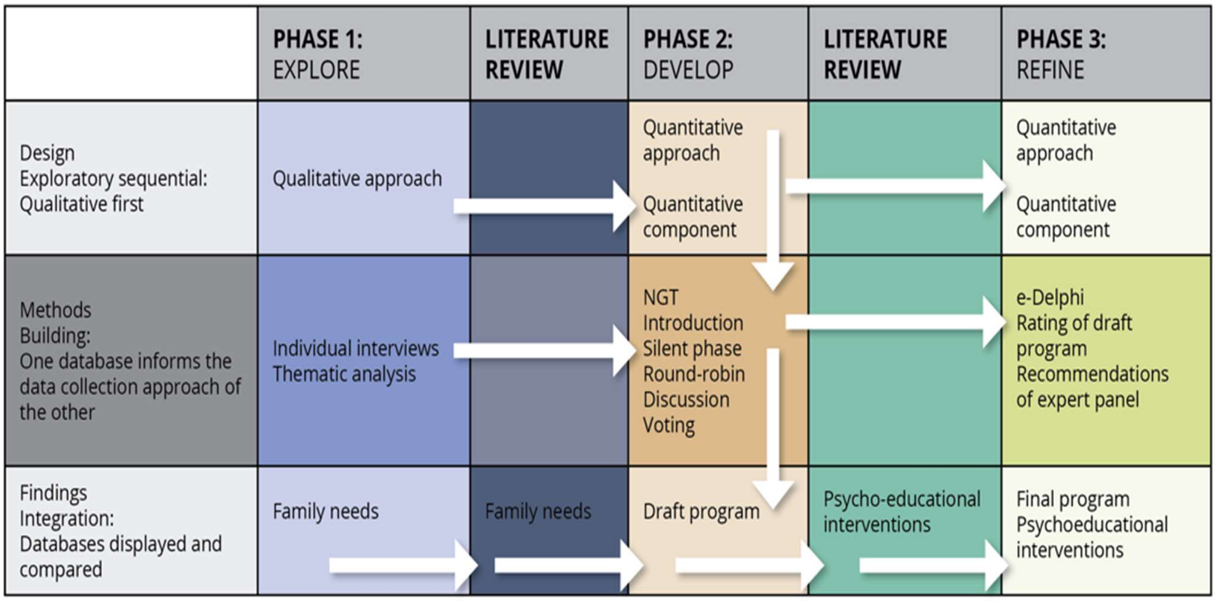
A research design is the overall plan for addressing a research question, including specifications for enhancing the integrity of the study (Polit & Beck 2017:513). Polit and Beck (2017:510) describe research methodology as the steps, procedures and strategies taken to investigate the problem being studied and to analyse the collected data. Table 1.2 summarises the research design and methodology

Table 2.2 Research design and methodology

Phase	Phase 1 Qualitative, exploratory and descriptive	Phase 2 Psychoeducational program development	Phase 3 Refinement of the program
Research question	What are the needs of family members caring for MHCUs in Vhembe district Limpopo Province?	How can a psychoeducational program to provide support to family members caring for MHCUs in Vhembe district, Limpopo Province be developed?	How can the draft psychoeducational program to provide support to family members caring for MHCUs in Vhembe district, Limpopo Province be refined?
Objective	To explore and describe the psychosocial needs of family members caring for MHCUs	To develop a psycho-educational program to support families caring for MHCUs in Vhembe district of Limpopo Province, using the nominal group technique	To refine the draft psycho-educational program to provide support to family members caring for MHCUs in Vhembe district, Limpopo Province, using the e-Delphi technique.
Approach	Qualitative	Qualitative and quantitative	Qualitative and quantitative
Method	Individual interviews	Nominal group technique	e-Delphi technique
Population	Family members	Stakeholders involved in mental health care and support of family members of MHCUs	Local and international mental health experts.
Sampling	Purposive	Purposive	Purposive
Data collection	Individual semi-structured interviews	NGT (Introduction, Silent phase, Round Robin, Discussion, Voting)	e-Delphi (Likert scale questionnaire to rate the components of the psychoeducational program)
Data analysis	Thematic analysis	Statistical analysis of consensus rates and NGT content analysis	Statistical analysis of consensus rates and content analysis of recommendations

In this study, the researcher used a multimethod design to obtain a detailed and deeper understanding of the research problem. The researcher selected an exploratory sequential design where the qualitative findings of phase 1 informed phases 2 and 3 (Fetters, Curry & Creswell 2013:2134). The needs of the families generated from phase 1 informed the subsequent program development and refinement process in phases 2 and 3. In phase 1, a qualitative approach was used to explore and describe family members' needs. In phase 2, a nominal group technique (NGT) (qualitative and quantitative) was used to generate ideas from stakeholders on what should be included in the draft program. In phase 3, an e-Delphi technique was used to refine and reach consensus on the final program. Table 1.3 summarises the exploratory sequential approach.

Table 1.3 Exploratory sequential design



	PHASE 1: EXPLORE	LITERATURE REVIEW	PHASE 2: DEVELOP	LITERATURE REVIEW	PHASE 3: REFINE
Design Exploratory sequential: Qualitative first	Qualitative approach		Quantitative approach Quantitative component		Quantitative approach Quantitative component
Methods Building: One database informs the data collection approach of the other	Individual interviews Thematic analysis		NGT Introduction Silent phase Round-robin Discussion Voting		e-Delphi Rating of draft program Recommendations of expert panel
Findings Integration: Databases displayed and compared	Family needs	Family needs	Draft program	Psycho-educational interventions	Final program Psychoeducational interventions

(Fetters et al 2013:1,2)

1.7.1 Phase 1: Exploration and description of the needs of family members caring for MHCUs in Vhembe District

This section briefly describes the research design, population, sampling and sample, data collection and analysis, and measures to ensure rigour (see chapter 3 for full discussion).

1.7.1.1 Qualitative, exploratory, descriptive and contextual approach

In this phase, the researcher used a qualitative, exploratory, descriptive and contextual approach to explore and describe the needs regarding caregiving of MHCUs by family members caring for MHCUs. The researcher used a qualitative approach to describe the participants' emotional and personal experiences and understand the deeper meaning from their perspective (Grove & Gray 2018:17). To gain more insight, the researcher explored the needs of families caring for MHCUs in Vhembe district of Limpopo province. A descriptive approach allows the researcher to describe and document aspects of the topic as they occur naturally (Polit & Beck 2017:471). In this study, the researcher described family members' needs as narrated by them and conducted one-to-one in-depth interviews at the homes of the family members in the context where they care for MHCUs.

1.7.1.2 Population

The target population is the entire set or aggregation of objects, persons, events or units in which a researcher is interested and that meet certain criteria (Botma, Greeff, Makhado &

Mulaudzi 2022:260). The accessible population refers to a group or objects that are available to the researcher for a particular study (Brink, van der Walt & van Rensburg 2018:208). In phase 1, the target population was all family members caring for known MHCUs who visit community health centres for monthly follow-up, while the accessible population was family members of MHCUs who attended their treatment reviews at the community health centres.

1.7.1.3 Sampling and sample

The researcher used purposive or non-probability sampling to select the district, community health centres, and participants. Vhembe District was selected because it has the highest mental health admission rate of the districts (Health Systems Trust, 2015:218). All eight community health centres were selected because of the high numbers of MHCUs treated at the facilities to obtain a good presentation of the population. To be included in the study, family members had to have two or more years' experience of caring for a relative with mental illness and be willing to participate. The sample size consisted of 16 family members.

1.7.1.4 Data collection

Data collection refers to the gathering of information to address a research problem (Polit & Beck 2017:725). Data were collected in one-to-one semi-structured interviews, supplemented by field notes, using an interview guide (see Annexure D). The purpose of individual interviews was to collect information-rich data. A research assistant was employed as the geographical area was widely scattered. The interviews were audio-recorded with participants' consent and lasted 30-45 minutes. The central question that guided the interview was "What are your needs regarding caregiving to your family member with mental illness?" followed by probing questions.

1.7.1.5 Data analysis

Data analysis refers to the systematic organization and synthesis of research data, conducted to reduce, organize, and give meaning to data (Polit & Beck 2017:725). The researcher analysed the data using Braun and Clarke's (2013:120) six steps of thematic analysis (see chapter 3 for discussion).

1.7.1.6 Rigor

Qualitative researchers adhere to trustworthiness, using credibility, dependability, transferability, confirmability and authenticity (Polit & Beck 2017:161 & 747) (see chapter 3).

1.7.2 Phase 2: Development of a psychoeducational program to support family members caring for MHCUs in Vhembe District

In this phase, the researcher used a qualitative and quantitative approach to develop a draft psychoeducational program to support family members caring for MHCUs.

1.7.2.1 Nominal group technique

A nominal group technique (NGT) includes both qualitative and quantitative methods. NGT is a structured face-to-face group session with the purpose of achieving group consensus and action planning on a chosen topic (Varga-Atkins, Bunyan; McIsaac & Fewtrell 2011:4). NGT was used to develop a draft psychoeducational program to support family members caring for MHCUs.

1.7.2.2 Population

The population included the following stakeholders: healthcare providers who render care, treatment and rehabilitation services to MHCUs and their family members; policy developers, and community representatives involved in providing support to families of MHCUs.

1.7.2.3 Sampling and sample

The researcher used purposive sampling to recruit 21 stakeholders involved in mental health care and support of family members of MHCUs based on their area of expertise and years of experience (see chapter 3 for discussion).

1.7.2.4 Data collection

A NGT creates an environment of engagement and consensus to facilitate inputs from the group members (Botma et al 2022:251). Stakeholders attended a one-day workshop to address the research question: How can a psycho-educational program to provide support to family members caring for MHCUs in Vhembe district be developed? Table 1.4 summarises the NGT.

Table 1.4 Steps followed during the Nominal Group Technique

Topic	Activities
Introduction	The researcher welcomed the participants and explained the purpose and procedure of the meeting, and gave a power point presentation on the purpose, objectives and findings of phase 1. The researcher presented a key question on a flip chart and read it aloud to the participants for feedback
Silent generation of ideas	The facilitator provided the participants with sheets of paper with questions to be addressed and asked them to write down all ideas that came to mind. While jotting down their ideas, the participants were prohibited from discussing their ideas with each other. Time: 40 minutes.
Sharing ideas/ Round robin	The facilitator invited the participants to share the ideas generated. The facilitator recorded each idea on a flip chart, using the participants' words. The round robin continued until all ideas had been presented. There was no debate about items and participations were encouraged to write down any new ideas that might arise from what others indicated. This process ensured that all participants had an opportunity to contribute and provided a written record of ideas generated. Time: 30 minutes.
Group discussion	The participants were invited to ask for clarification on ideas that were not clear or further details about any of the ideas that others had produced. The facilitator ensured that each participant was allowed to contribute, and that discussion of all ideas was thorough without spending too long on a single idea. The process was kept as neutral as possible, avoiding judgement. A moderator listed the themes in order of importance on the flip chart. Items with similar meaning were clustered together. Time: 45 minutes.The NGT stakeholders ranked the interventions individually according to their order of priority.
Voting and ranking	The recorded ideas were prioritised in relation to the original question. Following voting and ranking, the results were released immediately. The meeting concluded with having reached a specific outcome.

1.7.2.5 Data analysis

During the group discussion of the NGT, the findings were categorised into themes. The participants reached consensus on the themes and ranked the proposed themes (interventions) that formed part of the draft psychoeducational program (see chapter 3 for discussion).

1.7.2.6 Rigor

In the NGT trustworthiness was obtained through truth-value, applicability, consistency, neutrality, and authenticity (Botma et al 2022:291) (see chapter 3 for discussion).

1.7.3 Phase 3: Refinement of the draft psychoeducational program to support family members caring for MHCUs in Vhembe District

In this phase, an e-Delphi technique was used to address the research question: How can a psychoeducational program to provide support to family members caring for MHCUs in Vhembe district, Limpopo Province be refined?

The Delphi method is done with a panel of experts with knowledge and expertise in the study subject, using a series of questionnaires to gather data, which continues until the experts reach consensus (Habibi, Sarafrazi & Izadyar 2014:8; Jacob, Duffield & Jacob 2017:1982). In this study, the Delphi method was conducted by e-mail in two rounds, based on reaching consensus. Consensus was achieved by means of indicating the points using a five-point Likert scale to evaluate the draft psychoeducational program using the inputs from each e-Delphi round in order to yield a reliable family support program.

1.7.3.1 Population

The population comprised academics (researchers who have published articles on the topic of concern), local and international qualified mental health specialists representing government, non-government organizations and mental healthcare service managers responsible for mental healthcare programs.

1.7.3.2 Data collection

Data was collected in two e-Delphi rounds, which was determined by reaching consensus. During the first round, a questionnaire with a checklist was e-mailed to the panel members to rate the reliability of each component of the program and write their recommendations and general comments (Polit & Beck 2017:267). The draft psychoeducational program, cover letter and consent form (see Annexure H) were also sent. The panel feedback was analysed and the psychoeducational program adapted. Feedback on the psychoeducational program adapted in the first round was provided to the panel members to consider and make further recommendations.

1.7.3.3 Data analysis

Data analysis involved both quantitative and qualitative data. The researcher collated the consensus rate from the responses based on the Likert scale to indicate agreement and determined consensus rates. The experts' comments or suggestions were analysed to identify themes and categories.

1.7.3.4 Rigor

The trustworthiness, reliability and validity measures are discussed in chapter 3.

1.8 SIGNIFICANCE OF THE STUDY

The findings of the study contributed to the body of knowledge on psychoeducation for families with relatives diagnosed with mental illness. The results are significant for policy makers, family members caring for MHCUs, and nursing education and practice.

1.8.1 Policy makers

The study recommendations may assist the Department of Health and policy makers to develop and implement evidence-based family-centred primary healthcare policies and programs to address the bio-psychosocial needs of family members caring for MHCUs. The psychoeducational program is intended to strengthen a community-based mental health care model.

1.8.2 Nursing education

The SANC and Department of Health can use the findings to include psychoeducation modules in nursing education curricula related to mental health care training.

1.8.3 Nursing practice

The findings of the study should give mental health care providers a better insight into the educational and supportive needs of family members of MHCUs and provide family-focused interventions to help them cope better with the caregiving burden.

1.8.4 Family caregivers

The program should assist family caregivers and members to acquire knowledge and skills to improve the care given to MHCUs to reduce relapse and readmission. Furthermore, they should learn to deal with the emotions and stress caused by caregiving.

1.8.5 Nursing research

The findings of the study add to the body of knowledge regarding psychoeducation for families with a relative diagnosed with mental illness. The study may motivate other researchers to implement, evaluate and adapt the psychoeducational program in different contexts.

1.9 DEFINITIONS OF KEY TERMS

In this study, the following key terms were used as defined below.

- **Caring.** Caring means to commit and to look after others and provide for their needs (*Oxford English Dictionary* 2020:102). In this study, caring referred to the efforts of family members to provide for the physical, psychological, spiritual, social and financial needs of MHCUs at home.
- **Family burden.** Family burden refers to the level of multifaceted strain and responsibilities of the family members who assume a caretaking function for a relative with a mental health problem over time (Kneisl & Trigoboff 2014:633; Liu, Hefferman & Tan 2020:442). In this study the family burden entailed the objective and subjective

burden experienced by the family members as they interacted with their internal and external environment. The MHCU forms part of the external social environment of family members.

- **Mental Health Care User (MHCU).** A MHCU refers to a person receiving care, treatment and rehabilitation services or using health care services at a health establishment aimed at enhancing the mental health status of the user (Mental Health Care Act, 17 of 2002). In this study, a MHCU was a person who had been admitted in a mental health care facility in Vhembe district and had been on psychiatric treatment for a minimum of two years, and was presently receiving care, treatment and rehabilitation services at a community health care centre. The acronym, MHCU is used interchangeably with patient.
- **Mental health.** In this study, mental health was seen as a dynamic interactive process in the individuals' living environment in terms of their interaction with others. The relative mental health status of the family member caring for the MHCU is reflected by interactions intended to promote the mental health of the MHCU and the family (University of Johannesburg 2017:4). Mental health refers to the successful performance of mental functions, resulting in productive activities, establishing and maintaining relationships with other people.
- **Mental illness.** The Mental Health Care Act, 17 of 2002, section 10 states that mental illness refers to a positive diagnosis of a mentally related illness, in terms of accepted diagnostic criteria, made by a mental health care practitioner, authorized to make such a diagnosis. In this study, mental illness referred to any mental disorder which has been diagnosed according to the Diagnostic and Statistical Manual 5™ (DSM 5) classification (American Psychiatric Association 2013). Mental health problems of the family members caring for the MHCU are reflected by interactions that interfere with the mental health of the MHCU and the family (University of Johannesburg 2017:4).
  Mental illness refers to a clinically significant behavioral or psychological syndrome or pattern that occurs within a person and is associated with distress or disability. The term psychiatric illness is used interchangeably with mental illness. It implies that individuals who do not meet the criteria for mental health are therefore mentally ill.
- **Program.** A program refers to a plan of things that will be done or included in the development of something (*Oxford English Dictionary*, 2012). In this study, a program referred to a series or sessions of educational information and psychological support provided by primary health care psychiatric nurses to family members taking care of MHCUs in order to equip them with knowledge and skills to enhance their ability to cope better with the caregiving responsibility.

- **Psychoeducation.** Psychoeducation refers to an intensive and responsive process aimed at empowering the family and the patient with basic knowledge and competence about the illness, provide insight into the illness, promote relapse prevention and engage in crisis management and suicide prevention (Sarkhel et al 2020:S319). In this study, psychoeducation referred to an interactive process between the primary health care psychiatric nurses and the family members which involved education on mental illness and its management; skills training according to the needs of the family (e.g., coping skills, interpersonal skills), and the facilitation of psychological support and guidance to the family members of the MHCUs. The psychoeducation provided to family members had as its outcomes the provision of holistic care to MHCUs.

1.10 ETHICAL CONSIDERATIONS

Ethics deals with matters of right and wrong. When humans are used as study participants, care must be taken to ensure that their wellbeing and rights are protected (Polit & Beck 2017:138). In this study, ethical principles were adhered to in order to ensure that the rights of the participants were protected. Accordingly, the researcher obtained permission to conduct the study, and observed the ethical principles of beneficence, respect for human dignity and justice (Polit & Beck 2017:139).

1.10.1 Permission to conduct the study

The researcher obtained permission to conduct the study from the School of Health Care Sciences Postgraduate Research Committee and the Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria (see Annexure G). Permission was obtained from the Department of Health, Limpopo Province research review committee (see Annexure F) and Vhembe District (see Annexure F). Permission was also obtained from the CEOs of Siloam Hospital, Tshilidzini Hospital, Malamulele Hospital, and Hayani Hospital in Vhembe district for the NGT (see Annexure F). The Vhembe District Department of Health granted permission for conducting an NGT with health care providers (see Annexure F).

The researcher requested participants to sign an informed consent form for the interviews (see Annexure A), NGT (see Annexure B), and for the e-Delphi technique (see Annexure C) before engaging in interviews and completing the questionnaires.

1.10.2 Respect for human dignity and justice

This principle includes the right to self-determination and the right to full disclosure (Polit & Beck 2017:211). The researcher treated the participants as autonomous individuals; informed them of the purpose of the study, that participation was voluntary, and that they were free to withdraw from the study at any time should they wish to do so. The researcher described her responsibilities and the benefits of the study, allowed the participants to ask questions, and informed them that all information would be treated confidentially (Polit & Beck 2017:141).

1.10.3 Informed consent

Informed consent involves participants' right to make informed, voluntary decisions to participate, which requires full disclosure, and no deception or concealment (Polit & Beck 2017:731; Grove & Gray 2018:96). The researcher explained the purpose of the study, including risks and benefits. The participants were informed of their right to participate or not, and to withdraw at any time without any risk or prejudice. The participants were given an opportunity to ask any questions they wished. The researcher requested the participants to sign the informed consent form (see Annexure A, B and C).

Informed consent means that participants have sufficient information about the study, comprehend that information, and have the ability to consent to or decline participation voluntarily (Polit & Beck 2017:143). The authors further added that the content of the informed consent include the following information to participants: participant status; the goal of the study, type of data, data collection procedures; nature of commitment participants selection; potential risks involved in the study, potential benefits; alternatives; compensation; confidentiality pledge; voluntary consent and sponsorship (Polit & Beck 2017:143). See Annexure A for the qualitative phase, Annexure B for the NGT, and for the e-Delphi technique see Annexure C.

1.10.4 Privacy, anonymity and confidentiality

The right to privacy meant that the participants had the right to anonymity and to assume the data collected would be kept confidential (Polit & Beck 2017:156). The participants' anonymity was assured by using participant numbers instead of names in all three phases. Participants were asked to keep all information discussed in the NGT workshop confidential. Furthermore, the audio-recordings were only reviewed by the researcher and the supervisor and will be kept with the transcripts under lock and key for 15 years. Only the researcher and supervisor had access to the information.

1.10.5 Scientific honesty

The researcher respected and upheld scientific honesty by protecting the integrity of the data collected, and not forging or reporting anything that was not done (Brink et al 2018:37). Throughout the study, the researcher kept an audit trail by recording the research process and steps.

1.10.6 Beneficence

Beneficence includes the right to freedom from harm and discomfort and the right to protection from exploitation (Polit & Beck, 2017:139). The researcher ensured that a psychologist was available to refer participants who experienced emotional discomfort during the interviews. Two participants were referred for emotional support, but they did not require long-term interventions.

1.11 OUTLINE OF THE CHAPTERS

The study consists of eight chapters. Table 1.5 lists the chapters and their titles.

Table 1.5 Chapters of the thesis

Chapter	Title
1	Orientation to the study
2	Theoretical framework and study context
3	Paradigm, research design and methodology
4	Phase 1: Qualitative findings on healthcare needs of family members and literature review
5	Phase 2: Nominal group technique findings and literature review
6	Development of a psychoeducational program to support family members caring for mental health care users
7	Phase 3: Refinement of a psychoeducational program using e-Delphi technique
8	Conclusions, limitations, and recommendations

1.12 CONCLUSION

This chapter discussed the aim and objectives, research design and methodology, significance and ethical considerations of the study, and defined key terms. Chapter 2 discusses the theoretical framework and context of the study with reference to the literature review.

CHAPTER 2
THEORETICAL FRAMEWORK AND STUDY CONTEXT

2.1 INTRODUCTION

Chapter 1 introduced the background, problem, aim and objectives, as well as the research design and methodology of the study.

This chapter discusses the Theory for Health Promotion in Nursing (THPN) (University of Johannesburg 2017:5-12) as the theoretical framework for the study; and the study context which includes the policy and legislative framework for promotion of mental health of the family members of MHCUs.

2.2 THEORY FOR HEALTH PROMOTION IN NURSING

The THPN was selected for the study because of the underlying philosophy of holism, considered fitting to address the support needs of families caring for MHCUs. The assumptions, purpose, and concepts of the theory are described next.

2.2.1 Assumptions

The THPN utilizes a pragmatic approach which entails that research is undertaken to improve practice in nursing (University of Johannesburg 2017:11). This study was therefore practical as it aimed to improve practice in nursing by addressing the needs of family caregivers of MHCUs in rural communities of Vhembe District, Limpopo Province. The researcher is of the opinion the that it is crucial to address the holistic health needs of the family members to ease the burden of care and improve the caregivers' quality of life. The study was conducted in three phases. In order to identify the needs of the families caring for the MHCUs, phase 1 wished to answer the question: "What are the needs of family members caring for MHCUs in Vhembe district Limpopo province?''.

The THPN is based on the following assumptions (University of Johannesburg 2017:11):

- The person is seen holistically in interaction with the environment in an integrated manner.
- The environment includes an internal and external environment. The internal environment consists of body, mind and spiritual dimensions.
- The external environment consists of physical, social and spiritual dimensions.
- Nursing is an interactive process which facilitates the promotion of health.
- Nursing interactions indicate a mutual involvement between the nurse and the patient.

- The nurse is a sensitive, therapeutic professional who demonstrates knowledge, skills and values to facilitate the promotion of health.

2.2.2 Purpose

The purpose of the theory is the promotion of health of the individual, family, group and community. In this study, the promotion of health focused on the health of family members living with and providing care to an MHCU in a home environment.

2.2.3 Components and concepts applied to the study

The central components of the theory are person, nursing, environment, and health. Other concepts related to the study include mental health, promotion of health and resources.

- **Person**

A person is seen as an individual who is a whole person and embodies dimensions of body, mind and spirit (University of Johannesburg 2017:5). The individual functions in an integrated, interactive manner with the environment.

The body includes the anatomical structures and physiological (biological) processes pertaining to the individual. The mind includes the intellectual, emotional and volitional processes of the individual. The intellect refers to the capacity and the quality of the psychological processes of thinking, association, analysis, judgement and understanding of which the individuals are capable. Emotion is a complex state that can be divided into the individual's affection, desire and feelings. Volition is a process of decision-making in executing a choice by the individuals. Spirit refers to that part of individuals reflecting their relationship to God. The spirit consists of two interrelated components which have an integrated function, namely conscience and relationships. The conscience is the component which distinguishes between right and wrong. Relationships refer to individuals' interaction with themselves and their God (University of Johannesburg 2017:11).

In this study, 'persons' referred to family members caring for an MHCU. The family members were regarded as holistic beings composed of physical, mental, social and spiritual aspects. The researcher believes that family members have the potential to access their own feelings and empower themselves and other family members toward health. They also have the choice and potential to bring about change in their lives and decide where they want to be in future. The researcher regarded the spiritual dimension as their ability to reflect and respond to the self and the environment.

- **Nursing**

Nursing is a goal-directed service to support the individual, family and/or community to promote, maintain, and restore health. Promotion of health refers to ensuring a greater degree of wholeness for the individual, family, and/or community. Maintenance of health refers to preserving the comprehensive health status of the individual, family and/or community. Restoration of health refers to facilitation or support to return to previous levels of health of individuals, families and/communities (University of Johannesburg 2017:11).

A specific therapeutic nurse-patient relationship is unique in that the psychiatric nurse is the voice of the patient when he/she exercises the advocacy role (Evans, Nizette & O'Brien 2016:73). Middleton (2020:811) define a psychiatric nurse as a person who directs efforts towards the promotion of mental health, prevention of mental disturbances, through early identification of nursing problems and intervention in emotional problems, and follow-up care to minimise long-term effects of mental disturbances. In this study, a psychiatric nurse referred to a primary health care nurse trained in mental health who provide psychosocial support to the family members caring for the MHCUs in their local communities. Professional nurses enter into a relationship with the family members during the provision of comprehensive nursing care. Promotion of health refers to nursing activities contributing to a degree of wholeness for the family members of MHCUs in Vhembe District, Limpopo Province.

- **Environment**

The environment includes the internal and external environment. The internal environment consists of dimensions of body (physical), mind (psychological) and spirit (spiritual). The external environment consists of physical, social and spiritual dimensions. The patterns of interaction between the internal and external environment determine the person's health status (University of Johannesburg 2017:6). Physical refers to the physical and chemical agents/structures in the external environment of the individual/family/group/community. Social refers to the human resources in the individual's/family's/group's/community's external environment. Spiritual refers to the values and religious aspects in the individual's/family's/group's/community's external environment (University of Johannesburg 2017:11).

In this study, the researcher wished to identify the needs of the families. The external environment might reflect the family's current social status, such as family income, interpersonal relationships with the extended family, and cultural and religious beliefs systems which might impact on the family unit. According to the THPN (University of

Johannesburg 2017:4-7), interaction between these environments is necessary in assisting the family members to cope with care provision and utilize their resources to promote health.

- **Health**

Health is a dynamic interactive process in the patient's environment. The interactions in the person's environment reflect the relative physical, psychological, social and spiritual health status of family members. This interaction contributes to or interferes with the promotion of health. Health is viewed as a state of mental, physical, psychological, social and spiritual wholeness (University of Johannesburg 2017:11). In this study, health referred to the families' physical, psychological and spiritual wholeness or well-being. Mental health promotion implicates the mobilization of internal and external resources to achieve the wellness of the family caring for the MHCUs.

- **Mental health**

Mental health refers to holistic well-being where individuals accept themselves, acknowledge their actions and accept responsibility to re-organize their lives in order to enhance their psychological, physical, social and spiritual well-being. Individuals also express and realize their own unique and individual talents and potential. Mental health is an integral part of health reflecting wholeness (University of Johannesburg 2017:4). In this study, mental health referred to a dynamic interactive process in the family members' environment which affects the relative mental health status of the family and the MHCU.

According to Coronel-Santos and Rodríguez-Macías (2022:11) mental health is defined as the internal process of self-care, centered on the self-awareness and self-regulation of the human being, in which the person seeks to balance feelings, thoughts and behaviors, intrapersonal, and interpersonal, to approach an optimal state of wellbeing and absence of mental disorders based on universal values and symptoms, and in relation to biological, social, psychological, and environmental factors. Thus, mental health is a state of wellbeing that is achieved by a process of internal self-care related to external and internal factors of the person.

- **Promotion of health**

Health promotion includes the promotion, maintenance and restoration of health and is aimed at the facilitation of resource mobilisation of an individual, family, group and community. In this study, it referred to mobilization of resources by all stakeholders involved in mental health care in the primary health care settings in Vhembe District. Mobilisation of resources is a mutual, purposeful activity between the nurse or midwife and the patient where opportunities for the promotion of health are utilized. It also includes the identification and bridging of obstacles in the promotion of health. In this study, the psychiatric nurses could utilize the professional and non-professional resources from government and non-governmental organizations to support the family members of MHCUs.

- **Resources**

Resources in the environment include any assets or means of facilitation in the promotion of health. The resources in the family's internal environment can be physical, mental and spiritual. The resources in the family's external environment can be physical, social and spiritual.

2.3 LEGISLATION AND POLICY ON MENTAL HEALTH CARE

This section discusses the UN 2030 Agenda for Sustainable Development, the Mental Health Care Act, 17 of 2002; the Primary Health Care Package for South Africa, and the National Mental Health Policy Framework and Strategic Plan 2013-2030.

2.3.1 UN 2030 Agenda for Sustainable Development 2010-2030

In 2015, the United Nations (UN) General Assembly adopted and published the *2030 Agenda for Sustainable Development*, which is aimed at ending poverty in all its forms and envisages a world of universal respect for human rights and human dignity, the rule of law, justice, equality and non-discrimination (UN 2015:1). The sustainable development goals (SDGs) are a universal call to action to end poverty, protect the planet and improve the lives and prospects of everyone, everywhere (UN 2015:2). The main sustainable development goals (SDGs) are to attain healthy, thriving lives and well-being, free of preventable disease, disability, injury, and premature death; eliminate health disparities, achieve health equity, and attain health literacy to improve the health and well-being of all. By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment, and promote mental health and well-being (UN 2015:2). Investing in health is a necessity and a means to achieve the SDGs (UN 2015). In South Africa, the mental health policy and strategic plan (DOH 2013:1) aims to improve mental health and well-being, including families' caregiving burden.

In this study, psychoeducation serves as a strategy to promote mental health and prevent mental illness. This would promote the achievement of SDG 3: Good health and well-being, which aims to ensure physical and mental well-being for all ages, including alleviating family members' caregiving burden of MHCUs.

2.3.2 WHO Comprehensive Mental Health Action Plan, 2013-2020

Mental healthcare delivered in a primary healthcare setting would benefit MHCUs and families because the population as a whole would have access to care early and without interruption. This would also improve health outcomes, recovery, and social integration. Strong informal community mental health services and support groups could complement and strengthen the primary healthcare services provided (WHO 2008).

It is important to integrate physical and mental health care to limit or prevent addressing patients' physical and mental health needs in a disconnected way. Providing mental health services in primary health care involves diagnosing and treating people with mental disorders; putting in place strategies to prevent mental disorders and ensuring that primary health care workers are able to apply key psychosocial and behavioural science skills, such as interviewing. Challenges to integrating mental health into primary care include lack of training in mental healthcare services for the staff working in primary health care; unavailability of resources; poor communication between management and staff, and lack of skills among PHC nurses in identifying signs of mental illness and misdiagnosis (WHO & World Organization of Family Doctors, 2008).

In 2013, the World Health Organization introduced the *Comprehensive Mental Health Action Plan 2013-2020* aimed at improving the management of mental health of whole populations, including family members and MHCUs through promotion, prevention, care, treatment and rehabilitation in order to reduce the global burden of mental disorders. In 2019, the WHO extended the Action Plan to 2030. The plan aims to empower local communities, particularly MHCUs and their caregivers, to actively participate in the promotion of mental and physical well-being to assist them in achieving recovery within their communities. In 2003, the WHO introduced guidelines on the organization of services for mental health policy and service, incorporating different settings and levels that include primary care, community-based settings, general hospitals and specialized psychiatric hospitals (see Figure 2.1).

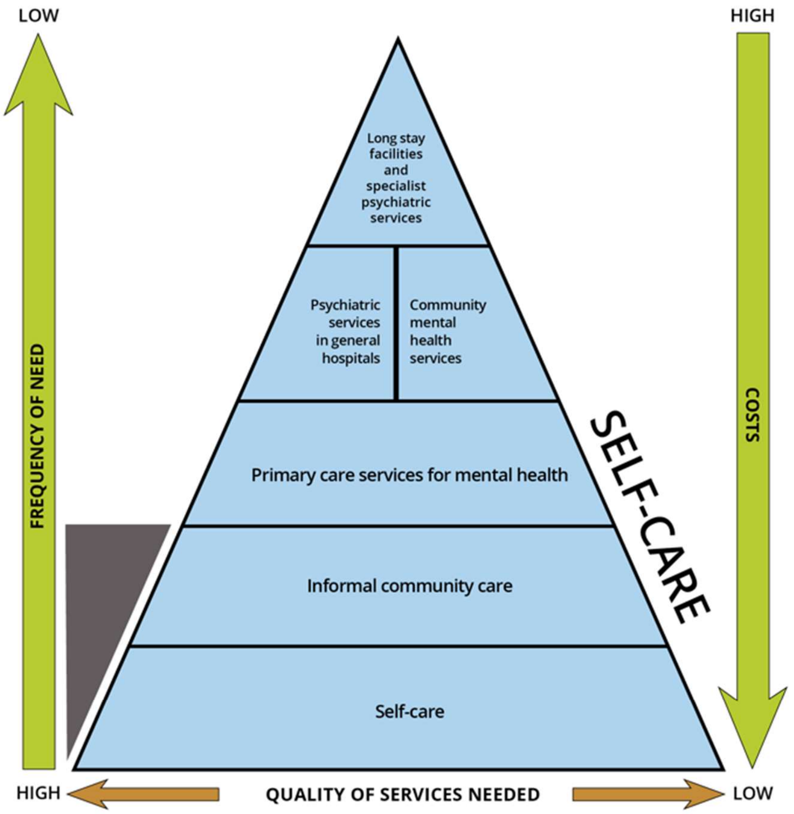


Figure 2.1: WHO Service Organization Pyramid for an Optimal Mix of services for Mental Health. Source (Adapted from World Health Organization 2008a)

2.3.3 Mental Health Care Act, 17 of 2002

In South Africa, the Mental Health Care Act, 17 of 2002 ensures that the human rights of MHCUs are protected, which is in line with the Constitution of the Republic of South Africa Act, 108 of 1996. Section 27 of the Constitution states that everyone has the right to have access to health care services. The core principles of the Mental Health Care Act are human rights for users; decentralisation and integration of mental health care at primary, secondary and tertiary levels of care, focusing on care, treatment and rehabilitation of people who are mentally ill. The Act advocates for a rehabilitative, community-based model of mental health care. This approach was meant to reduce the stigma attached to mental illness (Burns 2008:47).

The Act improves access, makes primary health care the first contact of mental health care with the health system, and promotes the integration of mental health care into general health services and the development of community-based services. In terms of the Act, MHCUs should be treated in the least restrictive environment and mental health should be fully integrated into all levels of care. The Act advocates the deinstitutionalisation of MHCUs so that they are treated in their families and communities. However, lack of knowledge, skills and resources frequently results in emotional, financial and social burdens and difficulties for family caregivers.

The Mental Health Care Act, 17 of 2002 prescribes a 72-hour assessment before commitment to facilities. The Act stipulates that when the assessment period has expired and the MHCUs' condition has improved to a point at which they are considered not to be a danger to themselves or others, but still lack capacity to consent to voluntary treatment, they can be discharged into the care of their family members. The intention of the Act is to empower family members and help ensure that they actively participate in the care of the MHCUs (Szabo & Kaliski 2017:69).

Furthermore, the Act allows the family members to make an application for involuntary or assisted care, treatment and rehabilitation services of an MHCU who is in need of in-patient care. Section 40 of the Act mandates the South African Police Service to assist the families with apprehension of the MHCU who is likely to inflict harm to self or others. The Act stipulates that any person who witnesses any form of abuse must report it in the prescribed manner so that the rights of the MHCUs and their families are protected. The Act directed that a family member can appeal within 30 days of the date of the written notice issued in terms of section 35 against the decision of the head of the health establishment to the Review Board. This means family members are given a platform to air their grievances with regard to care, treatment and rehabilitation of the MHCUs (Szabo & Kaliski 2017:71).

The guidelines direct that 72-hour assessment be done as near as possible to the homes of the MHCUs within the communities. Therefore, the family members have an opportunity to visit the MHCUs and become more involved in the treatment program during the interactive process with the multidisciplinary team. Furthermore, the MHCUs must be treated in the least restrictive environment. Families are involved in the completion of documents during initial admission procedure and assessment to obtain a detailed collateral history from the responsible caregivers (Szabo & Kaliski 2017:71).

The Mental Health Care Act, 17 of 2002 recognises health as a state of physical, mental and social well-being and directed that mental health should be provided as part of primary, secondary and tertiary health services. The Act emphasises the need to promote the provision of mental health care services in a manner which promotes the mental well-being of MHCUs, their families and communities at large. However, in 2014, community mental health and psychosocial rehabilitation services were still underdeveloped (Burns 2014:9).

2.3.4 Primary Health Care Package for South Africa

In 2003, the Department of Health (DOH 2003:1) introduced the Primary Health Care Package for South Africa and set norms and standards to improve the physical and mental health and social well-being of individuals, families and society at large. This comprehensive health care service package stressed the importance of providers' and patients' rights and responsibilities in health care and the importance of community services as part of primary health care (DOH 2003). Regarding mental health care, the package indicated that individual, group and family therapy would be done by psychiatric nurses but should not exceed 10 sessions for mental health promotional activities.

Community health centres render a primary health care service which includes health promotion, psychiatry and mental health services to all citizens of all ages (Massyn, Padarath & Peer 2017:3). The key priorities for primary health care in South Africa are to address the large burden of disease through health promotion and wellness by inter-sectoral processes at both national and local levels, and to develop the capacity of communities to engage meaningfully with the health sector through formal and informal mechanisms of participation and enhanced community-based services (Massyn, Padarath & Peer 2017:4).

Although South Africa has deinstitutionalized patients with serious mental illness, there has been little or no parallel development of community-based mental health service to accommodate MHCUs. The burden of psychiatric disability in the context of chronic poverty and unemployment marginalizes families who care for MHCUs. In 2010, Lund, Kleintjes, Kakuma and Fisher (2010:400) found a substantial mental health workforce shortage, with 1.2 psychiatrists and 7.5 psychiatric nurses per 100,000 people, which was nearly 10 times less than many high-income countries. Mental health professionals are concentrated in urban locations, with some rural provinces having one or no psychiatrist, leading to great disparities in care. In 2015, Rural Rehab South Africa (RuReSA) (2015:20) reported that rural areas accounted for almost half the country's population but still remained the most underserved and marginalized. MHCUs and their family members needed to be empowered with knowledge and skills on the management of mental conditions through psychoeducational interventions provided by primary mental health care professionals (RuReSA 2015:21).

2.4 CONTEXT OF THE STUDY

The study was conducted in Vhembe District, Limpopo Province. This section describes Vhembe district geographical location, health care services, and health care services staffing. The context covers community health centres and health care workers of all categories, including healthcare professionals and non-healthcare professionals, mental health nurses and general nurses, and MHCUs.

2.4.1 Vhembe district geographical location

Vhembe District is located in the northern part of Limpopo Province. It borders with Zimbabwe and Botswana in the north-west and Mozambique in the south-east through the Kruger National Park. It comprises four health sub-districts, namely Musina, Mutale, Thulamela and Makhado. The district has a population of 1 387 625, with a population density of 54.2 persons per km2 and falls in socio-economic Quintile 2, among the poorer districts, and has an estimated medical scheme coverage of 6.4%. Vhembe is one of the 11 National Health Insurance (NHI) pilot districts (Health Systems Trust 2015:565)

According to the STATSSA (2018:14), Vhembe district municipality had 382 358 households, Thulamela had 130 321, Makhado had 116 371, Musina had 43 730 and Collins Chabane had 91 936 households. Thulamela municipality had the highest number of households followed by Makhado, Musina and Collins Chabane municipalities. The district covers 27 969 148 square kilometres of land with a total population of 1 393 949 people.

2.4.2 Vhembe district health care services

Vhembe District has six functional district hospitals, one regional hospital, one specialized mental hospital (the only designated mental hospital that admits chronic, state and mentally challenged patients from all districts of Limpopo province), 115 clinics, eight community health centres and 19 mobile clinics. Eight district hospitals offer first level of care and one regional hospital offers secondary level of care. Outreach health service is provided by mobile clinics to the community. Three general hospitals do not have mental health care units but admit MHCUs for 72-hour assessments and observation in the general hospital in mental health care units (Vhembe District Municipality 2020/2021:75).

All primary health care facilities provide a comprehensive primary health care package. All clinics have good communication systems and access to internet connectivity. Facilities have a supply of electricity, clean water and sanitation. Sixty clinics provide primary health care services for 24 hours on-call system. Eight community health centres and five clinics provide 24-hour service. The Central Chronic Distribution and Dispensing of Medicine (CCMDD) program is implemented in all the community health centres where the study was conducted (Vhembe District Municipality 2020/2021:75).

According to the South African Nursing Council (SANC 2019:3), primary health care nurses are allowed to renew the doctor's prescription but not to prescribe except in emergency situations All primary health care nurses, irrespective of training in mental health, are allowed to prescribe but with restrictions (e.g., they are not allowed to initiate prescriptions but are allowed to continue prescriptions). Two of the clinics have emergency medical practitioners stationed in the facility for the provision of emergency services. The clinics have adherence clubs formed by chronic patients who have demonstrated compliance with medication. The club members are given a supply of medication lasting for two to three months. A severe shortage of professional support staff and infrastructural challenges compromise the provision of quality primary healthcare services (Rabie, Coetzee & Klopper 2016:29).

Shilubane and Khoza (2014:282-283) found that non-mental health nurses referred problems with MHCUs to mental health nurses. Every community health centre had a mental health coordinator referred to as a focal nurse allocated the responsibility of ensuring that the mental health service was running smoothly while working with other professionals and non-professionals (Shilubane & Khoza 2014:382-383). The mental health nurses engaged the family members of the MHCUs only when there were problems with the MHCU because the majority of the users were not accompanied for treatment follow-ups.

Tables 2.1 and 2.2 indicate the ratio of mental health nurses to MHCUs or family members.

2.4.3 Vhembe district health care services staffing

The eight community health centres of Vhembe district are staffed mainly by nurses and health care providers that include lay counsellors, peer supporters, health promoters, pharmacy assistants and support staff (DOH 2015).

There are 14 nurse managers consisting of one assistant manager and two operational managers in each community health centre and some facilities do not have adequate managers responsible for supervision to ensure quality of primary health services. In the eight community health centres, out of 136 primary health care professional nurses, 60 are trained in mental health and two professional nurses with advanced psychiatry are allocated in the mobile clinic. The district has a functional mental health review board and one advanced psychiatric nurse practitioner acting as district mental health coordinator. Municipal ward-based outreach teams, consisting of community health workers, provide health promotion, support and follow up to patients in the communities. There are 210 community health care workers who conduct an average of seven home visits in rural areas and four home visits in deep rural villages and are able to refer MHCUs who show signs and symptoms of relapse to the focal nurse (mental health nurse) (DOH 2015).

The community health centres are staffed with multidisciplinary teams that conduct outreach mental health services on a monthly basis. The teams consist of a clinical psychologist, occupational therapist and social workers stationed at the district and regional general hospital of Vhembe district. A psychologist and medical doctor visit the facility once a week to see MHCUs referred by the primary health care nurses and do six-monthly reviews of medication of chronic MHCUs. There is only one psychiatrist in Vhembe district who visits the district hospitals on a monthly basis stationed at a mental hospital (Mulaudzi, Mashau, Akinsola & Murirwa 2020:5**).**

In 2017, Sodo and Bosman (2017:20) found that community health workers were given the responsibility of tracing MHCUs who defaulted medication. However, community health workers' involvement in the health system was largely to support the HIV/AIDS program, with little attention given to providing mental health services, and deployment through a system of non-governmental organization (NGO) contracts (Sodo & Bosman 2017:20).

Table 2.1 Mental health nurses and MHCUs in Vhembe District community health centres

	Community health centre	**No of MHCUs**	**No of mental health nurses**	**Ratio of mental health nurses to MHCUs**
1.	Bungeni	93	10	1:9
2.	Makhado	70	4	1:18
3.	Mphambo	15	4	1:4
4.	Mutale	86	4	1:22
5.	Thohoyandou	150	14	1:11
6.	Tiyani	78	11	1:7
7.	Tshilwavhusiku	94	5	1:19
8.	William Eddie	80	8	1: 8
	Total	**666**	**60**	

Source: Vhembe district community centres attendance register and staff establishment (2021**:**np)

Table 2.2 Primary health care nurses, community health workers and MHCUs

	Community health centre	**Nurse managers**	**PHC nurses**	**Mental health nurses**	**Percentage of mental health nurses**	**CHWs**	**MHCUs**	**Social orkers**
1	Bungeni	1	16	10	62.5	34	93	01
2	Makhado	3	18	4	22.2	24	70	6
3	Mphambo	1	17	4	23.5	40	15	2
4	Mutale	3	15	4	26.6	13	86	3
5	Thohoyandou	3	24	14	58.3	19	150	2
6	Tiyani	3	16	11	68.7	8	78	2
7	Tshilwavhusiku	3	17	5	29.4	18	94	2
8	William Eddie	3	13	8	61.5	54	80	3
	Total	14	136	60		210	666	21

Source: Vhembe District Community Health Centres organogram (2021**:**np)

The rural villages of Vhembe district face challenges such as poor roads; shortage of water; shortages of support staff and health care professionals, especially mental health care practitioners, and poor infrastructure that compromise the provision of quality health care. A high level of crime in healthcare facilities negatively affects 24-hour service provision and a poor relationship exists between police officers and stakeholders (Vhembe District Municipality 2019/20 IDP Review:104).

2.5 CONCLUSION

This chapter outlined the THPN, policy and legislative framework for promotion of mental health of the family members of MHCUs, and the study context, including descriptions of the community health care centres of Vhembe district. Chapter 3 describes the paradigm, research design and methodology of the study.

CHAPTER 3
PARADIGM, RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

Chapter 2 outlined the theoretical framework for the study, policy and legislative framework for the promotion of mental health of the family members of MHCUs, and the study context.

This chapter describes the paradigm, research design and methodology of the study.

3.2 PARADIGM

Polit and Beck (2017:720) describe a paradigm as a world-view or a way of looking at natural phenomena that encompasses a set of philosophical assumptions that guides one's approach to inquiry. The research paradigm thus provides the researcher with a frame of reference to ask and answer the research questions. A paradigm is a way of thinking about something or a belief system that guides how we do things, or establishes a set of practices ranging from thought patterns to action (Creswell 2014:18).

In this study, the researcher adopted pragmatism as the research paradigm. Pragmatism is a world-view and a set of assumptions about how things work; a basic set of beliefs that guide action (Creswell 2014:35). The philosophy searches for solutions that a community engages in with the purpose of changing an identified social problem (Prasad 2021:7). Pragmatism believes that reality is constantly renegotiated, debated, interpreted, and therefore the best method to use is the one that solves the problem. Using a pragmatist paradigm, the researcher used a sequential explanatory design to obtain a clearer picture of the participants' reality and answers to the research questions (Creswell 2014:35). Community participation was considered pivotal to find the most feasible and workable solutions to the problems that negatively impacted on the lives of family members of MHCUs. Individual interviews were done at participant family members' home settings and stakeholders were engaged in an NGT workshop to identify interventions to address family members' needs as a way of providing support.

The paradigmatic perspective will be discussed in terms of the history of pragmatism, pragmatism as a research paradigm, and philosophical assumptions of pragmatism.

3.2.1 Historical overview of pragmatism

Historically, pragmatism was divided into the early period from 1860 to 1930 and the neopragmatic period from 1960 to the present. The early American pragmatists were Charles Sanders Peirce, William James, John Dewey, George Herbert Mead and Arthur F. Bentley. These philosophers rejected the scientific notion that a social science enquiry was able to access the ‘truth’ using a single scientific research method (Mertens 2010:38).

Dewey examined pragmatism as a philosophy and its orientation to solving real problems. Dewey’s philosophical idea was to demonstrate a new direction in which philosophy moved away from abstract thinking towards an emphasis on human experience (Morgan 2014:1049). Dewey focused on the nature of experience and maintained that (1) actions cannot be separated from the situations and context in which they occur; (2) actions are linked to consequences in ways that are open to change (if the situation of the action changed, the consequences would also change, despite the action being the same), and (3) each individual’s knowledge is unique based on individual experience, considering that much of the knowledge is socially shared (Morgan 2014:1049).

Wahyuni (2012:71) highlights that one should view research philosophies as a continuum rather than an option that stands in opposite directions. Pragmatism believes that objectivist and subjectivist perspectives were not commonly exclusive. The main emphasis is on what works best to solve the research problem. Thus, pragmatist researchers have an opportunity to use both quantitative and qualitative research designs to enable them to better understand social reality (Wahyuni 2012:71).

3.2.2 Pragmatism as research paradigm

A pragmatic approach draws on what works to solve the problems, using diverse approaches, and is not committed to a single system of philosophy and reality. The world we live in is seen to have several realities that are open to enquiry (Polit & Beck 2017:160; Morgan 2013:7-8). Thus, as a research paradigm, pragmatism orientates itself toward bringing solutions to practical problems in the real world. This endeavour occurs when the researcher confronts situations that do not fall within the existing knowledge base (Morgan 2013:7-8).

Dewey developed a five-phase or step process of enquiry (Morgan 2013:65) that can be summarized as follows:

1. The enquirer encounters a problematic situation in the clinical area that cannot be explained by previous experience. In this study, the researcher observed that MHCUs were discharged home after a short in-patient stay. Families experienced burdens in the care of the MHCUs as they lacked the necessary knowledge and skills to provide care, treatment and rehabilitation. In this study, the researcher observed that MHCUs

are frequently readmitted in the mental health care units. They spent more time in the hospitals than in their communities. MHCUs are not adequately supervised by the family members as evidence by high rate of relapses of MHCUs in Vhembe district. Poor supervision of the treatment program by the family members could be due lack of the knowledge and skills to provide care, treatment and rehabilitation.

2. The enquirer reflects on and defines the nature of the problem. The researcher observed that many MHCUs admitted in mental healthcare units of the general hospital in Vhembe district were well known to the service. When interacting with the family members they expressed feelings of anger, frustration, loss, grief, and being powerless, indicating that they were “lost and left out” by the mental health system. Family members reported that they are not being empowered with knowledge and skills on the management of the mental illness. For example, families and patients can be taught to identify the symptoms of relapse before relapses takes place. In addition, they can also be educated on the management of relapse in their communities by the mental health nurses.
3. The enquirer searches for potential solutions that could bring about practical solutions to solve the problem. In this study, the researcher developed a psychoeducation program as a solution to support the family members caring for a member with mental illness.
4. The enquirer reflects on the likely consequences of putting potential solutions into action. The findings of this study should give the mental health providers a better insight into the support needs of family members of MHCUs and provide the necessary family-focused interventions to help them cope better with care provision.
5. The enquirer tests what appears to be the best solution for resolving the problem. The developed family psychoeducation program was refined using the e-Delphi technique.

Researchers as pragmatists have freedom of choice of the methods, techniques and procedures of research that best meet their needs (Polit & Beck 2017:160). The main goal of using two methods is to use the strength of one method to enhance the strength of the other method. In this case each method serves a different purpose, and one method builds on the other (Creswell 2018:17).

In this study, the researcher addressed the research problem by using multiple approaches to answer the research question. In phase I, the researcher explored the needs of family members caring for MHCUs in Vhembe district, Limpopo Province. Individual semi-structured interviews with family members were used to collect data in phase 1. The findings of phase I were presented to the participant stakeholders in phase 2 during an NGT workshop aimed at development of the psychoeducational program to support family members of MHCUs. The final phase refined the program using an e-Delphi technique with experts in the field of mental health, policy and program development, such as academic researchers and mental health care practitioners.

3.2.3 Philosophical assumptions of pragmatism

Pragmatism is underpinned by ontological, epistemological, and methodological assumptions.

3.2.3.1 Ontological

Ontology is the study of being or reality. Ontological assumptions are concerned with the reality that is being investigated (Creswell & Poth 2018:33). The pragmatic researcher switches between two views: External reality and the multiple perceptions of reality in participants' minds and thus between different research approaches and methods. The same phenomenon is studied from different positions that contributes to triangulation and cross-validation (Maarouf 2019:8).

In this study, the family members were given a platform to share the reality of their needs related to caring for a MHCU. Secondly, stakeholders with diverse experiences in mental health issues were given an opportunity to develop a draft psychoeducational program to address the needs of family members caring for MHCUs. This reality of what works and practical solutions to problems in clinical settings formed the basis for what concepts to include in the psychoeducational program.

3.2.3.2 Epistemological

Epistemology refers to the relationship between researcher and participant (Creswell & Poth 2018:18). Pragmatism creates a link between the ontological and epistemological pragmatic assumptions. Researchers switch between being objective and subjective and in consequence switch between accepting observable and unobservable knowledge (Maarouf 2019:9). Pragmatists conclude that all knowledge of the world is based on experience and is social knowledge. Individual knowledge is unique as it is based on individual unique experiences. Pragmatic epistemology ensures that the researcher is free to connect with the relevant participants for the phenomenon under study (Tashakkori, Johnson & Teddlie 2020:208).

In this study, the researcher engaged with different participants of diverse backgrounds and expertise in terms of knowledge and experiences. The researcher triangulated the data collection and analysis methods to acquire knowledge. The researcher believed that knowledge could be obtained through individual interviews (engaging family members to explore their life-world of caregiving to MHCUs), an NGT workshop as well as an e-Delphi technique to yield the best solutions for the research problem. The psychoeducational program holistically addresses the needs of families caring for MHCUs.

3.2.3.3 Methodological

Methodological assumptions refer to how researchers know what they know, and the way researchers obtain knowledge (Polit & Beck 2017:13). Pragmatism is the best philosophical foundation to answer research questions in that it justifies the truth of what works best to solve the problem in clinical practice. The researcher has freedom of choice of the methods, techniques and procedures to conduct the research project (Polit & Beck 2017:160).

The researcher was not restricted to a single method but able to resolve the research problem using diverse approaches, making it more flexible and feasible to find appropriate solutions. In this study, a qualitative method, NGT workshop with stakeholders and an e-Delphi technique were used to gather knowledge from participants and reach a level of consensus on the program.

3.3 RESEARCH SETTING

Vhembe district in Limpopo Province was purposively selected as the research setting for this study as it is one of the five districts in Limpopo Province. All eight community health centres in Vhembe district were selected as they have a high number of the MHCUs (see Chapter 2 for detailed description).

3.4 RESEARCH DESIGN

The study used a multimethod design by using a series of complementary methodologies, chosen to answer the research question (Anguera, Blanco-Villasen, Losada, Sa´nchez-Algarra, & Onwuegbuzie 2018:2765). The design was mostly qualitative in nature, with small quantitative components in the NGT (ranking of ideas) and the Delphi (consensus rates).

3.4.1 Rationale for a multimethod research design

The rationale for using a multimethod approach was to obtain a better understanding of the research problem and to provide evidence-based findings and a different picture from when one approach is used. This allowed the researcher to view the research problem from multiple perspectives (Creswell 2018:213). The application of multiple research approaches draws on the strength of each method to answer the research questions. It views problems from multiple perspectives to enhance and enrich the meaning of particular solutions (Creswell 2018:215).

This study was guided by an exploratory sequential design. In phase 1, the researcher collected qualitative data from family members caring for MHCUs. The data were analysed, and the findings informed data collection in the subsequent phase (Fetters et al 2013:3). In phase 2, an NGT (qualitative and quantitative) approach was employed to generate ideas from stakeholders on which topics should be included in the draft psychoeducation program. In Phase 3, an e-Delphi technique (quantitative and qualitative) was used to refine the psychoeducational program and reach consensus on the final program from a team of experts (see chapter 1, Table 1.2)

Integration of the phases of the study took place through building, where one database informed the data collection approach of the other (Fetters et al 2013:3). The results from phase 1 informed the data collection of phase 2, meaning the latter built on the former.

3.4.2 Qualitative approach

A qualitative approach is flexible, capable of adjusting to new information in the course of data collection; tends to be holistic, aimed at an understanding of the whole; often involves merging various data-collection strategies and requires qualitative researchers to be become intensely involved, and lastly, relies on ongoing analysis of data to formulate subsequent strategies and determine when data collection is done (Polit & Beck 2017:463).

The researcher endeavoured to understand the whole picture from multiple perspectives (family members, mental health care stakeholders and experts), and identify the many factors involved in caregiving to sketch the larger picture that emerged. In phase 1, The researcher learnt about the problem from family members' frame of reference to develop a complex and holistic picture of the problems experienced by family members. The researcher believed that knowledge could be obtained through interviewing the participants as the researcher interacted with them. In phase 2 the perspectives of stakeholders were obtained during NGT discussions and in phase 3, comments and recommendations were obtained from experts. The researcher entered the research setting with an open mind ready to be immersed in the complexity of the situation in order to gather information holistically from all angles of the phenomenon. The qualitative approach was exploratory, descriptive and contextual.

3.4.2.1 Exploratory

The purpose of exploratory research is to seek new insights, ask questions and asses phenomena in a new light (Rahi 2017:2). The researcher explored the physical , psychological, social and spiritual needs of families caring for MHCUs in Vhembe district of Limpopo Province. In the NGT and e-Delphi, the perspectives of stakeholders and experts in the field were explored. The researcher chose the exploratory method to gain new insight, obtain new ideas, and enhance knowledge on the phenomenon under study.

3.4.2.2 Descriptive

According to Polit and Beck (2017:471), a descriptive approach allows a researcher to describe and document aspects of the phenomenon as it naturally occurs. In this study, the researcher interviewed family members caring for MHCUs at their homes allowing them to describe their needs while the researcher used effective communication skills as an advanced mental health nurse practitioner to gain a deeper understanding and rich data. During the interviews, the researcher took field notes. The views of the NGT and the e-Delphi participants were described and integrated in the psychoeducational program.

3.4.2.3 Contextual

In contextual research, the researcher aims to provide descriptions of details, meanings, and context, typically from the perspective of the people living it (Leavy 2017:5). In this study, the researcher conducted face-to-face, semi-structured interviews at the homes where the families provided day-to-day care to MHCUs. Furthermore, attention was given to how caregiving was experienced by the family caregivers in relation to their caregiving needs. Thus, the researcher remained focused and contextual throughout the interviews. The NGT was conducted with the input of local stakeholders. The e-Delphi constituted a wider population, and the experts were selected because of their experience and knowledge in the field of mental health care and family support.

3.4.3 Quantitative approach

A quantitative research approach is a formal, objective, rigorous, and systematic process of collecting numerical data. Numerical data are collected to describe the new situation or event, examine relationships among variables, and determine the effectiveness of interventions developed (Grove & Gray 2018:30). Phase 2 commenced with workshop with stakeholders who are involved in the care of MHCUs and their families, to develop a psychoeducational program to support family members caring for MHCUs in Vhembe district Limpopo province using a NGT. Phase 3 entailed the refinement of psychoeducational program to support family members caring for MHCUs using e-Delphi consensus method and reach consensus. In phase 3, a quantitative approach was followed and a questionnaire was designed for the e-Delphi expert panel to review the draft psychoeducational program for supporting family members caring for MHCUs in Vhembe district in Limpopo Province. The questionnaire contained variables for validation of the program using a 4-point Likert scale that led to reliable results (see chapter 7 for discussion).

3.5 RESEARCH METHODS

Research methods refer to the techniques, steps, procedures and strategies used by researchers to plan a study, and to gather and analyse data in a systematic fashion relevant to the research objectives and questions (Polit & Beck 2017:160). The research methods are discussed under the following subheadings for each phase: study population, sampling and sample, data collection and analysis.

3.5.1 Phase 1: Exploration and description of the needs of family members caring for mental health care users

Data was collected from family members caring for MHCUs, using in-depth individual interviews.

3.5.1.1 Population

A research population refers to the entire set of elements, individuals or objects having some common characteristics in which a researcher is interested (Polit & Beck 2017:273), and meet certain criteria for inclusion in a given universe (Grove & Gray 2018:229).

In phase 1, the target population was all family members caring for known MHCUs who visited community health centres for monthly follow-up at district health centres of Limpopo Province, while the accessible population was family members caring for the MHCUs who met the inclusion criteria and whose MHCUs attended their treatment reviews at the community health centres of Vhembe district. Family members who are living in the same household with MHCUs were purposively selected. The researcher believed that they were more knowledgeable and experienced regarding the phenomenon under study as they spent most of their time taking care of the MHCU.

3.5.1.2 Sampling and sample

A sample is a selected subset of the accessible population to represent the entire population in a study while sampling refers to a process of selecting a portion of people, events, behaviours or other elements to participate and represent the entire population (Polit & Beck 2017:739). The study used purposive, non-probability sampling. Purposive sampling is based on the researcher's judgement of the participants who are especially knowledgeable or have experience of providing care to the MHCUs at home (Polit & Beck 2017:740; Grove & Gray

2018:479).

Sample size in qualitative research relies on quality of information obtained from persons rather than on the size of the sample. The sample size is determined by the scope of study, saturation of information and quality of collected data (Grove & Gray 2018:251; Creswell & Poth 2016:186). Saturation occurred when no new data emerged in the interviews. Thus, the researcher stopped collecting data when categories (or themes) were saturated, and the participants provided no new insights or information.

a) District and primary health care facilities

Non-probability purposive sampling was used to select the district, community health centres and participants. Limpopo Province consists of five districts, and Vhembe district was purposively selected based on statistics of admission rates which was highest of all the district (District Health Barometer 2014-2015:218). All eight community health centres were selected because of high numbers of MHCUs treated at these primary health care facilities and to ensure good presentation of the population is obtained.

b) Participants

The researcher used purposive sampling to select the family members who were knowledgeable and experienced regarding the phenomenon under study and who the researcher believed would provide information-rich data. Family members with two or more years' experience of caring for a relative with mental illness were selected to participate in the study.

3.5.1.3 Recruitment of participants

The researcher distributed the Vhembe district approval letter (see Annexure F) during an appointment with the facility nurse managers of all the health centres to introduce the study. The nurses and a team of community health workers assisted with sending invitations to the responsible family members of the MHCUs, and included those who did not accompany their MHCUs to the clinic for monthly follow-up visits. The researcher also approached and recruited prospective participants as they accompanied MHCUs for treatment follow-ups. The researcher obtained cell phone numbers of the family members from the MHCUs who came for follow-up. The researcher informed the family members of the study and explained the purpose and objectives to them. Recruitment ceased after 16 family members agreed to participate in the study. The family members were informed that they were selected because they have knowledge about the topic. Thereafter the date and time for the interview was secured which was convenient for the participants. The researcher and the prospective participant exchanged telephone numbers.

To be included in the study, family members had to

- Be 18 years and older and involved in the care of a relative diagnosed with mental illness according to Diagnostic and Statistical Manual of Mental Disorder (DSM-5) (APA 2013) as on the MHCU's file.
- Be living with the MHCU.
- Have provided care to the MHCU for a minimum of two years.
- Be able to speak Tshivenda or to express themselves in English.
- Give voluntary informed consent.

The researcher excluded family members who

- Were not 18 years or older or not involved in the care of a relative diagnosed with mental illness.
- Did not live with the MHCU.
- Had less than two years' experience of caregiving for the MHCU
- Were not fluent in Tshivenda or able to express themselves in English.

3.5.1.4 Data collection

Data collection refers to the gathering of information to address a research problem (Polit & Beck 2017:725). Grove and Gray (2018:470) define data collection as gathering information relevant to the research purpose or specific objectives, research questions or hypothesis of the study.

The researcher collected data in face-to-face semi-structured interviews, using an interview guide (see Annexure D). This method provided a detailed picture of participants' perceptions or beliefs about the research topic. The purpose of using individual interviews was to gather in-depth and rich data (Brink et al 2018:158). The researcher selected interviews rather than focus groups because the participants were geographically far apart.

a) Pilot interview

The researcher conducted a pilot interview to verify whether the questions of the interview guide were well phrased and the time required for interviewing (Brink et al 2018:161). The researcher conducted two in-depth interviews with two family members at one community health centre one month prior to the study. The participants were not included in the study. The questions and methods were deemed appropriate by the researcher and supervisors to obtain the required data.

b) Interviews

The researcher asked the managers of the community health centres to secure a private room which was free from distraction to accommodate participants who might prefer to be interviewed at the community health centre. All the participant family members chose to be interviewed at home. The researcher telephonically arranged a convenient date and time for meeting with the participants to establish rapport before the actual data collection with the family members who agreed to participate in the study. Data collection commenced at the beginning of April and ended in June 2020, and was delayed by the COVID-19 lockdown alert level as the researcher had to wait for the lower level of lockdown restrictions protocol.

Data collection commenced after informed consent was signed by the participant. Before the interview was conducted, the researcher obtained verbal permission from the MHCU so that the family members would feel at ease and to avoid conflict between the MHCU and the participant. The participants were given an information sheet about the research purpose, objectives and research questions as well as an informed consent form to sign and complete (see Annexure A). For participants who could not read or write, the researcher read the information sheet aloud. The participants gave verbal consent and made a cross on the consent form as signature. The researcher obtained the participants' permission to audio-record the interview as well as their demographic data and the field notes.

The interviews were conducted in the home setting and most of the interviews were done during the weekends according to the participants' preference. The home setting was flexible and convenient to the family members. The interviews were audio-recorded and lasted 30-45 minutes. The researcher reminded the participants about the interview telephonically two days before and on the day of the meeting. Before the interview started, the researcher explained the purpose of the study and the reason for interviewing the participant. The researcher also explained that they were part of the study because they were more knowledgeable about the topic and to provide a platform to narrate their lived experiences of the support they needed. The participants were informed that they were under no obligation to participate in the study and had the right to withdraw at any stage of the study should they wish to do so. The researcher told participants that they could refuse to answer questions that were too sensitive or caused emotional discomfort. Two participants who became emotionally affected were supported by the researcher and referred for further counselling by a psychologist. They did not require long-term interventions. The participants were encouraged to share their experiences related to their needs freely.

The researcher ensured adherence to the COVID-19 restriction measures throughout data collection. The researcher provided sanitizer and face masks for the participants. The interviews were conducted in a ventilated private space free from distractions. The researcher obtained background information from the participants, including their years of caregiving to the MHCU, their age, occupation and relationship with the MHCU.

The interviews were conducted in Tshivenda and English, because the researcher was fluent in both languages. The central questions which guided the interview was:

- *What are your needs regarding caregiving to your family member with mental illness?*
- *What are your challenges with regard to the care of your family member diagnosed with mental illness?*
- *What kind of support do you need to help you cope with the caregiving responsibility?*

Probing questions were asked when necessary (see Annexure D for interview guide). At the end of the interviews, the researcher thanked the participants for their time and information.

c) Role of the researcher

The role of the researcher is described under communication, reflexivity and bracketing.

i) Communication

The researcher established rapport and maintained an attitude of unconditional acceptance, respect, empathy, openness and honesty. The researcher employed effective communication techniques to facilitate the interview in order to get in-depth accounts of the life-world of caregiving at home. The researcher appeared relaxed, maintained an open posture and eye contact and leaned slightly forward to convince the participant that the researcher is listening. As the participants narrated their lived experiences in caring for the MHCUs in relation to their needs, the researcher listened and communicated carefully throughout the interview session (Middleton 2020:170-171) as follows:

- **Listening:** The researcher listened, paid attention throughout the interview, giving participants the opportunity to narrate their stories without interruption.
- **Probing:** Probing questions were asked, emanating from the participants’ answers, to allow participants to elaborate on responses, deepen the response to a question, and to increase the richness of information obtained during data collection. For

example, the researcher would give a probing statement like “tell me about it’’ so that a deeper understanding was reached.

- **Minimal verbal response:** The researcher used minimal verbal response, rather nodding her head, saying “mm”, “yes”, “continue” to allow free flow of information and encourage participants to talk. This made the participants feel relaxed and willing to talk about their experiences.
- **Clarifying:** The researcher sought clarification on statements that she did not understand to avoid assumptions and misinterpretation of verbal and non-verbal messages.
- **Reflecting:** The researcher reflected the message conveyed by repeating the participant’s as a question in order for the participant to expand on the important points which were valuable to answer the research question.
- **Focusing:** The researcher gave participants full attention as they deliberated their own experiences with regard to exploration of their healthcare needs in order to help them focus.
- **Paraphrasing:** The researcher rephrased the participants’ words, but without losing the meaning. This encouraged the participants to give more information.
- **Validating:** The researcher paid attention to both verbal and non-verbal clues and interpreted their non-verbal communications, such as vocalization, facial expressions and body gestures and recorded these as field notes to give the collected data more meaning.
- **Silence**: This involved perceiving the participants’ body movement, facial expressions and quality and tone of voice. The researcher kept quiet to allow the participants to think and continue to talk at their own pace without interference.

ii) Reflexivity

To ensure that data collection was free from bias and perspective, the researcher applied reflexivity and bracketing throughout the study. Reflexivity means “turning the researcher lens back onto oneself to recognize and take responsibility for one’s own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation” The researcher can incorporate reflexivity into qualitative study by writing notes on observations made about the data collection process (Creswell 2018:182).

The researcher used reflexivity and engaged herself in conscious self-awareness and thoughtful consideration during the study. The researcher continually evaluated her personal experience, inter-subjective dynamics and the research process itself. Reflexivity was applied through self-examination, self-awareness, and reflective notes. Reflexivity allowed the researcher to be critical about what she heard and how best to give meaning to what was heard. The researcher offered the participants a platform to share their experiences and opened herself up to learn from them. Throughout the process, the researcher wrote reflective notes about her own perceptions and experiences to bracket her perception and interpretation from the phenomenon being studied.

iii) Bracketing

Bracketing is a process of recognizing and holding in abeyance preconceived beliefs and views about a phenomenon being studied (Polit & Beck 2017:471). This qualitative research technique requires researchers to identify their personal preconceptions and beliefs and consciously set them aside for the duration of the study (Grove & Gray 2018:468). The researcher had 24 years of experience of working in mental care units and interacting with families of MHCUs. The researcher held back preconceived and Christian beliefs and values from interfering with individual interviews. The participants were given a platform to talk freely while the researcher applied effective communication skills.

Before starting data collection, the researcher ensured that she bracketed her own values, perspectives, philosophies, ideas and any personal biases that might have influenced the question or results of the study. The researcher suspended prejudice and prejudgement in order to prevent her expectations from shaping the data collection or imposing her preconceived ideas on the findings.

d) Field notes

Field notes refer to records of activities, or a means of documenting applicable information observed where words are inadequate to describe experiences during interviews (Polit & Beck 2017:521). Field notes provide written information about interviews that may be helpful in understanding the participants' expression. The researcher took observational and reflective notes.

i) Observational notes

Observational notes involve recording objective descriptions of observed events, conversations, information about actions, and dialogues within the context that they happened (Polit & Beck 2017:521). In this study, the researcher took observational notes based on what was seen, heard and detected during the individual interviews. Important information like date and time of reporting, and participants' style and behaviour of communication were taken into consideration during the recording of observational notes. Table 3.2 lists examples of observational notes recorded by the researcher.

Table 3.1 Examples of observational notes

Date of reporting observation field notes
Although the participants were informed on time and several reminders two days before the appointment, they chose their own date and some participants did not own their invitation.
Time of reporting the field notes
Most of the participants did not report as scheduled. Some reported 15-35 minutes late, I had to wait patiently while engaging those who were already there in conversation in order for them not to feel bored. Before the commencement of the individual interview, I ensured that participants were relaxed and ready for the interview. Despite the delays, no participants withdrew from the study. One participant withdrew from the study due to bereavement. The participant lost the brother due to COVID-19 related complications after an appointment was arranged. Individual therapy was provided and then was referred for counselling by psychologist or a counsellor.
Participants' style and behaviour of communication
Virtually all the participants interviewed voiced their ideas and expressed their feelings, especially when telling stories of their psychosocial healthcare needs. Out of the 16 participants only one became emotional at a certain point during the interview session. I encouraged her to cry as sharing tears is also a therapy on its own, I could not apply a therapeutic touch due to COVID-19 restriction protocol. I just offered her a tissue to wipe hre tears and gave her a glass of water to drink. I paused for a while being silent, then after a while I observed that she seemed to have stopped crying. I asked her if I could continue with the interview. She responded by saying ''Yes, I am fine let us continue."

b) Reflective notes

Reflective notes are the researcher's notes on her thoughts, feelings, personal experiences, insights or ideas and concerns in the field during the research (Polit & Beck 2017:520). Reflective notes helped the researcher to maintain reflexivity and bracketing. Table 3.2 provides examples of reflective notes recorded by the researcher.

Table 3.2 Example of reflective notes

On the day of the interview, I was impressed by the way the participants were welcoming. Before I could locate the respective homes of the participants, I managed to get hold them telephonically so that they could direct me. The road was worse than expected as it was damaged by heavy rains, but I managed to reach them though it took longer. I found them prepared to welcome me. A private conducive space was prepared by the participant, free from disturbance, with chairs made available placed far apart, sanitizers or a container with water for hand washing as measures to mitigate the spread of COVID-19 infection.

During the collection of data, I felt deeply touched as the participants shared lived experiences of surviving in a life-world characterized by experience of psychological, social, physical, spiritual and financial stresses associated with caring for the family member with mental illness, which is a life-long commitment. The worst scenario is when you find that there is no shared responsibility amongst the other near relatives, community members and the department of health as there is poor collaborative effort. The feeling of being emotionally and psychologically drained was a dominant perception. Some of them talked at the top of their voices and at times displayed an irritable mood as the interview continued. One participant could not hold her tears as she narrated how challenging the situation was impacting her life. Caregivers indicated that they no longer had their own social life at all since they were caught up in caregiving which is happening in silos. They expressed how they suffered stigma and discrimination from society, which made them withdraw from social contact.

3.5.1.5 Data analysis

Data analysis refers to the systematic organization and synthesis of research data (Polit & Beck 2017:725). Data was analysed thematically following Braun and Clarke's (2013) six steps of thematic analysis. Thematic analysis refers to the process of discovering commonalities across participants and seeking natural variation (Polit & Beck 2017:536). The method was chosen because it provides a flexible approach which yields a rich and detailed yet complex account of data; does not require intensive theoretical and technological knowledge; is easy to apply and is useful in examining perspectives of different research participants (Braun & Clarke 2013:121). The following steps were followed during data analysis.

Step 1: Familiarise yourself with the data.

After data collection the researcher listened to the recording many times and transcribed the interviews and the field notes. During this step, the researcher immersed herself in the data to get familiar with the depth and breadth of the raw data collected. The researcher repeatedly read the data and made sure she understood what the participants said. The researcher remained vigilant and honest about her own perspectives, preconceived ideas, values and beliefs.

Step 2: Generate initial codes.

The researcher generated the initial codes by classified phrases and words used by participants that are connected to the research questions. Coding involves generating pitchy labels for important features of the data that is relevant to the research questions. The identified codes capture the semantic and conceptual reading of the data. During this step, the researcher remained focused by giving equal attention to all information retrieved from participants that may form the basis of themes.

Step 3: Search for themes

In this step, the researcher organized and retrieved all data that had been initially coded, and the list of different codes identified across the data set. Themes were created by identifying similarities in the data by aligning codes. The researcher aligned codes and looked for information with similar meaning to search for themes.

Step 4: Review themes

During this phase, some themes developed branches or subcategories whereas other which are not real themes collapsed on the way. The researcher reflected on whether the themes told a convincing and compelling story about the data. Reviewing of themes involved the refinement of identified themes. The researcher ensured that data within themes were categorized meaningfully so that there were clear, identified distinctions between themes. The researcher read all the organized data for each theme to determine whether they appeared in a coherent pattern. After reviewing the themes, selected themes were refined into themes that were specific enough to capture sets of ideas.

Step 5: Define and name themes.

The researcher defined and refined the themes to determine whether a theme contained a category or subcategory. The process was followed by writing up each theme to get the story that each theme portrayed. The researcher critically examined how each of the themes fitted into the overall story in relation to the research questions. The researcher wrote a detailed analysis of each theme, for example asking the question “What story does this theme tell?’’ It means identifying the essence of each theme.

The data was independently analysed by the researcher and an independent coder (experienced in qualitative data analysis) after which consensus was reached on the findings.

Step 6: Produce the report.

The last step involves weaving together the analytic narratives to provide a coherent and persuasive story about data and contextualizing it in relation to existing literature. The interpretation was based on the researcher’s understanding of the topic with evidence from literature reviewed.

3.5.1.6 Literature review

A literature review was done after data analysis to identify the uniqueness of the findings.

The main purpose of the literature review in qualitative research exercise is to put the study findings in the context of what is already known in the body of knowledge. A literature review is done to enable the researcher to identify relationships and variations between the present and previous studies as well as the potential contribution of the present study to the knowledge pool (Polit & Beck 2017:743).

3.5.2 Phase 2: Development of draft psychoeducational program to support family members caring for mental health care users

In this phase, the findings from the individual interviews with family members informed the data collection approach in the NGT. The participants in the NGT were informed about the findings from the individual interviews and the literature review, which guided their decisions in drafting the program.

The NGT was used to generate ideas from stakeholders to assist in drafting a psychoeducational program to support family members caring for MHCUs. A one-day workshop was held with stakeholders involved in mental health care and support of families, using an NGT to generate ideas and reach consensus as a group on what content should be included in creating an ideal comprehensive psychoeducational program. The findings assisted the researcher to draft the psychoeducational program. The population, sampling, data collection and analysis of the NGT are discussed next.

3.5.2.1 Population

The population included stakeholders, health care providers who render care, treatment and rehabilitation services to MHCUs and their family members, policy developers, and community representatives who play a role in provision of support to MHCUs together with their families. The population of the NGT had two categories of stakeholders. The first group were health care providers (community health workers, psychiatric nurses, community health centre managers, social workers, occupational therapist, clinical nurse practitioners, review board members, nurse educators in mental health nursing) who were working in clinical health establishment and had direct contact and interaction with the families caring for mental health care users. The second group were leaders in the communities who play an influential role in health care issues and included church leaders or pastors, community representatives of SANCO (South African National Civic Organization) and traditional health practitioners.

3.5.2.2 Sampling and sample

The participants were purposively selected based on their knowledge, area of specialization, years of experiences in the mental health field, and the role they play in the community by providing support to the families caring for MHCUs. The clinic managers provided the researcher with the contact numbers of potential participants. The researcher also identified potential participants that she knew as a members of the community. To be included in the NGT, participants had to be:

- Health care providers: primary health care nurses, medical doctors, mental health coordinators, review board members, occupational therapy technicians and community health workers who provided care, treatment and rehabilitation to MHCUs for a minimum of two years.
- Non-health care workers: traditional healer, traditional leader, church leader, based on their experience of working with family members of MHCUs and impact in the society in supporting the MHCUs and their families.
- Policy developers and clinic managers based on their leadership role in policy development and implementation as health care program leaders.
- Willing to participate.

Stakeholders who did not meet the above criteria were not included in the study.

Twenty-four potential participants were invited telephonically, personally, or through their personal e-mails, and 21 responded positively and were included as they met the inclusion criteria. The stakeholders in the NGT consisted of community health workers, psychiatric nurses, a community health centre manager, social workers, an occupational therapist, a clinical nurse practitioner, a review board member, a nurse educator in mental health nursing, a church leader or pastor, community representative and traditional health practitioner.

3.5.2.3 Data collection

The NGT was used to create an environment of engagement and consensus to facilitate inputs from the group members (Botma et al 2022:330). The main reason for engaging different stakeholders in the NGT workshop was to generate data on what should be covered in the psychoeducational program for supporting family members caring for MHCUs. Another reason was that an NGT is a structured face-to-face group session with the purpose of achieving group consensus and action planning on a chosen topic (Mullen, Kydd, Fleming & McMillan 2021:2). The participants are individuals who have expert insight into a particular field of interest, which in this study referred to stakeholders who were experts in mental health issues and working with members of MHCUs.

The stakeholders attended a one-day workshop to address the research questions:

- *How can a psychoeducational program to provide support to family members caring for MHCUs in Vhembe district be developed*?
- *How can the program address the healthcare needs of family members caring for the MHCUs?*
- *What components or aspects do you think should be included in the psychoeducation program*?

The data collection is discussed according to the preparation and steps of the NGT.

a) Preparation

Permission to conduct the NGT workshop with health care providers at Thohoyandou Health Centre was obtained from the Vhembe District PHC manager. Permission to engage the mental health care providers and the practitioners was requested from the CEO of public district hospitals with mental health care units and the mental health institutions. Permission to conduct the NGT workshop was granted by the CEO managing the Vhembe public hospitals (see Annexure F)

The researcher prepared a boardroom in one of the community health centres with the assistance of the community health centre area managers. The room was large enough to accommodate all the participants with chairs and a table arranged in a u-shape. The researcher prepared the following stationery: a box of black pens, plain A4 sheets, A3 sheets, flip charts, attendance register form, biographical data form, information sheet, different colour board markers, voice recording devices, laptop, projector, extension cords, hand sanitizers and extra face masks. A flip chart was placed at the centre at the open end of the U-shaped table.

The steps of the NGT outlined by Sondergaard, Ertmann, Reventlow and Lykke (2018:5) were adopted and are discussed as follows:

b) Step1: Introduction and explanation

The participants were requested to sign the attendance register as they had already been screened for COVID-19 at the main gate. The researcher ensured that every participant used hand sanitiser before entering the venue and wore a face mask. The attendance register indicated their names, contact numbers, institution or place of work and signatures. The participants were also asked to complete a participant information and informed consent document (see Annexure B). Lastly the participants were requested to fill in the stakeholders' biographical data form that contained the following information: gender, age, current position, highest qualification and years of experience (see Annexure H). The clinic manager welcomed the stakeholders and introduced the host who were the researcher and the supervisor who acted as the moderator for the discussion. The participants were then given an opportunity to introduce themselves. The researcher introduced herself and the purpose of the workshop. Permission to record the session was requested.

The researcher and supervisor planned for the NGT during online meetings. During the meetings the roles were clarified, whereby the researcher's role was to present phase 1 findings, and the moderator's role was to facilitate the NGT workshop.

The researcher gave a PowerPoint presentation on the introduction and background, study purpose, objectives and the findings of phase 1. The participants were given copies of the findings to familiarise them with the health care needs expressed by the family members. During this phase, the moderator presented key questions on a flip chart and read them aloud to the participants for feedback: What content or components do you think should be included in the psychoeducational program? How can the psychosocial needs of the family members caring for mental health care users be addressed?

During the NGT workshop, individually written narratives, recorded group discussions and field notes (written by the researcher) were used to collect data.

c) Step 2: Silent generation of ideas

The participants were given time to write down answers to the key questions, without conferring or intergroup discussion, based on their experience and knowledge. The moderator provided each participant with a sheet of paper with the key questions to be addressed and asked them to write down all ideas that came to mind. The participants were informed that they were not allowed discuss their ideas with each other. This step took approximately 40 minutes.

d) Step 3: Round robin

The moderator invited each participant to state their thoughts and ideas from the silent phase. The participants took turns in sharing their ideas. The ideas were recorded by the moderator on a flip chart (see Annexure H). All ideas were written down by the moderator until no new ideas were put forward by the participants. At that stage there was no debate about items and the participants were encouraged to write down any new ideas that might arise from what others had indicated. This process ensured that all participants got an opportunity to make an equal contribution and provided a written record of ideas generated. The moderator recorded each idea on a flip chart using the words spoken by participants and thanked participants for the valued contributions. The ideas were recorded until there no new ideas were put forward by the participants (see Annexure H). The step took approximately 60 minutes.

e) Step 4: Discussion or clarification

The participants were invited to seek clarification on ideas that were not clear. All the members of the group actively participated in the clarification and discussion of issues that were not clearly phrased.

Ideas were named and grouped into themes, without discarding any item. The moderator listed themes on the flip chart for every member to see. Similar ideas were grouped together by the participants themselves with assistance from the moderator. The moderator allowed each participant to contribute to the discussion of ideas without spending too much time on a single idea. The participants clustered identical items, put similar items together and gave each cluster of items with a similar meaning a heading.

After documentation of ideas, the moderator asked if all the participants were satisfied with the items written. This step formed part of the data analysis process. A total of seven themes emerged from the discussions on which the participants reached group consensus. This step lasted 45 minutes.

f) Step 5: Voting and ranking

Based on the themes indicated, the participants were asked to rank each theme using a 7-point Likert scale from 1 to 7. The researcher requested the participants to ask questions when they did not understand so that the researcher could clarify areas of misunderstanding. A plain sheet of A4 paper was provided for each participant to indicate the ranking in order of importance. Based on the seven themes provided, each participant was asked to allocate a score ranging from 1 to 7, considering the priority of the theme. The step was allocated 10-15 minutes. After the ranking was done, the moderator calculated the scores and wrote the themes on the flip chart in order of importance.

3.5.2.4 Field notes

The researcher kept a record of observational and personal notes during the NGT workshop.

Table 3.3 Examples of observational notes

Date of arrival at the NGT venue
Two participants called telephonically in the morning while another one sent an e-mail in the morning to make an apology as they had commitments which were beyond their control and one indicated that he had tested COVID-19 positive. One participant, just after entering the boardroom, received an emergency telephone calling for her immediate attention.
Time of arrival at the NGT venue
The workshop started late due to stakeholders who reported 30 minutes late although the researcher had given several reminders about the workshop venue and time.
Stakeholder participant style and behaviour and communication during NGT workshop
After the introduction and aim of the workshop was highlighted, the participants were free to open up and express their ideas about the question posed by the moderator. They explained and elaborated their ideas clearly. In the first few hours**??** the group communicated in English then a member raised the matter that there were other members who did not understand English. The researcher then started to interpret to bring them on board. The participants adhered to the rules of NGT. For example, during idea generation all of them did not consult each other but were busy jotting down their personal ideas freely.

Table 3.4 Examples of reflective notes

During data collection in the NGT workshop, I observed that the participants who arrived a bit late had failed to identify the boardroom as there was no direction written at the community health centre gate to show them where to go. Secondly, another delay to commencement of the NGT workshop was caused by signing of the consent form for participation in the study and audio-recording permission. During the meeting a group of mental health care practitioners admitted that they did not give psychosocial support to the family members caring for mental health care users especially during relapse crises. They stated that SAPS members disappointed them because when they were called to apprehend MHCUs who were physically aggressive, they would ask if the user had killed someone, which is very painful and left the poor family members devastated and overwhelmed. One mental health care provider shared a lived experience of caring for a family member herself who is an MHCU suffering from epilepsy who just woke up early hours of the morning without eating nor taking medication which complicated the family supervision of treatment. The participant was very emotional and desperately in need of assistance. The researcher listened attentively, showing interest, understanding and respect for what she was going through. The researcher as an advanced psychiatric nurse provided counselling after the session and planned for ongoing sessions in future.

3.5.2.5 Data analysis

The data analysis commenced during the NGT stakeholders’ discussion which gave rise to seven major themes. The researcher collated the data after the NGT in order to identify themes and categories that emerged. Qualitative data obtained during the NGT discussions was analysed using the same procedure followed in phase 1 (see section 3.8.2.3). Quantitative data was analysed by computing the average score for each theme and ranking the themes accordingly.

The data consisted of group discussions, field notes, individual written narratives (written by participants in Step 2), and transcripts of recorded workshop proceedings. Some participants wrote their narratives and expressed themselves in Tshivenda, which the researcher translated into English. The data assisted the researcher to conclude the draft psychoeducational program to support family members caring for MHCUs in Vhembe district Limpopo Province (see chapter 5 for discussion of findings).

3.5.3 Phase 3: Refinement of the psychoeducational program for supporting family members caring for MHCUs.

Phase 3 addressed the last objective of the study and focused on refinement of the program for supporting the family members caring for MHCUs. The participants in the NGT developed the components of the draft program based on their own suggestions and findings of the individual interviews. The researcher further developed and refined the draft program by studying the findings of Phase 1 and 2 to ensure all findings were reflected in the psychoeducational program. The researcher also integrated the theoretical framework and applicable literature reviewed to ensure the program contained all the components necessary to meet the needs of families caring for MHCUs.

3.5.3.1 Research method

In this phase, the refinement of the psycho-educational program was done using the e-Delphi technique with a panel of experts to ensure high quality guidelines. This method was used to answer the research question: “How can a psycho-educational program to provide support to family members caring for MHCUs in Vhembe district, Limpopo province be refined?”

The researcher selected the e-Delphi technique because it is a practical and structured approach particularly suitable for getting ideas from different experts. The e-Delphi technique is a method for obtaining judgements and views from an expert panel about a topic of interest to seek consensus on the issue without direct confrontation. The e-Delphi technique is an online method that uses a multistage self-completed questionnaire with individual feedback to determine consensus from a group of experts (Polit & Beck 2017:160; McMillan, King & Tully 2016:655). A Delphi panel is done with individuals who have knowledge and expertise in a phenomenon under study (Habibi et al 2014:10). The Delphi method is useful to collect ideas from experts on a specific topic and discover the underlying assumptions or perspectives among the experts (Habibi et al 2014:12).

3.5.3.2 Population

The population of phase 3 were stakeholders who were specialists in the field of psycho-educational program development, practising psychiatric nurses from government institutions, practising advanced psychiatric nurses, social workers, occupational therapists, psychiatrists, district mental health coordinators, and clinical psychologists from the government and private sectors. The stakeholders included mental health care service managers who were responsible for implementation of the mental health care programs in various healthcare settings.

To be included in the study, the participants had to:

- Be experts in the field of mental health.
- Be academics knowledgeable about mental health as well vested in the area of research and program development or have influence in the implementation of health service programs.
- Have two years or more experience working in the mental health specialty field or have extensive practical experience in the area.
- Be willing to participate in the study.

3.5.3.3 Sampling and sample

The researcher used purposive and snowball sampling. Snowball sampling is a non-probability technique in which participants meeting the sample criteria are asked to assist in locating others (Polit & Beck 2017:476). According to Jorm (2015:893), there is no official consensus on the number of participants that should participate in an e–Delphi technique. It is up to the researcher to decide and rationalise. According to Mc Millan et al (2016:5) results will be more stable, the greater the number of experts. The authors also state that it is preferable to have at least six, and no more than 12 specialists from the same health discipline. It is advised to invite at least 30 experts in order to minimise disappointment because it might be challenging for all experts to participate during the entire Delphi process.

The researcher sent invitations by e-mail. The researcher’s supervisors, and experts known to the researcher were asked to assist with locating experts in mental health who had knowledge and expertise in the study field. The researcher searched the health databases to identify authors with recent publications in the mental health area, particularly related to support of MHCUs and their families. The researcher identified and invited 35 potential participants who met the requirements in accordance with the inclusion criteria but only 25 accepted the invitation to participate. The researcher sent the questionnaire to these 25 experts of which 22 returned the completed questionnaire.

3.5.3.4 Data collection

The researcher conducted two rounds of the e-Delphi technique and consensus was reached after the second round.

In the first round, an informed consent form, cover letter with instructions, and the draft psychoeducational program was e-mailed to the e-Delphi panel members together with a checklist requesting them to rate the reliability of the program. They were expected to write their recommendations and general comments independently without interacting with each other (Polit & Beck 2017:267). Once the panel feedback was received, the next step was data analysis and modification of the psychoeducational program. Feedback on the psychoeducational program adapted in the first round was provided to the panel members. This gave participants an opportunity to generate new insights and alter their responses during the second round based on the review and recommendations made by other experts.

3.5.3.5 Data analysis

Data analysis involved both quantitative and qualitative data. Decision rules must be established to assemble and organize the judgments and insights provided by Delphi participants (Hsu & Sandford, 2007:4). After the researcher analysed the data in each round, the content of the psychoeducation program was adapted and sent again to the same expert panel members for feedback about the findings. The feedback process gave the e-Delphi members an opportunity to reassess their initial judgements. The researcher collated the consensus rate from the responses based on the Likert scale to indicate agreement and quantitative analysis was used to determine consensus rates. The open-ended recommendations were analysed with content analysis as used in phase 1 and 2.

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3.6 RIGOR

To ensure the trustworthiness of the study, the researcher used the strategies of credibility, dependability, confirmability, transferability and authenticity to assess the degree of confidence in the study (Polit & Beck 2017:746). Reliability and validity are discussed as it relates to the study.

3.6.1 Credibility

Credibility refers to confidence in the truth of data, including its interpretation. Anny

(2014:276) states that credibility establishes whether the findings represent the original views intended by the participants. In this study credibility was achieved through prolonged engagement with participants, peer debriefing by supervisors, and triangulation prolonged engagement, persistent observation, triangulation, peer debriefing and member checking (Brink et al 2018:172).

- **Prolonged engagement**

According to Polit and Beck (2017:561) prolonged engagement involves investing sufficient time in the data collection process so that participants feel enough confidence and trust in the researcher to allow for the adequate study of the cultural context and adequate checks for misinformation and distortions. In this study, the researcher ensured credibility by establishing rapport and trust and through prolonged engagement with the participants before and during the interviews. The interviews lasted for 30-45 minutes. The researcher was fully immersed in the participants' world to gain deeper insight into and an understanding of the context (Anney 2014:276). Moreover, the researcher reminded the participants of the purpose of the study and how the study would benefit family members caring for the MHCUs.

- **Member checking**

Member checking involves soliciting study participants' reaction to preliminary findings and interpretation of the data (Polit & Beck 2017:564). Immediately after conducting individual interviews with the participants, the researcher gave feedback to ensure accuracy of data collection and interpretation. The NGT participants were given the opportunity to check the findings as recorded on the flipchart.

- **Triangulation**

Triangulation refers to the use of multiple methods to collect and interpret data about the phenomenon under study, so as to produce an accurate representation of reality. Triangulation is used to ensure that the most comprehensive approach was considered to solve the research problem (Brink et al 2018:219; Polit & Beck 2017:563). In this study the researcher used semi-structured interviews, field notes, an NGT and e-Delphi technique as data-collection methods. The researcher used participant and method triangulation to enhance credibility. The participants included family members, mental health care professionals, community leaders and experts in the field to ensure inclusion of a wide variety of experiences and perceptions.

- **Peer debriefing**

Peer debriefing refers to sessions with peers to review and critique a research report or proposal and make recommendations about publishing or funding the research (Polit & Beck 2017:738). The research proposal was reviewed by the researcher's supervisors and the postgraduate committee of the School of Health Care Sciences of the University of Pretoria. The supervisors provided revision and recommendations throughout the study.

3.6.2 Dependability

Dependability refers to the stability of data over time and conditions (Polit & Beck 2017:743). In this study, the researcher gave a detailed description of data collection and a thick description of used methods. An independent coder who is an expert in qualitative data analysis was used, and consensus was reached on the qualitative data collected in phase 1 to minimize subjective bias. The NGT and e-Delphi data analysis was checked by the researcher's supervisors. Audio-recordings were transcribed immediately after the interviews and NGT and cross-checked against the field notes. The researcher provided a full description of the methodology and context of the study to ensure the dependability of the data collected.

3.6.3 Transferability

Transferability refers to the generalization of data; that is, the extent to which the findings can be transferred to or applied in other settings (Polit & Beck 2017:747). Transferability refers to the probability that the study findings have meaning to others in similar situations. The researcher provided sufficient, thick descriptions of the methodology and data so that researchers can transfer the findings to other contexts.

3.6.4 Confirmability

Confirmability is a criterion for integrity in qualitative research and refers to the objectivity or neutrality of the data and interpretations. Confirmability is a means of establishing that the data collected represents the information provided by the participants and that the interpretations are not influenced by the researcher's preconceptions or imagination (Polit & Beck 2017:723). The researcher remained objective throughout to ensure confirmability. Raw data was made available on the recorder and transcripts to cross-check against the themes. The researcher bracketed all preconceived ideas about the needs of family members caring for MHCUs and kept reflective notes.

3.6.5 Authenticity

Authenticity refers to the degree to which researchers faithfully and fairly show a range of realities in the collection, analysis, and interpretation of data. Authenticity in a report conveys the tone of participants' lived experiences and fairly describes the participants' experiences so that it is a truthful picture of their perceptions and experience (Polit & Beck 2017:720). The researcher included participants' direct quotations of their experiences to ensure authenticity. In this study, the researcher kept field notes and transcribed audio-recorded data.

3.6.6 Validity and reliability

According to Polit and Beck (2017:161), quantitative researchers adhere to two criteria, namely validity and reliability in evaluating the quality of their study. Validity and reliability were adhered to in order to ensure rigour of the quantitative aspects of the NGT and e-Delphi technique.

3.6.6.1 Validity

Validity refers to the degree of soundness of the study's evidence to determine whether the results are clear, convincing and well-grounded, and to establish whether the instrument measures what it is supposed to measure. The validity of a data-collection instrument is the extent (degree) to which it measures what the researcher sets out to measure. External validity is the extent to which findings can be generalised to the population beyond the sample (Polit & Beck 2017:160).

In this study the researcher ensured the validity of the research instrument in measuring what it is intended to measure. Pilot testing of the e-Delphi questionnaire was done with two stakeholders who were not part of the main study to determine the feasibility of the research instrument. The researcher revised the questionnaire based on the feedback from the pilot test prior to the e-Delphi technique. The researcher ensured validity during the voting phase of the NGT group discussion by involving one of the supervisors as the moderator who is well experienced in conducting NGT workshops and analysing quantitative data.

3.6.6.2 Reliability

Reliability refers to the degree of accuracy, consistency, or dependability of an instrument and the information obtained in the study (Polit & Beck 2017:160). Reliability of the data-collection instrument refers to the consistency with which it measures the target attributes. According to Brink et al (2018:171) reliability and validity are closely related in that reliability is part of the validity because an instrument that does not give reliable results cannot be considered valid. Reliability of the e-Delphi questionnaire was obtained when the researcher presented the research instrument to the supervisors to review and indicate their comments. To ensure the replicability, consistency and dependability of information obtained in the study, a moderator was used in the NGT to ensure that the participants were not influenced during the voting phase and voting was done anonymously.

3.7 CONCLUSION

The chapter discussed the research paradigm, design, methods and rigor used in the three phases of the study.

Chapter 4 discusses the findings on the needs of family members caring for MHCUs.

CHAPTER 4
PHASE 1: QUALITATIVE FINDINGS ON HEALTHCARE NEEDS OF FAMILY MEMBERS AND LITERATURE REVIEW

4.1 INTRODUCTION

Chapter 3 presented the paradigm, research design and methodology of the study. This chapter discusses the findings of phase 1 on the needs of family members caring for MHCUs in Vhembe district, Limpopo Province, with reference to literature reviewed.

Data were collected in individual semi-structured interviews with 16 family members who voluntarily agreed to participate in the study. Two interviews were conducted in English and 14 were conducted in Tshivenda. The interviews were audio-recorded and translated and transcribed. The researcher asked a colleague fluent in Tshivenda to cross-check the translations. During data collection the researcher recorded field notes. Data saturation occurred after ten interviews, but the researcher conducted six more interviews.

This chapter discusses the participants' sociodemographic profile, themes, sub-themes and categories that emerged from the data analysis.

4.2 PARTICIPANTS' SOCIODEMOGRAPHIC PROFILE

The study was conducted with 16 family members caring for MHCUs in Vhembe district, Limpopo Province, South Africa. Of the participants, 11 were females and five were males; three were aged 20-28; two were aged 40-42; two were aged 57-59; five were aged 63-69, and four were aged 72-79. Regarding education, five participants had no education (non-education); three had primary, three had secondary and five had tertiary education. Regarding marital status, four participants were single; one was unmarried; five were married; five were widows and one was a widower. Of the participants, one was employed as a nurse; one was doing an internship; one was self-employed; one was a Grade 12 scholar; six were pensioners, and three were retired (see Table 4.1).

The participants were caregivers of MHCUs with different types of mental illnesses, including schizophrenia, bipolar disorder, substance induced disorder, and epilepsy with psychosis. The duration of the MHCUs' illnesses ranged from four years to 20 years and longer. Two family caregivers were not living with the MHCU in the same household but were neighbours staying next-door to the MHCU. Most of the participants were parents and seven were the mothers of the MHCUs. Table 4.1 presents the participants' sociodemographic profile.

Table 4.1 Participants' sociodemographic profile

	Gender	Age	Marital status	Occupation	Relationship to the MHCU	Number of family members	Years of care provision	Level of education
P1	F	42	Single	Nurse	Daughter	2	21	Tertiary
P2	F	40	Married	Self-employed	Wife	4	15	Secondary
P3	F	59	Married	Unemployed	Sister	5	10 >	Non-educated
P4	F	76	Widow	Old age pensioner	Mother	3	10>	Non-educated
P5	M	28	Single	Unemployed	Brother	2	20	Tertiary
P6	F	69	Married	Old age pensioner	Mother	3	10	Primary
P7	F	26	Single	Internship	Sister	11	4	Tertiary
P8	M	63	Widower	Retiree	Father	3	10>	Tertiary
P9	F	63	Single	Retiree	Sister	4	20>	Secondary
P10	M	20	Unmarried	Scholar	Grandson	11	10 >	Secondary
P11	M	74	Married	Old age pensioner	Father	14	10>	Primary
P12	F	72	Married	Old age pensioner	Mother	13	10 >	Non-educated
P13	F	79	Widow	Old age pensioner	Mother	5	10 >	Non-educated
P14	F	65	Widow	Retiree	Mother	5	19 >	Tertiary
P15	M	57	Widow	Unemployed	Mother	3	20 >	Primary
P16	F	67	Widow	Old age pensioner	Mother	2	20>	Non-educated

Abbreviations: P = Participant number; MHCU = Mental health care user; F= Female, M = Male

4.3 NEEDS OF FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS

Three themes emerged from the data analysis, namely psychosocial experiences of family members, healthcare needs of family members, and healthcare expectations. Each theme had sub-themes and categories as in Table 4.2. The findings are discussed and supported by direct verbatim quotations. To ensure anonymity, the participants were given numbers: P1, P2 to P16. The findings are discussed with reference to literature reviewed.

Table 4.2 Needs of family members caring for mental health care users

Themes	Sub-themes	Categories
1.Psychosocial experiences of family members	1.1 Psychological experiences of family members	1.1.1 Feeling of fear for own safety and that of the MHCU 1.1.2 Feeling shame and embarrassment 1.1.3 Feeling powerless 1.1.4 Feeling emotional distress and loss 1.1.5 Feeling depressed 1.1.6 Feeling unable to cope with caregiving demands
	1.2 Social experiences of family members	1.2.1 Lack of social support 1.2.2 Lack of shared responsibility
2.Healthcare needs of family members	2.1 Physical healthcare needs	2.1.1 Need for physical health support
	2.2 Psychological healthcare needs	2.2.1 Need for psychological counselling 2.2.2 Need to acquire healthy ways of coping with caregiving challenges. 2.2.3 Need to establish a nurse-family therapeutic relationship.
	2.3 Social needs	2.3.1 Need for de-stigmatization and non-discrimination 2.3.2 Need for social support and contact 2.3.3 Need for personal safety and security
	2.4 Financial needs	2.4.1 Additional costs to sustain the MHCU 2.4.2 Need for permanent disability grant for MHCU 2.4.3 Need for employment opportunities for the MHCU 2.4.4 Need for suitable housing
	2.5 Educational and information support needs	2.5.1 Knowledge on mental illness, its causes, signs and symptoms, course and prognosis, and treatment options 2.5.2 Identification of early warning signs of relapse and its management 2.5.3 Information about management of day-to-day challenging behaviours 2.5.4 Information on substance abuse by the MHCU 2.5.5 Information on medication adherence 2.5.6 Information on side-effects of psychotropic drugs and management thereof
	2.6 Spiritual support needs	2.6.1 Need for traditional practitioner consultation 2.6.2 Need for pastoral support care
3.Healthcare expectations	3.1 Expectations of healthcare system	3.1.1 The provision of community-based psychiatric rehabilitation with sufficient resources. 3.1.2 Availability of suitable psychotropic medications at the community health centres 3.1.3 Assistance from the South African Police Service during crises 3.2.4 Home visits by healthcare providers

4.4 THEME 1: PSYCHOSOCIAL EXPERIENCES OF FAMILY MEMBERS

Psychosocial experiences emerged as the first theme with two sub-themes, namely psychological experiences and social experiences. The sub-themes had several categories.

Table 4.3 Psychosocial experiences of caring for mental health care users

Themes	Sub-themes	Categories
1.Psychosocial experiences of family members	1.1 Psychological experiences of family members	1.1.1 Feeling of fear for own safety and that of the MHCU 1.1.2 Feeling shame and embarrassment 1.1.3 Feeling powerless 1.1.4 Feeling emotional distress and loss 1.1.5 Feeling depressed 1.1.6 Feeling unable to cope with caregiving demands
	1.2 Social experiences of family members	1.2.1 Lack of social support. 1.2.2 Lack of shared responsibility

4.4.1 Sub-theme 1.1: Psychological experiences of family members

The participants caring for the MHCUs experienced a range of negative emotions, including feeling of fear for own safety and that of the MHCU, powerless, shame and embarrassment, depressed and unable to cope.

4.4.1.1 Feeling of fear for own safety and that of the MHCU

Due to the demanding nature of day-to-day caregiving to MHCUs, the participants experienced feeling helpless, especially when the MHCUs displayed challenging behaviours, for example, running away from home, verbal and physical aggression. They reported that they felt helpless when they did not know what to do to make the MHCU behave in an acceptable manner. Most of the participants expressed feeling hopeless as they had been caring for their relative with mental illness for years, but there was no hope that the caregiving burden would change for the better, especially when they saw the MHCUs' condition deteriorating. Some participants expressed concern over who would take over care provision when they passed on. According to participants:

I will go and report to the police station. The police officer will then come and apprehend her. Here in the village people do not come to assist me, they are afraid of her. They do not help me anyway because she is known to beat people. Oh! they do not assist me, and it is a problem as I am alone fighting with her. Because people around this village are afraid of her, even if I scream: "Yo, yo, help me!" they do not respond; she can rather kill me. (P16)

Some participants reported feeling helpless and hopeless when faced with emergency management when MHCUs relapsed or were not emotionally stable:

Can you see we are all affected, and this causes depression? What are we going to do? Nothing really. During the relapse episode, if you are working somewhere far from home, with whom are you going to leave him? Who will provide care? (P5)

This role I am fulfilling has destroyed me, so seriously, I do not have energy since you could see that even today I am still challenged. I am not someone who is free, who is healthy, I can only be healthy when I see my patient being healthy, you see my daughter [referring to the researcher] I can only be happy if my patient is looking happy. But if she is not well…me too, I also get ill and feel so helpless. (P12)

I never knew that the situation [mental condition of the MHCU] would change … I was accused [the participant was accused of neglecting the MHCU after she dropped the patient at the hospital for follow-up care leaving the patient in the care of the nurses as she felt she needed to sleep as she was to report to work in the evening] when I was innocent. The person is a male [a security officer] who was so verbally aggressive. By the way I was so tired as I was in deep sleep. I felt so helpless because the person does not know the challenges I am facing, with regard to caregiving to the old lady. (P1)

In South Africa, Ntsayagae, Myburgh and Poggenpoel (2019:4) found that family caregivers reported negative emotions, feeling helpless as the disease progressed, when they could not help their relative, and when they were afraid when the relative was aggressive. Helplessness became eminent when the family caregivers failed to manage the crisis perpetuated by the MHCU. In this study, this was a major source of stress reported by participants who struggled to apprehend the MHCUs as they did not have someone to help. Emotional distress occurs when the family experience difficulties to live with a MHCU, and provide the care that the patient needs (Mokwena & Ngoveni 2020:6).

4.4.1.2 Feeling shame and embarrassment

Most of the participants reported that they lived in fear because of the verbal aggression and aggressive outbursts displayed by the MHCUs. Female participants especially felt afraid and powerless, which negatively affected their physical and mental well-being. These feelings were triggered by the MHCUs' unpredictability and socially unacceptable behaviours that caused embarrassment in public. One participant described being afraid of being embarrassed at funeral gatherings, accompanying the MHCU to the clinic, and sleeping with her in the same room:

She cannot go [to the clinic] alone, I need to accompany her since we have been told that we should always accompany them … I even sleep in the same room with her. When I attended funerals before khofisi [COVID-19] I used to go with her. I am usually afraid that she may behave in an unacceptable manner in public at funerals. (P4)

One participant was constantly worried about the whereabouts of the MHCU who sometimes just disappeared without informing anyone; being frustrated when the MHCU skipped a medication dose when she failed to come home, and fearing being attacked by the MHCU:

The time when she did not want to drink her treatment…would just collect and throw the pills away. She did not want to use her medication. She would throw away the pills as she believed that she was not mentally ill and furthermore believed that I want to kill her…I cry a lot, a lot, at times when I am sitting alone here, I start to think that if she relapsed and found me seated relaxed like this when we are only two in the house, what will happen? Definitely she will kill me. I am always scared. (P16)

Some participants feared that the MHCUs would become victims of sexual abuse or murder. According to one participant:

Holding people hostage, human trafficking, people are raped and so on, raping and at times they kill people. This is the reason I am saying it is really bad out there in this world, even kids are taken away, you find a child left alone. Hear on the news that a child disappeared when searched around and could not be found anywhere. (P16)

One participant described constantly being worried about her sister and phoning her daughter:

Because when she has relapsed, she cannot sit down, she will be pacing up and down, roaming around and leaving home. It pains me a lot as I constantly get worried about her health status. I always phone her daughter who is nineteen years old because I am afraid that she might leave home without being noticed, and so her daughter keeps watching her so that she does not escape at night. It would be difficult to trace her whereabouts. Previously we used to ask someone who had a car to assist us and go around checking her all over the village. But because she is able to take the pills, I see that she is much better. (P3)

One participant described being afraid of embarrassment in public as the MHCU undressed in public places:

After she had epileptic fits, she would run away, undress and take off her clothes in public. I would be called. She would say "so and so is calling me" then she would run away…When she does all that, other kids will be watching. I wish she would drink the pills and get well. If she would drink her pills, we could sit down with her and talk when she does not go to the street… That worries me a lot in my life, that is my worst pain. (P3)

Two participants highlighted the embarrassment caused by negative remarks from the community:

When you go out there in the community, it is painful and embarrassing because people usually pass remarks that you are not taking care of the patient. (P9)

That puts pressure on you since when the patient is not well, and has relapsed from his mental condition, when you look at community members, they just watch or ask what is happening? All that I have indicated causes a lot of frustration and embarrassment to us as a family. (P5)

As in these findings, in Malaysia, Azman, Singh and Suleiman (2019:465) found that family members expressed feeling anxious about leaving female patients alone in the house for fear of them being raped. In South Africa, some participants blamed themselves for the mental illness in the family, felt embarrassed and ashamed over the MHCUs' behaviour and asked God what they had done to deserve the situation. Some families feared that mental illness is caused by superstitions and witchcraft, while others believe that it is associated with spirituality (Monyaluoe et al 2014:135).

In a literature review, most of the studies reported that family members felt ashamed of being related to a MHCU because of the person's strange behaviours in public. They feared the stigma attached to mental illness and to be devalued in social circles (Yin, Li & Zhou 2020:153).

4.4.1.3 Feeling powerless

In this study, powerlessness reflected feeling helpless, uncertain, overwhelmed and fearful that the MHCU might become dangerous. The participants felt powerless to do anything to solve the problem when the MHCUs posed a danger to themselves and other family members; when they experienced relapse, refused to take medication and required emergency admission, or needing help from police officers. The participants felt powerless because they lacked knowledge and skills on the management of mental illness. They also felt powerless because they could not control the MHCUs' unacceptable behaviour. According to participants:

For example, she wants to fight with us, she swears at me while she can find me seated not doing anything. I said I will see how far she can go. I prayed telling myself that I am not going to be affected by this situation. (P7)

Just look at me [removing the mask and showing the scars on her face where she was bitten]. She bit me when I wanted to apprehend her, she wanted to beat me up. She is very aggressive, fights a lot, and beats people. (P16)

Lack of support contributed to participants' intense feelings of powerlessness. Some of the participants described receiving no support from the neighbours or the police when they needed to apprehend the MHCU during relapse:

That puts pressure on you since the patient is not well, he has relapsed from his mental condition, when you look at the community members they just watch or ask, "What is happening?" All that I have indicated causes a lot of frustration to us as a family. (P4)

There was a time when my mother went there and sat there [at the police station] for the whole day and was told that the police van was not available. My mother had previously been to the police station and she was told the van was not there. One time my sister visited them and was also told the same story of unavailability of the police van, only to find that the officers had agreed amongst themselves that this person [MHCU], they cannot manage to apprehend him. (P4)

They [police officers] do not respond to our calls; they only respond when you go there. Then they will come and help you once you go there. (P16)

In Japan, violence to family caregivers by relatives with schizophrenia was a common occurrence and could lead to death (Kageyama, Solomon, Yakoyama, Nakamura, Kobayashi & Fujii 2018329). Kageyama et al (2018:340) found that three-quarters of informal primary caregivers had experienced verbal and physical violence, and more than a quarter of family caregivers had thought of murder-suicide and had a death wish for the patient.

Labrum, Zingman, Nossel and Dixon (2021:17) found that violence was also due to high levels of conflict that family members and persons with serious mental illness experience. A study in the South Africa found that violence by MHCUs was a barrier to receiving support from other people, such as neighbours, next of kin and health care professionals (Monyaluoe et al 2014:9684). In their study at a tertiary level psychiatric hospital in South Africa, Maluleke and van Wyk (2017:9678) found that female mental health nurses were constantly exposed to violence and sexual harassment at their work stations; got injured physically, and experienced emotional trauma.

4.4.1.4 Feelings of emotional distress and loss

Most of the participants reported that they experienced emotional strain caused by the stress of taking care of family members with mental illness which demanded their constant time and energy. The participants described caring for the MHCUs as challenging and painful even though they felt it was their duty due to the emotional bond between them. Some participants revealed that MHCUs alleged that they had bewitched them, assaulted them and threatened to kill them even though they were doing everything to support them. Some participants experienced emotional pain from the stress of the MHCUs' dependence on them as stressful and negatively affected the psychosocial well-being of the family members. One participant described the emotional pain associated with having to wash soiled linen of her husband who was incontinent when he had epileptic seizures:

This situation is very painful…I am feeling pain emotionally. This situation makes me feel tired and exhausted. Look, I am supposed to wash the soiled linen, changing the linen, but he is another woman's child, and it is so cold, then this is happening [The participant became tearful]. (P2)

One participant stated that the emotional distress affected her blood pressure:

Yes, it does happen to me [experience of depressed mood] because right now I am taking pills for blood pressure. Okay, there are times when you look and find that it can cause your blood pressure to go up. (P14)

One participant revealed that the emotional distress caused forgetfulness:

Emotionally when I look at it, I am affected in that I feel that my mind is also not working well during that time. If I go out in the sun and find that I happened to forget something I wanted to take. I fail to understand it, and would say if I were God, I would have taken my mother when her children are grownups. (P3)

A participant experienced disappointment caused by the onset of the mental illness which destroyed the MHCU's future:

It is painful because he passed matric [Grade 12] being well, then when you see him being mentally ill it is very painful…therefore counselling is mandatory. As you expected him to go to the university…it is painful really. Counselling will help me to learn the skill of how to manage mental illness. It will assist me to learn that if this happens, what must be done. (P5)

Another participant shared her feelings of loss when her daughter, who holds a university certificate, lost her job:

It was a straightforward dismissal that one. By the time we could produce information that she is a mentally ill person we could not win because that one is a private company…I request that the elder one get employed because in my view the disability grant makes one admit that indeed he or she is *mentally ill. Which can make the person worse, conditionally the person may not want to look for something, which can make her improve her life. I wish that the government would consider offering them employment since she is having her university certificate. They need to be recognized, they also have the right to employment like other people, it helps them. (P14)*

A study in Singapore found that primary informal caregivers experienced higher levels of emotional distress that affected their daily activities, health, and finances. They also experienced a lack of family support and lowered self-esteem (Chang, Zhang, Jeyagurunathan, Lau, Sagayadevan, Chong & Subramaniam 2016:7). In Limpopo Province, Banyini (2012:85) found that the aging parents of MHCUs were concerned about what would happen when they died. The participants also grieved for the loss of talents and future caused by the onset of mental illness. Families often experience feelings of guilt, anger, and anxiety, which can be transmitted to the patient (Banyini 2012:87). A literature review showed that family members expressed a high level of emotional burden because of self-blame and guilt (Yin et al 2020:154).

4.4.1.5 Feelings of depression

Most of the participants reported symptoms of depression triggered by the caregiving burden. The participants reported feeling sad, withdrawal from social contact, sleep deprivation, and constant worry and concern about the challenging behaviours displayed by the MHCUs. Some participants were concerned about future care when they died, the MHCUs who were financially dependent on them, with no hope of getting employment, and their limited capacity to establish marital relationships. One participant said that caregiving pressure led to her depression:

My daughter, who is not staying far from this place, told me one time that this pressure is too much for me to handle, it [caregiving] will affect me psychologically and make me suffer from depression. I told her that deep inside, I feel emotionally drained so much. (P4)

Participants explained the depression as a painful emotional burden:

I am burdened because a person is ill and without being cured…It is a burden and a very painful experience for me living with a patient. Many years living with a mentally ill patient is painful. (P13)

Another participant shared how she was emotionally affected when her sister refused to eat due to persecutory delusions:

Sometimes when I cook food, she will say I am not going to eat your food because you poured poison *in the food… and at times I find myself crying. (P7)*

One participant reported having suicidal thoughts because he was burdened by the caregiving demand as he was the primary caregiver:

Sometimes while I am thinking over and over again, I also think of committing suicide, so that I can kill myself (P10)

According to Maina, Mauri and Rossi (2016:237), depression is characterized by emptiness, irritability, a feeling of sadness that together with specific cognitive and somatic symptoms leads to significant distress or impairment in functioning. In this study, some participants showed emotional distress as they could not stop their tears and reported that they experienced suicidal thoughts. Some reported crying, others had psychosomatic complaints, and described living in fear that the MHCU might kill them.

A study in Zimbabwe by Marimbe et al (2016:10) highlighted that the caregivers wished that they could be given hope by the health care professionals. In their review of studies in low-, middle- and high-income countries, O'Dwyer, Janssens**,** Sansom, Biddle, Mars**,** Slater, Melluish, Reakes, Andrewartha and Hastings (2021:20-21) found that the proportion of primary family caregivers experiencing suicidal ideation ranged from 2.7% to 71%, with evidence of suicidal attempts, deaths caused by suicide and homicide-suicidal death.

Ntsayagae et al (2019:5) found that family caregivers experienced a variety of negative emotions such as feeling hopeless, shame and fear, and powerless. In their study in rural Ghana, Ae-Ngibise, Doku, Asante and Owusu-Agye (2015:3-6) reported that caregivers reported financial difficulties, social exclusion, depression, and inadequate time for other social responsibilities as their main challenges. Emotional distress in taking care of the MHCU was frequently reported by family caregivers when they thought about their loved ones who were sick, and the embarrassment and stigma shown toward them by the public. Family caregivers were concerned about the MHCUs' safety, especially if MHCUs get lost in the street or when they become disruptive and violent (Iseselo & Ambikile 2017:7).

4.4.1.6 Inability to cope with caregiving demand

The participants reported that they were struggling to cope with care provision demands which they found challenging and emotionally draining on their physical and mental wellbeing. Some participants indicated developing psychosomatic problems such as hypertension and insomnia related to stress. Some participants reported crying a lot, thinking deeply about the

MHCUs' illness, having suicidal thoughts, and being unable to cope with the caregiving burden. According to participants:

I am taking pills for blood pressure. Okay, there are times when you look at and find that it can cause you blood pressure to go up. (P14)

I am also receiving pills as you see me it was caused by this situation, the pills is for blood pressure. (P12)

It is obvious that the sleeping pattern will be affected. You cannot sleep when someone is sick, you may sleep for five minutes, three hours or two hours. You will be thinking since I do not know, how I am going to do it? Even if I can tell myself that I am going to take him to the hospital, where will I get the money to pay for transport…who can offer it free of charge? No one will do that. If he becomes violent and when his condition has deteriorated, who will assist me to apprehend him, am I going to call the relatives to help me? Who will assist me because nowadays people are afraid of Corona virus, they will be scared to touch him thinking that they will be infected since he is mentally ill? (P5)

Emotionally, when I look at it, I am affected such that I feel that my mind is also not working well during that time. If I can go out in the sun and only to find that I happen to forget something I wanted to take. (P3)

Sometimes as I am thinking over and over again, I also think of committing suicide, so that I can kill myself (P10)

Then I went to the clinic, they said you are suffering from stress-related problems, my head was so heavy, neck pains experienced, lack of energy so they said that is stress. They even asked me about what is bothering me. (P7)

According to Ntsayahae et al (2019:6), ineffective coping refers to managing internal or external demands that exceed the resources of the individual. Ineffective coping is associated with limited psychosocial formal support form significant others, health professionals, traditional and political leaders as well as community members. The participants described caring for the MHCUs as challenging, stressful and painful.

The sole responsibility of care provision to a family member affected by a serious mental illness often falls on the family members, who experience numerous challenges, particularly in the rural context. The caregiving is perceived as a source of psychosocial distress characterized by family members' inability to cope with the caring demand and burden. The burden of caring often falls on the family members who provide all the necessary support

(Iseselo & Ambikile 2016:1). Caregiving has an emotional, physical and social impact on family caregivers and ineffective coping mechanisms affect their mental well-being (Ntsayagae 2017:91).

The participants felt overburdened and lacked social support from close family members and the community. A study in Thulamela Municipality, Vhembe District in Limpopo Province found that the participants experienced burnout due to lack of coping and expressed a preference for long-term mental healthcare for the MHCUs to allow them to live their own lives (Matambela 2019:175). Family members caring for the MHCUs used different productive coping strategies in dealing with care burden in Indonesia that included problem solving, hard work, involvement, positive thinking, resting, and physical entertainment (Yunita, Yusuf, Nihayati & Hilfida 2020:6).

4.4.2 Sub-theme 1.2: Social experiences of family members

The participants reported that they did not receive adequate social support from their relatives, friends, health care providers and community members. Two categories emerged from this sub-theme, namely lack of social support and lack of shared responsibility.

4.4.2.1 Lack of social support

Most participants shared experiences of lack of support from family relatives, friends and neighbours, especially during MHCUs' relapse leading to crises. The participants reported feeling lonely, housebound and isolated, as they were not given the necessary social support and they remained responsible for caring for the MHCUs. According to participants:

I am crying because my heart is feeling some pains. I have contacted the close relatives of my husband reporting that he is doing this and that. I do not need anything from them; I do not need their money, just if they can come to see us to prove that they love me, to show that they are supportive. So, I am only supported by my siblings. (P2)

So that I can visit, but you know today, it is not easy to leave a house without anyone. I cannot go anywhere as such, it is just hanging on like this, day in and day out, I cannot move to somewhere. (P14)

I am taking care of her. If she becomes ill, I am able to handle it if I am around, I could come to attend to the crisis. What I noticed being done by the neighbours, they just stand by the fence and watch the drama and listen to what is happening. Can you see? (P15)

I just need to stay here, no ways. I am always staying here at home. I cannot leave her alone as I do *not know what will happen next. People cannot assist her, they will just look as they do not care, they are also afraid of her. Even when I am in a facing a difficult time [crisis situation when she has relapsed], I can call them but will not come for my rescue. They usually say, she is her daughter she must face it, she must see what to do. Some will say she knows what is happening. (P16)*

In Zimbabwe, participants reported rejection by relatives and being unable to attend family gatherings because they could not leave the MHCUs alone. This increased the burden of care by adding to the caregivers' frustrations (Marimbe et al 2016:8). Ntsayagae et al (2019:4) reported that the time and effort spent in caregiving impaired caregivers' social and occupational lives and did not give them time to socialize. However, in a study in Northwest Province, South Africa, the participants reported receiving assistance from their neighbours (Mokgothu et al 2015:4).

In this study, few participants reported getting assistance from community members during a crisis situation (acute psychosis, suicidal acts and homicidal behaviour). In Iran, Shamsaei, Cheraghi and Esmaeilli (2015:10) found a positive relationship between social support and psychological well-being. Support provided a buffer against burden of care coupled with stress experienced by caregivers (Shamsaei et al 2015:10).

4.4.2.2 Lack of shared responsibility

The participants reported not having their own time as they felt trapped in care provision in the home setting, which created a stressful situation. They reported lack of shared responsibility with other family members like siblings, no relief or social life, and no community support in times of emergency. According to participants:

You can get affected in all sides because if we are referring to the body. I can still remember when one doctor who ordered bed rest for me. When I realize that I am staying with my mother whom I always taking care of her, it is not possible that I should be on a bed rest because I need to take care of her constantly. At times, she will wake you up, swearing at you (P1)

Another problem is getting a helper whom I can keep for a longer period. If I find a helper today, she will only come and help for two to three months and decided to leave us. You will find that you hired the helper because you want her to supervise the treatment program of the patient…Not at all, as I said, it is not easy…Even a helper who might be earning a lot of money, irrespective of whether you might have promised to give her this and that all would seem to be in vain. She can come and work for only one month, then she will go and no longer come back. (P1)

Here in the village people do not come to assist me, they are afraid of her. They do not help me *anyway. Because she is known to beat people. oh, they do not assist, it becomes a problem as I am alone in this struggle (P16)*

I cannot run away from this situation; I cannot go out to see my family's relatives. I just cannot…It is very difficult for me to undertake a journey because of the caring demand for these two people. My siblings never attempt to relieve so that you get a break. I never saw my daughter who gave birth to a baby who is now two months old, I have never seen my grandchild (P14)

One participant suggested day-care rehabilitation centres to share the responsibility:

If there was a place for them where they can say that in the morning, they can wake up and bath then leave to that place for day care. They can be kept there for the day with gates locked being accompanied by their relatives. Then in the evening they are taken home, I think it is better. I believe their illness can be manageable, as they will be busy doing something (P1)

In Central Brazil, Souza, Guimarães, de Araújo Vilela, de Assis et al (2017:4) found that depression, being over 60 years old and receiving no help from other family members negatively affected the caregivers' physical, psychological, and social health and added to the burden. In India, Chadda (2014:224) found limited community support for patients suffering from serious mental illness and their families. Society had an ambivalent attitude towards helping them yet there was a need to establish community-based mental health facilities, which would reduce long distances travelled to seek help. Long-stay facilities were needed for MHCUs who did not have good support systems and those with ageing caregivers.

Social isolation and lack of social support can also be a result of family members' social withdrawal to avoid the stigma attached to mental illness. Some participants in studies included in a review indicated that they try to avoid contact and interactions with family members, friends, and acquaintances because they did not want to be confronted about the condition of the MHCU (Yin et al 2020:154).

4.5 THEME 2: HEALTHCARE NEEDS OF FAMILY MEMBERS CARING FOR MHCUs

The healthcare needs of family members caring or MHCUs had five subthemes: physical healthcare needs, psychological healthcare needs, social needs, financial needs, educational and informational needs, and spiritual needs.

Table 4.4 Healthcare needs of family members caring for mental health care users

Theme	Sub-theme	Category
2.Healthcare needs of family members	2.1 Physical healthcare needs	2.1.1 Need for physical health support
	2.2 Psychological healthcare needs	2.2.1 Need for psychological counselling 2.2.2 Need to establish a nurse-family therapeutic relationship
	2.3 Social needs	2.3.1 Need for de-stigmatization and non-discrimination 2.3.2 Need for social support and contact
	2.4 Financial needs	2.4.1 Additional costs to sustain MHCUs 2.4.2 Need to provide MHCUs with permanent disability grant 2.4.3 Need for employment opportunities for MHCUs 2.4.4. Need for suitable housing
	2.5 Educational and information support needs	2.5.1 Knowledge on mental illness, its causes, signs and symptoms, course and prognosis and treatment options 2.5.2 Identification of early warning signs of relapse and its management. 2.5.3 Information about management of day-to-day challenging behaviours 2.5.4 Information on substance abuse by the MHCU 2.5.5 Information on medication adherence 2.5.6 Information on side-effects caused by psychotropic drugs and management thereof
	2.6 Spiritual support needs	2.6.1 Need for traditional practitioner consultation 2.6.2 Need for pastoral support care

4.5.1 Sub-theme 2.1: Physical healthcare needs

Caring for a family member with mental illness in the community is accompanied by a burden which negatively affects the primary caregiver's quality of life. One category emerged from this subtheme, namely need for physical health support.

4.5.1.1 Need for physical health support

The participants reported multiple health problems, yet they suffered in silence because they neglected their own health as they prioritized the MHCUs' healthcare needs. For example, they complained of headaches, general body pains, lack of sleep for several days, and hypertension. They need help and support with these physical problems to ensure they do not develop into chronic problems. According to participants:

Yes, I do feel pains in my body, heaviness of my body, difficulty to walk, as well feeling pains when I sit down. (P3)

It is obvious that the sleeping pattern will be affected. You cannot sleep when someone is sick, you *may sleep for five minutes, three hours or two hours. You will be thinking…since I do not know how I am going to do…. (P5)*

I then consulted the doctor, a medical doctor, who told me that I am affected by stroke. I told the doctor that no it could not be stroke; it is the heart, which is so painful. As I get worried about something, it builds up and ultimately led to a serious problem. Then I went to the clinic, they said you are suffering from stress related problems, my head was so heavy, neck pains experienced, lack of energy so they said that is stress. They even asked me as to what is bothering me. (P6)

Long ago I used to experience bodily pain, now I no longer feel anything as such. (P13)

At times I experience backache because of lifting her [an elderly family member] time and again. If she did not mess herself, I just take the napkins, clean her and smear Vaseline then I can put another napkin on. If she has soiled herself, I cannot do that, I have to place her in the bath to wash her thoroughly. (P14)

The participants expressed their need to meet health care providers, especially nurses, to give them an opportunity to raise their healthcare needs since it is difficult for them to go the local community health centre and leave the MHCU alone. Regular medical checks by primary health care nurses might serve as family support to see how they were coping, and a means of prevention and promotion of mental health and physical well-being. According to a participant:

Maybe the health care workers may visit the family, maybe once in three months to find out how we are coping so that we are able to give them the report, which can lessen the burden of care on our side just like now as we are communicating with you… We hope the department will plan something, after they compile a list of our needs. As family members, we would experience less burden of caregiving to a family member with mental illness (P5)

Monyaluoe, Mnandaba, du Plessis and Koen (2014:6) found that some family members were affected by the negative experiences which resulted in health problems that required medication. In Ghana, caregivers' health problems included confusion, stress, depression and hypertension as well as lack of sleep when MHCUs showed unacceptable behaviours (Ae-Ngibise, Doku, Asante & Owusu-Agyei 2015:4).

4.5.2 Sub-theme 2.2: Psychological healthcare needs

The participants' psychological needs related to the demands of providing long-term care to the MHCUs, which is a stressful responsibility. Two categories emerged, namely need for psychological counselling and need for establishment of a nurse-family therapeutic relationship.

4.5.2.1 Psychological counselling

The participants revealed several negative emotions and indicated a need for counselling sessions to help them to cope with the situation. According to participants:

Even counselling I need it because we are thinking too much. Sometimes she can decide to kill herself or kill us. So, I really want counselling. Counselling will help us to refrain from persistent memories of all these things which she is doing. (P12)

Now that I know you, I can be able to call and say, Mrs Mbedzi I am experiencing this…what must I do? She can help me by giving advice to say, do this and that, can you see? (P2)

I need counselling if as a person you could be told what type of illness this is. Families living with a member suffering from mental illness, how they should manage them. (P14)

It is painful because he passed matric (Grade 12) being well, then when you see him being mentally ill, it is very painful therefore counselling is mandatory. As we expected him to go to university, it is painful really. Counselling will help me to learn the skill to manage mental illness, and to learn that if this happens what must be done. Counselling will teach us how we can accept the situation. (P5)

Counselling involves a trained professional who abides by accepted ethical guidelines and has acquired the skills and competencies for working with diverse individuals who are in distress or have life problems that led them to seek help. The parties establish an explicit agreement (informed consent) to work together toward mutually agreed on or acceptable goals using theoretically based or evidence-based procedures that, in the broadest sense, have been shown to facilitate human learning or human development or effectively reduce disturbing symptoms (Sommers-Flanagan & Sommers-Flanagan 2015:9).

When caregivers of MHCUs with schizophrenia were asked about the supportive interventions they needed, they stated the need for family support and counselling, rehabilitation and financial needs (Shinde et al 2014:518-519). The caregivers had no prior knowledge about schizophrenia and also advocated for supportive interventions such as counselling and family support. Interventions such as psychoeducational programmes as well as promoting wider social care support might help to address caregiver distress leading to improved quality of life. This calls for health care professionals in government and private sectors to take the lead in various domains, for instance managing expectations of family members' assistance in caregiving tasks (Chang et al 2016:7)

4.5.2.2 Need to establish a nurse-family therapeutic relationship.

The participants felt that the establishment of a nurse-family relationship by primary health care nurses could assist them to cope with their caregiving task. Furthermore, it would help reduce the caregiving burden and minimize negative thoughts by encouragement. Therapeutic relationships with MHCUs would also help counsel MHCUs who were abusing substances. According to participants:

Perhaps the health care workers could visit the family, maybe once in three months, to find out how we are coping so that we would be able to give them a report. We would get an opportunity to report indicating that we are observing this and tell them that the patient is smoking cigarettes and dagga excessively, which could lessen our burden of care - just as we are communicating with you... we need some kind of counselling for us and the patient. You could sit down with him and tell him that when you are like this, you need to take care of yourself. (P5)

They [primary health care nurses and community health workers] do not come here; No one has ever visited us in this house. Even counselling, I need it because we are thinking too much. Sometimes she could decide to kill herself or kill us. Therefore, I really want counselling. Counselling will help us to refrain from persistent memories of all the things that she is doing. (P7)

Sometimes as I am thinking over and over again, I also think of committing suicide, so that I can kill myself. I need someone to encourage me, to encourage me and my sister…About life issues in general… (P10)

One participant indicated that health care workers did not fulfil the family's psychological need for a therapeutic relationship:

They [health care workers] just asked if the patient had taken her pills, the patient may say: I drank them. Just like that, in fact it is just to check if she is available, then they will sign for each other then they will pass to the next family. (P1)

A study in Zimbabwe revealed that most of the caregivers said they lacked knowledge about mental illness because it had never been explained to them since the MHCU was diagnosed with the condition (Marimbe et al 2017:209). The caregivers indicated the need for a family-nurse therapeutic relationship to address the knowledge deficit issues and to spend time with the caregivers at their homes.

A therapeutic nurse-client relationship is the foundation on which mental health nursing is established. It involves a mutual relationship in which both parties must recognize each other as unique and important human beings. In psychiatric nursing and mental health, a nurse-patient relationship is an essential component for provision of evidence-based clinical practice. Enhancement of a therapeutic relationship in mental health care will help increase patient and family satisfaction which serves as an indicator of effective service provision (Townsend 2014:134).

Stuart (2014:13) defines a therapeutic nurse-patient relationship as a mutual learning experience and corrective emotional experience for the patient. It is based on the principle of nurse and patient mutual respect and acceptance of sociocultural differences. The nurse in this relationship uses personal qualities and clinical skills in working with the patient to bring about insight and behavioural change, and provide hope for a better future to patients and their families. The core component**s** of nurse-patient relationships include trust, communication, empathy, genuineness, empowerment, respect, continuity of care and patient confidentiality (Penda, 2017:np). In her original theory of interpersonal relations, Peplau (1997:162-167) views the role of the nurse as providing physical care, conveying safety, security and protection to patients, and elements needed to establish an effective nurse-client relationship.

4.5.3 Sub-theme 2.3: Social needs

The participants' social needs referred to three categories, namely the need for de-stigmatization and non-discrimination, for social support and contact, and for personal safety and security.

4.5.3.1 Need for de-stigmatization and non-discrimination

The participants suffered from stigma and discrimination from other family members and the community as a whole, which affected their mental well-being. The participants indicated that MHCUs were provoked and called names by the community, and fear and stigma prevented the family and neighbours from assisting them when MHCUs relapsed. According to participants:

That puts pressure on you since when the patient is not well, he has relapsed from his mental condition, when you look at the community members, they just watch or ask: "What is happening?" All that I have indicated causes a lot of frustration to us as a family. (P5)

Street children, they like provoking her because she is a mental health care user. Sometimes you find *that other families do not reprimand their children. Instead of saying to them that this person is an adult who is suffering from mental illness and who needs to be respected, they do not do that. (P1)*

Since you do not have someone to protect you, you cannot dodge or escape the emotional abuse, people telling you that your mother is Vha a penga [is mentally ill] using insulting words…You will find that the children of those who are mentally disturbed experience stigma. (P1)

The employer and co-workers said that they could not live with him. People can say whatever they want, they said bad things but I realized that it is because they do not know what is happening. If it can happen to them, how would they feel and how will they manage the situation? (P2)

In Dar es Salaam, Tanzania, Iseselo et al (2016:8) found that stigma was caused by lack of knowledge about the nature of mental illness. Most caregivers wished to understand the origins of mental disorders and requested that education regarding mental illness be provided in order to prevent stigma and discrimination. A study in Australia found that social distancing was lower among mental health nurses because they had more experience of working with people with mental illness and therefore felt safe in their knowledge and skills to interact with MHCUs. Moreover, they had a personal interest in caring for MHCUs, as shown by their choice of specialty (Ku & Ha 2015:6). In Indonesia, Subu, Wati, Netrida, Priscilla, Dias, Abraham, Slewa-Younan & Al-Yateem (2021:7-9) indicated that stigma extended to both patients and mental health nurses.

In their study in South Africa, Mothwa, Moagi and van der Wath (2020:4) found that inadequate social support and social stigma made it difficult for families to cope with state mental health care users. Some participants suspected that the community harboured negative feelings towards the patients (Mothwa et al 2020:4).

In their study in Jordan, Dalky, Qandil, Natour and Janet (2017:269) reported that stigma led to MHCUs having an inferior position in the community and health system, which resulted in mental health services being given low priority. Social stigma had negative outcomes in individuals' health and life. This brings a call to the clinicians to focus more on minimizing the stigma and promoting physical, and general well-being of patients and family members to maintain good quality of life (Dalky et al 2017:274).

4.5.3.2 Need for social support and contact

The participants expressed the need for social support which would accord them an opportunity to interact with the outside world. Most participants had no social life, felt isolated, and were housebound because of constantly caring for the MHCUs. According to participants:

Rightfully I am not used to visiting people. I am not used to that kind of life. I ask myself which problem am I going to solve by going to someone's house whereas I had left my own problems at home. I am supposed to remain here at home. (P14)

I must always be next to her making sure that she is sharp. You always need to be there. You cannot even go out and socialize with other people, such as attending parties, you cannot go out. Even if I can go out, I must report back on time as she has to drink her medication in the morning and afternoon. (P10)

I cannot lock him inside the house. Moreover, the gate is always open as such. I cannot visit our relatives because of that problem [constantly supervising the user's medication]. (P9)

I cannot go out to work; you must always remain here in the house. If she becomes ill, you will find the neighbours having stolen things, such as cups and the kitchen utensils (P15)

One participant caring for a husband with epilepsy and psychosis indicated a lack of support from the in-laws:

I have contacted the close relatives of my husband reporting that he is doing this and that. I do not need anything from them; I do not need their money, just if they can come to see us to prove that they love me, to show that they are supportive. So, I am only supported by my siblings. (P2)

A family-inclusive recovery-oriented approach recognises the crucial role of families in supporting MHCUs. In the African context, caregiving of the MHCU remains the sole responsibility of the family. In Australia, the families usually carried the greatest responsibility as MHCU hospital admission length of stay was reduced (Hercelinskyj & Alexander 2019:442, 465). In Tanzania, participants indicated lack of social support from both inside and outside the family. The social distance between relatives and caregivers increased as patients' symptoms worsened (Iseselo et al 2016:6). Shamsaei et al (2015:5) indicated that participants highlighted the benefits of social support included receiving assistance in the care role and empathy and encouragement. Increased experiences of subjective social support correlated with a lower degree of patients' psychotic symptoms which reduced burden of care.

4.5.3.3 Need for personal safety and security

The participants indicated that they lived in fear and did not feel secure due to the MHCUs' verbal and physical aggression. Some participants stated that the MHCUs assaulted them and threatened to kill them. Some MHCUs threatened to burn the house and locked the participants outside. This caused psychological and emotional trauma and worsened the participants' frustration. According to participants:

When she is mentally disturbed, she does not want to see me totally so, when she sees me, she fights me. She alleges that I am the one who is bewitching her and says I want to kill her. When I am seated here at home, I need to be vigilant because if she can caught me she will injure me because she is very strong and powerful. (P16)

When you look at me [removing a mask and showing the facial scars where she was bitten by the MHCU], she bit me when I wanted to apprehend her the time, she wanted to beat me up. She is very aggressive, fights a lot and beats people (P16)

They had a fight previously. The younger sister fought with the elder one because she did not want to share the food with her. (P14)

When we tell her to take her pills, she says "Hei! Hey! do not tell me. What! What I will burn this house. (P7)

For example, sometimes when I am not around, he will close the door, my mother will not manage to get inside, she had to sleep outside, or sometimes she will take her blankets and sleep at the kitchen (P5)

Some participants stated that the delay and reluctance of the police response to provide safety measures made them feel threatened and unsafe:

It is not easy to call the police van. Sometimes they delay coming, but they will end up responding. During that time she was climbing this tree [participant pointing at the tree]. I was thinking that maybe it is caused by dagga abuse. (P11)

Yes, police officers. It was very difficult to get them to assist me, but because they know that I know the law I told them that you need to come because it is your duty. They responded by saying if they come, I must also be there. I told them that I am available. When they arrived here, he was not violent but was cooperative. They do not understand, sometimes they will say that we do not want to handle a mentally ill patient because he/she is dangerous. If the police officers say he is dangerous, what about us? Because they are supposed to render that service to help us as community members. (P5)

The participants stressed that they felt at risk of injury or being killed by the MHCUs when they were physically aggressive. Aggression refers to behaviours aimed at causing harm. It is an act that leads to violation of other peoples' right to safety. Violence is physical behaviour which causes injury to self or others or damage to property (Middleton 2020:261).

In Ghana, Ae-Ngibise et al (2015:5) found that caregivers experienced emotional distress when MHCUs displayed aggressive or abusive behaviour towards them. Mokguthu et al (2015:6) emphasise that it is necessary to empower families with knowledge and skills to maintain MHCUs' mental condition. Teaching them about early warning signs and symptoms of relapse and coping skills would be of help.

A higher level of caregiver burden was associated with being female, having a low education level, being unemployed or a housewife, having a low-income level, having insufficient family support in patient care, having insufficient information or support from healthcare professionals. The level of burden was found significantly high for caregivers of patients who had a potential for violence, had attempted suicide, or had behavioural problems (Kızılırmak & Küçük 2016:53)

4.5.4 Sub-theme 2.4: Financial needs

The participants indicated that caregiving for a MHCU was financially stressful. Three categories emerged: additional costs to sustain the MHCU, the need to provide MHCUs with a permanent disability grant, and the need for employment opportunities for MHCUs.

4.5.4.1 Additional costs to sustain the MHCU

The participants revealed that their financial expenses to sustain the MHCUs included costs for basic needs, transport, fulfilment of ancestral rituals in order treat the mental illness, buying medication, and burial societies. According to participants:

They want to eat, when I get my old age grant money, I buy everything, mealiemeal [maize flour used to cook porridge] tshisevho [something to eat with the pap, like meat or vegetables] with my money…these are the people I am supporting financially. I feel as if I am going mad; I don't even know how to say it. I feel I am mad nne ndo tangana thoho [I feel I am mad]. I buy bread, will say go and buy bread. (P4)

I give him some money to go to the clinic…monthly treatments about R40.00: R20.00 for going to the clinic and R20.00 for coming back home, each and every month. (P4)

I will be thinking, I do not know how I am going to do it. Even if I tell myself that I am going to take him to the hospital, where will I get the money to pay for transport, whose car will I get…who can offer it *free of charge? No one will do that… (P5)*

When he started to be ill, I was robbed because I was told his illness is caused by the ancestors. I had to take him there as you know, it is the ritual to fulfil the wishes of the ancestors, we were expected to buy many things…I had to go to the people who lend money so that I must do the ritual…borrowed a lump sum of money… (P17)

Financial needs are another thing. You may find that there are mentally ill individuals who are not working; others have lost their jobs because of mental illness. There was a time when the Department was unable to distribute the pills to the patients, we found ourselves not having money, and even the patient himself had nothing. We had to go to the chemist shops since there was nothing we could give to the patients. (P5)

Patients sometimes suffer, when they go to the clinic only to find out that there is no medication. You found that your medication did not come, so you are supposed to go… When we find out that there is no medication, they tell us that we must try to go to the chemist so that we can get help because there are no medications at the clinic. If the patient cannot get them, her behaviour will change because…this person survives by pills. If she fails to get them, she cannot be well, and the illness will recur. (P12)

In their study, Iseselo et al (2016:5) found that the participants' main concern was how to get money for transport when the family income was too low. Participants with a relative who used more than two types of medication did not get the second medication from the hospital and had to purchase it at private pharmacies. As a result of lack of money, they used only one type of medication because they could not afford to buy the second one (Iseselo et al 2016:5). A study in Ethiopia found that caregivers were not employed and not able to work mainly because they quit working or reduced their working hours to be at home to take care of their mentally ill relatives. The caregivers indicated that most of their expenses were due to the patients' destroying household items through destructive and violent behaviour, expenses for transportation to health institutions, and fees for treatment which was costly (Ayalew et al 2019:5)

4.5.4.2 Need to provide MHCUs with a permanent disability grant.

The participants caring for MHCUs who did not receive a disability grant reported the added financial burden experienced in the provision of their day-to-day care. Some participants indicated that the MHCUs were given temporary disability grants, for only six months or one year; some only had their old age pension. According to participants:

I could no longer remember I forgot; it is about six years. At times it is cut-off where you find that she *gets nothing at the end of the month. She will get up and go to the hospital; they will give her again after they have checked her, found out if she was using her treatment, and assess her mentally. It is then it is approved again if all is well. (P16)*

He was given a temporary one. Yes, but previously he was given, but it was cut off. They said he might be fine. (P5)

Now as I speak, I do not have a cent…at times even the refrigerator is empty, when there is nothing. Can you see that the money when you look it is used to provide the needs of the whole family and for the community activities? They should be given disability grant because financial problem is giving me too much stress, since the money I am getting cannot buy anything. It is used for buying food, clothes and those things… (P4)

But the pills really help him a lot, I am sure. My prayer is that if the disability grant is permanent, it should not be cut-off. (P13)

We tried it and it was given for only one year, then it was cut off. I then went to the hospital so that it could be renewed. They said it was renewed but when we visited SASSA [South African Social Security Agency] they rejected him despite him taking medication. (P4)

The participants indicated that their income was insufficient to provide for the MHCUs' needs. In South Africa, the Department of Social Services provides a social intervention strategy called SASSA (South African Social Security and Assistance) meant to alleviate poverty. Disability grants are given according to the financial income test as well as the nature and extent of the mental disability. The report of the holistic assessment forms part of the application process (Baumann 2015:746). In this study, the participants indicated a lack of knowledge regarding the disability grant application process.

4.5.4.3 Need for employment opportunities for MHCUs

The participants were concerned about the limited employment opportunities for MHCUs despite having educational qualifications. According to participants:

I wish that the government would consider offering them an employment since she is having her certificate. They need to be recognized, they also have the right to be employed like other people. It helps them. (P14)

Now he is stable, He was even working at the bank. Unfortunately, he was retrenched and is presently looking for other employment. As parents, we expected him to have a career, a better one because they are four children: two daughters and two sons. All the siblings are educated and are working, they *hold qualifications except him (P8).*

The contract signed said three days without any evidence of sickness is dismissal… It was a straightforward dismissal that one. By the time we could produce information that she is a mentally ill person we could not win, because that one is a private company (P14)

Employment can assist with the rehabilitation of my brother, finance him then he can further his studies like doing security courses where he can get employed. Maybe he can get employed at the hospital where the healthcare providers will be able to monitor him easily. The department must provide employment opportunities for these individuals… (P5)

A study in the United States of America found that employment was an important intervention for MHCUs and contributed towards a meaningful life (Drake & Wallach 2020:1). Unemployment worsens MHCUs' mental health and physical well-being whereas employment can improve mental health. Drake and Wallach (2020:1) argued for a new treatment paradigm in mental health that emphasised employment, because supported employment was an evidence-based intervention that could help MHCUs to be integrated in the community successfully. The benefits of employment included self-reliance, self-confidence, respect of others, personal income and community integration. Employment decreased dependence on disability social grants (Drake & Wallach 2020:2-3).

Unemployment may be a result of stigmatisation against MHCUs. Discrimination occurs when there is limited work and hiring possibilities and a lack of assistance with employment for MHCUs (Yin et al 2020:151).

4.5.4.4 Need for suitable housing

The study was conducted in a rural district which was part of the former Venda homeland. It is regarded as the second poorest district in the province with 67% of adults living in poverty (Statistics South Africa 2018:23). The demographic data indicated a high unemployment rate. The participants stated a need for housing as some of their houses had been destroyed by heavy rains and others had inadequate room to accommodate the MHCUs. According to participants:

Like also during the rainy days my kitchen has been destroyed by the heavy rains There was a kitchen there [pointing] which I had built, it fell recently when we had heavy rains. If I could be assisted I could rebuild it again. I have window frames, all this happened to fall. I used to have everything, but the heavy rains destroyed everything. (P15)

I have a financial burden that is too much to handle, as you can see [pointing to the houses which were destroyed by heavy rains]. (P4)

I do not have accommodation; I do not have adequate accommodation. Because our money is going to Vho-matshonise [people who lend money]. (P17)

Because you can see this house, it is incomplete, and the roof is leaking. It leaks a lot when it rains, we must put up some containers for the rainwater. (P3)

Service providers were concerned about homelessness and unfulfilled accommodation expectations affecting MHCUs (Lavhelani, Maluleke, Mulaudzi, Masutha, Makhubele, Manyuma et al 2020:3). Accommodation is a serious problem faced by family members because it is difficult for MHCUs to stay with their families and MHCUs often end up roaming the streets. One of the factors that contribute to homelessness of MHCUs is family rejection (Lavhelani et al 2020:3).

4.5.5 Sub-theme 2.5: Educational and information support needs

The participants indicated an urgent need for education and information support from the healthcare providers. Most participants reported that they were not given adequate information on diagnosis, treatment options and management of the MHCU to enable them to cope better with community-based care. The following categories were identified: knowledge on mental illness, its causes, signs symptoms, course and prognosis and treatment options; identification of early warning signs of relapse and its management; information about management of day-to-day challenging behaviours; information about dagga and alcohol abuse by the MHCU; information on medication adherence; information about side-effects caused by psychotropic drugs and management thereof, and the need to be empowered with various skills.

4.5.5.1 Knowledge on mental illness, its causes, signs and symptoms, course and prognosis, and treatment options

The participants indicated a lack of knowledge on the MHCUs’ mental health conditions, causes, signs and symptoms, prognosis and treatment. According to participants:

I need counselling if as a person if you could be told what type of illness this is. Families living with a member suffering from mental illness, how should they manage them? (P14)

It is only that I do not understand how come if a person is taking medication every time yet still has this problem. It is like there is a specific time the illness should just come back. We are aware that the *medication is intended to make him stable, still you find the illness recurring…what is really happening? I am more concerned about this because I want to understand what is happening. (P2)*

The knowledge acquired by the nurses and us is not the same. Perhaps if…they could capacitate us, for example by telling us that regarding mental illness there are one, two and three. At times, we easily get angry if the mental health care user is behaving in some way. We need to be taught how to deal with such challenges, told that we are not supposed to lose our temper like that. (P5)

The participants indicated a lack of knowledge on the type of medication prescribed for the MHCUs, as they were not actively involved in the treatment programme. According to participants:

Yes, such as if the nurses can come, they find me and then tell me how to do some of the things since I never went with her to the clinic. They can let me know how these pills are used and the indications, or perhaps say the pills will take so many months, and after that they will be changed. The nurse will be health educating me so that I can realize no matter what happens, I must not stop supporting her. (P3)

We know a bit about the medication though I may not be able to call the pills by their names since I am not a doctor. But, for example, we are told that the mental health care user should drink all his pills. If one is missing, I will run to the hospital [name of the facility removed] to collect his pills. (P5)

One participant appreciated the provision of information on the reason for changing the medication, and another wondered about the possibility of medication with less side-effects:

Then I explained everything to the doctor. I told the doctor that she has children and now she is getting the injection. She needs to do the laundry for her children. I was concerned since she was unable to wash her children's clothes. Then they changed the injection, because they said that it was too strong, they gave her another one. (P16)

The medication that suits him with lesser side-effects, because he experienced a lot of side-effects including muscle stiffness. (P8)

A study in Nigeria found that 24% of family caregivers knew about their relatives' type of mental illness of their relatives; 16% knew the correct name of the drugs, and 30% could recognize the signs and symptoms of relapse (Jack-Ide & Amegheme 2016:10). In this study only one participant out of 16 participants knew the MHCU's psychiatric diagnosis. Educational information about mental illness helped family members to develop a positive attitude and acceptance of the mental condition of the family member and assisted them to optimize the support to the MHCU (Tlhowe, du Plessis & Koen 2017:34).

In Iran, Shamsaei et al (2015:6) found that MHCU carers wanted mental health professionals to teach them about the causes, treatment and prognosis of the illness and to be available to answer questions. Many participants indicated that they did not know what medications the MHCUs were taking, possible side effects or what changes to look for or expect from the psychotropic medication.

4.5.5.2 Identification of early warning signs of relapse and its management

The participants revealed that they learned about the early warning signs and symptoms of relapse through their own experiences. If they had knowledge about the symptoms of relapse, they could plan intervention strategies to lessen the symptoms and reduce the duration of the illness as early intervention would be sought. According to participants:

…they can only tell me, if she is talking irrelevantly, it will ring a bell, saying, that you have to come this side. If she can start to be talkative… (P3)

At times I will find him laughing and talking alone, also that behaviour makes me realize that he is not well. I will then ask him: Did you take your tablets? When you talk to him, he will respond normally but the time when the illness is showing up, he will just keep quiet and not respond, then I realize I need to take him to the hospital after which he will become much better. (P5)

Previously the illness recurred when he said he was attending a church somewhere when he stopped taking his medication. At church, sometimes they are told by their spiritual leaders to discontinue taking medication. We took him to the hospital [name removed] and they informed me that he was not drinking his medication. (P4)

Once I see her behaving strangely, I will take her into the house and give her the pills because I now know where they are kept. After I give her the medication, she will then be all right (P15)

In Iran, Mousavi, Norozpour, Taherifar, Naserbakht and Shabani (2020:5) found that family members had little knowledge about bipolar I disorder. The findings indicated that the participants had misconceptions about mental disorders which were associated with the belief that mental illness was caused by supernatural powers. They lacked knowledge about the effects of psychopharmacological treatment on the patients, were unable to identify the medication by name, and the indications as well as the time it took for the medication to show positive effects (Mousavi et al 2020:5).

Family psychoeducation informs family members about specific categories of mental illness, signs and symptoms, medication prescribed for MHCUs, signs and phases of relapse episodes, treatment and the fluctuating course of the illness. The content should also include the medication categories, side-effects, and adverse effects (Kneisl & Trigoboff 2014:635; Selick et al 2016:371).

4.5.5.3 Information about management of day-to-day challenging behaviours

Most of the participants reported that they found it difficult to convince the MHCUs to take the medication every day as some lacked insight into their mental illness. When the MHCUs refused to drink medication, the participants felt overwhelmed and helpless, especially when there were poor support systems. The participants reported disturbing behaviours resulting from mental illness and needed information on how to deal with violence and aggression. According to participants:

When she is mentally disturbed, she does not want to see me at all so when she sees me, she fights me. She alleges that I am the one who is bewitching her and says I want to kill her. When I am seated here at home, I need to be vigilant because if she can catch me, she will injure me because she is very strong and powerful. (P16)

She does not trust other people, if she finds boiled water in the kettle, she will not use the water. Instead she will empty the kettle and pour some water then boil it. She believes that she would be killed. Because it is so painful really. Looking at a child in a family cooking her own food and eating food alone and who fails to share the food with her sister's child. I feel bad about it. (P14)

Some participants reported MHCUs roaming around aimlessly, were concerned about their safety, and did not know how to deal with this behaviour. According to participants:

I believe it is stress, we did not know what to do. She left home and went to Malamulele on foot. Even at the hospital, they know at Letaba Hospital, they know all what I am saying. (P11)

Because when she has relapsed, she cannot sit down she will be pacing up and down, roaming around and leaving home. It pains me a lot, as I constantly get worried about her health status. I always phone her daughter who is nineteen years old because I am afraid that if she can leave home without being noticed, so that she keeps an eye watching her so that she does not escape at night. (P3)

In their study, Iseselo et al (2016:6) found that participants had difficulty managing patients' daily behaviour and were concerned that there was no one else who would be able to handle their unpredictable behaviour. They were the only ones who had learned how to handle the patients' behaviour and were afraid that the patients would attack them. Ntsayagae et al (2019:8) found that family members caring for a relative with mental illness felt at risk of being injured or murdered by the patient and lived in constant fear. The violence and aggression may be directed at the caregivers and immediate family members, or to members of the community (Mokwena & Ngoveni 2020:6).

4.5.5.4 Information on substance abuse by MHCUs

The participants reported that some MHCUs abused substances, such as cannabis, which worsened their condition. Substance use also negatively affected compliance with medication because when under the influence of substances, MHCUs would not remember to take medication. Furthermore, they were at risk for injuries, and it strained the relationship between the participants and the MHCUs. According to participants:

He is smoking dagga, which makes his condition worse, so it needs some kind of counselling for us and the patient. You may sit down with him and tell him that when you are like this, you need to take care of yourself. (P5)

I always tell him to stop drinking because I do not like it. This will affect the way you drink your medication because alcohol is not your life, it is not the life of a person who is drinking the medication. I warned him that going around the community was not good when an illness recurs. I will not be able to afford to go to the hospital to visit him when he is admitted…. The problem is caused by this one who is drinking alcohol. If he goes out, he will come back being drunk, he sometimes falls…I have been telling him to stop drinking alcohol. I used to tell him: "I have brought you up, you did fall in the holes but now as an adult you do not want to listen". I have been telling him to come back home in time. If you try to advise a person and the person does not want to take your advice... (P4)

One participant emphasised the need for substance abuse counselling:

Maybe if he can get counselling, I know it is difficult to stop smoking compared to alcohol because many people you often hear reporting that they stopped drinking so easily, but it is not the case when it comes to smoking dagga. Smoking worsened the illness. (P5)

Substance use impacts negatively on the physical, social, psychological and spiritual health of the MHCUs, family and society. MHCUs who abuse substances increased the participants' caregiving burden.

In South Africa, legislation that deals with substance abuse to reduce its harm, demand and supply is in place. The National Drug Master Plan (2019-2024) (Department of Social

Development 2020) was adopted by the South African government to curb the prevalence of substance use. Effective intervention strategies to curb the substance abuse problem, should also address problems such as poverty, unemployment and inadequate education/skills development because socio-economic problems are multifaceted. Therefore, a holistic, multi-level, multi-sectoral intervention is required for all role players such as government departments, non-governmental organisations, and community and faith-based organisations (Setlalentoa, Ryke & Strydom 2015:97).

4.5.5.5 Information on medication adherence

The participants reported that they found it difficult to persuade the MHCUs to take their medication every day as prescribed. Most of the participants reported that MHCUs defaulted medication, which led to frequent readmissions; refused to go to the clinic for follow-ups, and when MHCUs refused to take their medication, they did not know how to manage that behaviour. According to participants:

Maybe if you can talk to her that she needs to take the medication. When we tell her to take her pills, she says hey! hey!, shouting at us: Do not tell me. What! I will burn this house! (P7)

The time when she did not want to drink her treatment, would just collect and throw the pills away. She did not want to use her medication. She would throw away the pills as she does not believe that she is mentally ill and furthermore holding the belief that I am want to kill her. (P16)

The problem of not drinking her medication is frustrating us because the illness sometimes comes back and in a serious manner. She becomes so angry for the whole day and at times she will be swearing at us then decide not to communicate with anyone and not talking to anyone, also insulting people. At least these days she is able to sleep. In the beginning she was unable to sleep during the onset of her illness. (P7)

Some participants described how they developed strategies, including bribing, to ensure that the MHCUs took their medication every day as prescribed:

I just have to remind him; I will just say after he had finished eating: Do you know which pills to take? He will then drink the pills, but I will observe him to make sure indeed, he had swallowed the pills. Every day I will say: Please drink the medication. In the evening, I will again ask: Do you know which pill to drink now? He will answer by saying: Yes, I know. After he had finished eating his food, he will say: I am drinking. Then I will respond by saying: It is fine, let me see. (P9)

After I noticed that she was throwing away the pills I made a plan in which I would pour the pills in her *food so that she did not see me doing it. Yes, I was forced to do that. I will even rob her by telling her that we are going to buy something at the shops up there next to the clinic at the centre of the village. I would do that so that she could then go to the clinic. (P16)*

The participants reported that MHCUs refused medication which increased their frustration as they did not know how to manage it. In their studies, Ntsayagae et al (2019:4) found that participants reported concern over MHCUs defaulting medication leading to recurrence of the mental illness. Mokgothu et al (2015:4) found that families of MHCUs reported that they explained to the MHCU the importance of going back to the hospital for follow-up and also encouraged them to stop using alcohol and drugs to prevent relapse. Education, gender and age are the significant factors that were associated with non-compliance in psychiatric treatment. Longitudinal studies are recommended on provider/patient relationship and related social, financial, educational and clinical factors affecting compliance (Gohar, Talib & Mehmood 2020:22)

4.5.5.6 Information on side-effects of psychotropic drugs and management thereof

Some participants reported that the MHCUs experienced side-effects from the medication and rendered them unable to perform their daily household duties and affected their functioning. The participants did not know how to deal with the side-effects and wanted information on the medication and the side-effects. According to participants:

Appetite is too much, too much appetite. If you happen to cook veggies, like spinach, it's not something she will eat. If she intended to eat, she should have put margarine and mayonnaise in it. (P14)

I suspect it's because of the pills, even when she is scrubbing the floor, she can't do it well and she would leave a leaf under the sofa. She does not have the zeal to strive for perfectionism (P14)

She does not even fetch a single piece of wood. If I do not hire someone, there will be a problem. It is because she is a person who after drinking her medication, will sit down on a mat the whole day. She spends most of the time sleeping during the day. (P15)

They are making him unable to do anything here at home. He does not do anything here. He even said that "mom you see I used to work, now I cannot do that any longer." I can also confirm that I can see it because the pills destroy him… he would be looking like this [demonstrating tremors and dystonic reactions of the hands] (P4)

One participant, the husband of the MHCU, shared how side-effects affected their sexual relationship, and that he felt ashamed to mention it to the doctor:

Another thing is when you want to have a u ka muroho [sexual relationship] with your wife, she will not be interested. As a husband, you cannot go the doctor and tell them that by the way you are giving my wife the medication which makes her not have any interest in engaging in sexual relationship. It is so difficult to mention it. (P15)

Antipsychotic side-effects significantly affect treatment adherence which has a detrimental impact on long-term outcomes. A validated rating scale must be used to routinely check side-effect impact on adherence to treatment and the relationship with antipsychotic medicine negatively, which leads to poor long-term outcomes. In order to improve antipsychotic experience and ensure long-term positive outcomes, side-effects must regularly be systematically assessed, using a validated rating scale commencing at an early stage in care. Monitoring of side-effects should be done starting at an early stage in care in order to enhance the antipsychotic experience and assure long-term good outcomes (Hynes, McWilliams, Clarke, Fitzgerald, Feeney, Taylor, Boland & Keating 2020:1).

A study in Iran on the family challenges of caring for MHCUs reported not receiving proper education from health professionals on mental illness about indications of psychotropic medication and its side effects (Shamsaei et al 2015:6). In this study, the participants expressed the need for education on medication and related side-effects. If the family members are not empowered with knowledge about medication, they find it difficult or impossible to supervise the treatment plan. Du Plessis, Poggenpoel, Myburgh and Temane (2021:9) found that family members reported tension, stress, anxiety, resentment, depression with accompanying feelings of powerlessness and hopelessness, a sense of entrapment, disruption in their family life and relationships, financial difficulties, physical ill-health, restriction in social and leisure activities, and a general decrease in the quality of life as a result of caring for MHCUs living with depression who were non-compliant to psychiatric medication.

4.5.6 Sub-theme 2.6: Spiritual needs

The participants expressed their spiritual needs based on their religious beliefs. The study found that participants caring for MHCUs sought support from traditional and church leaders that helped them to survive the caring burden. Two categories emerged from this sub-theme, namely the need for traditional practitioner consultation and the need for pastoral support care.

4.5.6.1 Need for traditional practitioner consultation

Some participants consulted traditional doctors before taking the MHCUs to western doctors, which is a common practice in African culture. After participants noted that the MHCUs' did not improve, they opted for western medicine. According to participants:

Many traditional healers were consulted. I went to the traditional healers four times…we took him to the traditional healers, but there was no help. (P13)

The illness started some years back. As you know, people will always try somewhere for help before consulting western medical doctors, but in 2002 they observed that all the efforts of the traditional practitioners were not working, they then decided to consult the hospital. (P5)

He stayed there in the ward for a long time. As Africans, we also tried to consult traditional practitioners. However, there was no help from the traditional doctors. (P8)

She is my wife and is a mentally ill person. I have been staying with her since she was declared a mentally ill person, trying everything, seeking help from traditional healers. But all was in vain. (P15)

A frequent source of misunderstanding revolved around how to find solutions to the patients' challenging behavioural problems. One parent might prefer to seek help from a traditional healer for treatment while the other might seek spiritual healers. However, most caregivers resolve to seek out professional treatment (Iseselo et al 2016:6). Jack, Wagner, Petersen, Thom, Newton, Stein, Kahn, Tollman and Hofman (2014:7) found that in South Africa, the use of traditional medicine was common but no data was available on the motivation for use, costs, or effectiveness of these treatments. In their study in South Africa, Mokgothu et al (2015:4) found that many families emphasized that they used their faith in God in support of the MHCU as an internal strength while some families practised their faith or spirituality in the form of prayer as most of them were Christians.

4.5.6.2 Need for pastoral support care

The participants indicated that they were given spiritual counselling by their church leaders, which helped them to cope with the burden of care. According to participants:

The pastors would pray for us when I ran short of food, they provided food, bathing and washing soap. (P16)

Our pastors visited us and prayed for us, and laid their hands on us. They visit us when the patient is not well and bring spiritual healing to the patient. (P12)

Some participants reported that their prayer partners were supportive to them and soothed their emotional pain:

In this village, there is a certain woman who is my prayer partner. She would wake up early in the morning and come to my place then we would pray together. She said to me, you know, what you are going through is not easy. You cannot make it alone. Every day when I come here in the morning, I find you crying. (P2)

Some participants shared their experiences of having trust in God to intervene in the situation, and revived themselves with prayer:

I trust that the God I pray to will intervene in this situation which is troubling me when I experience problems when the patient's mental illness recurs (P12).

When I get up, I make sure I have my own time alone, reviving myself by the word of God as I will be listening. What I do every day, when I pray, I ask God to give me enough sleep, I ask for enough sleep. If there is not something that might disturb me, I can sleep so well. I can sleep. (P14)

Spirituality is an important driving force to give meaning and purpose to nursing adding a complete understanding of the health needs of families (Domingo-Osle & Domingo 2020:1272). Iseselo et al (2016:8) found that family caregivers sought religious support as the only means of hope and encouragement to reduce the burden of care. They said that their religious practice gave them peace of mind and helped them to endure the caregiving situation. They believed that praying helped to reduce the MHCUs' suffering as well, which made their faith indispensable to continued caregiving, irrespective of MHCUs' distressing behaviour. Different consultation was sought to find solutions or treatments. Some were advised to seek treatment from traditional healers but when they found no relief, they turned back to God and sought hospital services.

A study in Uganda found a severe shortage of mental health resources and poor access to health care services and primary caregivers relied mainly on spiritual and traditional care (Verity, Turiho**,** Mutamba & Cappo 2021:8). Places of worship were perceived as social support systems and networks of care for people with mental illness. Religion-based networks are potentially good resources to support MHCUs at the community level. However, the participants acknowledged that some religions preached beliefs that potentially hindered adherence to medications provided in the health facilities.

4.6 THEME 3: HEALTHCARE SYSTEM EXPECTATIONS

The participants expressed a need for support from the public healthcare system. Two sub-themes emerged, namely expectations from healthcare systems and expectations from healthcare professionals.

Table 4.5 Healthcare system expectations

Theme	Sub-theme	Category
3. Healthcare expectations	3.1 Expectations from the healthcare system	3.1.1 Provision of community-based psychiatric rehabilitation services 3.1.2 Availability of psychotropic medications at community health centres 3.1.3 Assistance from the South African Police Service during crisis. 3.1.4 Home visits by healthcare providers

4.6.1 Sub-theme 3.1: Expectations from healthcare system

The participants indicated their healthcare system expectations and needs. Four categories emerged, namely provision of community-based psychiatric services, availability of psychotropic medications at community health centres, and assistance from South African Police Services during crisis and home visits by healthcare providers.

4.6.1.1 Provision of community-based psychiatric rehabilitation services

The participants stated that the MHCUs were in need of community-based psychiatric services including rehabilitation and day care services. Such services could keep the MHCUs busy and occupied during the day, relieve their boredom, provide interaction with other MHCUs and provide some relief for the caregivers. The services should teach the MHCUs occupational and social skills suitable to their level of cognitive functioning that might assist in generation of income. According to participants:

If there was a place for them where it can be said that in the morning they can wake up and bath, then leave to that place for day care. They [MHCUs] can be kept there for the day with gates locked accompanied by their relatives. Then in the evening they are taken home, I think it is better. I believe their illness can be manageable, as they will busy doing something. (P1)

Employment can assist with the rehabilitation of my brother, finance him then he can further his studies like doing security courses where he can get employed. (P5)

When she is doing nothing but just sitting at home it makes her think deeply and get more worried. I think it could be better if we look for a school where she will be able to interact with other people also affected by mental problems. (P7)

Azma, Singh and Sulaiman (2019:466) found that the absence of mental health services, stigma attached to mental illness, and unavailability of rehabilitation services impacted negatively on the burden of family members caring for persons with mental illness. Day, Starbuck and Petrakis (2017:437) found that after attending a family group intervention, family caregivers reported better understanding of psychotic clinical manifestations, recovery, medication, relapse prevention and substance use management. The availability of peer support and help during group therapy allowed participants to discuss similar issues and learn from counsellors and peers who had similar experiences (Haskell, Graham, Bernards, Flynn & Wells 2016:8).

4.6.1.2 Availability of suitable psychotropic medication at community health centres

The participants indicated the need for the availability of suitable psychotropic medication at community health centres. Most of the participants claimed when the MHCUs took medication they became mentally stable, but they complained of side-effects. Some participants reported their dissatisfaction with disabling side effects of the medications, especially the intramuscular depot treatment, which rendered the MHCUs unable to function independently. According to participants:

She is doing well when she is taking her pills. Previously in the past the pills made her not be able to hold things. The pills were making her weak; she could not hold anything and even a little something and she could not manage to hold it. I mean the smallest object she would not (P16 elderly mother of the MHCU).

The injection is not good for her that time while she was at hospital [name removed] they used to give her, but she experienced some problems like drooling of saliva, tremors, and body shaking [demonstrating with the hand how tremors disturbed her]. If they can give her the injection, they will also prescribe some tablets to manage the problems of the side-effects caused by the injection. No! No! We prefer the tablets, not injection. The injection is not good for her, she is weak. (P7)

Yes, if they can inject her, she will not even manage to pick up her child, because she will be paralyzed. Previously they injected her at Giyani. She came back looking like this [participant demonstrating the tremors and stiffness of the muscles]. (P11)

She needs to do the laundry for her children. I was concerned since she was unable to wash her children's clothes. Then they changed the injection. (P16)

The participants stated that sometimes when the MHCUs visited the community health centres, they did not receive their supply of psychotropic medication. The participants emphasised that medication shortages were frustrating because they had to buy medication from the pharmacy, adding to their financial stress and negatively affecting their caregiving. According to participants:

When we find out that there is no medication, they tell us that we must try to go the chemist, so that we can get help because there are no medications at the clinic. If the patient cannot get them, her behavior will change because she is surviving on the pills. This person survives on pills if she fails to get them, she cannot be well then the illness will recur. (P17)

There was a time when the Department of Health was unable to distribute the pills to the patients, we found ourselves without money, and even the patient himself had nothing. We had to go to the chemist since there was nothing we could give to the patient. When we got to the pharmacy, it cost R400.00 and we found that the pills will only cover about a week. (P5).

Two participants indicated the problem of transport when they had to go and collect the medication at the hospitals:

At times it is difficult to get the medication at the clinic then they can send you to [naming the hospital], sometimes even at the hospital you may not get it. It is possible that you don't get medication then they will send you to the chemist to buy some medication there. (P10)

We have to collect the medication at [name of district hospital] if they are out of stock at the community health centre which is expensive in terms of transport money, because the hospital is far from this place. (P5)

Sadock and Sadock (2015:489) state that when long-acting medication is used instead of oral medication compliance is improved. Semahegn, Torpey, Manu, Assefa, Tesfaye and Ankomah (2018:4) found that patients complained of prominent side effects including fatigue, tiredness, lethargy, feeling of dizziness, sleepiness and sedation. These side-effects contributed to medication non-adherence. In addition, adherence to medication is often affected by beliefs and perceptions about side effects (Semahegn et al 2018:4).

A study in Malaysia found that when the psychotropic medication was out of stock at the health care facilities, family members caring for MHCUs used their financial aid money to buy medicine for the patients (Azman et al 2019:468). In Dar es Salaam, Tanzania, Iseselo and Ambikile (2017:6-8) found that affordability and availability of psychotropic drugs given to MHCUs on a monthly basis were a serious problem affecting low- and middle-income countries because of lack of funds. In South Africa, the Department of Health (2013:29) states that essential psychotropic drugs should be made available at all levels of care.

4.6.1.3 Assistance from the South African Police Services during crises

The participants emphasised that they needed assistance from the police during MHCUs' acute relapse episodes. The participants stated that the police services did not respond quickly when they needed urgent assistance. When the MHCUs displayed aggression and violent behaviours, the police officers made excuses not to assist them. The participants felt unsafe, fearful and anxious. According to participants:

They [police] do not respond to our calls, they only respond when you go there. Then they will come and help you once you go there. (P16)

It is not easy to call the police van, sometimes they delay coming, but they will end up responding. During that time, she [MHCU] was climbing this tree [participant pointing at the tree]. I was thinking that maybe it is caused by dagga abuse. (P16)

One time my sister visited them and was told the same story of unavailability of the police van…Only to find that the officers had agreed amongst themselves that this person, they cannot manage to apprehend him. (P5)

Sometimes when you try to call the law enforcers, they will tell you, see what you can do, we are not going to come now. See how you can apprehend him. Yes, police officers. It was very difficult to get them to assist me, but because they know that I know the law I told them that you need to come because it is your duty. They responded by saying if they come, I must also be there. I told them that I am available…They do not understand, sometimes they will say that we do not want to handle a mentally ill patient because he is dangerous. If the police officers are saying he is dangerous, what about us because they are to render that service to help us as community members? (P5)

The Mental Health Care Act, 17 of 2002, section 40 stipulates that if a member of the South African Police Service (SAPS) receives information or from personal observation learns that a person is likely to inflict serious harm to self or others because of mental illness or profound intellectual disability, the SAPS member must apprehend the person and submit him or her to the health care establishment for care, treatment and rehabilitation. In case the person is violent or dangerous the members of SAPS may use the restraining measures as deemed necessary to apprehend the person. The role of the police is to ensure safety and the role of health care providers is to promote recovery and resilience of patients. Crises are defined as critical times for immediate intervention and treatment, including peer support leading to positive outcomes for the individual, family and non-violent communities (Steadman &

Morrissette 2016:1055).

4.6.1.4 Home visits by healthcare providers

The participants expressed a need for support visits by the healthcare professionals. They felt that home visits would assist them in reducing the burden of care. The participants indicated that the healthcare professionals would teach them how to take care of the MHCUs, assess how they were coping with caregiving, the MHCUs' condition and adherence to their medication, and observe side effects, and give them practical advice on caregiving. Some participants also felt that these visits could help facilitate registration for grants. According to participants:

If you can help her, I mean to say if you can come every week to assist us by checking her if indeed, she is drinking her pills as prescribed. (P12)

Perhaps health care workers could visit the family, maybe once in three months to find out how we are coping so that we can give them a report. We would get an opportunity to report indicating that we are observing this and telling them that the patient is smoking cigarettes and dagga excessively, which could lessen the burden of care on our side, just like now as we are communicating with you. (P5)

Some participants said that home visits would help establish a nurse-patient relationship in which the nurse would talk about compliance to encourage MHCUs to take their medication:

So that when she is around you can come and talk to her encouraging her to take medication. If you can advise her on the dangers of not taking her treatment (P7 sister to the MHCU)

The next participant indicated that visits by social workers can help to secure disability grants:

For the Department of health to pay us a visit, it has never happened…they are not coming to see the mental health care users. In reality, they only see him coming to the clinic to take the treatment…When they are supposed to consider an application for the grant; they only check the list indicating how many times he takes the medication, not visiting the mental health care user to see the environment where he stays. I mean when he is supposed to be given a disability grant (P5 Brother of the MCU)

Participants further shared that during home visits they expected counselling to be provided for them:

They do not come here; no one ever visited us in this house. Even counselling, I need it because we are thinking too much. Sometimes she can decide to kill herself or kill us. So, I really want counselling. Counselling will help us refrain from persistent memories of all these things. (P7)

Townsend (2014:817) states that primary health care mental health nurses should monitor MHCUs' adherence to the regimen of psychotropic drugs. However, there are barriers to conducting home visits such as shortage of healthcare professionals in primary healthcare facilities. Home visits are rarely done by community healthcare workers despite poor support systems for the MHCUs. A study in Ghana found that caregivers of children with disabilities benefited from the support programme which also included monthly home visits by the facilitators. In addition the authors showed that home visits were used as an approach to actively engage with the caregivers and evaluate whether what was taught was put into practice (Zuurmond, Nyante, Baltussen, Seeley, Abanga et al 2019:50-51)

The inclusion of caregivers in shared decision making is crucial. Clinical decision making and health outcomes for both patients and caregivers can be improved by the involvement of caregivers in the treatment programme. However, caregiver involvement in shared decision making needs further attention in research. For example, more information is needed on caregiver skills that facilitate joint decision making and strategies for resolving conflicts between caregivers and patients (Hamann & Heres 2019:420).

4.7 CONCLUSION

This chapter discussed the findings on the healthcare needs of family members caring for MHCUs, with reference to the literature. The findings indicated that the family members caring for the MHCUs experienced a range of psychosocial problems and support needs as well as healthcare expectations. Chapter 5 discusses the findings of the NGT to develop a psychoeducational programme conducted with stakeholders in Vhembe district, Limpopo Province.

CHAPTER 5
PHASE 2: NOMINAL GROUP TECHNIQUE FINDINGS AND LITERATURE REVIEW

5.1 INTRODUCTION

Chapter 4 discussed the findings from phase 1 on the needs of family members caring for MHCUs in Vhembe district, Limpopo Province, with reference to literature reviewed. This chapter discusses the findings of phase 2 from the nominal group technique (NGT) workshop conducted with stakeholders in Vhembe district, Limpopo Province to explore and describe the psychoeducational interventions needed to support family members caring for MHCUs.

5.2 PARTICIPANTS' SOCIODEMOGRAPHIC PROFILE

The NGT was conducted with 21 stakeholders who were willing to participate in the study and could express themselves in either English or Tshivenda. The participants consisted of community health workers, psychiatric nurses, a community health centre manager, social workers, an occupational therapist, a clinical nurse practitioner, a review board member, a nurse educator in mental health nursing, a church leader or pastor, a community representative, and a traditional health practitioner. The participants' sociodemographic profile included gender, age, current position, educational level, and institution or place of employment. The participants were between 30 and 67 years old. The mean age of participants was 48.5 years old. Most of the participants were healthcare workers from the Department of Health. Table 5.1 presents the participants' sociodemographic profile, and Figure 5.1 the occupational profile.

Table 5.1 Participants' sociodemographic profile

Variable	Category	Number
Gender	Male	3
	Female	18
Age in years	30-67	21
Institution	Vhembe district hospitals	9
	Nursing education institution	1
	Primary health care facility	7
	Community structures	4
Current position Occupational category	Social worker	4
	Occupational therapist	1
	Psychiatric nurse	2
	Advanced psychiatric nurse	5
	Nurse educator	1
	Mental health review board member	1
	Local area clinic manager	1
	Community health worker (CHW)	2
	SANCO (Civic) member	1
	Church leader	1
	Traditional health practitioner	2
Educational level	Primary level	1
	Secondary level	0
	Certificate	6
	Diploma	5
	Degree	3
	Honours degree	4
	Master's degree	2
Years of experience in the position	All categories of stakeholders	1-28

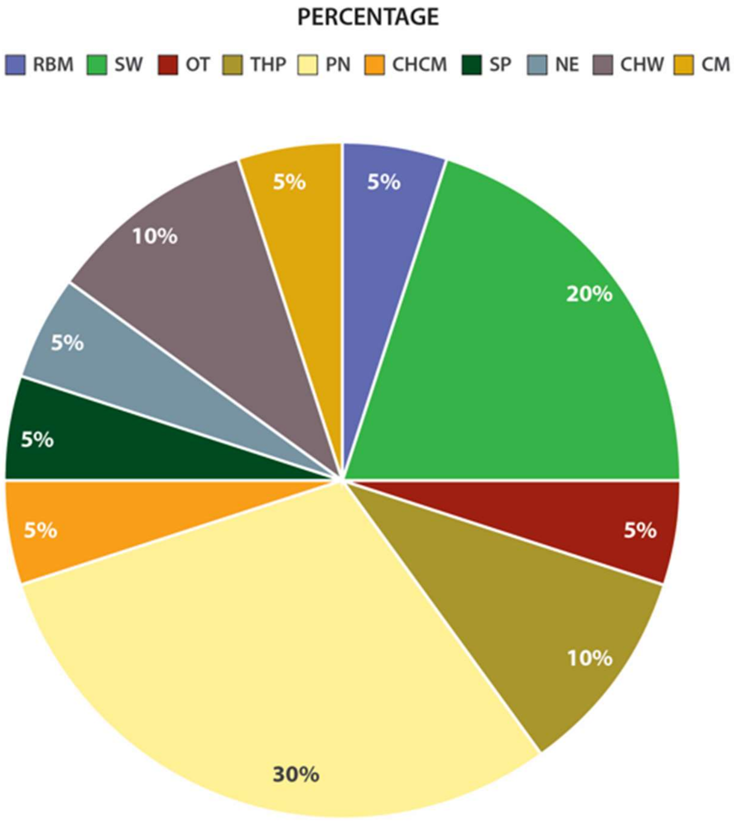

Figure 5.1 Percentages of participants' occupational categories (n=21)

Key: SW=Social worker; OT Occupational therapist; THP= Traditional Health Practitioner; PN=Psychiatric nurse; CHCM=Community health centre manager; SL=Spiritual leader; NE=Nurse educator; CHW=Community health worker; RBM= Review board member; CM=Civic member

5.3 FINDINGS OF THE NOMINAL GROUP TECHNIQUE

During the NGT, data was collected by means of written narratives, audio recordings, which were transcribed verbatim and translated from Tshivenda to English and vice versa during group discussions, and field notes. Before the NGT workshop commenced a PowerPoint presentation was done wherein the researcher presented the findings of phase 1 of the study to familiarize the NGT participants with needs of family members.In Step 1, the participants were asked to individually write narratives firstly, on how to address the healthcare needs of family members using a psychoeducational programme, and secondly, what components or interventions should be included in the psychoeducational programme to support family members caring for MHCUs. In Step 2, the participants shared their written ideas in a round robin. In Step 3, all the ideas were discussed, and grouped into themes and categories. The discussions were audio-recorded and transcribed. The researcher took field notes during the NGT workshop. Data were collected until consensus was reached on the themes and categories.

In the last step of the NGT, the participants identified seven themes consisting of different interventions to address the psychosocial healthcare needs of family members. The themes were ranked according to importance and kind of intervention needed to support the family members. The seven themes were: Interventions to provide information and education, family support by the community, physical care of the MHCUs, social support, financial assistance, spiritual care, and health care services support. The themes and categories are discussed with supporting verbatim quotations from the participants' written narratives and audio-recorded discussions during the NGT. A literature review for each theme is provided. Table 5.2 presents the themes and categories that emerged from data analysis. Table 5.3 shows the participants' code numbers and characteristics.

Table 5.2 Themes and categories of the psychoeducational programme content

Themes	Categories
1. Interventions to provide Information and education	1.1 Mental health education on mental illness (causes, signs and symptoms, prognosis and treatment options) 1.2 Psychotropic medications, side-effects and their management 1.3 Management of challenging behaviours
2. Interventions to enhance family support by the community	2.1 Reduction of stigma and discrimination against family members and MHCUs 2.2 SAPS assistance during crises 2.3 Engagement of the MHCUs in community activities
3. Interventions to enhance physical care of the MHCUs and family members	3.1 Maintenance of personal hygiene of MHCUs 3.2 Assessment of physical health status of the MHCU and family members
4. Interventions to provide social support	4.1 Suitable housing for MHCUs 4.2 Shared responsibility between health care providers and family members
5. Interventions to provide financial assistance	5.1 Provision of permanent disability grants 5.2 Establishment of income-generating occupational activities 5.3 Provision of employment opportunities
6. Interventions to enhance spiritual supportive care	6.1 Collaborative care by health professionals, church leaders (pastors) and traditional health practitioners 6.2 Respect for the beliefs of MHCUs in relation to treatment programme 6.3 Involvement of church leaders in rehabilitation of the MHCUs
7. Interventions to ensure health care provision by health care providers	7.1 Provision of family therapy and counselling 7.2 Home visits by health care providers 7.3 Availability of psychotropic drugs 7.4 Rehabilitation (sheltered employment for the MHCUs, skills training and support groups) 7.5 Mental health education awareness campaigns

Table 5.3 Participants' code numbers, occupation, age, ethnicity and gender

No	Occupational category	Age	Ethnic group	Gender
P1	Nurse educator	59	Venda	F
P2	Psychiatric nurse	43	Tsonga	F
P3	Advanced Psychiatric nurse	43	Venda	F
P4	Advanced Psychiatric nurse	53	Venda	F
P5	Community health worker	48	Venda	F
P6	Community health worker	55	Tsonga	F
P7	Community health worker, Thulamela municipal committee member, civic block member	54	Venda	F
P8	Psychiatric nurse	47	Venda	F
P9	Traditional health practitioner	52	Venda	F
P10	Advanced Psychiatric nurse	48	Venda	F
P11	Social worker	31	Venda	F
P12	Occupational therapist	34	Venda	F
P13	Social worker	40	Venda	F
P14	Traditional health practitioner	30	Venda	M
P15	Advanced Psychiatric nurse	47	Venda	F
P16	Mental health coordinator, clinical nurse practitioner	52	Venda	F
P17	Social worker	34	Venda	F
P18	Social worker	32	Venda	F
P19	Advanced psychiatric nurse	56	Venda	F
P20	Local area manager	55	Venda	M
P21	Pastor	67	Tsonga	M

5.3.1 Theme 1: Interventions to provide information and education

Information and educational interventions emerged as the first theme, with three categories, namely mental health education on mental illness (causes, signs and symptoms, prognosis and treatment options), psychotropic medications, side-effects and their management, and management of challenging behaviours.

5.3.1.1 Category 1.1: Mental health education on mental illness (causes, signs and symptoms, prognosis and treatment options)

The participants indicated that in order to meet the information and educational healthcare needs of families, mental health talks with regard to mental illness, causes, signs and symptoms, prognosis, and different treatment options to treat the MHCUs should be given to the families. The participants wanted families to be empowered about mental illness and acquire more knowledge and skills on management of the mental health conditions which would allay fears related to MHCUs' challenging behaviour. According to the participants, knowledge deficits increased the stress level associated with caring for MHCUs which was demanding and exhausting. Some of the participants put themselves in the position of the family members and wrote their narratives in the first person. According to participants:

By reaching out to the communities at large and addressing these issues from the causes, symptoms, severity and how to deal with it [mental illness]. (P18 written narrative)

They must be taught about signs and symptoms of mental illness so that they have more knowledge about the condition, treatment, and side-effects of treatment. Other mental health care users when they are given treatments become weak, experience insomnia so that family members must know how to deal with it. In case that person experiences sleeplessness, insomnia, signs and symptoms of side-effects of treatment must be taught to the family members. (P2 audio recording)

As a family [participant adopting the position of a family of an MHCU], we need to be taught about the treatment of the person who is ill mentally. We need information about how to see the signs and symptoms of relapse. Further than that we also need to know the causes of mental illness before it started…As families we need more information about the treatment the person is getting, information about how to see and recognise the signs of relapse. This programme could assist us as a family in how to manage the person during relapse. As a family we need to know causes of mental illness so that we can prevent it before relapsing. (P8 written narrative)

Training to empower them, health education for the family members. Health education for the family members and patients in order to have knowledge about mental illness. (P16 written narrative)

The programme must see to it that the mental health care providers give health talks to the community radio, TV [television], community meetings about the signs and symptoms, causes of mental illness, prognosis, and treatment plan. (P3 written narrative)

Healthcare providers must teach the signs and symptoms of mental illness, treatment and side-effects of Rx [treatment] and to consult when there is a need. (P2 written narrative)

5.3.1.2 Category 1.2: Psychotropic medications, side-effects and their management

The second category was the need for provision of mental health education on psychotropic medications, side-effects and their management. The participants indicated that the families need information and education particularly on the psychotropic medications that the MHCUs were taking. Family members need to have knowledge about the side-effects caused by the psychiatric medications as well as the management of side-effects. The participants gave examples of side-effects that contributed to refusal to take medication, such as sexual dysfunction and increased appetite, leading to obesity. Furthermore, the participants indicated that families need to be informed about the strategies that they could use to enhance adherence to medication by the MHCUs to prevent frequent relapse. According to participants:

Unfortunately, after-effects of the medication make MHCUs refuse medication and I think it is important to take it. Education about medications and what they do to the body, how to reduce the effects and what to do when such effects occur. (P19 written narrative)

To add to the issue of medication, it is like when on the medication…things are not the way they used to be before. That increases the desire not to use medication. So, I think there is a need to educate the family more about medication, and what they are supposed to do as families when things are not going well with medication. (P19 audio recording)

As a family [participant adopting the position of a family of a MHCU], we need to be taught about the treatment of the person who is ill mentally. We need information about how to see the signs and symptoms of relapse. Further than that we need to know the causes of mental illness before it started. (P8 audio recording)

Treatment of side-effects must be addressed. Some mental health care users when they are given treatments become weak, experience insomnia, so that family members must know how to deal with it. (P1 written narrative)

…need to be given information about the side-effects of medication also to know what to do to manage the side-effects. (P6 written narrative)

5.3.1.3 Category 1.3: Management of challenging behaviours

The third category that emerged is the need to educate the family members and provide them with skills on how to manage challenging behaviours. Families experienced the challenge of not being able to manage challenging behaviours displayed by the MHCUs. These included dealing with relapse episodes, aggressive behaviours, refusal of medication and roaming around the streets in the early hours without having taken food and medication. According to participants:

I (participant sharing personal experience of caregiving to a patient with mental illness and epilepsy) have a patient who is suffering from mental illness and also has epilepsy. This person when you wake up in the morning when you want to help him you will not find him as he left home early in the morning, without informing anyone about his whereabouts. You are surprised when someone from the community comes to the house to report that he is destroying property. When you go to look for him, you find him beating people…you find that he is unmanageable and uncooperative. I then suggest that police officers should be contacted. (P5 audio recording)

The programme could assist family members on how to manage the person during relapse…the patient leaves home in the early hours of the morning without eating food and taking medications

(P5 written narrative)

So, it depresses us…when the mental health care users end up killing people and destroying property. (P3 written narrative)

The healthcare workers must show that sometimes mental illness relapse can occur out of the blue …for example, if this happens, what it means. We need to be taught or shown practically. (P9 written narrative)

There should also be enough facilities for violent MHCUs, not the current situation in Vhembe district where a patient must first commit a crime so that they can be admitted at a mental health institution. It is painful to wait for such and open a criminal case against our loved ones, even worse if they commit this crime against other community members and not family. It is evident that they are uncontrollable. They should be institutionalized until such time as they are regarded safe to be at home by the medical team. (P11 written narrative)

Brief family psychoeducation can be effective in informing families regarding the nature of the disease and MHCUs' inability to control symptoms while encouraging them to take the medication and decreasing patients' stress. This would ultimately lower the recurrence and readmission rates. Offering information on mental illness, diagnosis, aetiology, prognosis, treatment, and long-term course of serious mental illness, is essential for the consumers of mental health services (Stuart 2013:164).

In Beijing, China, Fan, Ma, Ma, Zhang, Xu, Shi, Chen, Lamberti and Caine (2019:6) found that health education and mutual support groups provided by community members offered an opportunity to increase the knowledge and skill of the caregivers which reduced the psychological pressure (Fan et al 2019:6). In a study in South Africa on re-integration of male state patients (MHCUs admitted after a crime committed), Lavhelani et al (2020:6) found that family caregivers stated that state patients could only be re-integrated into family and community if they could adhere to the medication to prevent recurrence of mental illness.

5.3.2 Theme 2: interventions to enhance family support by the community

Interventions to enhance family support by the community had three categories, namely reduction of stigma and discrimination against family members and MHCUs, South African Police Service (SAPS) assistance during crises, and engagement of the MHCUs in community activities.

5.3.2.1 Category 2.1: Reduction of stigma and discrimination against family members and MHCUs

According to the participants, family members suffered from stigma and discrimination inflicted by other families and the community at large which negatively affected their physical and mental well-being. The participants concluded that awareness campaigns could assist to mitigate stigma and discrimination which hampered the social support needed by families and community members. They recommended information to be disseminated to the families, community leaders and the youth. According to participants:

> *Stigmatization and discrimination can be reduced through empowerment of the community members through chiefs and civic members who should be taught how to live with mental health care users. (P3 written narrative)*
>
> *Community campaigns on mental health to spread awareness to reduce stigmatization and discrimination by healthcare workers and relevant stakeholders. (P13 written narrative)*
>
> *To eat/sit together with MHCUs without discrimination, including the family members and MHCU in support groups and to plan with the family and MHCU for the future. (P15 written narrative)*
>
> *Involving the family members and other stakeholders in the community, stigma is a problem at home and in the community therefore it should be addressed. Mental illness should be approached and made known. (P21 written narrative)*
>
> *Help the family to first understand and accept their mental health care users and their illness. If they understand and accept, people in the community can also understand to accept them. (P13 written narrative)*
>
> *Healthcare workers should identify the primary schools. Stigma can be addressed in future generations. On the issue of the mental health awareness, I think we should do it with the young ones. If children from a young age are taught about mental illness, they will grow up having a better understanding and knowing how to handle mental disorders as young ones. I think if we could involve the young ones, it would help a lot. (P12 audio recording)*

5.3.2.2 Category 2.2: South African Police Service assistance during crises

The second category to enhance family support by the community was SAPS assistance during crises. The participants raised concern over lack of support from the SAPS who failed the families. Families did not receive assistance during crises when MHCUs needed admission to the hospital. The participants suggested that there should be a dedicated SAPS officer and office solely responsible for management of the mental health issues as a mechanism to improve service rendered by the SAPS. According to participants:

The SAPS can help by restraining the MHCUs if they are aggressive and pose potential danger to themselves or others. (P13 written narrative)

But the SAPS are the ones who disappoint us a lot. They refer us to the emergency officers, and the emergency service providers refer us to the SAPS. This means they need to be trained because they have different information. Sometimes I go and have a meeting with them. They want the patient to be aggressive and kill someone or destroy property, then they will go to where the patient is and apprehend the patient. I think they must have information; they need to know that even if there are no signs and symptoms of aggressive behaviour, they ought to attend to the MHCU and family. (P16 written narrative)

The SAPS need to go back to their old ways of doing things where they used to fetch the patient in their own cars and go with them to the hospital with the family. (P18 written narrative)

Regarding the SAPS, there should be an office or a facilitator to assist the relatives in case they do not get assistance. For instance, when opening a case because the mental health care user has done something wrong or in case they need to respond and take the patient to the hospital, there should be an office which deals specifically with mental health care users. A dedicated SAPS office where they can go straightaway that will address their problems immediately because they are usually transferred from pillar to post when they need assistance… This would ease the family care burden. (P10 audio recording)

The SAPS can help by restraining the MHCUs if they are aggressive and pose potential danger to themselves or others. (P13 written narrative)

5.3.2.3 Category 2.3: Engagement of the MHCUs in community activities

The engagement of the MHCUs in community activities was the third category to enhance family support by the community. MHCUs are often excluded due to stigmatized attitudes from the community. The participants were of the opinion that when MHCUs were involved in activities in their local communities, it would foster community acceptance and understanding of mental illness. The participants indicated that community leaders like the village chiefs, civic and church leaders could take the lead in supporting the engagement of MHCUs in activities such as sports and church programmes. According to participants:

The issue of social groups so that they can come together with other families to lessen the stress. They must all do physical exercises. They must be involved in activities, such as home activities and church activities because it is good to be given a chance to perform tasks. Being a mental health *care user, you might find that you are being excluded when people say this is a mentally ill person…. They must be engaged in physical exercises. If other people are going to the sports ground, they must also do physical exercises. (P1 audio recording)*

…the mental health care users must be involved in the community activities. It will help to prevent discrimination in order for them to feel accepted in the community. *So, I think that the issue of activities in the community is very important. (P16 written narrative)*

To be given information on how to empower the patients in the family and community to enable them to perform different kinds of activities, and enable them to participate in group activities, e.g., soccer, traditional dances. Involve mental health care users in community programmes, e.g., civic associations. (P4 written narrative)

Provide support groups for MHCUs and family members living with MHCUs or to primary caregivers. (P13 written narrative)

Activities for the patients in the community must be established in order for the patients and the family not to feel discriminated against. (P16 written narrative)

Stigma is defined as a mark of disgrace or discredit that is used to identify and separate people whom society sees as deviant, sinful, or dangerous. These misperceptions about vulnerable subgroups of the population must be corrected (Stuart 2014:166). In their study of challenges experienced by South African families caring for state patients on leave of absence, Mothwa et al (2020:5) found that participants experienced judgemental attitudes from community and family members. Mental health stigma is demonstrated in different ways including discrimination, isolation and limited access to healthcare services (Lund, Peterson, Kleintjies & Bhana 2012:404). Stuart (2014:17) found that it is necessary to target the behavioural outcomes of stigmatisation at individual and institutional level in order to promote full and effective social participation for MHCUs.

A crisis is an acute, time-limited state of disequilibrium resulting from a situational development or social source of stress. Families caring for MHCUs experience crisis situations stemming from MHCUs' episodes of relapse when their usual method of dealing with the problem is inadequate. According to Kneisl and Trigoboff (2014:218), involuntarily committed MHCUs may need assistance from police depending on the level of aggression when the families ask for help in apprehending the person.

5.3.3 Theme 3: Interventions to enhance physical care of the MHCUS and family members

The third theme was interventions to enhance physical care of the MHCUs and family members and had two categories, namely maintenance of good personal hygiene of the MHCU, and assessment of physical health status of the MHCUs and family members.

5.3.3.1 Category 3.1: Maintenance of good personal hygiene of the MHCU

The need to provide for basic needs was the first intervention to maintain good personal hygiene of the MHCU. The participants reported the need to meet the basic needs of the MHCUs including food, clothes and toiletries to maintain good personal hygiene to appear presentable in public. According to participants:

> *Another thing is that mental health care users must be like other persons, they must appear clean. If we look at the communities, we often actually find that this one is a mental health care user because of the general appearance. They are not clean at all, so the family is supposed to take care and other people should also make sure that they are clean. (P1 audio recording)*
>
> *The mentally ill person is a physical being. He has the right to good food, good health as well as proper clothing. (P21 written narrative)*
>
> *Mental health care users must be provided with money so that they can buy food and clothes so that they can be clean. (P3 written narrative)*
>
> *I (participant adopting the position of family of an MHCU) expect that when I take my patient to the health care facilities, I will get equipment and medication and things that I can use when I assist the patient to bath, such as gloves. (P7 written narrative)*
>
> *The person needs food, clothes and toiletries to maintain good personal hygiene. (P8 written narrative)*

5.3.3.2 Category 3.2: Assessment of physical health status of the MHCUs and family members

The assessment of the physical health status of the MHCUs and family members is important. Family members must have the knowledge and skills to differentiate between physical health problems and mental illness symptoms so that they can seek medical attention without delay to avoid complications. The participants further indicated the need to provide the health care workers with diagnostic equipment such as blood pressure apparatus, thermometers and glucometers for detection of abnormalities. The participants added the need for the provision of protective clothing (PPE), like gloves to prevent cross infection, when they go for home visits. The participants emphasised the need for regular check-ups of the MHCUs and their family members. According to participants:

> *Furthermore, the community health care workers must come with machines to check the BP (blood pressure), sugar and patents' temperature, by doing so it would mean they really care… The people who visit the villages must have equipment to check BP, temperature, and sugar level so that we know the patients' health status. (P7 written narrative)*
>
> *…need to be educated to be able to know that the patient is sick physically, to differentiate between the signs and symptoms of mental and physical illness. (P4 written narrative)*
>
> *During admission in the ward assessment of MHCUs and the family members, physical assessment should be done by the health care professionals and referrals be done when necessary. (P10 written narrative)*
>
> *…the healthcare workers and everyone who works with them when they do home visits to support the family, must provide caregivers with medication, gloves and other equipment to check the health condition of the patient. (P7 written narrative)*

People with mental illness are usually not given equal opportunities to access physical and medical care in primary health care settings as psychiatric nurses pay more attention to the mental illness while neglecting the total person. MHCUs are at risk of medical or physical disorders owing to lifestyle factors or as a result of psychotropic medication which causes some side-effects (Kneisl & Trigoboff 2014:689). In Australia, Evans et al (2017:124) found that people with mental illness often died younger from untreated physical health problems or conditions. Family caregivers frequently report uncooperative behaviours displayed by MHCUs, such as refusal to bathe, eat or be taken care of by family members which is burdensome for caregivers (Anokye 2018:330).

5.3.4 Theme 4: Interventions to provide social support

Interventions to provide social support had three categories, namely suitable housing for the MHCUs, shared responsibility between the health care providers and the family members.

5.3.4.1 Category 4.1 Suitable housing for the MHCUs

Suitable housing for the MHCUs was the first intervention to provide social support. The participants maintained that the MHCUs need to be provided with suitable housing as accommodation was a problem for them and family members. The participants stated that providing MHCUs with Reconstruction and Development Programme (RDP) houses would assist in restoring their dignity by not having to rely on family members. According to participants:

> *They must have employment opportunities for the MHCU and suitable housing. Supported accommodation is the best where qualified staff are able to supervise patients. They must have good housing because MHCUs are sometimes attacked and raped. The patients must be given a permanent disability grant so that they have good housing. Some MHCUs' houses do not have doors, so they are not safe which exposes them to rape as people can get in and rape them. (P7 Audio recording)*
>
> *Mentally ill people should be given houses suitable for their needs; a home with a security fence and gate so that the patient is safe to avoid rape. (P6 written narrative)*
>
> *A programme to make sure that the MHCUs will get suitable housing as it is not easy for them to look for a job. (P3 written narrative)*
>
> *The chiefs/civic and social workers must motivate for RDP houses and MHCUs to be given first priority when it comes to housing programmes. (P9 written narrative)*
>
> *Like anybody, I would like the patient to be employed and have a salary to maintain his or her family, e.g., suitable housing with sufficient food, electricity etc. (P4 written narrative)*

5.3.4.2 Category 4.2: Shared responsibility between the health care providers and the family members

Shared responsibility between the health care providers and the family members was an important intervention to provide social support. Support from health care providers is needed to rebuild strained relationships in the families. There was also a need for frequent home visits for the purpose of monitoring MHCUs' compliance with medication. This might bring about some behavioural changes in MHCUs when families and health care providers work together in the treatment plan unlike working in isolation. Moreover, interacting with the families would facilitate evaluating how the family members were coping with caregiving responsibilities. The participants added that the family members should be involved in the treatment programme which would help them to have a better understanding of mental illness and its management. According to participants:

Health care workers must support families frequently rebuilding broken relationship. Patients behave well in the presence of staff. (P19 written narrative)

Support from health care workers through engaging MHCUs in some activities. Including the family members with MHCUs for future plans [what to be done next]. (P15 written narrative)

However, we need support from health care workers [participant adopting the position of a family member of an MHCU] because we are ashamed because we are staying with a person who is mentally ill since we do not have more information about mental illness. We live in fear because the MHCUs sometimes become aggressive. (P8 written narrative)

The clinic nurses and social workers should come and do counselling at home after discharge…There should be ongoing visitation at homes by nurses and social workers to check how family members are coping with the MHCU. There should be a facilitator who checks if medication is available at the clinic or hospital. (P10 written narrative)

5.3.4.3 Category 4.3: Establishment of support groups

The participants indicated establishing family support groups where the families could have the space and time to share their experiences with other families who cared for MHCUs. The participants stated that families could learn from each other how to cope effectively with the care burden and management of their stress. According to participants:

Include the family members with mental health care users in support groups. (P15 written narrative)

Group counselling where family members caring for MHCUs meet and share their experiences and ways they cope with their circumstances should be established and funded. (P11 written narrative)

Psychological support can be enhanced by starting a psychosocial support group where the MHCU, healthcare provider and family discuss mental illness issues and challenges, try to find solutions and are able to support one another emotionally. (P12 written narrative)

The support groups should be established for family members separately, separately for patients within the community where they reside, where patients would meet with other patients with similar challenges. (P19 audio recording)

Psychological resilience increased with an increase in social support. Providing social support to the caregivers, encouraging them to proactively utilize the support, and enhancing coping skills was helpful in developing resilience and mitigating distress. One of the goals of community support intervention is to provide safe housing for the MHCUs (Stuart 2014:734).

Worrall, Schweizer, Marks, Yuan and Lloyd (2018:11) define support groups as meetings of people with similar experiences, such as caregivers of MHCUs, aimed at the provision of psychological, social, and emotional support and establishment of friendship. Professionally facilitated, family-led support groups, psychoeducation carer support groups, and professionally facilitated, program-based support groups for people living with mental illness have been found particularly effective (Worrall et al 2018:11). In rural primary health care settings, groups were therapeutic, cheap, provided a platform for mutual support through information sharing and assisted family members to manage the stress associated with caregiving demands (Baumann 2015:692-693).

5.3.5 Theme 5: Interventions to provide financial assistance

One of the challenges experienced by MHCU caregivers was economic as most MHCUs were not employed. Three categories emerged from this theme, namely, provision of permanent disability grant, establishment of income-generating occupational activities, and provision of employment opportunities.

5.3.5.1 Category 5.1: Provision of permanent disability grant

The participants indicated that providing all MHCUs with a permanent disability grant was important as it would minimize frequent relapses and assist in relieving the families' financial constraints. In addition, MHCUs and family members should be given talks on financial management skills to prevent abuse of social grants. According to participants:

Most of the MHCUs we found that they were given a temporary disability grant and after some time when that grant was no longer there, they became frustrated, and relapsed. (P3 written narrative)

Provide financial assistance to MHCUs who qualify to receive help from the state and also be assisted in the management of the grant to prevent mismanagement of grant. Advocate for MHCUs to be given a permanent disability grant which would help to reduce relapses. (P4 written narrative)

Financially I say that they must get full D/G [disability grant] because people who live with the mentally ill person often do not go to work because they are looking after the patient as they can relapse… (P3 audio recording)

When a disability grant is received in the family, the patient usually does not want family members to use it. We have experienced squabbles because of the social grant money. Perhaps there is a need for family members to be assisted on how far they are supposed to use the disability grant money belonging to the patient. (P19 audio recording)

5.3.5.2 Category 5.2. Establishment of income-generating occupational activities

The participants recommended that MHCUs be empowered to start projects in order to generate income; for example, gardening, car washing, and farming because they have minimal chances of being employed. These income-generating activities could be facilitated by occupational therapists as part of their expertise and focus. Family members could also be included in skills training to address the burden of unemployment. According to participants:

> *Skills training of the MHCUs, like gardening/sewing etc, could assist them and the programme could include family members to lift the burden of joblessness. (P19 written narrative)*
>
> *Extra money through small business or gardening skills. (P1 written narrative)*
>
> *The patient should be trained in doing hand works. Employment opportunities for the MHCU is important and should be created. Support can be done through rehabilitation linking the MHCUs with information about different stakeholders where they can get assistance e.g., D/G [Disability grant] (P17 Individual written narrative).*
>
> *With the disability grant the MHCUs could be empowered to start some projects in order to generate extra income, such as gardening, car washing and piggery.* **(***P12 written narrative)*
>
> *Engage in social activities in the community. We could start projects where patients could generate income. (P12 written narrative)*

5.3.5.3 Category 5.3: Provision of employment opportunities

The participants were of the opinion that it is important to support families and MHCUs through providing employment opportunities by accessing the Expanded Public Works Programme (EPWP) for which they met the requirement criteria. This is a national program aimed at providing poverty and income relief through temporary work for unemployed South Africans

> *The family do not have much money to support the person. The person who is mentally ill needs food, toiletries… so they need a social grant which would assist the person to meet financial demands. (P8 written narrative)*
>
> *So financially there should be development of projects through engaging the business sector so that the MHCUs would have an income, have a chance of being employed. (P9 written narrative)*

I would like the program to ensure that MHCUs get permanent a permanent disability grant and suitable shelter (housing) as it is not easy to look for a job as the one who takes care of the MHCU. (P3 audio recording)

The MHCUs should be assisted with a disability grant/social grant by social workers and doctors. The chiefs/civic leaders and social workers must motivate for RDP houses and MHCUs be given first priority when it comes to housing programmes. Development of projects in the community though assistance from businesspeople. (P10 audio recording)

Like anybody I would like the patients to be employed and have a salary to maintain their family, e.g., suitable housing with sufficient food, electricity etc. (P4 audio recording)

In Ghana, Ae-Ngibise et al (2015:6) found that caregivers lacked financial support and had no external support from other sources. Unlike other African countries South Africa provides disability grants to the MHCUs who meet the requirements stipulated. Although few of the users are disability grant recipients the state grant proved to be inadequate to meet the basic needs of the families and their patients (Baumann 2015:745). Moreover, the grant was not issued permanently, but is subject to renewal every six months. The process makes the family members feel frustrated and distressed.

In India, mental health rehabilitation centres run income-generating programmes for therapeutic engagement, skills training, and income generation of out-patients, aged 20–60 years. The centres provide a range of income-generating programs, including the manufacturing of household consumables such as paper products, textile products, handcraft products and food products; and running cafeterias and petty shops (Roy, Jayarajan & Sivakumar 2022:160-166).

According to Baumann (2015:745), one of the key functions of the social worker is to offer financial assistance to families and MHCUs, for example, by meeting their housing and employment needs. Food parcels can be given and assistance with application for social grants. In Oklahoma, Townsend (2015:816) found that community residential areas provided employment assistance and leisure time activities. Unemployment amongst the MHCUs is a eflection of societal stigma and discrimination that is a global problem (Townsend 2015:812-816).

5.3.6 Theme 6: Interventions to enhance spiritual supportive care

Three categories emerged as intervention to enhance spiritual supportive care, namely collaborative care by health professionals, church leaders (pastors) and traditional health practitioners, respect of belief system of MHCUs in relation to treatment programme, and involvement of church leaders in rehabilitation of the MHCU.

5.3.6.1 Category 6.1: Collaborative care by health professionals, church leaders (pastors) and traditional health practitioners

The participants were of the opinion that spiritual supportive care could benefit the family members caring for the MHCUs in order to cope more effectively. The involvement of pastors and traditional health practitioners was important support. The participants added that the MHCUs' religious beliefs should be acknowledged, however they should continue taking medication to prevent readmission. Belief systems of the family members and the MHCUs should be respected, not be undermined. The participants stated that collaboration would assist the health care providers to refer when the need arose. According to participants:

To combine spiritual therapy and medication or health support so that they can enhance the coping mechanism. (P13 written narrative)

Pastors and traditional practitioners must be there to assist because mental illness is associated with spiritual things. (P2 written narrative)

Pastors must support them, visit families that are stigmatized…they must pray for them together with the patients. (P3 written narrative)

On the spiritual aspects I mean in the belief pattern. Let us involve them, only those who believe in God… or traditional healers or spiritual healers because sometimes you find that they are being forced to go where they do not want to go for treatment. (P10 written narrative)

I think the pastors are needed because the old ladies will tell you something that will make you confused regarding the source of mental illness. For example, like saying mental illness is caused by witchcraft, supernatural causes. (P6 audio recording)

The program should inform people about the importance of religious belief and what this religion uses, but not forget the importance of taking medication on a daily basis. (P18 written narrative)

On the spiritual side, I think pastors do not understand the issue of mental illness. If there was a workshop for the spiritual and traditional leaders on issues of mental illness and mental health to avoid defaulting from medication…a workshop for traditional healers and faith healers would help because all these treatment modalities go together. (P19 audio recording)

5.3.6.2 Category 6.2: Respect for the belief system of MHCUs in relation to treatment program

The participants highlighted that in order to address the spiritual needs of the MHCUs and their families, their preferred belief system or religious practice should always be respected when deciding the type of treatment program. However, the MHCUs should be encouraged to continue taking medication, even while they were receiving spiritual supportive care. According to participants:

> *Spiritual versus medical, when do I seek spiritual help from either traditional healers or pastors? (P17 written narrative)*
>
> *Involvement of traditional and spiritual healers according to the belief pattern of families with MHCUs on management/treatment programme to prevent confusing the MHCUs. (P10 written narrative)*
>
> *To inform them about the importance of religious belief and what the religion uses but not forgetting the importance of taking medication on a daily basis. (P18 written narrative)*
>
> *To combine spiritual therapy and medication or health support so that they can enhance the coping mechanisms. (P13 written narrative)*
>
> *To take the MHCUs to church so that the pastors can pray for them depending on their belief systems. (P7 written narrative)*

5.3.6.3 Category 6.3: Involvement of church leaders in the rehabilitation of the MHCUs

The participants expressed the need for pastoral supportive care after discharge. Pastors have a crucial role to play in supporting the families. Pastors' involvement in the rehabilitation program as influential leaders would provide the families with hope. The participants believed that pastoral influence could bring about behavioural changes, such as stopping alcohol abuse. According to participants:

> *Pastors to be actively involved in families, they should involve MHCUs in activities. (P19 written narrative)*
>
> *To inform them about the importance of religious beliefs and what the religion uses but not forgetting the importance of taking medication on a daily basis. (P18 written narrative)*
> *I can take the patient to church so that the pastor can pray for him taking into consideration the belief system. (P7 written narrative)*

There should be pamphlets from spiritual healers according to the beliefs of families with MHCUs on management/treatment programmes to prevent confusing the MHCUs. (P10 written narrative)
I would like my patient to consult pastors as God is above everything. That will remove him from thinking of alcohol abuse. (P3 written narrative)

Also, the issue of spiritual involvement is important because as they go to church depending on their belief, pastors should be involved as people who are conducting the service and preach and testify that they allow them to do so. (P16 audio recording)

In black African populations traditional healers have a vital role to play as they are the first contact for mental health consultation. It is estimated that 70% of South Africans consult traditional healers while 80% utilize both western medicine practice and traditional treatment concurrently. In the past traditional practitioners and Western healthcare professionals did not work together in South Africa. Recently, there has been a call for collaboration between these services for delivery of quality health care services to a diverse population (Baumann 2015:52).

A study in Iran found that spirituality-based interventions had significant positive effects on reducing stress, anxiety, and depression in patients with mental disorders. Due to the high incidence of stress, anxiety, and depression associated with care burden on caregivers, the programme emphasised promoting their mental health status in providing better care for these patients. Spirituality-based interventions are considered an inexpensive and available supportive resource (Khosravi, Fereidooni-Moghadam, Mehrabi & Moosavizade 2022:103).
Ntsayagae et al (2019:7) found that family caregivers considered spirituality a form of coping with their caregiving burden. Caregivers found belief in God and hope for the future a coping mechanism as they learned to cope better by being hopeful that when they put their trust in God one day their relative living with mental illness would be healed.

5.3.7 Theme 7: Interventions to ensure health care provision by health care providers

Five interventions emerged to ensure health care provision by health care providers, namely family therapy, counselling, home visits by health care providers, ensuring availability of psychotropic drugs and rehabilitation by providing sheltered employment for MHCUs, skills training and establishment of support groups as well as mental health education through awareness campaigns.

5.3.7.1 Category 7.1: Provision of family therapy and counselling

The participants expressed the need for supporting the family through provision of counselling sessions and offering family therapy, which they indicated could be done telephonically to serve as a means of helping the families to cope better. This therapeutic intervention would assist the families to learn how to live with the MHCUs and relieve feelings of helplessness. In addition, family therapy would provide an opportunity for families to partner with the health professionals in planning future management of the MHCU. The participants suggested that counselling could be offered in groups or individually to provide a space for sharing experiences and learning coping strategies. According to participants:

> *Counselling of family members/MHCUs in the home setting could also help. Telephonic counselling/support will help the patients realise that they are being monitored regularly and that can lead to behaviour change by the patients. (P19 written narrative)*
>
> *The program can assist with counselling, family therapy, and psychoeducation. (P17 written narrative)*
>
> *This programme can help us to improve giving the MHCU support because families also need counselling about how to live with the MHCU during home visits done by the health care worker to give support and counselling. (P8 written narrative)*
>
> *In relation to the therapeutic relationship…I think psychologically it is important for the staff members to visit and also do family counselling in a family set-up, not in a hospital set-up but a family set-up…maybe once a month that could make the patient realise that there is monitoring. As patients respect staff members better than their family members, so the presence of staff members providing family visits could assist in changing the behaviour of our patients to their families. Separate counselling sessions for family and MHCU thereafter a joint one can be done. (P19 audio recording)*
>
> *During admission of MHCUs, counselling should be offered by the health care providers and during the visitation of MHCUs, it should be ongoing. (P10 written narrative)*
>
> *Group counselling where family members caring for the MHCUs meet and share their experiences and ways they cope with their circumstances should be established and funded. (P11 written narrative)*

5.3.7.2 Category 7.2: Home visits by health care providers

The participants said home visits by the health care providers should be done with the aims of checking whether the MHCUs were adhering to the prescribed medication, evaluating the care rendered to the family members, and giving relevant psychoeducation. Other indications for home visitation were to offer counselling and family therapy, to assess the home environment, and to teach the families communication skills which would help them to relate well with the MHCUs. The participants agreed that home visitation should preferably be done by the clinic nurses and the social workers. According to participants:

> *Home visit - family therapy in a home set up might restore relationships. Counselling of family members/patients in the home setting could also help. (P19 written narrative)*
>
> *They need to do home visits most of the time and support where we are lacking in as far as care giving to the MHCU is concerned to evaluate whether the patient is taking medication correctly. (P6 written narrative)*
>
> *The programme could ensure home visits by establishing a multidisciplinary team responsible for taking care of the patients, which must have enough money for the programme in order to have transport and enough staff members. (P16 written narrative)*
>
> *There should be ongoing visitation at home by nurses and social workers to check how family members are coping with the MHCUs. (P10 written narrative)*
>
> *Provide supportive home visits to assess home living conditions and provide the necessary support. (P13 written narrative)*

5.3.7.3 Category 7.3: Availability of psychotropic drugs

Psychotropic medication should always be available at the health care facilities as this helps to keep MHCUs stable. The participants recommended that, where possible, medication should be delivered at MHCUs' homes because at times they refused to go to the hospital or clinic. Some participants suggested that to prevent medication shortages at the clinic one person should be allocated who would be responsible for checking that sufficient medication was in stock. According to participants:

> *Medication should always be available and accessible at all times. The support needed is to always have medication and pills so that when the patient relapses, they will be able to take care of him or her at the right time. (P14 written narrative)*
>
> *By making sure that the health department orders a lot of medication which is always available. Medication should be delivered at the homes because at certain times it is difficult to get the medication at the clinics and hospitals. (P6 written narrative)*
>
> *Ensure that patients do not have to travel long distances to get medication. What to do if they don't get medications, what to do if they don't find the medication at a nearby clinic. (P17 written narrative)*

Sometimes the patient refuses to go to the clinic or hospital so we are asking the nurses who go around the village to take their medication home for the patient. If the patient refuses to go to the clinic, what should we do? (P7 written narrative)

By having more trained practitioners and making sure that the health department orders a lot of medication, which is always available through provision by car specifically for that service. (P18 written narrative)

There should be a facilitator who checks whether medication is available at the clinic or hospital. (P10 written narrative)

5.3.7.4 Category 7.4: Rehabilitation by providing sheltered employment for the MHCUs, skills training and establishing support groups

The participants indicated that rehabilitation by providing sheltered employment for the MHCUs, skills training and establishment of support groups could be achieved through skills training of MHCUs and their family members in, for example, gardening and needlework to reduce unemployment. Some participants highlighted the establishment of family support groups to provide a platform for health care providers, family members and MHCUs to discuss mental health issues, challenges and suggest possible solutions for health-related problems. Provision of sheltered employment for the MHCUs in the Vhembe district was emphasised to keep them occupied. According to participants:

To be given information on how to empower patients in the families and communities to enable them to perform different kinds of activities and enable them to participate in group activities like soccer and traditional dances. (P6 written narrative)

So, the last issue is that MHCUs must be involved in community activities. It would help to prevent discrimination in order for them to feel accepted in the community. So, I think that the issue of activities in the community is very important. (P16 audio recording)

The government should consider these people in EPWP [Expanded Public Works Programme], those who are not receiving disability grants. (P18 written narrative)

Rehabilitation should start at home by training the family members how to treat the patient. Rehabilitation can be done by initiating physical wellness programmes, like sports, for these patients. (P18 written narrative)

By starting a psychosocial support group where MHCUs, healthcare providers and families discuss mental health issues and challenges and try to find solutions and support each other. (P12 written *narrative)*

Starting and strengthening disability centres where our patients can be kept during the day. (P12 written narrative)

Activities for the patients in the community must be established in order for them and their family members not to feel discriminated against. (P16 written narrative)

5.3.7.5 Category 7.5: Mental health education through awareness campaigns

The participants indicated that giving health education at local churches and community gatherings, targeting learners, students and members of the community through community radio and pamphlets could improve individuals' mental health literacy. Community campaigns on mental health are indicated to reduce the stigmatization and discrimination of family members and MHCUs resulting in social isolation and depression. According to participants:

Community education programs on acceptance of mentally ill patients could help. Community campaigns on mental health to spread awareness and reduce stigmatization and discrimination by healthcare workers and other stakeholders. (P13 written narrative)

The program could facilitate knowledge sharing on mental illness by giving health pamphlets at churches to community gatherings, students through community radio stations and involvement of traditional healers. (P1 written narrative)

The program should ensure that the mental health care practitioners give health talks on community radio, TV, and during community meetings about the signs and symptoms, causes of mental illness, prognosis, and treatment plans. (P3 written narrative)

I just want to emphasise the issue of information. It means we need to get more training, workshops and health education. To give one example, here in (name of the municipality) we do have the MDT [multi-disciplinary team], we have to go to the schools, secondary and primary schools, where we teach them about substance abuse as one of the issues that can cause mental disorders. During these school visits we have students who do not have information so we give them information which will assist and also awareness campaigns. (P16 audio recording)

The community must be taught to accept MHCUs as human beings. By giving presentations at different institutions, like schools, about mental illness gives them a better understanding of MHCUs. We can also make presentations by asking for radio/television slots where we can address mental illness issues. (P12 written narrative)

On mental health awareness, I think we should do it with the young ones. If children from a young age are taught about mental illness, they will grow up having a better understanding and knowing how to handle mental disorder as young ones. I think if we could involve the young ones, it would help a lot. (P12 audio recording)

One of the key functions of a nurse is to engage the family in the treatment programme in the MHCU. Families should be supported and trained in different life skills (Gharavi, Stringer, Hoogendoom, Boogaarts, Van Raaij & Van Meijel 2018:7; Akbari et al 2018:7). Health care providers should offer counselling and family therapy to enable caregivers to deal with their stress associated with caring for MHCUs. Failure to provide the necessary guidance leads to negative outcomes in quality of life (Gharavi et al 2018:7).

Counselling helps individuals to analyse interpersonal and intrapersonal processes to understand and improve them. In Pakistan, Siddiqui and Khalid (2019:1329) highlighted the need to counsel the family caregivers when they accompanied their family members for their health needs. Family assessment should be done before counselling which helps to determine the healthcare needs, such as physical, psychological, social and spiritual support so that the appropriate treatment modalities can be offered. With regard to the psychological aspect, enquiring about the emotional state of family members of MHCUs could help to screen for family members who are at risk of emotional burnout associated with caregiving responsibility. The primary care provider could provide mental health first aid to the family members, such as supportive counselling to help ease their stress and improve their problem-solving skills and coping mechanisms (Siddiqui & Khalid 2019:1331).

Family members' unmet need for support highlights the need for nurses and other community mental healthcare professionals to assess complex family needs and to intervene (Selick et al 2017:370). The healthcare professional takes the lead in the establishment of the support groups, but thereafter it is responsibility of the group members to ensure the sustainability of the support group otherwise it may not work. In South Africa there is a mental health organization called South African Depression and Anxiety Group (SADAG), which provides the following services to consumers: assistance with daily activities, social and recreational activities, advocating for those with disability, information sharing, raising of funds, and therapeutic interventions like skills teaching and providing counselling (Middleton 2020:81).

It is of value to visit MHCUs, who were discharged from hospital, at their homes as a means of showing psychosocial support. Home visits provide healthcare professionals with an opportunity to interact with the patient and family as a whole, to build a therapeutic relationship, and also to inspect whether the environment is clean or chaotic. Home visits are poorly resourced due to shortage of health care providers and transport (Monyaluoe et al 2014:6-7; Lavhelani et al 2020:6-7).

In South Africa, community mental health services operate like the United Kingdom model which is made of a multidisciplinary team serving a certain catchment area. The team mostly respond to challenging issues, like non-compliance to medication and early signs of relapse. According to Baumann (2015:728), community-based rehabilitation (CBR) assists the MHCUs by identifying the barriers for them not to be employed and income-generation opportunities. In addition, CBR provides access for skills training in preparation for work (Baumann 2021:729). Sivakumar, Roy, Reddy, Angothu, Jagannathan, Muliyala et al (2022:5) emphasised the significance of engagement of MHCUs through a combination of skills training, information and recreational activities.

5.4 RANKING OF NGT THEMES

The themes were ranked by the participants as indicated in Table 5.4. The researcher decided to keep the sequence in the psychoeducational program as in Table 5.2, to align with the findings of Phase 1. The health care interventions formed the last component of the program as it provides a compilation to the program through listing the healthcare professionals' responsibilities with regards to all the interventions.

Table 5.4 Ranking of NGT themes

Themes	Ranking
Interventions to provide Information and education	1
Interventions to enhance family support by the community	2
Interventions to enhance physical care of the MHCUs and family members	3
Interventions to provide social support	4
Interventions to ensure health care provision by health care providers	5
Interventions to provide financial assistance	6
Interventions to enhance spiritual supportive care	7

5.5 CONCLUSION

This chapter discussed the findings of the NGT workshop of phase 2 regarding psychoeducational interventions for addressing the support needs of family members caring for MHCUs. Chapter 6 describes the drafting of a psychoeducational programme to support the family members caring for the MHCUs in Vhembe District, Limpopo Province.

CHAPTER 6

DEVELOPMENT OF A PSYCHOEDUCATIONAL PROGRAM TO SUPPORT FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS

6.1 INTRODUCTION

Chapter 5 presents the findings of data collected from stakeholders during phase 2 of the NGT workshop. The results are discussed in relation to the psychoeducational interventions for addressing the healthcare needs of family members caring for MHCUs. This chapter entails the development method and the draft psychoeducational program to provide psychoeducation to families of MHCUs.

6.2 DEVELOPMENT OF THE DRAFT PSYCHOEDUCATIONAL PROGRAM

The draft psychoeducational programme to support family members caring for MHCUs has been developed from firstly, integration of the findings of phase 1 and phase 2, secondly, integration of the theoretical framework and, thirdly, applicable literature. As the finding of Phase 1 and Phase 2 of the study was integrated, more than envisaged components emerged to be included in the psychoeducational program, which appeared to be falling outside the concepts covered in the definition of the psychoeducational program. The researcher consulted the supervisors to address the discrepancy, and an agreement was reached that the components should not be removed to make the psychoeducational program more comprehensive to yield holistic support to meet the physical, psychological, social, and spiritual needs of the family members caring for the MHCUs. A program development method is followed to ensure rigour of the programme.

6.2.1 Integration of phase 1 and 2 findings

Integration might occur within the research question, within data collection, within data analysis or in the interpretation when data are merged (Creswell & Creswell 2017:225). According to Fetters et al (2013:10), integration of datasets can occur through data transformation, narratives and joint displays. Integration in this study uses the qualitative findings of phase 1 to inform phase 2 which consists of qualitative and quantitative data (ranking of themes). The findings in this research are integrated through narratives and joint display. The findings for each phase were described separately. Thereafter, the results were jointly displayed by organising and summarising the findings of both qualitative datasets obtained from the individual interviews and NGT. See Table 6.1.

In Table 6.1 the corresponding (similar) findings between the two datasets are tabled in the same rows next to each other. The sections highlighted in yellow were categorised under a different theme in the NGT compared to the interview data. The sections highlighted in green were discussed in a different sequence in the NGT findings, compared to the interview data. The sections highlighted in grey represent findings that were either identified in the interview findings or in the NGT, but not in both datasets.

Table 6.1 Integration of findings: Phase 1 and Phase 2

Design: Exploratory sequential qualitative	**Phase 1 (Qualitative findings)** **Individual semi-structured interviews N=16**	**Phase 2 (Qualitative findings)** **Nominal group technique (NGT) N=21**
Methods: Sequential methods (Integration through building)	Qualitative (face-to-face individual semi-structured interviews with family members)	Qualitative-quantitative (NGT with stakeholders)
Interpretation and reporting of integrated findings of phases 1 and 2	**Healthcare needs of family members caring for MHCUs**	**Interventions to meet the psychoeducational healthcare needs of family members caring for MHCUs**
	INTEGRATION OF FINDINGS	
	1. Educational and information support needs 1.1 Knowledge of mental illness, its causes, signs and symptoms, course and prognosis and treatment options (diagnosis of MHCU, symptoms of mental illness, indication for different psychotropic drugs) 1.2 Identification of early warning signs of relapse and its management. (education and information about detection of signs and symptoms of relapse to respond promptly. 1.3 Information about the management of day-to-day challenging behaviours (to effectively deal with unacceptable behaviours such as aggression, refusal of medication) 1.4 Information regarding substance abuse by the MHCU (alcohol and cannabis abuse) as a contributory factor to non-adherence to medication and relapse. 1.5 Information regarding medication adherence (side-effects caused by psychotropic drugs and management thereof)	**1. Interventions to provide information and education** 1.1 Mental health education on mental illness (causes, signs and symptoms, prognosis, and treatment options) 1.3 Management of challenging behaviours 1.2 Psychotropic medication, side effects and management
	2. Physical healthcare needs 2.1 The need for physical health support (physical health problems, regular medical checks by PHC nurses to promote mental health and physical well-being, home visits by nurses to assess and support).	**2. Interventions to enhance physical care of the MHCUs and family members** 2.2 Assessment of physical health status of the MHCU and family members 2.1 Maintenance of personal hygiene of MHCUs

Design: Exploratory sequential qualitative	**Phase 1 (Qualitative findings)** **Individual semi-structured interviews N=16**	**Phase 2 (Qualitative findings)** **Nominal group technique (NGT) N=21**
	3. Social needs 3.1 The need for de-stigmatisation and non-discrimination (stigma and discrimination from other family members and the community as a whole) 3.2 The need for social support and contact (social isolation, providing continuous care, peer support groups to share ideas with other families to relieve distress).	**3. Intervention to enhance family support by the community** 3.1 Reduction of stigma and discrimination against family members and MHCUs 3.2 Engagement of the MHCU in community activities **4. Interventions to provide social support** 4.2 Shared responsibility between health care providers and family members
	4. Financial needs 4.1 Various additional costs to sustain the MHCU (costs for meeting the basic needs) 4.2 The need to provide MHCUs with a permanent disability grant 4.3 The need for employment opportunities for MHCUs (MHCUs' employment - some have qualifications and the right to employment) 4.4 The need for suitable housing (inadequate accommodation posing challenges to the families, Department of Social Development to provide housing).	**5. Interventions to provide financial assistance** 5.1 Provision of permanent disability grants 5.2 Establishment of income-generating occupational activities 5.3 Provision of employment opportunities. 4.1 Suitable housing for the MHCUs
	5. Spiritual support needs 5.1 The need for traditional practitioner consultation (traditional healers perceived to be the first point of contact before healthcare interventions). 5.2 The need for pastoral support care (spiritual counselling by church leaders, prayer partners and believing in God to cope with the burden of caregiving)	**6. Interventions to enhance spiritual supportive care** 6.1 Collaborative care by health professionals, church leaders (pastors) and traditional health practitioners 6.2 Respect for the belief system of the MHCUs in relation to treatment programme 6.3 Involvement of church leaders in the rehabilitation of the MHCUs
	6. Healthcare expectations in terms of healthcare expectations from the health system and healthcare providers 6.1 The provision of community-based psychiatric rehabilitation with sufficient resources (to relieve boredom and to provide some kind of relief for caregivers). 6.2 Availability of psychotropic medications at the community health centres (shortage of medication, private payment for medication adding to financial stress)	**7. Interventions to ensure healthcare provision by healthcare providers** 7.4 Rehabilitation (sheltered employment for MHCUs, skills training and support groups) 7.3 Availability of psychotropic drugs

Design: Exploratory sequential qualitative	**Phase 1 (Qualitative findings)** **Individual semi-structured interviews N=16**	**Phase 2 (Qualitative findings)** **Nominal group technique (NGT) N=21**
	6.3 Assistance from the South African Police during the crisis (when MHCUs are aggressive, difficulties in getting assistance from SAPS).	2.2 SAPS assistance during crisis 7.5 Mental health education awareness campaigns
	7. Psychological health care needs (falls under the scope of the healthcare providers) 7.1 Provision of family therapy and counselling (to deal with a range of negative emotions, family therapy and counselling to help them to cope) 7.2 The need to acquire healthy ways of coping with caregiving challenges (learn healthy ways of coping such as stress management and problem-solving skills to deal with guilt, anger, anxiety and loss of hope and the caregiving responsibility). 7.3 Home visits by health care providers (to reduce the burden of care, assess coping with caregiving tasks, condition of MHCU, adherence to medication, side effects and provide practical advice about caregiving skills)	**7. Interventions to ensure healthcare provision by healthcare providers** 7.1 Provision of family therapy and counselling 7.2 Home visits by health care providers

KEY: FM=family member RDP= Reconstruction Development Program SAPS=South African Police Service

6.2.2 Integration of theoretical framework

The key concepts of THPN were integrated in the program as follows:

6.2.2.1 Mental health

The outcomes of the program, as shown in Table 6.2, are based on the components of mental health. Mental health refers to holistic well-being in the promotion of wholeness. This implies that individuals accept themselves, acknowledge their actions and accept responsibility to re-organise their lives in order to enhance their psychological, physical, social and spiritual well-being. Individuals also express and realise their own unique and individual talents and potential (University of Johannesburg 2017:4).

6.2.2.2 Internal and external environment

The program mobilises resources in the internal environment of family members and MHCUs through physical (assessment and physical care of MCCUs), psychological (counselling and mental health education) and spiritual (spiritual coping) interventions. The external environment is reflected in physical (housing and financial), social (community), and spiritual (religious) interventions.

6.2.2.3 Promotion of health though mobilisation of resources

Health promotion includes the promotion, maintenance and restoration of health and is aimed at the facilitation of resource mobilisation of an individual, family, group and community (University of Johannesburg 2017:4). In the program mental health promotion refers to the mobilisation of resources in the internal and external environment of the MHCUs and their family members. Examples of internal resources include emotional, cognitive and physical abilities of MHCUs and family members; and of external resources include professional and non-professional resources from government and non-governmental organisations, churches, pastors, health care providers and traditional healers. See Table 6.2 for resources to be mobilised in the program.

6.2.3 Integration of literature

The program interventions and outcomes were informed by the study findings, but also by the following literature sources that provided critical components to be included in a psychoeducational program.

Family psychoeducation is defined as an intervention with systematic, structured and didactic knowledge transfer for an illness and its treatment, integrating emotional and motivational aspects to enable families to cope with illness to improve treatment, adherence and efficacy

Family psychoeducation aims to provide psychosocial support, hence the prefix “psycho”, information and education to families, aimed at building the capacity of carers to improve their caring skills (Ekhtiari et al 2017:239-264).

The content of psychoeducation includes the following: mental illness, course of the illness, the role of a family, early warning signs of relapse, problem-solving, crisis intervention, medication and management strategies to improve compliance, decrease relapse and decrease readmission rates. The content of psychoeducation also includes communication and problem-solving skills training, lifestyle and stress management, and the importance of family involvement as primary care providers (Tsui & Tsang 2017:76; Motlova et al 2017:451). Life skills training helps the family caregivers to maintain a healthy and well-balanced life with the ability to recognise and manage emotions, identify and to acknowledge present and potential problems, recognise long and short-term consequences of behaviour, manage negative feelings, be self-assertive, manage conflict, make and implement sound decisions and affirm positive behaviour with self-praise and increased self-regard. Psychoeducation is delivered coupled with other interventions, such as active follow-up, home visits, social skills training, crisis management or psychosocial rehabilitation (Middleton 2020:220).

Psychoeducation programmes are commonly facilitated by clinicians, for example, a mental health nurse and the clinical psychologist, as they form part of the community multidisciplinary outreach teams and also because they are referred to as mental health practitioners (MHCA No. 17 of 2002). However, in low-and-middle–income countries (LMICs), such as South Africa, a task-shifting model can be followed where non-professional staff help to facilitate health promotion programs such as psychoeducation (Mari, Razzouk, Thara, Eaton & Thornicroft, 2009:np).

Psychoeducation may be carried out with one family, referred to as single-family psychoeducation, or in multiple family groups. It may vary in length of sessions, number of sessions and the settings may be different, for example, clinics and hospitals or at a consumer’s home. The psychoeducation program may vary in how much it emphasises behavioural, cognitive, informational, clinical, rehabilitative and family theory and techniques, problem-solving, communication and consultative therapeutic aspects (McFarlane 2016:2). Different modes or teaching and facilitation strategies are utilised, for example, face-to-face contact, online through e-health and m-health interventions (Middleton, 2020:219). It is offered in a simple and understandable form by means of lectures, demonstrations, group discussions, information leaflets, educational videos and educational theatre programs.

The number of sessions varies depending on the scope of the program and the targeted audience. For example, a psychoeducational program designed for informal caregivers was scheduled weekly with two-hour sessions. The intervention included seven sessions on relevant topics. All sessions had two facilitators: a psychologist and a professional expert in the theme of each session; all sessions were structured into two components: information followed by emotional support (Alves, Teixeira, Azevedo, Duarte & Paul 2015:71).

In Canada, Selick et al (2017:371) identified the barriers and facilitators to implementing family support and education in an early psychosis intervention programme as follows: interest of the family, readiness to participate; unique family support needs /preferences regarding timing, length and content of the intervention; ability to access support, staff training and availability of resources. The authors recommend a flexible, tiered approach to care, to better meet family needs and increase rates of uptake of family support.

According to Sin and Norman (2013:2), one of the ingredients of psychoeducation programme is the incorporation of ethical cultural aspects to make the programme acceptable to the families. In the current study, the traditional health practitioner formed part of the stakeholders in the NGT workshop. Mirseppassi, Tabatabaee, Sharifi and Mottaghipour (2018:75) developed a series of workshops and supervision sessions to train group leaders for implementation of a group psychoeducation program for patients and families. Clinicians' understanding of the importance of patient and family psychoeducation is essential in sustainability of such programs.

6.3 PSYCHOEDUCATION PROGRAM DEVELOPMENT

The program was developed using the integrated empirical evidence derived from the phase 1 individual interviews (Chapter 4) and phase 2 NGT (Chapter 5). Guided by the theoretical framework, the integrated findings were used to develop seven interventions to address the physical, social, psychological and spiritual healthcare needs of family members caring for MHCUs. The interventions are the following: Interventions to provide information and education; interventions to enhance family support by the community; interventions to enhance physical care of MHCU and their family members; interventions to provide social support; interventions to ensure health care provision by health care providers; interventions to provide financial assistance and lastly interventions to enhance spiritual supportive care. See Figure 6.1.

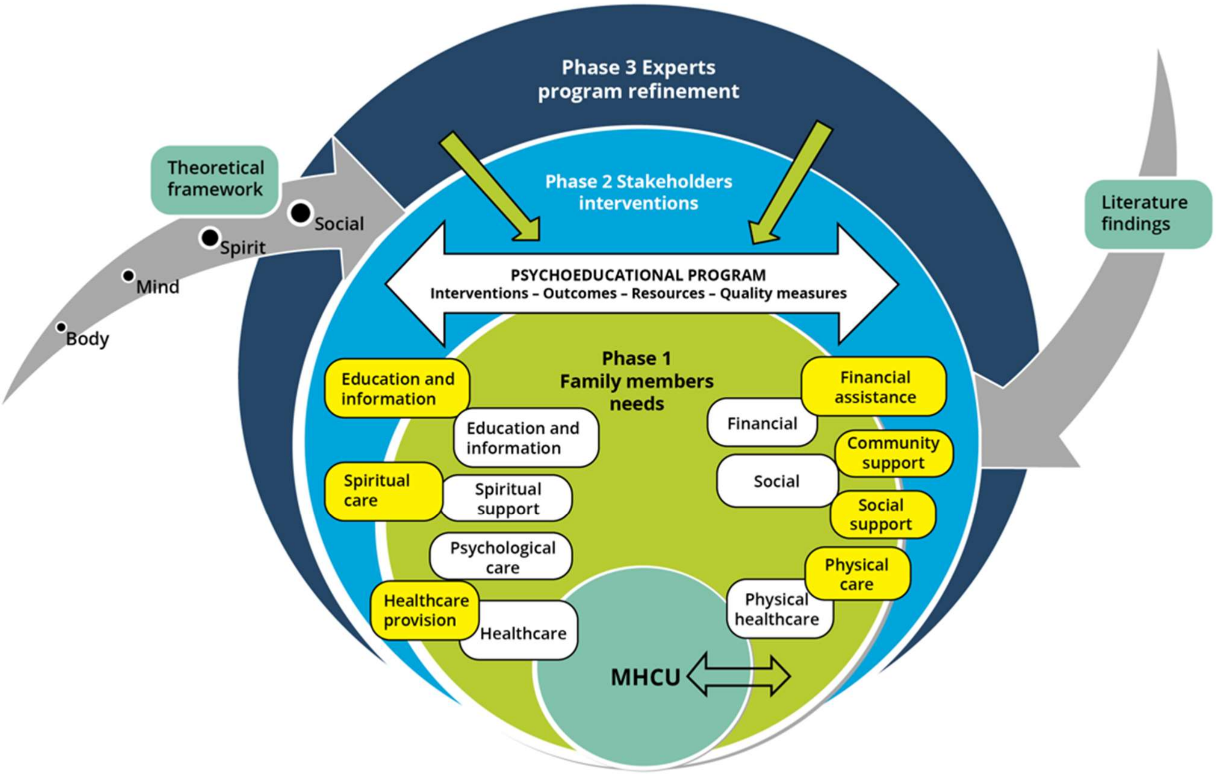

Figure 6.1 Program development

The researcher used the guiding steps of the family psychoeducation process and the characteristics of the family psychoeducation program described by the Substance Abuse and Mental Health Services Administration (SAMHSA 2009:10) to develop the program to support family members caring for MHCUs. This evidence-based method was chosen because the family psychoeducation approach views mental illness as the object of treatment, not the family.

6.3.1 Guiding steps to the development of a psychoeducational program

The following steps in family psychoeducation guide the program development in this research (SAMHSA 2009:10).

6.3.1.1 Step 1: The creation of a vision

The vision of this study is to develop a psychoeducational program aimed at supporting the family members taking care of MHCUs in the Vhembe district Limpopo province. See chapter 1.

6.3.1.2 Step 2: Form advisory groups

According to SAMHSA (2009:10), the program development process should include consumers, families, key community stakeholders and health care providers from different clinical backgrounds. The researcher engaged the families in phase 1 and various stakeholders in phase 2.

6.3.1.3 Step 3: Establish program standards that support implementation.

It is recommended that program developers should take into consideration the establishment of program standards to ensure adherence to the standards set by the regulating and licensing bodies (SAMHSA 2009:10). The psychoeducational program was externally reviewed by a panel of Delphi experts before its publication. The Delphi panel refined the psychoeducational program in Phase 3. The psychoeducational program development is aligned with the Mental Health Care Act, 17 of 2002, and the National Mental Health Policy Framework and Strategic Plan (2013-2020). The two documents play an important role in mental health service delivery as they prescribe the care, treatment, and rehabilitation of MHCUs and protect their rights (South Africa 2002). The Act improves access, makes primary healthcare facilities the first contact of mental health care with the health system and promotes the integration of mental health into general health and community-based services.

The program is also aligned with the primary health care approach that is organised to reduce exclusion and social disparities in health, is people-centred, intersectoral, collaborative, and promotes the participation of all stakeholders (National Mental Health Policy Framework and Strategic Plan 2013-2030).

6.3.1.4 Step 4: Address financial issues and align incentives to support the implementation.

SAMHSA (2009:10) emphasises that psychoeducational programs should be funded by healthcare authorities and medical aids and private companies. In this study, the program will be implemented by clinics and community health centres, as well as public hospitals' multidisciplinary team members. These healthcare systems are funded by the Department of Health.

6.3.1.5 Step 5: Develop a training structure tailored to the needs of different stakeholders

According to SAMHSA (2009:10), the training should include the key stakeholders. Training of stakeholders in this study will happen as a post-doctoral activity and recommendations in this regard are made in the last chapter.

6.3.1.6 Step 6: Monitor fidelity and outcomes to maintain and sustain program effectiveness.

The researcher set outcomes to measure effectiveness in the last column of the program, see Table 6.2.

6.3.2 Characteristics of the family psychoeducation program

To ensure a reliable and valid program, the researcher included components in the program as recommended by SAMHSA (2009:28) See Table 6.2. A designated mental health care professional will be identified to oversee the program, and session frequency and long-term planning are specified. The quality of the program is ensured through the use of a therapeutic alliance, structured group sessions, a problem-solving process and the monitoring and recording of family responses. The program includes precipitating factors, prodromal signs and symptoms and coping strategies (SAMHSA 2009:17). Moreover, the program developed in this study includes other components identified from the study findings. An educational curriculum with outcomes and recommendations for the use of multimedia is specified in the program (SAMHSA 2009:26). A stage-wise provision of services is followed in the following order: Engagement, three or more joining sessions, an educational workshop and multifamily group sessions. The mental healthcare professionals assertively engage all potential consumers and family members by phone, mail or in person on an ongoing basis.

Table 6.2 Psychoeducation program for family members of MHCUs (draft)

Designated mental healthcare professional to oversee the program:					
Long-term follow-up plan:					
Plan to engage all potential family members by phone, by mail or in person on an ongoing basis:					
Interventions to provide information and education for families				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Provide mental health education to families on: o types of mental illness: causes, signs and symptoms, prognosis, and treatment options o psychotropic medications, side effects and management o management of challenging behaviours o recognising the signs and symptoms of relapse o crisis management o strategies for helping MHCUs to accept and adhere to treatment. o strategies for preventing relapse o ways to communicate with MHCUs and support them. o life skills to enable them to maintain a healthy and well-balanced life • Provide families with access to appropriate and up-to-date reading material	• Knowledge of causes, signs and symptoms, different types of mental illness, prognosis and treatment options. • Ability to deal with challenging behaviours such as delusions, hallucinations and aggression. • Knowledge about the nature and warning signs of mental illness. • Enhanced understanding, knowledge and ability to manage daily support and problems and maintain a healthy lifestyle • Improved adherence to medication by the MHCU. • Reduction in hospital readmissions of MHCUs • Reduced length of in-patient admission periods • Effective management of relapse episodes	• Face-to-face presentations • Group discussions • WhatsApp groups • Videos • Telephone calls • Reading material • Multi-family groups, consisting of 8-12 members. • Online presentations • Pamphlets • Lehutla meetings (Community gatherings)	Bi-monthly sessions on an ongoing basis	1. Therapeutic alliance 2. Engage family members with warmth, empathy, acceptance, and attention to individual needs. 3. Structured group sessions • Engagement • Three or more joining sessions • An educational workshop • Multifamily group sessions. 3. Structured problem-solving approach	Monitor and record families' reactions to MHCUs and the program. Monitor and check MHCUs' follow-up booklets and clinic files for any involvement of family members in therapeutic activity by the health care provider/ practitioner. Routine screening and treatment of physical illness in all consultation.

	Availability of reading materials on mental health topics in public and online spaces				
Designated mental healthcare professional to oversee the program:					
Long-term follow-up plan:					
Plan to engage all potential family members by phone, by mail or in person on an ongoing basis:					
Interventions to enhance family support by the community				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Implement and reinforce mental health policies • Link the families of MHCUs with the local legal forum • Educate SAPS members to assist families during crises as mandated by the Mental Health Care Act, 17 of 2002. • Identify a responsible and dedicated SAPS member to deal with mental health issues • Empower the families through: ○ contacting the SAPS when faced with crises ○ providing information on SAPS involvement, and processes to be followed when in need of police services for support ○ ways to source support from neighbours and the community • Conduct mental health anti-stigma and discrimination awareness campaigns through:	• Reduced self-stigma and discrimination. • Reduced isolation of family members. • Positive attitudes among community members towards MHCUs and their families. • Increased awareness of mental illness • Enhanced understanding, knowledge and ability of professional and non-professional groups in the community to manage mental health responsibly. • Active participation of community members in raising awareness of mental illness • Informed SAPS members about their role in assisting families in crisis situations. • Community leaders taking a leading role in raising awareness	• Radio talks • Face-to-face presentations • Group discussions • Legal forums seminars and workshops • School visits • Reading material • Community campaigns and meetings	Quarterly sessions with stakeholders Quarterly community campaigns	1. Consumer-stakeholder-family alliance 2. Community participation in raising mental health awareness. 3. Community leaders facilitating educational work 4. Consumer rights in policies and procedures related to mental health 5. Use of multimedia tools during community forums 6. Information resources for management of psychiatric relapse or crisis. 7. Resources to support families and MHCUs to engage in different social activities.	Monitor and record families' reaction to MHCUs and the program. Monitor and check MHCUs' follow-up booklets and clinic records for any kind of support of MHCUs and family by community stakeholders.

○ targeting primary and secondary schools, ward-based primary health and multi-disciplinary teams with a specific focus on substance abuse ○ educating civic and traditional leaders to raise mental health awareness in the community. ○ encouraging MHCUs and their families to attend mental health awareness campaigns according to the national mental health calendar, for example, family days at facilities in October. ○ educating community healthcare workers to reduce stigma and to provide families and the community with mental health education, referral, and support. • Engage MHCUs in recreational, employment, and religious community activities	and supporting the families of MHCUs. • Family members receiving support from neighbors and community with open communication.				
Designated mental healthcare professional to oversee the program:					
Long-term follow up plan:					
Plan to engage all potential family members by phone, by mail or in person on an ongoing basis:					
Interventions to enhance physical care of MHCUs and family members				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Advocate for provision of basic resources such as food parcels and housing benefits for MHCUs • Educate family members on: ○ Supervision of self-care activities to maintain personal hygiene of MHCUs.	• Improved personal hygiene of MHCUs. • Improved physical health of MHCUs and families. • Improved self-esteem and acceptance from community.	• Face-to-face health education • Group discussions • WhatsApp reminders • Videos	Monthly during follow up visits Ongoing as required	1.Therapeutic alliance 2. Engage family members with warmth, empathy, acceptance and attention to individual needs. 3.Structured group sessions	Monitor and record families' reaction to MHCUs and the program. Monitor and check MHCUs' follow-up

○ Nutrition and physical mobility to ensure a healthy lifestyle and address eating disorders. • Assess the physical health status of the MHCU and family members. • Screen MHCUs for early identification of physical conditions and refer as needed. • Ensure MHCUs' treatment is reviewed by doctor/psychiatrist on a 6-monthly basis. • Educate community health care workers to assess the physical status of MHCUs and family members for early referral. • Provide personal protective equipment for community health care workers when providing basic home-based nursing care to MHCUs • Conduct counselling for couples when the MHCU experiences sexual dysfunction caused by the side effects of medication • Refer to a dietician or medical practitioner as needed.	• Healthy eating and exercise habits • MHCUs receive six-monthly reviews by the medical doctor and psychiatrist to ensure suitable medication regimen. • Early identification of physical and medical conditions leading to prompt treatment to prevent complications. • MHCUs maintain healthy relationships.	• Reading material • Family sessions • Demonstrations • Referral pathways		• Engagement • Three or more joining sessions • An educational workshop • Multifamily group sessions. 4. Structured problem-solving approach 5. Skills training and ongoing guidance about maintaining physical health	booklets and clinic records for improved physical care provided by family caregivers. Monitor and check clinic records for adherence to six-monthly reviews by a medical doctor or a psychiatrist
Designated mental healthcare professional to oversee the program:					
Long-term follow-up plan:					
Plan to engage all potential family members by phone, by mail or in person on an ongoing basis:					
Interventions to provide social support				**Quality measures**	
Interventions	**Outcomes**	• **Resources to be used**	**Frequency of interventions**		
• Motivate and encourage shared responsibility between health care providers and family members.	• MHCUs verbalise feelings of being empowered and respected. • Families participate in the treatment program of MHCUs.	• Face-to-face presentations • Group discussions • WhatsApp groups	During monthly follow up	1. Consumer-family-mental health practitioner (medical doctor, psychiatrist social workers	Monitor and record families' reactions to MHCUs and the program.

• Recommend permanent disability grants for MHCUs. • Advocate for provision of employment opportunities • Empower family members to source support from neighbours and community members. • Advocate for involvement of MHCUs in community programs and associations • Engage MHCUs in their recovery process through productive activities during periods of remission. • Improve social skills and self-esteem through social skills training groups. • Advocate for involvement of MHCUs in income generation to enhance a sense of identity and being an active member of the community. • Establish a disability day-care centre. • Establish social support groups for MHCUs and family members to relieve stress and share experiences and solutions. • Refer to social worker or occupational therapists as needed	• Family members provided with individual counselling and support. • Families verbalise feelings of being supported in caregiving. • Reduced burden of care and problem-focused coping. • MHCUs with suitable housing meeting safety and security needs • MHCUs receiving permanent disability grants. • MHCUs involved in local community activities. • MHCUs employed in government and private sectors. • Improved level of functioning of MHCUs. • Social support groups for MHCUs and family members • Availability of sustainable skill development programs for MHCUs to generate income. • Day care centres in the local communities.	• Videos • Telephone • Reading materials • Family meetings • Community meetings • Referral pathways	Ongoing and continuous interventions	and occupational) therapist alliance for social support. 2. Structured problem-solving approach 3. Social skills training and ongoing guidance about management of mental illness	Monitor and check MHCUs' follow-up cards and clinic records for recorded social support interventions.
Designated mental healthcare professional to oversee the program:					
Long-term follow up plan:					
Plan to engage all potential family members by phone, by mail or in person on an ongoing basis:					
Interventions to provide financial assistance				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		

• Advocate for permanent disability grants for MHCUs who are eligible. • Advocate for income generation through development of occupational activities and projects • Engage stakeholders to ensure employment and occupational projects for MHCUs. • Advocate for employment opportunities for MHCUs • Lobby for funding of community projects. • Create community links between the Department of Police, Home Affairs, Social Services and Poverty Alleviation and Department of Health • Monitor the writing of medical and social work reports to process applications for disability grants.	• MHCUs granted permanent disability grants. • MHCUs involved in income generation occupational activities and Expanded Public Works Programme • Reduced financial burden on the families of MHCUs. • Family members and MHCUs informed on resources such as Families of South Africa • Awareness of family members of available resources for assistance with grant application protocols. • Established community network with Department of Police, Home Affairs, Social Services and Poverty Alleviation and Department of Health	• WhatsApp groups • Reading materials • Internet resources • Referral pathways • Community forums	Assess during follow-up sessions and home visits	1. Consumer-family-mental health practitioner therapeutic alliance for financial support. 2. Structured problem-solving approach 3. Skills training and ongoing guidance about management of mental illness	Monitor and record families' reactions to MHCUs and the program Monitor and check MHCUs' follow-up booklets and clinic files for financial intervention provided
Designated mental healthcare professional to oversee the program:					
Long-term follow-up plan:					
Plan to engage all potential family members by phone, by mail or in person on an ongoing basis:					
Curriculum: Interventions to enhance spiritual supportive care				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Encourage collaborative care among health professionals, church leaders and traditional health practitioners. • Respect the belief system of the MHCUs in relation to treatment programmes. • Involve church leaders in the rehabilitation of MHCUs.	• Partnerships between health care professionals, church leaders and traditional health practitioners in the provision of mental health care services. • MHCUs taking preferred roles in church activities.	Training sessions with feedback Face-to-face presentations and visits Group discussions WhatsApp messages Videos	Two-monthly training sessions Ongoing meetings as required	1.Consumer- family -faith healer practitioners (traditional health practitioner and church leaders) alliance for spiritual support.	Records indicating referrals of MHCUs to the hospital or PHC facility by the faith healers. Records of referrals made to the faith healers

• Educate and involve traditional health practitioners to encourage treatment compliance. • Encourage church leaders/ ministers to involve MHCUs in church activities to build their self-esteem. • Encourage MHCUs to practise spirituality in conjunction with their treatment • Educate traditional medicine practitioners about mental health. • Encourage families to practise religion and spirituality according to their belief systems.	• Working relationships among the multidisciplinary team members, traditional health practitioners and church leaders. • Increased understanding of mental illness in the context of belief systems. • Acceptance of cultural differences in assessment and interventions such as acknowledgment of different perspectives regarding causes of mental illness and family values.	Reading material		2. Timeous referral of MHCUs to western medical doctors. 3.Engagement of family members with warmth, empathy, acceptance, and attention to individual needs.	by the health care professionals.
Designated mental healthcare professional to oversee the program:					
Long-term follow up plan:					
Plan to engage all potential family members by phone, by mail or in person on an ongoing basis:					
Curriculum: Interventions to ensure healthcare provision by healthcare providers				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Engage different stakeholders in the planning of mental health care services (MHCUs, family members, service providers and managers, review board members, policy makers, non-profit organisations (NPO) and community leaders. • Advocate for an adequate budget for mental healthcare service delivery. • Advocate for sufficient trained practitioners in mental health disciplines • Ensure accessibility of local community health care centres or primary health clinics	• Adequate budget for funding community-based mental health services. • Enough mental health care practitioners to effectively render mental community mental health services. • Community health centres and clinics with sufficient psychotropic medication • Individual and group counselling and psychotherapy for MHCUs and families conducted at the	Face-to-face consultations Group discussions WhatsApp groups Videos Telephonic consultations Reading material Family therapy Individual and group sessions Home visits Referral pathways	Monthly psychoeducational sessions at the clinic Monthly support groups Monthly follow up	1. Therapeutic alliance 2. Engagement of family members with warmth, empathy, acceptance, and attention to individual needs. 3. Structured group sessions • Engagement • Three or more joining sessions • An educational workshop	Monitor and record families' reactions to MHCUs and the program Monitor and check MHCUs' follow-up booklets and clinic records for healthcare interventions provided

• Ensure sufficient psychotropic medication at the community health centres and clinics. • Motivate for allocation of a designated person to ensure availability of medication at the community health centres and clinics. • Conduct home visits (nurses and community health care workers) to ensure compliance and trace MHCUs who defaulted. • Ensure delivery of medication at home when indicated to enhance medication adherence. • Provide telephonic counselling/ support when MHCUs cannot access the clinic. • Establish rehabilitation services for MHCUs to optimise their level of functioning! • Advocate for and provide therapeutic interventions (individual/couple, group/family) ○ Individual therapy for MHCUs using brief interventions, client-centred, cognitive-behavioural, trauma counselling, and problem-solving approaches ○ Family therapy to enhance family coping, problem-solving, communication and crisis intervention skills. ○ Group therapy for psychological support of MHCUs.	community health centres by relevant health professionals. • Availability of telephonic and one-on-one counselling. • Support groups for MHCUs and their family members to reduce psychological stress. • Availability of skills training for MHCUs and families • Family members achieving an optimal level of functioning and a reduced burden of care as evidenced by: ○ reduced psychological stress. ○ increased sense of empowerment and assertiveness in seeking help ○ improved family relationships ○ ability to solve problems, make decisions and cope with stress and emotions. ○ a sense of self-efficacy and self-dependency ○ positive attitude towards mental conditions and accepting MHCUs. ○ positive caregiving experiences ○ communication and crisis management skills leading to reduced burden of care. ○ acceptance of MHCUs after discharge from mental health			• Multifamily group sessions. 4. Structured problem-solving approach	

○ Psychosocial support groups for MHCUs and families to share experiences related to care of MHCUs (challenges, solutions, effective coping skills, support, life skills and psychological first aid) to prevent mental illness of family members. • Build the capacity of families to provide appropriate self-help and peer-led support groups facilitated by NGOs • Give family members hope, whatever the diagnosis. • Provide assistance to families during relapse of MHCUs. • Provide support and information for involuntary admissions. • Establish a positive working relationship with multidisciplinary team members from local hospitals. • Involve family members in the treatment process of the MHCU. • Appreciate the effort of families in caring for MHCUs and reducing relapse. • Educate community health workers to refer MHCUs and families. • Educate healthcare providers in managing mental health problems, policies, regulations and referral and care pathways. • Involve families and MHCUs in policy development, planning and monitoring of mental health services.	institutions (community reintegration) • Effective multidisciplinary outreach teams conducting home visits as needed with primary health care nurses and community health care workers. • Reviewed mental health care policies to enhance family support. • Increased compliance with treatment and rehabilitation programs by MHCUs • Family members receiving timeous assistance with crises. • Mental health care practitioners function independently and collaboratively. • Family members actively participating in the treatment programme of the MHCUs. • Family members actively involved in making decisions about MHCU treatment and health services. • Families and stakeholders in the community having knowledge and understanding of mental health policies and legislation. • Family members in possession of contact lists for health care providers and community resources like local legal forums				

• Provide a database for family members of health care providers and community resources. • Refer families in need of legal support (alleged financial, physical, sexual, emotional, and psychological abuse) • Refer family members and MHCUs to psychologists and occupational therapists as needed.	• Assistance provided during MHCUs' involuntary admission by the multidisciplinary team members in public hospitals. • Community stakeholders working together in mental health service delivery. • Interdisciplinary mental health care practitioners involved in supporting MHCUs and families, made up of social workers, occupational therapists, case managers, nurses, psychologists and psychiatrists.				

6.5 CONCLUSION

This chapter entails the development method and the draft psychoeducational program to provide psychosocial support to families of MHCUs. The draft psychoeducational program to support family members caring for MHCUs has been developed from firstly, an integration of the findings of phase 1 and phase 2, secondly, an integration of the theoretical framework, and, thirdly, the applicable literature. A program development method is followed to ensure the rigour of the program.

The next chapter presents the refinement of a psychoeducational program to support family members caring for Mental Health Care Users in the Vhembe district of Limpopo Province through the e-Delphi technique.

CHAPTER 7
PHASE 3: REFINEMENT OF A PSYCHOEDUCATIONAL PROGRAM USING E-DELPHI TECHNIQUE

7.1 INTRODUCTION

The previous chapter presented the development of the draft psychoeducational program. This chapter discusses the refinement of the psychoeducational programme for family members caring for MHCUs in the Vhembe district, Limpopo Province through a consensus method using an e–Delphi technique.

7.2 e–DELPHI TECHNIQUE AS A METHOD OF ACHIEVING CONSENSUS WITH EXPERT PANEL MEMBERS

This study followed a virtual e-Delphi technique where the draft program with an evaluation instrument was sent to both national and international experts via e-mails in two rounds to provide input or comments to refine the draft program. The e-Delphi worked well in this study because the experts had easy access to e-mail which they used for communication. The researcher found the e-Delphi process to be economical and facilitated rapid exchange of ideas between panel members via a self-completed questionnaire without face-to-face communication as recommended by Mc Millan et al (2016:658).

7.2.1 Recruitment and selection of experts for the e-Delphi

A letter of invitation, outlining the basic processes of the e-Delphi was sent requesting the experts to indicate their willingness to participate before the questionnaire was sent. The researcher identified and invited 35 potential participants who met the requirements in accordance with the inclusion criteria of phase 3 but only 25 accepted the invitation to participate. Of the 25 experts who indicated their interest in taking part, only 22 eventually agreed and signed the consent form to participate in the study. Table 7.1 and Figures 71 to 7.4 indicate the profiles of the 22 experts. The following documents were emailed to each participant: (1) letter of invitation, outlining the instructions and study objectives (Addendum R) and (2) information leaflet including the consent form (Annexure I), and (3) Delphi questionnaire.

7.2.2 Biographical data of experts

The biographical data of the panel of experts is summarised in Table 7.1.

Table 7.1: Biographical data of e-Delphi expert panel

No.	Employer	Professional qualifications	Current position	Experience in mental health/ academic research /policy/ programme development and implementation
1.	Department of Social Development	Bachelor's degree in social work Honour's degree in sociology Master's degree in sociology PhD candidate in sociology.	Social worker	Working as a social worker for 12 years in the Vhembe district mental health hospital.
2.	Department of Health, Limpopo province	Professional nurse Bachelor's degree in nursing education Master's degree in public health PhD in advanced mental health nursing	Acting Director and Mental Health Coordinator	32 years of experience in mental health field
3.	University of Venda	PhD (psychology)	Clinical psychologist and Student counsellor	10 years' experience in higher education institutions providing student psychotherapy and conducting awareness campaigns in mental health.
4.	Department of Health	MBBCH Diploma mental health Diploma HIV management Master's degree in public health	Registrar Family medicine	Worked in mental health for 10 years, current research in mental health.
5.	University of Venda	Advanced psychiatric nurse	Junior lecturer	22 years' experience
6.	University of Zululand	Educational psychologist	Associate professor	26 years of experience as a psychologist.
7.	University of Venda	Bachelor's degree	Lecturer	16 years
8.	Sefako Makgato Health Science University	Bachelor's degree Master's degree PhD Postgraduate diploma in psychiatric nursing	Lecturer	10 years' experience in mental health field, mental health research, developing and implementing mental health policies and programs.
9.	Department of Health	Advanced psychiatric nursing science (Honours degree). Master's degree in nursing science.	Registered professional nurse	22 years
10.	Weskoppies hospital	Master's degree in nursing and public health Advanced child psychiatry Bachelor's degree in nursing	Operational manager	10 years working as advanced mental health nurse in acute ward.
11.	Department of Health	Bachelor's degree in psychology Master's degree in public health Doctoral degree in gender and youth studies	Registered counsellor	Working in hospital, assisting patients with mental health challenges and their families
12.	Department of Health	PhD.in nursing.	Registered professional nurse	22 years
13.	FAMSA	BA Social work	Social worker	5 years of experience working at Vhembe in rehabilitation and skills development
14.	University of Pretoria	Doctoral degree in nursing: Research topic in forensic mental health Master's in mental health nursing and development and management Postgraduate diploma in health systems strengthening	Lecturer	More than 12 years in mental health 5 years in research 3 years in programme development

No.	Employer	Professional qualifications	Current position	Experience in mental health/ academic research /policy/ programme development and implementation
15.	Sefako Makgatho Health Science University	Master's degree in nursing	Lecturer	Mental health field (11 years) Lecturer mental health (22 years)
16.	Department of Health, Limpopo College of Nursing	Diploma in general nursing, psychiatry, community and midwifery Bachelor's degree in education and administration Master's degree in public health.	Nurse educator/ lecturer	10 years' experience
17.	Åbo Akademi University, Vasa, Finland	Professional nurse, Master of health sciences, PhD candidate	University teacher	Professional nurse in mental health care. Senior lecturer in mental health nursing for 10 years (University of Applied Sciences). Teacher of Mental First Aid courses (Finnish Association for mental health.
18.	University of Namibia	Doctoral degree in psychiatric nursing	Senior lecturer	40 years' experience in the mental health field
19.	Department of Health	Diploma in nursing (general, psychiatric, community and midwifery) Bachelor's degree in nursing Master's degree in nursing	Acting Assistant Manager	26 years of experience
20.	Vista clinic	Bachelor's degree in nursing Advanced nursing (child psychiatry)	Clinical nursing manager	22 years' experience mental health field Action research projects, quality coordinator and facilitator
21.	University of Venda	Diploma in nursing (general, community, psychiatry and midwifery) Bachelor's degree in nursing education and nursing administration Masters in psychiatric nursing science Doctoral degree in psychiatric nursing science	Lecturer	23 years' experience in the psychiatric unit: professional nurse and manager. 7 years working in a nursing education institution: lecturer.
22.	Department of Health, Tiyani mobile clinic	Diploma in nursing science (general, psychiatry, community and accoucheur). Diploma in post basic psychiatric nursing science.	Clinical nurse practitioner	8 years' experience in public general hospital: professional nurse. 2 years' experience in the UK in specialised adolescent hospital 8 years' experience at a mobile clinic leading the mental healthcare service team.

7.2.3 Questionnaire for the psychoeducational program refinement

The AGREE II (Brouwers et al 2017:1-2) instrument was used to identify the criteria which form part of the questionnaire used for the refinement of the draft psychoeducational program. See table 7.2. The AGREE II instrument outlines attributes like scope and purpose, stakeholders' involvement, rigour of development, clarity of presentation, and applicability, necessary for the study. The criteria identified are validity, reliability, applicability and clarity. The researcher used these criteria for experts to rate each aspect of the program during the refinement process on a 4-point Likert scale, which ranged from 1 – strongly agree to 4 – strongly disagree.

The questionnaire focuses on the extent to which the program was developed by the appropriate stakeholders and represents the views of its intended users.

Table 7:2 Questionnaire to refine the psychoeducational program

CRITERIA **Rating scale**	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
	1	**2**	**3**	**4**
Purpose The purpose of the program is to provide psychoeducational interventions to support and meet the needs of family members caring for MHCUs.				
Scope The psychoeducational program was developed for primary health care nurses trained in mental health, working in community health centres and clinics and involved in the care of MHCUs and their families.				
Stakeholders' involvement **Phase 2**: NGT was held with stakeholders, healthcare providers (mental health nurses, social workers, clinical psychologists, occupational therapists, psychiatrists, medical doctors and clinic managers), policy developers, higher learning institutions academics and non-healthcare providers (traditional health practitioners, church leaders) and community structure representatives who play a role in the provision of support to MHCUs and their families. **Phase 3:** Delphi technique is held with stakeholders including the mental health care practitioners who are experts in the discipline of mental health and policy and development, such as academic researchers, psychologists, advanced mental health nurses, social workers, occupational therapists, psychiatrists, medical doctors, and clinic managers to refine the psychoeducational program.				
Reliability The psychoeducational program is expected to produce the desired results.				
Validity The psychoeducational program is intended to guide healthcare providers in the provision of psychosocial support for family members caring for MHCUs				
Clarity The interventions for addressing the physical, social, psychological and spiritual needs of family members outlined in the psychoeducation program are clear, easily understandable, unambiguous and logical.				
Applicability The target population is clearly stated: Mental health care practitioners (mental health nurses, social workers, clinical psychologists, occupational therapists, psychiatrists, and medical doctors) involved in the care of MHCUs and their families.				
COMMENTS:				

Adapted from AGREE II (Brouwers et al 2017: 1-2)

7.2.4 Data collection e-Delphi

The data collection from the Delphi experts was conducted in subsequent rounds of four weeks each until consensus was reached. During each round, the e-Delphi experts were expected to read through the draft family psychoeducation program, rate the program on the questionnaire provided and write comments and their opinions. The ratings and comments of each e-Delphi expert were compared with the ratings and comments by fellow panel experts. Participants remained anonymous from each other, and the controlled feedback was facilitated by the researcher (Jorm 2015:889). Summaries of the opinions, ratings and refined psychoeducation program were e-mailed back to each expert. In each round, participants were given an opportunity to change their responses and concur with the views of the group or to choose to stay within their views. The two rounds of the e-Delphi are discussed in the next sections.

7.2.5 e-Delphi round 1

The first section of the data collection instrument consisted of the biographical information of the e-Delphi participants (Annexure I). The 22 experts were given three weeks to work and rate the draft program in accordance with the principles of quality program using the 4-point Likert scale to measure their level of agreement then make comments in the provided section. The participants were requested to scan the last signed page of the informed consent form and return all the documents to the researcher by e-mail. The descriptive information on the professional and academic experience of the 22 e–Delphi experts enabled the researcher to describe the sample.

7.2.5.1 Data analysis e-Delphi round 1

Some of the e-Delphi experts commented and gave input on the psychoeducational program without rating it and other experts indicated their ratings without comments. See Annexure I for input of the experts during round 1. Using the 4-point Likert scale, the number of replies was recorded in a table based on the degrees of agreement (Table 7.3). Each of the seven criteria was given a quality score in accordance with AGREE II criteria (Brouwers et al 2017:10). The results are mounted as a percentage of the highest possible score after adding all the expert participant item scores (Brouwers et al 2017:9-10). The formula used to determine the consensus rate is illustrated below (Brouwers et al 2017:9).

Maximum possible score = 4 (strongly agree) x 7 (items) x 22 (appraisers) = 616

Minimum possible score = 1 (strongly disagree) x 7 (items) x 22 (appraisers) = 154

Obtained score – Minimum possible score * 100
Maximum possible score – Minimum possible score

There are no empirical data to link specific quality scores with specific implementation outcomes. High quality guidelines are those >70% (Brouwers et al 2017:10).

7.2.5.2 e-Delphi round one findings

The demographic profile of the panel is depicted in Figure 7.1 (qualifications), 7.2 (gender), 7.3 (level of education) and 7.4 (employer). The responses from the e-Delphi expert panel ratings on the draft psychoeducational program were collated and are presented in Table 7.3 to indicate the specific rating of each criterion during round one. The overall consensus rate was 85%

The following themes emerged, based on the seven interventions indicated in Table 7.4: interventions, outcomes of the interventions, resources to be used and quality measures of the actions taken to provide the needed support. In addition, the comments were based on the criteria included in the questionnaire, such as the purpose of the program, stakeholders' involvement, reliability, validity, clarity and applicability of the draft psychoeducational program.

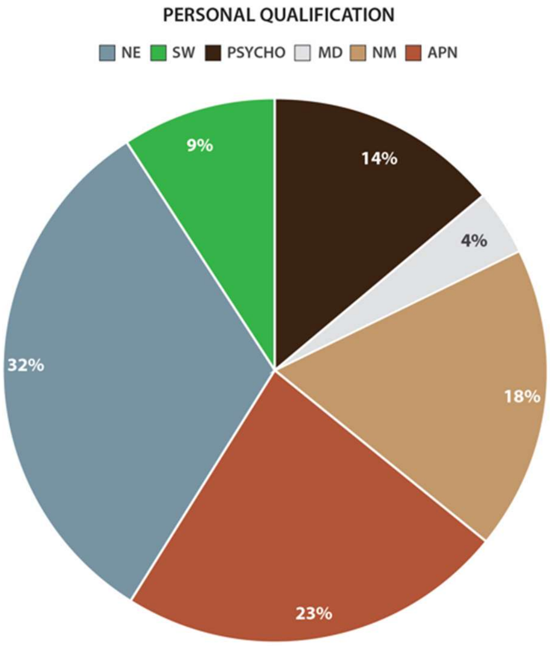

Figure 7.1 e- Delphi respondents according to professional qualification
Key: PSCHO= Psychologist, MD= Medical Doctor, NM= Nurse Manager, APN: Advanced Psychiatric Nurse NE= Nurse Educator, SW=Social Worker
The respondent according to professional qualifications was the following: psychologist (N=03) medical doctor (N= 01) Nurse Manager (N= 04) Advanced Psychiatric nurses (N=05) Nurse educator (N=7) Social Workers (N=02

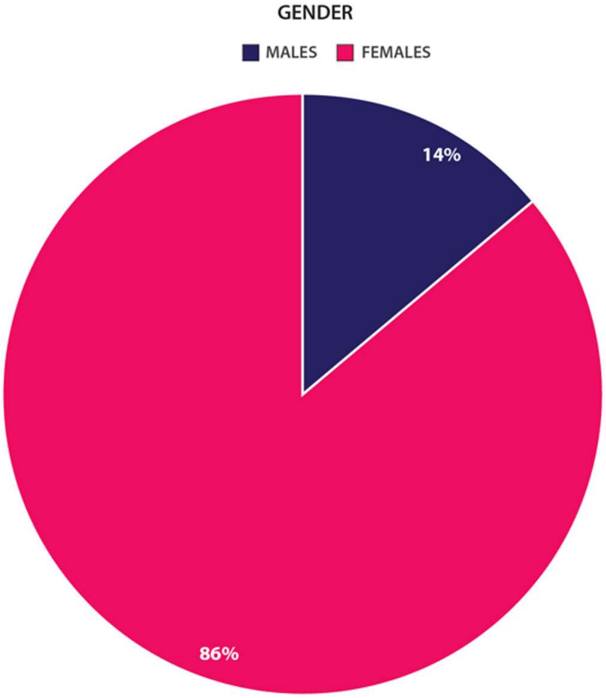

Figure 7.2 e- Delphi respondents according to gender
Respondents according to gender were the following: (N=19 females) and (N=3 males)

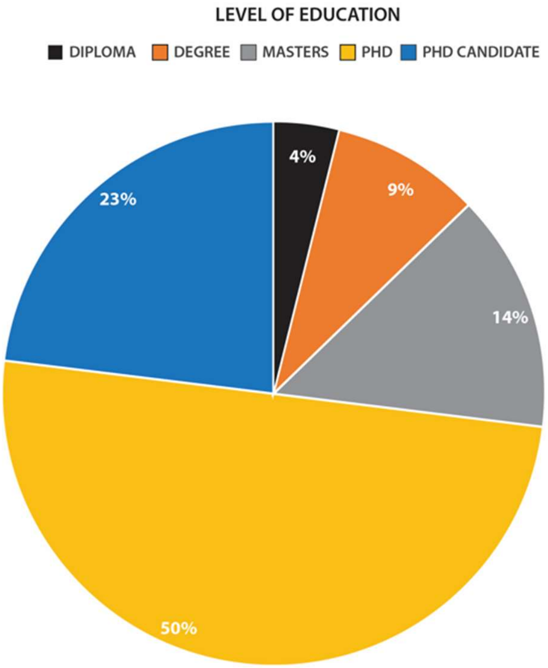

Figure 7.3 e- Delphi respondents according to the level of education
The respondent according to the Level of education were the following: Diploma : (N=1) Degree: (N=2) Master: (N=3) PhD: (N=11) PhD Candidate: (N=5)

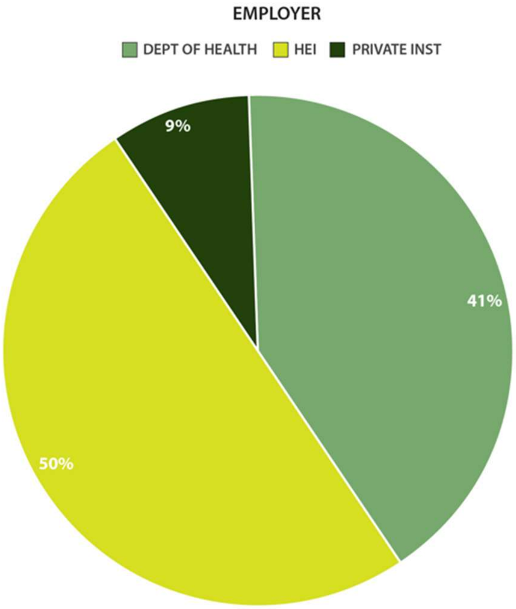

Figure 7.4 e- Delphi respondents according to the employer
KEY: DEPT OF HEALTH= Department of Health, HEI=Higher Learning Institution, PRIVATE INST= Private Institution
The respondents according to the employer were the following: Department of Health (N=09)
Higher Learning Institutions (HEI) (N=11) Private Institutions (N=02)

Table 7.3 Consensus rate of round one e-Delphi technique (n=22)

	PURPOSE				SCOPE				STAKEHOLDER INVOLVEMENT				RELIABILITY				VALIDITY				CLARITY				APPLICABILITY			
	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
1				*			*				*				*					*				*				*
2				*			*				*					*				*			*			*		
3				*				*				*				*				*				*				*
4				*			*					*		*				*						*			*	
5				*			*					*			*				*				*				*	
6				*		*					*				*			*						*				*
7				*				*				*			*					*			*					*
8				*				*				*				*				*				*				*
9				*				*		*					*				*					*				*
10				*			*				*				*				*				*				*	
11				*			*					*				*				*			*					*
12				*				*				*				*				*			*					*
13				*				*				*				*				*				*				*
14			*				*					*				*				*				*				*
15				*				*			*					*				*				*				*
16				*				*			*				*					*				*				*
17				*				*			*					*				*				*				*
18			*				*				*					*			*			*					*	
19				*			*					*			*				*				*				*	
20				*				*				*				*			*				*					*
21				*			*					*			*				*					*				*
22			*				*					*			*				*				*				*	
Total	**0**	**0**	**3**	**19**	**0**	**1**	**11**	**10**	**0**	**1**	**8**	**13**	**0**	**1**	**10**	**11**	**0**	**2**	**8**	**12**	**0**	**1**	**9**	**12**	**0**	**1**	**6**	**15**
Total				**85**				**75**				**78**				**76**				**76**				**77**				**80**
Consensus rate				**95 %**				**80 %**				**84 %**				**82 %**				**82 %**				**84 %**				**88 %**

Table 7.4 Summary of themes from round 1 e-Delphi technique

INTERVENTION/ CRITERIA	THEMES
INTERVENTION 1	**Interventions** • Health education on psychotropic medication should especially include the actions of such medication. • Assess the physical health status of the MHCU and family to exclude chronic diseases. **Outcomes** • Add a definition of mental illness. • Add an outcome on negative symptoms. • The outcome of Health education regarding psychotropic drugs, side effects, and management is not included in page 1. Suggested outcome: Increased knowledge and understanding of the needs of families. • All the outcomes in these sections should indicate the outcome in relation to the family's abilities or skills. Families should have the ability to facilitate adherence, then the outcome would be better adherence. **Resources to be used.** • Include sheltered employment. • m-health (mobile phones) can be used in relation to **plan to engage all potential family members by phone.** This can also be used as a resource to remind of the clinic follow-ups. • Facebook, Twitter and Instagram. • Frequency of intervention to be specified. • All MHCUs cannot be on permanent disability grants because some diagnoses are not permanent, and some can work until their condition worsens. **Quality measures** • Encouraging regular treatment reviews, at times a particular medication can be toxic in the human body and no longer effective for the purpose it is intended to serve. This is where such medication needs to be replaced or the dosage changed.
INTERVENTION 2	**Interventions** • Include assisting the community to understand the needs of MHCUs or how to meet them regarding social reintegration. • Outcome nr 7 Inform SAPS members about their role in assisting families in crisis situations - sound like interventions and not outcome – rephrase.
INTERVENTION 3	**Interventions** • Put more emphasis on nutritional needs and specific diets needed for mental health
INTERVENTION 4	**Interventions** • Feasibility of establishing a disability day-care centre is questionable. • Include intervention for vocational rehabilitation and social reintegration. **Outcomes** • The aim of daycare centre is to enhance skills, training, involvement in income-generating activities, and socialisation.
INTERVENTION 5	• Can be integrated in a newly formulated nr 4 because it is overlapping.
INTERVENTION 6	• Can be integrated in a newly formulated nr 4 because it is overlapping. **Interventions** • The church leaders also need education on mental illness and the role of medication adherence.
INTERVENTION 7	**Interventions** • Include mental status examination and crisis intervention. • Educate SAPS members to assist families during crises as mandated by MHCA No. 17 of 2002.
CRITERIA	No comments
PURPOSE	No comments
SCOPE	• The psychoeducation to also include mental health nurses, social workers and other allied health professionals working in mental health units that care for long-term stay for MHCUs.

INTERVENTION/ CRITERIA	**THEMES**
	• Point to consider the issue that some clinic managers are not psychiatrically trained.
STAKEHOLDERS' INVOLVEMENT	Inclusion of all stakeholders who participated in NGT
RELIABILITY	No comments
VALIDITY	No comments
CLARITY	Suggested that the interventions are classified according to related categories like "interventions for stakeholder support, interventions for family members" and so on
APPLICABILITY	The program may also cater for family members whose patients are admitted into long-term rehabilitation units Inclusion of dietitians since they are involved in the care of the MHCUs and their families
GENERAL COMMENTS	**Positive comments** • A psycho-educational program to support family members caring for mental health care users in the Vhembe district is a much needed program with many benefits, for example, mitigating the stigma and empowering families with knowledge and skills about how to take care of their loved ones suffering from mental illnesses. • A psychoeducational program is holistic in nature. It will help caregivers to understand the caregiving role better with the assistance of the mental health multidisciplinary team (MDT). • **C**ongratulations on this initiative. The Delphi program appears to be well-developed. • The program is clear and applicable, cutting across all disciplines involved in mental health care, including other community stakeholders. • The program is clear, reliable, valid and applicable to the family members. it is important for the family members to have the information so that they can cope with MHCUs in the community. This project is outstanding. • There is a need for psychoeducation of our community members on how to support the MHCUs and their families. • The questionnaire was able to address the purpose and significance of the study. • Reduce the program content to avoid repetitions. **Recommendations** • There is a need to evaluate the significance of support groups to MHCU as well as their family members they are benefiting from the program. • The psychoeducational program should be commenced as soon as the patient is declared a MHCU. • The use of WhatsApp social media as a resource, provided the issue of ethical consideration, i.e., confidentiality and informed consent is taken into consideration. • Intervention to improve the information systems to keep track of patients coming or not for follow-up; and also introduce systems monitoring their progress. **Clarity questions** • Frequency - Does it mean for each resource it will be done bi-monthly? • Awareness campaigns (are these similar to the Lekgotla meeting page 1?). How about empowering the families in that instance? **Grammatical errors and omissions** • "Advocate for permanent disability grant for MHCUs who are eligible" was repeated. • Insert the word "effective" healthcare provision by health care providers. • Spelling of Lehutla is incorrect. It is Lekgotla

7.2.5.3 Adjustments to the draft program after round 1

Considering the comments, inputs and suggestions made by the expert panel in round one, the researcher made certain adjustments to the draft psychoeducational program.

7.2.6 e-Delphi round 2

In this round, the panel that rated the draft psychoeducational program in round 1 was sent the adapted draft program, based on the comments and recommendations made in round 1. A cover letter summarising the findings of round 1, objectives of round 2 and the deadlines for round 2 was also e-mailed. The panel was again given three weeks to work on the adapted draft programme for further refinement. During this round, the experts had an opportunity to observe how their opinions differed from others. This allowed them either to maintain the ranking of their initial thoughts or to change their ratings accordingly (Hsu & Sandford 2007:4). The experts were again expected to return their responses by e-mail to the researcher. Reminders were sent to all 22 members who participated in round one. However, only 19 participated in round 2.

7.2.6.1 Data analysis e-Delphi round 2

The researcher analysed the ratings and the comments made by the e–Delphi expert panel in the same way as in round one. All the participants indicated their ratings on the questionnaire, however, eight of the participants did not comment, thus only 11 commented during round two.

7.2.6.2 e-Delphi round 2 findings

A summary of expert participants' ratings and consensus rates is shown in Table 7.5 for each criterion. Note the comments of experts in round 2 in Table 7.6. The overall consensus rate was 92%. The same themes emerged as in round 1, although there were fewer comments.

Table 7.5 Consensus rates of round 2 e-Delphi technique (n=19)

	PURPOSE				SCOPE				STAKEHOLDER INVOLVEMENT				RELIABILITY				VALIDITY				CLARITY				APPLICABILITY			
	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
1				*			*				*				*					*				*			*	
2				*			*					*				*				*				*				*
3				*				*				*								*				*				*
4			*				*				*				*				*					*				*
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18				*				*				*				*				*				*				*
19				*				*				*			*					*				*				*
Total			**2**	**17**			**5**	**14**			**3**	**16**			**6**	**13**			**3**	**16**		**1**	**1**	**17**			**3**	**16**
			6	**68**			**15**	**56**			**6**	**64**			**18**	**52**			**9**	**64**		**2**	**3**	**68**			**9**	**64**
Total				**74**				**71**				**70**				**70**				**73**				**73**				**73**
Consensus rate				**96 %**				**91 %**				**89 %**				**89 %**				**94 %**				**94 %**				**94 %**

Table 7.6 Summary of themes from round 2 e-Delphi technique

CRITERIA	THEMES
Scope	• The program can also be implemented at the hospital level by nurses caring for medium stay MHCUs and who are trained in mental health.
Involvement of stakeholders	• No comments
Interventions	• Interventions to enhance spiritual supportive care are essential for mental health care users and they are well described. The plan has great potential and will, when implemented, have valuable effects in the lives of mental health care users.
Positive comments	• The psychoeducational program is a great initiative because it assists the patients and those around them, as they also require support and lessons on mental illness to better assist their loved ones. The proposed initiatives and interventions are well thought out and will ensure that the patients get all the help they need. • The program is well structured and, if applied correctly, through this program the family caregivers would get to understand the needs and demands of caring for someone with mental illness. As a result, relapse and caregiver burnout will be reduced. • The study's intention to achieve what it is supposed to do is well outlined. The questions are clear. The validity and reliability ae well justifiable. • Very comprehensive program that addresses all the needs of MHCUs and their families. • Psychoeducation program that has been drawn is very clear and addresses all the fundamental human needs.
Negative remarks	• The plan is very extensive and contains many very important aspects of implication. However, the plan is still too long, and clarity is still a challenge.
General	• Nurses who will implement the program will need to be orientated on the program. • The psychoeducational program is expected to produce the desired results. Therefore, summarise the results you are referring to.
Recommendations	• In order for the success of program implementation will require staff to be allocated specifically to the program without any additional duties. • Nurses who will implement the program will need to be orientated on the program. • Psychoeducational program to be applied in all mental health care setting e.g., acute mental health care units, long-term hospitals

7.2.6.3 Adjustments of the draft program after round two

After considering the comments, input and suggestions made by the expert panel in round 2, the final adjustments were made.

7.3 DESCRIPTION OF THE FINAL PSYCHOEDUCATIONAL PROGRAM

The purpose of the program is to provide psychoeducational interventions to support family members caring for MHCUs. The psychoeducational program serves as a frame of reference and guide for healthcare providers when offering psychoeducation to families caring for MHCUs.

7.3.1 Development of the psychoeducational program

The psychoeducational program has been developed using findings retrieved from semi-structured interviews with family members caring for MHCUs based on their needs. The needs informed the development of psychoeducational program content relevant for the rural-based setting during a NGT. The guiding steps to a family psychoeducation process and the characteristics of a family psychoeducation program (SAMHSA 2009:10) guided the researcher during the program development. Applicable literature related to psychoeducation were integrated into the program; as well as relevant concepts of the theoretical framework (THPN). A Delphi technique was employed to refine the program according to the AGREE II instrument criteria (Brouwers et al 2017:1). The final psychoeducational program is presented in Table 7.7, showing the interventions, outcomes, resources to be used, frequency of interventions, and quality measures. The changes based on the comments of the expert participants are indicated in a different font color (orange) where the expert suggested changes, additions or removal of some interventions.

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Table 7.7 Psychoeducational program to support family members caring for MHCUs

<table>
<tr><td colspan="6">Designated mental healthcare professional to oversee the program:</td></tr>
<tr><td colspan="6">Long-term follow-up plan:</td></tr>
<tr><td colspan="6">Plan to engage all potential family members by phone, by mail or in person, on an ongoing basis:</td></tr>
<tr><td colspan="4">1. Interventions to provide information and education for families</td><td colspan="2">Quality measures</td></tr>
<tr><td>Interventions</td><td>Outcomes</td><td>Resources to be used</td><td>Frequency of interventions</td><td colspan="2"></td></tr>
<tr>
<td>• Provide mental health education to families on:
○ types of mental illness: causes, signs and symptoms, prognosis and treatment options
○ psychotropic medications: name, classification, indication, action, side effects and management
○ management of challenging behaviors
○ signs and symptoms of relapse
○ crisis management
○ strategies for helping MHCUs to accept and adhere to treatment.
○ strategies for preventing relapse.
○ ways to communicate with the MHCUs and support them.
○ life skills to enable family members to maintain a healthy and well-balanced life
○ the importance of treatment follow-up
• Provide families with access to appropriate and up-to-date reading material.</td>
<td>• Knowledge of causes, signs and symptoms, types of mental illness, prognosis and treatment options (including positive and negative symptoms of schizophrenia)
• Ability to manage challenging behaviors such as delusions, hallucinations and aggression.
• Knowledge about the nature and warning signs of mental illness.
• Understanding, knowledge and ability to maintain a healthy lifestyle.
• Improved adherence to medication by the MHCU.
• Reduction in hospital readmissions of MHCUs
• Reduced length of in-patient admission periods
• Effective management of relapse episodes
• Availability of mental health information in public and online spaces</td>
<td>• Face-to-face presentations
• Group discussions
• WhatsApp groups
• Videos
• Telephone calls
• Reading material
• Multi-family groups consisting of 8-12 members.
• Online presentations
• Pamphlets
• Lekgotla meetings (community gatherings)
• Workshops
• M-health (mobile phone)
• Facebook, Twitter, Instagram</td>
<td>Bi-monthly sessions on an ongoing basis</td>
<td>1. Therapeutic alliance
2. Engage family members with warmth, empathy, acceptance, and attention to individual needs.
3. Structured group sessions
• Engagement
• Three or more joining sessions
• Educational workshops
• Multifamily group sessions.
4. Problem-solving approach</td>
<td>Monitor and record families' reactions to MHCUs and the program.
Monitor and check MHCU's follow-up booklets and clinics file for involvement of family members in health education.</td>
</tr>
</table>

Designated mental healthcare professional to oversee the program:					
Long-term follow-up plan:					
Plan to engage all potential family members by phone, by mail or in person, on an ongoing basis:					
2. Interventions to enhance family support by the community				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Implement and reinforce mental health policies • Link the families with the local legal forums • Educate SAPS members to assist families during crises as mandated (MHCA). • Identify a responsible and dedicated SAPS member to deal with mental health issues • Empower the families through: ○ contact with and information on SAPS processes in case of crises ○ ways to source support from neighbors and the community • Conduct mental health anti-stigma and discrimination awareness campaigns (include substance abuse information) to: ○ primary and secondary schools, ward-based primary health and multi-disciplinary teams ○ civic and traditional leaders to raise community mental health awareness ○ community healthcare workers to provide families and the community with mental health education, referral, and support. • Encourage MHCUs and their families to attend mental health awareness campaigns (national mental health calendar). • Engage MHCUs in recreational, employment and religious community activities.	• Reduced self-stigma and discrimination. • Reduced isolation of family members • Positive attitudes among community members towards MHCUs and their families • Increased awareness of mental illness • Enhanced understanding, knowledge and ability of community structures and members to manage mental health responsibly • Active participation of community members in raising awareness of mental illness • Community leaders taking a leading role in raising awareness and supporting families of MHCUs • Family members' support from neighbors and community with open communication. • Informed and dedicated support from SAPS in times of crisis	• Radio talks • Face-to-face presentations • Group discussions • Legal forums seminars and workshops • School visits • Reading materials • Community campaigns and meetings • M-health (mobile phone)	Quarterly sessions with stakeholders Quarterly community campaigns	1. Consumer-stakeholder-family alliance 2. Community participation in raising mental health awareness. 3. Community leaders facilitating educational work 4. Consumer rights in policies and procedures related to mental health 5. Use of multimedia tools during community forums 6. Information resources for management of psychiatric relapse or crisis. 7. Resources to support families and MHCUs to engage in different social activities.	Monitor and record families' reaction to MHCUs and the program Monitor and check MHCUs' follow-up booklet and clinic records for any kind of support of MHCUs and family by community stakeholders.

Designated mental healthcare professional to oversee the program:					
Long-term follow up plan:					
Plan to engage all potential family members by phone, by mail, or in person on an ongoing basis:					
3. Interventions to enhance physical care of MHCUs and family members				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Advocate for provision of basic resources such as food parcels and housing benefits for MHCUs • Educate family members on: ○ Supervision of self-care activities to maintain personal hygiene of MHCUs. ○ Nutrition and physical mobility to ensure a healthy lifestyle. ○ Harmful effects of substance abuse on the body and brain • Assess the physical health status of MHCUs and family members • Screen MHCUs for early identification of physical conditions and refer as needed • Ensure MHCUs' treatment is reviewed by doctor/psychiatrist on a 6-monthly basis. • Educate community health care workers to assess the physical status of MHCUs and family members for referral. • Provide personal protective equipment to community health care workers to provide basic home-based nursing care to MHCUs • Conduct counselling for couples when MHCUs experience sexual dysfunction related to side effects of medication. • Refer to a dietician (for diet related the mental health condition) or medical practitioner as needed	• Improved personal hygiene of MHCUs • Improved physical health of MHCUs and families • Improved self-esteem and acceptance from community. • Healthy eating and exercise habits • Six-monthly reviews by the medical doctor and psychiatrist to ensure suitable medication regimen. • Early identification of physical and medical conditions leading to prompt treatment to prevent complications. • Family members and MHCUs show understanding of nutritional needs and dietary requirements	• Face-to-face health education • Group discussions • WhatsApp reminders • Videos • Reading material • Family sessions • Demonstrations • Referral pathways	Monthly during follow up visits Ongoing as required	1.Therapeutic alliance 2. Engage family members with warmth, empathy, acceptance and attention to individual needs. 3.Structured group sessions • Engagement • Three or more joining sessions • An educational workshop • Multifamily group sessions. 4. Structured problem-solving approach 5. Skills training and ongoing guidance about maintaining physical health	Monitor and record families' reaction to MHCUs and the program. Monitor and check MHCU'S follow-up booklet and clinic records for improved physical care provided by family caregivers. Monitor and check clinic records for adherence to six-monthly reviews by a medical doctor or a psychiatrist

Designated mental healthcare professional to oversee the program:					
Long-term follow-up plan:					
Plan to engage all potential family members by phone, by mail, or in person on an ongoing basis:					
4. Interventions to provide social support				**Quality measures**	
Interventions	**Outcomes**	• **Resources to be used**	**Frequency of interventions**		
• Encourage shared responsibility between health care providers and the family • Advocate for employment opportunities • Empower family members to source support from neighbors and community members. • Advocate for involvement of MHCUs in community programs and associations • Engage MHCUs in their recovery process through productive activities during remission. • Improve social skills and self-esteem through social skills training groups. • Advocate for involvement of MHCUs in income generation activities in the community. • Motivate the Department of Health and NGOs to establish a disability day-care centre and sheltered employment for the MHCUs. • Day care centre for skills training, socialization, vocational rehabilitation and income generation • Establish support groups for MHCUs and family members to relieve stress and share experiences and solutions. • Facilitate rehabilitation of MHCUs through access to resources, coordinating health and occupational activities, promoting education and inclusion in social activities. • Refer to social worker or occupational therapists as needed	• MHCUs verbalise feelings of empowerment and respect. • Families participate in the treatment program of MHCUs. • Families receive counselling. • Families verbalise feelings of being supported in caregiving. • Reduced burden of care, and problem-focused coping. • MHCUs safe and secure housing • MHCUs involved in local community activities. • MHCUs employed in government and private sectors. • MHCUs.improved level of functioning • Social support groups for MHCUs and family members • Availability of sustainable skills development programs for MHCUs to generate income. • Day care centres in the local communities • Sheltered employment available in the local communities. • Reduced family rejection of MHCU and improvement of integration of MHCU into their families and communities	• Face-to-face presentations • Group discussions • WhatsApp groups • Videos • Telephone • Reading materials • Family meetings • Community meetings • Referral pathways	Monthly follow ups Ongoing and continuous interventions	4. Consumer-family-mental health practitioner (medical doctor, psychiatrist social workers and occupational) therapist alliance for social support. 5. Structured problem-solving approach 6. Social skills training and ongoing guidance about management of mental illness	Monitor and record families' reaction to MHCUs and the program. Monitor and check MHCU'S follow-up card and clinic records for recorded social support interventions

Designated mental healthcare professional to oversee the programme:					
Long-term follow up plan:					
Plan to engage all potential family members by phone, by mail, or in person on an ongoing basis:					
5. Interventions to provide financial assistance				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Advocate for temporary / permanent disability grants for MHCUs who are eligible (some diagnoses are not permanent and MHCUs only need the grants when their conditions worsen). • Advocate for income generation through development of occupational activities and projects • Advocate for employment opportunities; engage stakeholders to develop employment and occupational projects for MHCUs. • Lobby for funding of community projects. • Create community links between the Departments of Police, Home Affairs, Social Services and Department of Health • Monitor the writing of medical and social work reports to process applications for disability grants.	• MHCUs granted permanent/ temporary disability grants. • MHCUs involved in income generation occupational activities and Expanded Public Works Programs • Reduced financial burden on the families of the MHCUs. • Family members and MHCUs informed about resources such as Families of South Africa • Awareness of available resources for grant application protocols. • Established community network with Departments of Police, Home Affairs, Social Services and Department of Health	• WhatsApp groups • Reading materials • Internet resources • Referral pathways • Community forums	Assess during follow-up sessions and home visits	4. Consumer-family- mental health practitioner therapeutic alliance for financial support. 5. Structured problem-solving approach 6. Skills training and ongoing guidance about management of mental illness	Monitor and record families' reaction to MHCUs and the program Monitor and check MHCUS' follow-up booklets and clinic files for financial intervention provided
Designated mental healthcare professional to oversee the program:					

Long-term follow-up plan:

Plan to engage all potential family members by phone, by mail, or in person on an ongoing basis:

6. Interventions to enhance spiritual supportive care				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Encourage collaborative care among health professionals, church leaders and traditional health practitioners • Respect the belief systems of the MHCUs in relation to treatment programs. • Involve church leaders in rehabilitation of MHCUs. • Educate and involve traditional health practitioners to encourage treatment compliance. • Encourage church leaders/ ministers to involve MHCUs in church activities to build their self-esteem. • Encourage MHCUs to practice spirituality in conjunction with treatment. Educate traditional medicine practitioners on mental health. • Encourage families to practice religion and spirituality according to their belief systems. • Educate church leaders on mental illness and medication adherence.	• Partnerships between health care professionals, church leaders and traditional health practitioners in the provision of mental health care services. • MHCUs taking preferred roles in church activities. • Working relationships among the multidisciplinary team members, traditional health practitioners and church leaders. • Increased understanding of mental illness in the context of belief systems. • Acceptance of cultural differences in assessment and interventions such as acknowledgment of different perspectives regarding causes of mental illness and family values	Training sessions with feedback Face-to-face presentations and visits Group discussions WhatsApp messages Videos Reading materials	Two-monthly training sessions Ongoing meetings as required	1.Consumer- family -faith healer practitioners (traditional health practitioner and church leaders) alliance for spiritual support. 2. Timeous referral of MHCUs to western medical doctors. 3.Engagement of family members with warmth, empathy, acceptance and attention to individual needs.	Record indicating referrals of MHCUs to the hospital or PHC facility by the faith healers. Record of referrals made to the faith healers by the health care professionals.

Designated mental healthcare professional to oversee the program:

Long-term follow up plan:					
Plan to engage all potential family members by phone, by mail, or in person on an ongoing basis:					
7. Interventions to ensure effective healthcare provision by healthcare providers				**Quality measures**	
Interventions	**Outcomes**	**Resources to be used**	**Frequency of interventions**		
• Engage stakeholders in the planning of mental health care services (MHCUs, family members, service providers and managers, review board, policy makers, NPOs and community leaders) • Advocate for an adequate budget for mental healthcare service delivery. • Advocate for sufficient trained practitioners in mental health disciplines. • Ensure access to community health care centres/ primary health clinics. • Ensure sufficient psychotropic medication at the community health centres and clinics. • Motivate for a designated person to ensure availability of medication at community health centres and clinics. • Conduct home visits (nurses and community health care workers) to ensure compliance and trace MHCUs who default. • Ensure delivery of medication at home when indicated to enhance adherence. • Provide telephonic counselling/ support when MHCUs cannot access the clinic. • Establish rehabilitation services for MHCUs to optimise their level of functioning. • Conduct MSE (mental status examination) of MHCUs during each follow-up visit. • Advocate for, provide or refer for therapeutic interventions:	• Sufficient resources for community-based mental health services: ○ budget. ○ mental health care practitioners to effectively render services ○ psychotropic medication at community health centres/clinics • Availability of: ○ individual and group counselling at the community health centres ○ telephonic counselling. ○ support groups for MHCUs and families. ○ skills training for MHCUs and families ○ contact list for health care providers and community resources • Families' optimal functioning and reduced burden of care evidenced by: ○ reduced psychological stress ○ sense of empowerment and assertiveness in seeking help ○ improved family relationships ○ ability to solve problems, make decisions and cope with stress ○ sense of self-efficacy. ○ positive attitude and acceptance towards MHCUs ○ positive caregiving experiences ○ early identification of relapse	Face-to-face consultations Group discussions WhatsApp groups Videos Telephonic consultations Reading materials Family therapy Individual and group sessions Home visits Referral pathways	Monthly psychoeducational sessions at the clinic Monthly support groups Monthly follow ups	1. Therapeutic alliance 4. Engagement of family members with warmth, empathy, acceptance and attention to individual needs. 5. Structured group sessions • Engagement • Three or more joining sessions • An educational workshop • Multifamily group sessions. 4. Structured problem-solving approach 5. Orientation of mental health and general nurses about the psychoeducational program.	Monitor and record families' reaction to MHCUs and the program Monitor and check MHCUs' follow-up booklets and clinic records for healthcare interventions provided Improve the information systems to keep track of MHCUs for statistical purposes, monitoring defaulters and progress

○ Individual brief interventions, client-centred, cognitive-behavioral, trauma counselling, and problem-solving approaches ○ Family therapy to enhance family coping, problem-solving, communication and crisis intervention skills ○ Group therapy for psychological support ○ Psychosocial support groups for MHCUs and families (share caregiving experiences, challenges, solutions, coping skills, and psychological first aid). ○ Crisis intervention when needed ○ Refer for legal support (alleged financial, physical, sexual, and psychological abuse) ○ Refer for multi-disciplinary interventions as needed • Build the capacity of families in self-help and peer-led support groups facilitated by NGOs • Give family members hope, regardless of the diagnosis • Assist families during relapse of MHCUs • Establish a positive working relationship with multidisciplinary team from local hospital • Educate healthcare providers in management of mental health problems, policies, regulations and referral and care pathways • Educate SAPS members to assist families during crises (in case MHCU has relapse and is violent) as mandated by the Mental Health Care Act, 17 of 2002. • Involve families and MHCUs in policy development, planning and monitoring of mental health services • Provide a database for families with health care providers and community resources.	○ communication and crisis management skills ○ acceptance of MHCUs after discharge (community reintegration) • Interprofessional care: ○ home visits as needed with primary health care nurses and community health care workers ○ mental health care practitioners function independently and collaboratively ○ support of MHCUs and families (social workers, occupational therapists, case managers, nurses, psychologists and psychiatrists) ○ assistance during MHCUs involuntary admission • Reviewed mental health care policies to enhance family support • Compliance with treatment and rehabilitation programs by MHCUs. • Family members receiving timeous crisis management • Family members participation in the treatment program of the MHCUs. • Families and stakeholders in the community with knowledge and understanding of mental health policies and legislation. • Community stakeholders collaborating in mental health service delivery. • Reduced relapse rate of MHCUs and up to date information of MHCUs, recorded in a secure system.				

7.4 CONCLUSION

Chapter 7 describes phase 3 of this study, which is the refinement of a psychoeducational program for family members caring for MHCUs in the Vhembe District, Limpopo Province, South Africa using an e-Delphi consensus method. The guiding principles in the program refinement are explained, namely, the criteria used to evaluate the program. The draft psychoeducational program is presented with the suggested changes recommended by the e-Delphi panel. The next, and final, chapter presents the evaluation, strengths, conclusions and recommendations of the study.

CHAPTER 8

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

8.1 INTRODUCTION

The previous chapter describes the refinement of a psychoeducational program to support family members caring for MHCUs in the Vhembe district, Limpopo province, South Africa, using a consensus method through the e-Delphi technique. This chapter describes the research conclusion, strengths and limitations and makes recommendations.

8.2 CONCLUSION OF THE STUDY

The conclusion of this study is based on its rationale and the extent to which the aim and objectives, outlined in chapter one, have been achieved.

8.2.1 Rationale of the study

In South Africa, when de-institutionalisation occurred in the 1970s, MHCUs were transferred from hospitals to the community without preparing the communities. As a result, the family members adopted the new role of being primary caregivers for their relatives with mental health problems. The rationale for this study was to develop a psychoeducational program for family members caring for MHCUs in the Vhembe district of the Limpopo province. A preliminary literature review by the researcher showed that the bulk of research provides information on the experiences of family members caring for MHCUs, which is a problem-centred approach, while limited studies exist on the development of strategies or programs for family support.

The psychoeducational program aims to support family members to cope better with their caregiving responsibility through acquiring the knowledge and skills to manage the MHCUs. Families dealing with their own emotions and the stress associated with caring for MHCUs, may lead to a reduced caregiving burden. Family members' mental health may improve when they receive support from community members, leaders and healthcare professionals.

The study used the Theory for Health Promotion in Nursing (THPN) (University of Johannesburg 2017: 5-8) as its guide. The THPN is based on a pragmatic paradigmatic approach which requires that research is undertaken to improve practice in nursing. The current study aims to improve practice in nursing by addressing the needs of family caregivers of MHCUs in rural communities of the Vhembe district, Limpopo province.

8.2.2 Phase 1

The objectives of phase 1 were to explore and describe the needs of family members caring for MHCUs in the Vhembe district, Limpopo province, South Africa. The researcher employed a qualitative, exploratory, descriptive and contextual design to explore and describe the needs of family members caring for MHCUs in order to support them. Data were collected through in-depth individual interviews with the family members caring for MHCUs. Data were analysed using a qualitative approach, following the six phases of thematic analysis of Braun and Clarke (2013:120). See chapter 3 for the phases of data analysis.

8.2.2.1 Summary of findings of phase 1

A detailed report of the findings of phase 1 is presented in Chapter 4. Data yielded three main themes**,** 10 categories and 44 subcategories, as indicated in Table 4.2. Psychosocial experiences emerged as the first main theme with two categories, psychological experiences and social experiences. Family members caring for MHCUs experience a range of negative emotions. These emotional experiences include feelings of helplessness and hopelessness, feelings of shame and fear, feelings of powerlessness, an inability to cope, feelings of emotional distress and loss and feelings of depression. Family members felt a lack of support and few opportunities to share their caregiving responsibilities with other relatives.

Healthcare needs of family members emerged as theme two with six categories, physical healthcare needs, psychological healthcare needs, social needs, financial needs, educational and information support needs and spiritual support needs. Family members reported multiple health problems, yet they suffered in silence, neglecting their own health as they prioritised the healthcare needs of the MHCU. The psychological needs are grouped into three categories. family members' needs for psychological counseling, their need to acquire healthy coping skills in dealing with the caregiving challenges and the need for the establishment of a nurse-family therapeutic relationship. Family members mentioned three subcategories of social needs, the need for de-stigmatisation and non-discrimination, a need for social support from their next of kin, a need for the provision of suitable housing and the need for personal safety and security. Family members indicated that giving care to a MHCU is stressful because of the financial costs. Three subcategories emerged from the category of financial needs, various additional costs to sustain the MHCU, the need to provide the MHCU with a permanent disability grant and the need for employment opportunities for MHCUs.

The need for education and information support by the healthcare providers, is based on participants' reports that they were not given adequate information about the diagnosis, treatment options and management of the MHCU. Inadequate information about mental illness, its treatment modalities, inadequate knowledge of the side-effects of the psychotropic medications and inadequate information about the management of day-to-day challenging behavior displayed by the MHCUs, were mentioned as causes of serious concerns which led to frustration. This category yielded the following subcategories: Knowledge of the mental illness, its causes, signs and symptoms, course and prognosis and treatment options, identification of early warning signs of relapse and their management, information about the management of day-to-day challenging behaviors, information regarding substance abuse by MHCUs, information regarding medication adherence, side-effects of psychotropic drugs and management thereof and the need to be empowered with various skills.

The healthcare expectations emerged as theme three. The family members expressed their expectations with regard to support from the public healthcare system. The healthcare expectations of family members fall into two categories, expectations from healthcare systems and expectations from healthcare professionals. Needs in terms of the public healthcare system yielded three subcategories: The provision of community-based day care for MHCUs, availability of psychotropic medications at the community health centres, and assistance from the South African Police Services during crises. Expectations from healthcare professionals yielded two subcategories, suitable psychopharmacological prescription medication and home visits by healthcare providers.

8.2.3 Phase 2

The objective of phase 2 was to develop a psychoeducation program to support family members caring for MHCUs in the Vhembe district. The development of the psychoeducational program was based on Phase 1’s empirical findings deducted from the needs of the family members caring for MHCUs.

8.2.3.1 Summary of findings of phase 2

The findings of phase 1 informed phase 2 where data was collected during a NGT workshop. The following themes emerged from the NGT, informational and educational interventions, family support by the community, physical care of the MHCUs, social support, financial assistance and spiritual and health care services support. See Table 5.2.

From theme one, three categories emerged, mental health education on mental illness (causes, signs and symptoms, prognosis and treatment options), psychotropic medication, side effects and their management and the management of challenging behaviours. Under the second theme, three categories emerged, reduction of stigma and discrimination against family members and MHCUs, SAPS’ assistance during crises, and lastly, engagement of

MHCUs in community activities. In theme three, the categories are: provision for basic needs and maintenance of good personal hygiene of MHCUs and assessment of the physical health status of them and their family members. Interventions to provide social support, the fourth theme, is made up of three categories: Suitable housing for MHCUs, shared responsibility between health care providers and family members and the establishment of support groups. The fifth theme consisted of three categories: The provision of permanent disability grants, the establishment of income-generating occupational activities and the provision of employment opportunities. The sixth theme yielded the following categories: Collaborative care by health professionals, church leaders (pastors) and traditional health practitioners, respect for the belief system of the MHCU in relation to the treatment program, and the involvement of church leaders in the rehabilitation of the MHCU. Five categories emerged from the last theme: Family therapy, counseling, home visits by health care providers, ensuring availability of psychotropic drugs and rehabilitation by providing sheltered employment for the MHCUs, skills training and the establishment of support groups, as well as general public mental health education through awareness campaigns.

The program was developed by the researcher through integrating phase 1 and 2 findings, literature findings as well as concepts from the theoretical framework.

8.2.4 Phase 3

The objective of phase 3 was to refine and validate the psychoeducational program to support family members caring for MHCUs, using an e-Delphi technique. To reach consensus, a Likert scale was used for rating of the draft program. The psychoeducational program for supporting family members caring for MHCUs was drafted in phase 2 during the NGT workshop. To ensure a rigorous process, the development and refinement of the program were carried out in accordance with the guiding principles constructed by the AGREE II instrument (Brouwers et al., 2017:9).

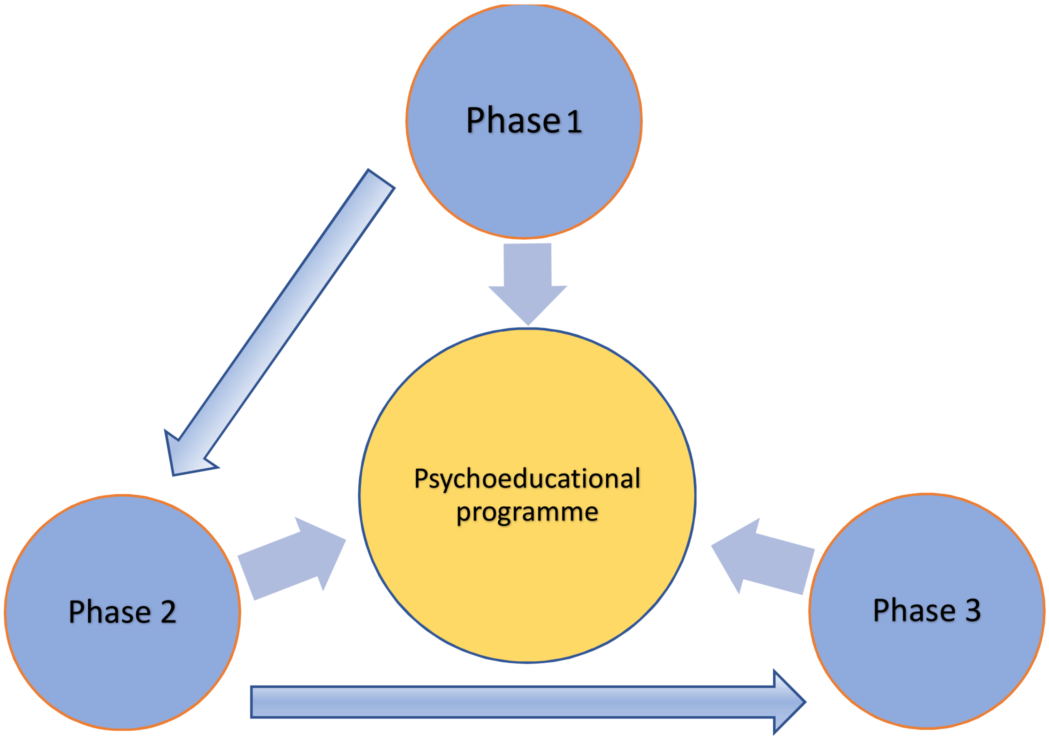

Figure 8.1 Summary of study phases

8.3 THE STRENGTHS OF THE STUDY

A theoretical framework was used as a guide to develop the psychoeducational program to ensure that the program addresses the needs of the families in a holistic way. The integrated findings were used to develop seven interventions to address the physical, social, psychological and spiritual healthcare needs of family members caring for MHCUs.

The multimethod approach ensured a better understanding of the research problem and different participants were used to collect rich data in three phases, to ensure the triangulation of data sources. In Phase 1, in-depth individual interviews highlight the problem as experienced by family members, In Phase 2, the NGT workshop included different stakeholders from the community and healthcare facilities to ensure the program met the needs of both the healthcare system and the community. Health care professionals from different backgrounds. like social workers and nurses, were sampled to ensure the credibility of the study.

The program was designed using a rigorous scientific process with comments obtained from both national and international mental health experts. The population of Phase 3 was stakeholders who are experts in the mental health field and academics in research related to mental health issues. Consensus was obtained among the participants with knowledge and experience in mental health. The researcher used the guiding steps to the family psychoeducation process and the characteristics of the family psychoeducation program to develop the program. This evidence-based method ensured that the researcher approached mental illness as the object of treatment, not the family. The criteria in Table 7.2 used to evaluate the program was adopted from the AGREE II instrument to assess attributes such as scope and purpose, stakeholders' involvement, rigor of the developed program, clarity of presentation and applicability.

8.4 LIMITATIONS OF THE STUDY

The study was restricted to community health centres and stakeholders in the Vhembe district. Therefore, the research findings cannot be generalised to all community health centres in SA. Data collection was carried out during the COVID-19 pandemic. This meant that the researcher had to wait for the lifting of the restrictions to conduct the interviews and NGT in person. In addition, electricity disruptions caused by load-shedding further negatively impacted meeting the deadlines of the study.

The problem with sufficient healthcare resources in South Africa may form a barrier to the successful implementation of the program. The program may also not be suitable for implementation in internationally resource-rich settings where most of the recommendations of the program may already be in place. The program is, however, suitable to adapt for use in other low-and-middle income countries.

8.5 UNIQUE CONTRIBUTION OF THE STUDY

To the best of the researcher's knowledge, this is the first psychoeducational program developed to support families caring for MHCUs in South Africa. In addition, this program is specifically aimed to support family caregivers of MHCUs in rural contexts in South Africa to ease the caregiving burden and promote the well-being of families. The study involves various experts, both locally and internationally, in the field of mental health. The multimethod approach uses diverse methods and ideas to provide answers to the research question. Triangulation of data sources enhanced credibility; knowledge was co-created by family members, stakeholders and mental health experts.

In phase I, the unique contribution was demonstrated with family members of MHCUs informing the designing of the program to achieve the best possible outcomes for MHCUs to mitigate the burden of care experienced by their family members. Family members were given a platform to share their lived experiences regarding caregiving and they described their physical, psychological, social, financial and spiritual healthcare needs, as well as their expectations from healthcare professionals.

In phase 2, different stakeholders from different organisations and communities were invited to participate in the development of the psychoeducational program. These include mental health practitioners, community leaders, traditional health practitioners, pastors and community health workers. The program is therefore based on the needs and suggestions of the community.

In phase 3, the psychoeducational the program was refined by an e-Delphi panel consisting of mental health experts chosen from different settings and geographical areas, nationally and internationally, as well as from government and non-governmental organisations.

The psychoeducational program can be used as a vehicle to ensure the implementation of the primary healthcare re-engineering model to render services to communities, families, and individuals. The program will improve access to mental health services and will facilitate the recovery of MHCUs and their families. The findings of the study provide insight into the negative impact of the burden of care on the quality of life of families. It is clear that there is a gap in the support offered to family members of MHCUs by healthcare providers. This implies that the implementation of psychoeducational program should be given priority in the health service agenda. The findings of this study will be disseminated during in-service training, workshops, seminars, research conferences and publications.

8.6 THE RECOMMENDATIONS OF THE STUDY

The researcher makes the following recommendations for nursing practice, nursing education, nursing management and future research.

8.6.1 Nursing practice

Based on the findings of the study, the following recommendations are made for nursing practice:

- Health care providers should build therapeutic alliances with family members caring for MHCUs during care, treatment and rehabilitation.
- Continued psychoeducational support for families caring for MHCUs should be provided by health care providers and community stakeholders.

- Capacity building of family members around the management of mental illness should be commenced as soon as the patient is diagnosed with mental illness.
- Family therapy and individual counselling should be available for families caring for MHCUs to enhance family coping, problem-solving, communication and crisis intervention skills.
- The psychoeducation programme needs to include social skills training such as communication skills, assertiveness skills, conflict resolution skills and decision-making skills. These will empower families to make informed decisions in the challenging situations they encounter while providing care to MHCUs.
- The programme should be implemented at hospital level by mental health nurses caring for short-term, medium-term and long-term stay MHCUs.
- Awareness campaigns about mental illness, with the aim of increasing mental health literacy and reducing the stigma attached to family members should involve community leaders.
- SAPS members must be educated as mandated by the Mental Health Care Act (No. 17 of 2002) to assist families during crises.
- Mental health care practitioners need to disseminate information about mental illness, its causes, prevention, various treatment options and the actions of the psychotropic drugs, including the side effects and their management.
- Mental health care practitioners should acknowledge MHCUs' spiritual needs and respect the beliefs of the family members caring for the MHCUs.
- Mental health care practitioners are required to encourage support from significant others to share in the caregiving burden.
- Mental health care practitioners need to lobby for government and non-government financial assistance for mental health programmes.
- MHCUs who qualify for permanent and temporary disability grants, should be identified to relieve the financial strain experienced by family members
- Early treatment seeking should be encouraged as this might facilitate the integration of MHCUs into society.
- Support groups for family caregivers of MHCUs should be encouraged and maintained.

8.6.2 Nursing management

Based on the findings of the study, the following recommendations are made for nursing management:

- Clinic managers must ensure the availability of psychotropic drugs for MHCUs in the community health centres.

- Managers should motivate for an increased number of nurses trained in mental health who will play the role of facilitators. Successful implementation of the program will require staff to be allocated specifically to the program without any additional duties.
- Clinic managers need to spearhead the rollout of the psychoeducational program through the provision of support and guidance to the facilitators of the program.
- Managers ought to ensure continuous workshops and in-service training to be provided to all healthcare providers and healthcare workers to improve their mental health literacy.
- Department of Health and Education needs to collaborate in reducing the stigma experienced by family caregivers in order to strengthen their self-esteem and create hope.
- Financial assistance should be lobbied for to sustain the psychoeducational program for supporting family members caring for MHCUs.
- Policies for family support and interventions must be formulated.

8.6.3 Nursing education

Based on the findings of the study, the following recommendations are made for nursing education:

- The inclusion of psychosocial interventions to support family members caring for MHCUs in the general nursing curricula.
- Nursing education institutions should roll out a one-year postgraduate diploma program to provide opportunities for general nurses to further their studies in mental health nursing to mitigate the shortage of mental health nurses.
- In response to the increased burden caused by mental health problems, training nurses in mental health nursing should be given priority.
- Training institutions need to provide continuing professional education in the integration of mental health into primary health care services.
- Development of a basic mental health literacy program so that new graduates will be in a better position to address the psychosocial needs of family members.
- Advanced mental health nurse practitioners must adopt a role of capacity building of the less experienced and non-mental health nurses.
- Nursing education institutions ought to provide short courses in mental health literacy to improve knowledge and understanding of mental illness by the health care providers in different health care settings.

- The integration of mental health nursing in general, midwifery and community health science programs to promote the mental health of individuals, families and the community at large.

8.6.4 Nursing research

Based on the findings of the study, the following recommendations are made for future research:

- The implementation of psychoeducational program interventions and evaluation of their effects on the MHCUs' recovery process.
- The views of healthcare providers regarding psychoeducational programmes for family members caring for MHCUs.
- The barriers and facilitators to the uptake of a family psychoeducational programme in primary healthcare facilities.
- Quantitative research to determine the healthcare needs of family members caring for MHCUs in bigger populations.
- The views of family members regarding psychosocial family support interventions for the improvement of their mental health literacy.
- Coping strategies used by family members caring for MHCUs in low-and middle-income countries.

8.7 CONCLUSION

The chapter presents the unique contribution, limitations and recommendations of the study. The study may enable mental health care practitioners to provide a holistic service to family members, thereby contributing to mental wellness in the South African population.

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ANNEXURE A

PHASE 1: INFORMATION TO PARTICIPANTS & INFORMED CONSENT DOCUMENT

STUDY TITLE: DEVELOPMENT OF A PSYCHO-EDUCATION PROGRAM TO SUPPORT FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS IN VHEMBE DISTRICT IN LIMPOPO PROVINCE.

Principal Investigator: MRS MBEDZI, TE
Supervisor: DR AE VAN DER WATH
Co-supervisor: DR MM MOAGI
Institution: UNIVERSITY OF PRETORIA
DAYTIME AND AFTER-HOURS TELEPHONE NUMBER(S):
Daytime number/s: Tel (015) 962 8679
After-hours number: 0839876045 / 0722114780
DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

Date	**Month**	**Year**		**Time**

Dear Prospective Participant
Dear Mr. / Mrs. ....………………………

1) INTRODUCTION

You are invited to volunteer for a research study. I am doing this research for PhD degree purposes at the University of Pretoria. This document gives information about the study to help you decide if you would like to participate. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about what we will be discussing during the interview.

2) THE NATURE AND PURPOSE OF THIS STUDY

The aim of this study is to develop a psycho-educational program to support family members caring for mental health care users in Vhembe district, Limpopo province. By doing so I wish to learn more about challenges experienced amongst family members providing care to mental health care users. You will be interviewed by the researcher in a place that is private and easy for you to reach.

3) EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPECTED FROM THE PARTICIPANTS

Phase one of this study comprises exploration of challenges experienced by family members. The findings will lead to the development of a psychoeducation program to support family members caring for the mental health care users. If you agree to participate, you will be asked to participate in an individual interview which will take about 45 minutes. The individual interview will be a one-on-one meeting between the two of us. I will ask you several questions about the research topic. With your permission, the interview will be recorded on a recording device to ensure that no information is missed.

4) RISKS AND DISCOMFORTS INVOLVED?

We do not think that taking part in the study will cause any physical or emotional discomfort or risk. The only possible risk and discomfort involved is that if questions feel too personal or makes you uncomfortable, you do not have to answer them. The treatment of the mental health care user will not affected in any way, whether you choose to participate in the study or not.

5) POSSIBLE BENEFITS OF THE STUDY

You will not benefit directly by being part of this study. But your participation is important for us to better understand the challenges experienced by family members providing care to mental health care users. The information you give may help the researcher to improve the provision of care to mental health care users in collaboration with family members.

6) COMPENSATION

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

7) VOLUNTARY PARTICIPATION

The decision to take part in the study is yours and yours alone. You do not have to take part if you do not want to. You can also stop at any time during the interview without giving a reason. If you refuse to take part in the study, this will not affect you in any way.

8) ETHICAL APPROVAL

This study was submitted to the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria, Medical Campus, Tswelopele Building, Level 4-59, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been given by that committee. The study will follow the Declaration of Helsinki (last update: October 2013), which guides doctors on how to do research in people. The researcher can give you a copy of the Declaration if you wish to read it.

9) INFORMATION ON WHO TO CONTACT

If you have any questions about this study, you should contact:

Dr A.E van der Wath at 012 3563172 and Dr M.M Moagi at 012 3563152.

10) CONFIDENTIALITY

We will not record your name anywhere and no one will be able to connect you to the answers you give. Your answers will be linked to a fictitious code number or a pseudonym (another name) and we will refer to you in this way in the data, any publication, report or other research output. All records from this study will be regarded as confidential. Results will be published in medical journals or presented at conferences in such a way that it will not possible for people to know that you were part of the study. The records from your participation may be reviewed by people responsible for making sure that research is done properly, including members of the Research Ethics Committee. All these people are required to keep your identity confidential. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records. All hard copy information will be kept in a locked facility at Department of Health Sciences at the University of Pretoria, for a minimum of 15 years and only the research team will have access to this information.

11) CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalised in any way should I wish to stop taking part in the study and my withdrawal will not affect my treatment and care.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.

___________________________________	_________________________
Participant’s name (Please print)	Date
___________________________________	_________________________
Participant’s signature	Date
___________________________________	_________________________
Researcher’s name (Please print)	Date
___________________________________	_________________________
Researcher’s signature	Date

ANNEXURE B

PHASE 2: INFORMATION TO PARTICIPANTS & INFORMED CONSENT DOCUMENT

Study title: DEVELOPMENT OF A PSYCHO-EDUCATION PROGRAM TO SUPPORT FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS IN VHEMBE DISTRICT IN LIMPOPO PROVINCE.

Principal Investigator: MRS MBEDZI, TE
Supervisor: DR AE VAN DER WATH
Co-supervisor: DR MM MOAGI
Institution: UNIVERSITY OF PRETORIA
DAYTIME AND AFTER-HOURS TELEPHONE NUMBER(S):
Daytime number/s: Tel (015) 962 8679
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DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

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Dear Prospective Participant

Dear Mr. / Mrs. ....

1) INTRODUCTION

You are invited to volunteer for a research study. I am doing this research for PhD degree purposes at the University of Pretoria. This document gives information about the study to help you decide if you would like to participate. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about what we will be discussing during the interview.

2) THE NATURE AND PURPOSE OF THIS STUDY

The aim of this study is to develop a psycho-educational program to support family members caring for mental health care users in Vhembe district, Limpopo province. You will be invited to attend a one-day workshop through the permission of the district manager coordinating mental health services in the Vhembe district Limpopo Province. The researcher will present the findings of phase one first to familiarise the participant with the overall aim of the study.

The researcher will facilitate the NGT with the help of an assistant researcher. By doing so I wish you together with other stakeholders to generate ideas on the development of a psychoeducational program for family members caring for MHCUs

3) EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPECTED FROM THE PARTICIPANTS

Phase two will commence with stakeholders, workshop. If you agree to be part of the study you be requested to attend a workshop which will take about three hours. The researcher will the purpose and the objectives of the study and present the findings of phase one first to familiarise the participant with the overall aim of the study through PowerPoint presentation.

The researcher will facilitate the NGT with the help of an assistant researcher. As a group member of the NGT you will asked to generate ideas on the development of a psychoeducational program for family members caring for MHCUs. The researcher will provide each participant with a sheet of paper with questions to be addresses and ask them to write down all ideas that comes to mind.

The group members will assess each idea suggested and assign a rating then give a score rated and the items with the highest scores will be included in the program. Data emanated from the group decision making process will be used to guide development of a family psychoeducational program.

4) RISKS AND DISCOMFORTS INVOLVED?

We do not think that taking part in the study will cause any physical or emotional discomfort or risk.

5) POSSIBLE BENEFITS OF THE STUDY

You will not benefit directly by being part of this study. But your participation is important for us to in that a psycho-education program will be developed to assist family members caring for the MHCUs.

6) COMPENSATION

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

7) VOLUNTARY PARTICIPATION

The decision to take part in the study is yours and yours alone. You do not have to take part if you do not want to. You can also stop at any time during the interview without giving a reason. If you refuse to take part in the study, this will not affect you in any way.

8) ETHICAL APPROVAL

This study was submitted to the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria, Medical Campus, Tswelopele Building, Level 4-59, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been given by that committee. The study will follow the Declaration of Helsinki (last update: October 2013), which guides doctors on how to do research in people. The researcher can give you a copy of the Declaration if you wish to read it.

9) INFORMATION ON WHO TO CONTACT

If you have any questions about this study, you should contact:

Dr A.E van der Wath at 012 3563172 and Dr M.M Moagi at 012 3563152.

10) CONFIDENTIALITY

We will not record your name anywhere and no one will be able to connect you to the answers you give. Your answers will be linked to a fictitious code number or a pseudonym (another name) and we will refer to you in this way in the data, any publication, report or other research output. All records from this study will be regarded as confidential. Results will be published in medical journals or presented at conferences in such a way that it will not possible for people to know that you were part of the study. The records from your participation may be reviewed by people responsible for making sure that research is done properly, including members of the Research Ethics Committee. All these people are required to keep your identity confidential. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

All hard copy information will be kept in a locked facility at Department of Health Sciences at the University of Pretoria, for a minimum of 15 years and only the research team will have access to this information.

11) CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalised in any way should I wish to stop taking part in the study and my withdrawal will not affect my treatment and care.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.

________________________________	________________________
Participant's name (Please print)	Date
________________________________	________________________
Participant's signature	Date
________________________________	________________________
Researcher's name (Please print)	Date
________________________________	________________________
Researcher's signature	Date

ANNEXURE C

PHASE 3: INFORMATION TO PARTICIPANTS & INFORMED CONSENT DOCUMENT

STUDY TITLE: DEVELOPMENT OF A PSYCHO-EDUCATION PROGRAM TO SUPPORT FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS IN VHEMBE DISTRICT IN LIMPOPO PROVINCE.

Principal Investigator: MRS MBEDZI, TE
Supervisor: DR AE VAN DER WATH
Co-supervisor: DR MM MOAGI
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DAYTIME AND AFTER-HOURS TELEPHONE NUMBER(S):
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DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

Date	**Month**	**Year**		**Time**

Dear Prospective Participant

Dear Mr. / Mrs. ....………………………

1) INTRODUCTION

You are invited to volunteer for a research study. I am doing this research for PhD degree purposes at the University of Pretoria. This document gives information about the study to help you decide if you would like to participate. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about what we will be discussing during the interview.

2) THE NATURE AND PURPOSE OF THIS STUDY

The aim of this study is to develop a psycho-educational program to support family members caring for mental health care users in Vhembe district, Limpopo province. You are invited to participate in the refinement and validation of a draft a psycho-education program developed to support family members caring for MHCUs. As a result, a more comprehensive family focused psycho-education program which addresses the psychosocial needs of families in line with the principles of primary health care program will be developed.

3) EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPECTED FROM THE PARTICIPANTS

In phase three the objective of refinement and validated is addressed by invitation of the experts from national and international countries, nongovernmental institutions and government institutions in the field of mental health are expected to participate in the process. It is expected that not more than two rounds of the Delphi will be sufficient to obtain consensus on the content of the program.

You will be requested to read thoroughly the draft program then rate the program in accordance with the given criteria and write comments on the space provided. Your ratings and comments will be compared with the work done by fellow experts. You will be asked to complete the biographical information in the first section of the instrument by providing descriptive information of your professional and academic experience. This will enable the researcher to describe the sample. No names or identities will be revealed in the research report or publications. The refinement process should take approximately 1 hour to complete. The Delphi process will take at least two rounds; you will be expected to respond within a period of one to two weeks in each round. Your participation and comments will be highly appreciated. Comments received in round one will be analysed and collated for further validation in round two. Attached is a consent form that should be returned with the draft support program should you agree to participate in the study. You will be expected to scan and send back the last signed page of the consent form to the researcher per e-email with related support program.

4) RISKS AND DISCOMFORTS INVOLVED?

We do not think that taking part in the study will cause any physical or emotional discomfort or risk.

5) POSSIBLE BENEFITS OF THE STUDY

You will not benefit directly by being part of this study. But your participation is important for us to enable the development of in that a psycho-education program to support family members caring for the MHCUs.

6) COMPENSATION

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

7) VOLUNTARY PARTICIPATION

The decision to take part in the study is yours and yours alone. You do not have to take part if you do not want to. You can also stop at any time during the interview without giving a reason. If you refuse to take part in the study, this will not affect you in any way.

8) ETHICAL APPROVAL

This study was submitted to the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria, Medical Campus, Tswelopele Building, Level 4-59, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been given by that committee. The study will follow the Declaration of Helsinki (last update: October 2013), which guides doctors on how to do research in people. The researcher can give you a copy of the Declaration if you wish to read it.

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Dr A.E van der Wath at 012 3563172 and Dr M.M Moagi at 012 3563152.

10) CONFIDENTIALITY

We will not record your name anywhere and no one will be able to connect you to the answers you give. Your answers will be linked to a fictitious code number or a pseudonym (another name) and we will refer to you in this way in the data, any publication, report or other research output. All records from this study will be regarded as confidential. Results will be published in medical journals or presented at conferences in such a way that it will not possible for people to know that you were part of the study.

The records from your participation may be reviewed by people responsible for making sure that research is done properly, including members of the Research Ethics Committee. All these people are required to keep your identity confidential. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

All hard copy information will be kept in a locked facility at Department of Health Sciences at the University of Pretoria, for a minimum of 15 years and only the research team will have access to this information.

11) CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalized in any way should I wish to stop participating in the study and my withdrawal will not affect my treatment and care.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.

____________________________ ____________________

Participant’s name (Please print) Date

____________________________ ____________________

Participant’s signature Date

____________________________ ____________________

Researcher’s name (Please print) Date

____________________________ ____________________

Researcher’s signature Date

ANNEXURE D
PHASE 1: INTERVIEW GUIDE

In-depth one-on-one interviews will be conducted during phase one. The researcher will spend 30 to 45 minutes with the family members of mental health care users during the interview. The interview will be directed by the three broad questions followed by probing.

- What are your needs regarding caregiving to your family member with mental illness?
- What are your challenges with regard to the care of your family member diagnosed with mental illness?
- What kind of support do you need to help you cope with the caregiving responsibility?

ANNEXURE E

PHASE 2: NOMINAL GROUP TECHNIQUE GUIDE

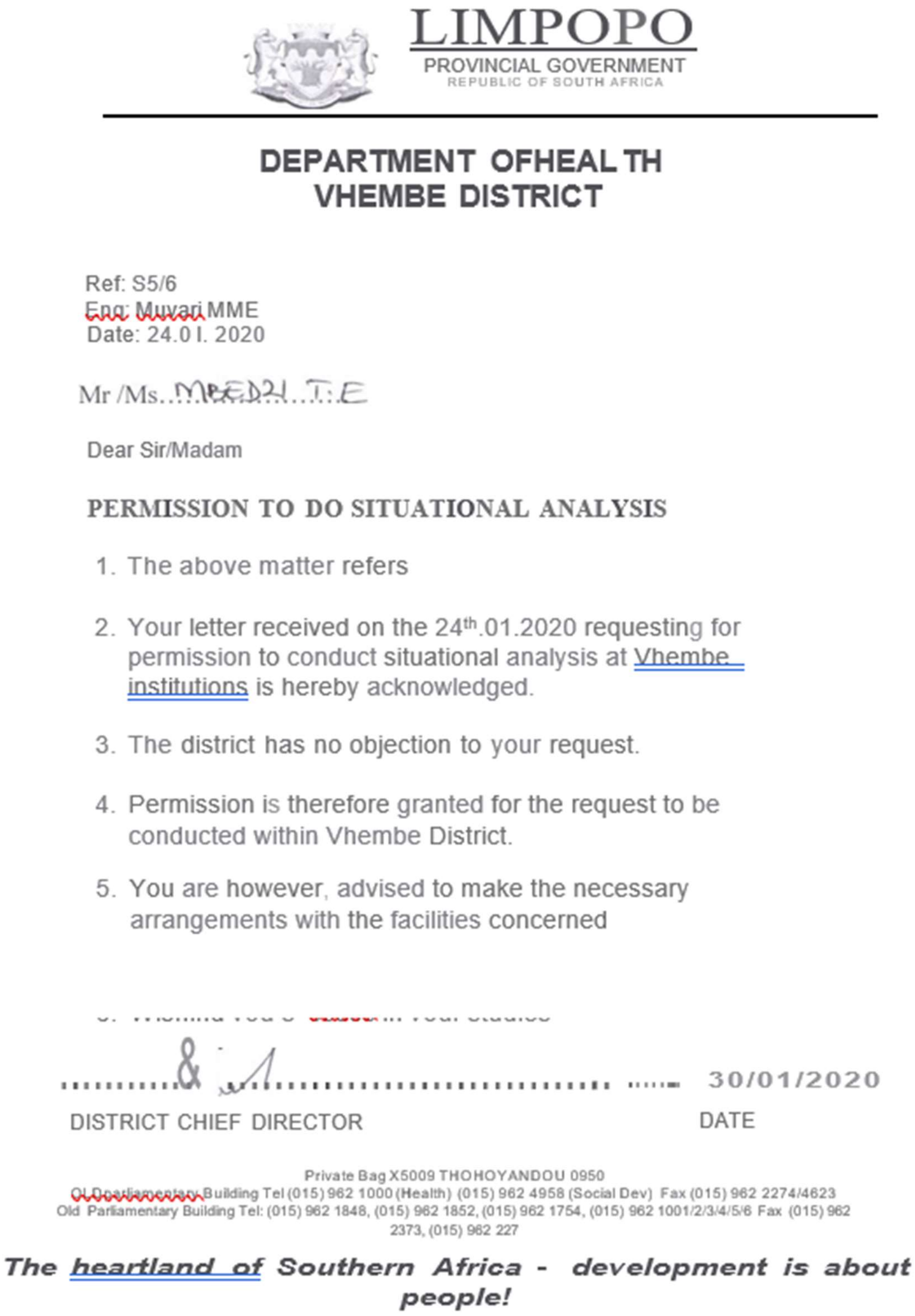
Stakeholders who are involved in the care, treatment and rehabilitation of mental health care users and their family members will be involved in a one-day workshop. The researcher will spend more than 60 minutes with the participants during the session.

The stakeholder brainstormed ideas in relation to how best we can meet the healthcare needs of family members caring for the mental health care users in order to assist with drafting of psychoeducational problem. This will be based on the findings of data collected from family members in Phase 1. The following main research question will be used as a guide: How can a psycho-educational program to support family members caring for MHCUs in Vhembe district, Limpopo province be developed?

PSYCHOLOGICAL	**GOALS**
▪ How can the program establish a provider-family therapeutic relationship?	(address feelings of helplessness, hopelessness, shame, fear, powerlessness, distress, loss, depression) (shared responsibility between family and health care providers)
▪ How can the program facilitate psychological counselling?	
▪ How can the program facilitate effective/healthy coping with caregiving demands/challenges (empowerment with various skills)?	
SOCIAL	
• How can the program assist families to generate social support?	(social and community support)
• How can the program address stigmatization and discrimination?	
• How can the program address the problems with assistance from the South African Police Service during crisis?	
PHYSICAL	
• How can the program address a need for physical health support?	
FINANCIAL	
• How can the program address financial needs?	(permanent disability grant, employment opportunities for MHCUs, suitable housing)
INFORMATIONAL	
• How can the program facilitate knowledge on mental illness?	(causes, signs and symptoms, course, prognosis, treatment options, early warning signs of relapse and its management, management of day-to-day challenging behaviors, substance abuse, medication adherence, side-effects and management thereof.
SPIRITUAL	
• How can the program accommodate spiritual needs?	(traditional practitioner consultation and pastoral support care)
HEALTH CARE	
• How can the program enhance the provision of community-based psychiatric rehabilitation?	(sufficient resources)
• How can the program ensure availability of appropriate psychotropic medications at the community health centers?	
• How can the program accommodate home visits by healthcare providers?	

ANNEXURE F

INSTITUTIONAL APPROVALS



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OFHEAL TH
VHEMBE DISTRICT

Ref: S5/6
Enq: Muvari MME
Date: 24.0 I. 2020

Mr /Ms..MBEDZI...T.E

Dear Sir/Madam

PERMISSION TO DO SITUATIONAL ANALYSIS

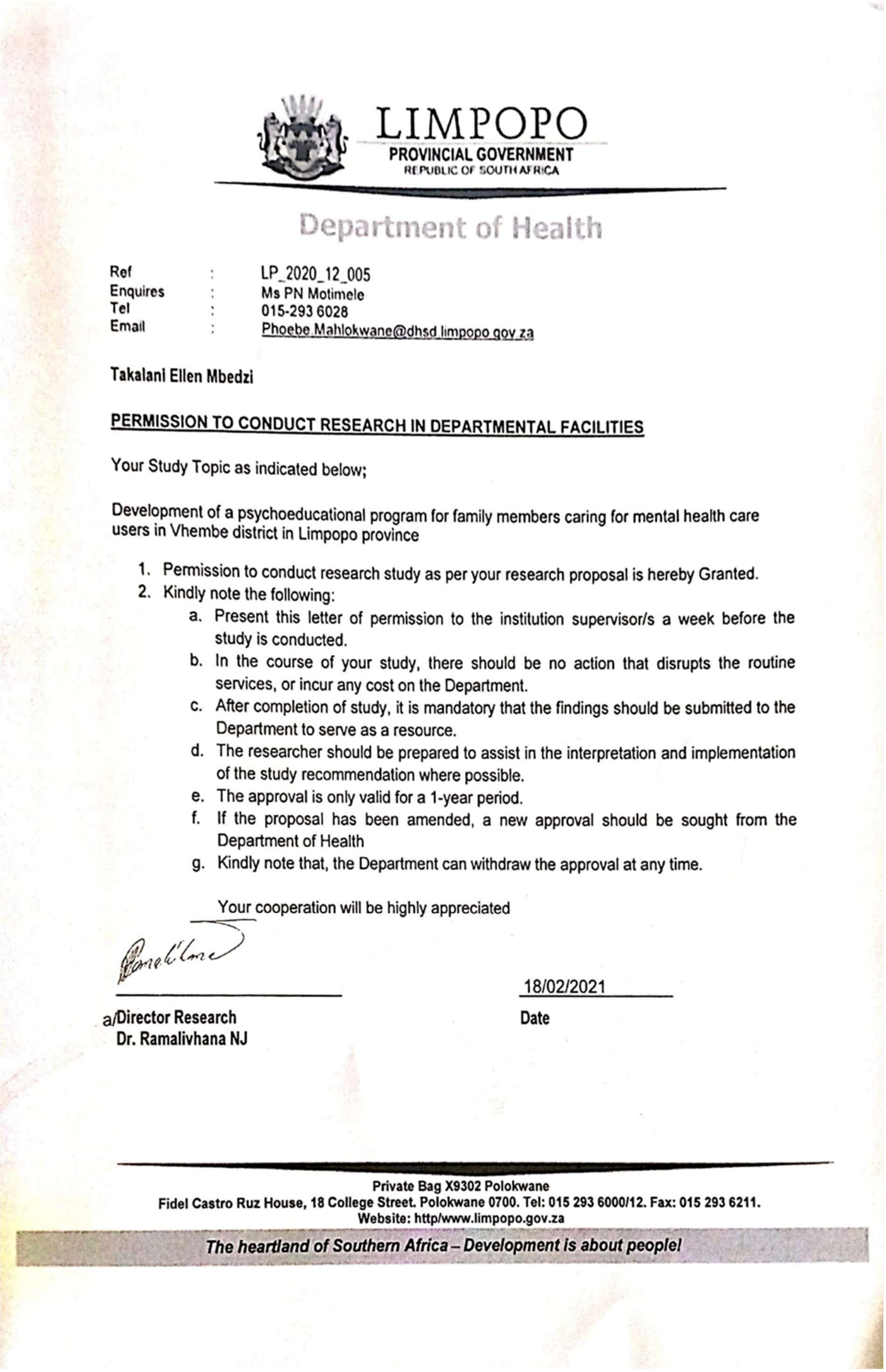
1. The above matter refers
2. Your letter received on the 24th.01.2020 requesting for permission to conduct situational analysis at Vhembe institutions is hereby acknowledged.
3. The district has no objection to your request.
4. Permission is therefore granted for the request to be conducted within Vhembe District.
5. You are however, advised to make the necessary arrangements with the facilities concerned

30/01/2020

DISTRICT CHIEF DIRECTOR DATE

Private Bag X5009 THOHOYANDOU 0950
OLDparliamentary 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 2373, (015) 962 227

The heartland of Southern Africa - development is about people!



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Department of Health

Ref : LP_2020_12_005
Enquires : Ms PN Motimele
Tel : 015-293 6028
Email : Phoebe.Mahlokwane@dhsd.limpopo.gov.za

Takalani Ellen Mbedzi

PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES

Your Study Topic as indicated below;

Development of a psychoeducational program for family members caring for mental health care users in Vhembe district in 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

18/02/2021

a/Director Research
Dr. Ramalivhana NJ

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

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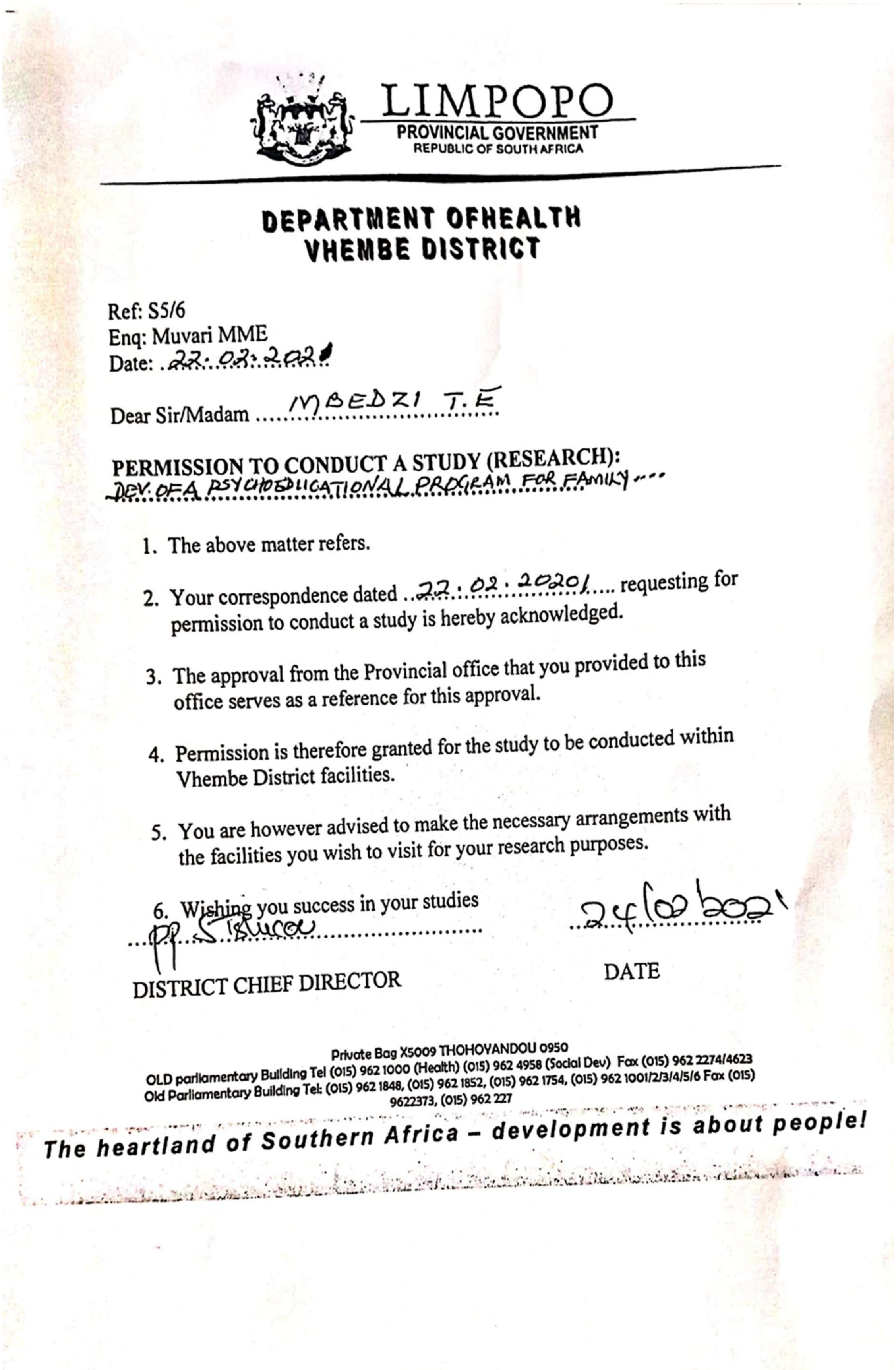

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OFHEALTH
VHEMBE DISTRICT

Ref: S5/6
Enq: Muvari MME
Date: 22.02.2021

Dear Sir/Madam MBEDZI T.E

PERMISSION TO CONDUCT A STUDY (RESEARCH):
DEV. OF A PSYCHOEDUCATIONAL PROGRAM FOR FAMILY....

1. The above matter refers.
2. Your correspondence dated 22.02.20201 requesting for permission to conduct a study is hereby acknowledged.
3. The approval from the Provincial office that you provided to this office serves as a reference for this approval.
4. Permission is therefore granted for the study to be conducted within Vhembe District facilities.
5. You are however advised to make the necessary arrangements with the facilities you wish to visit for your research purposes.
6. Wishing you success in your studies

pp

DISTRICT CHIEF DIRECTOR

24/02/2021

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) 9622373, (015) 962 227

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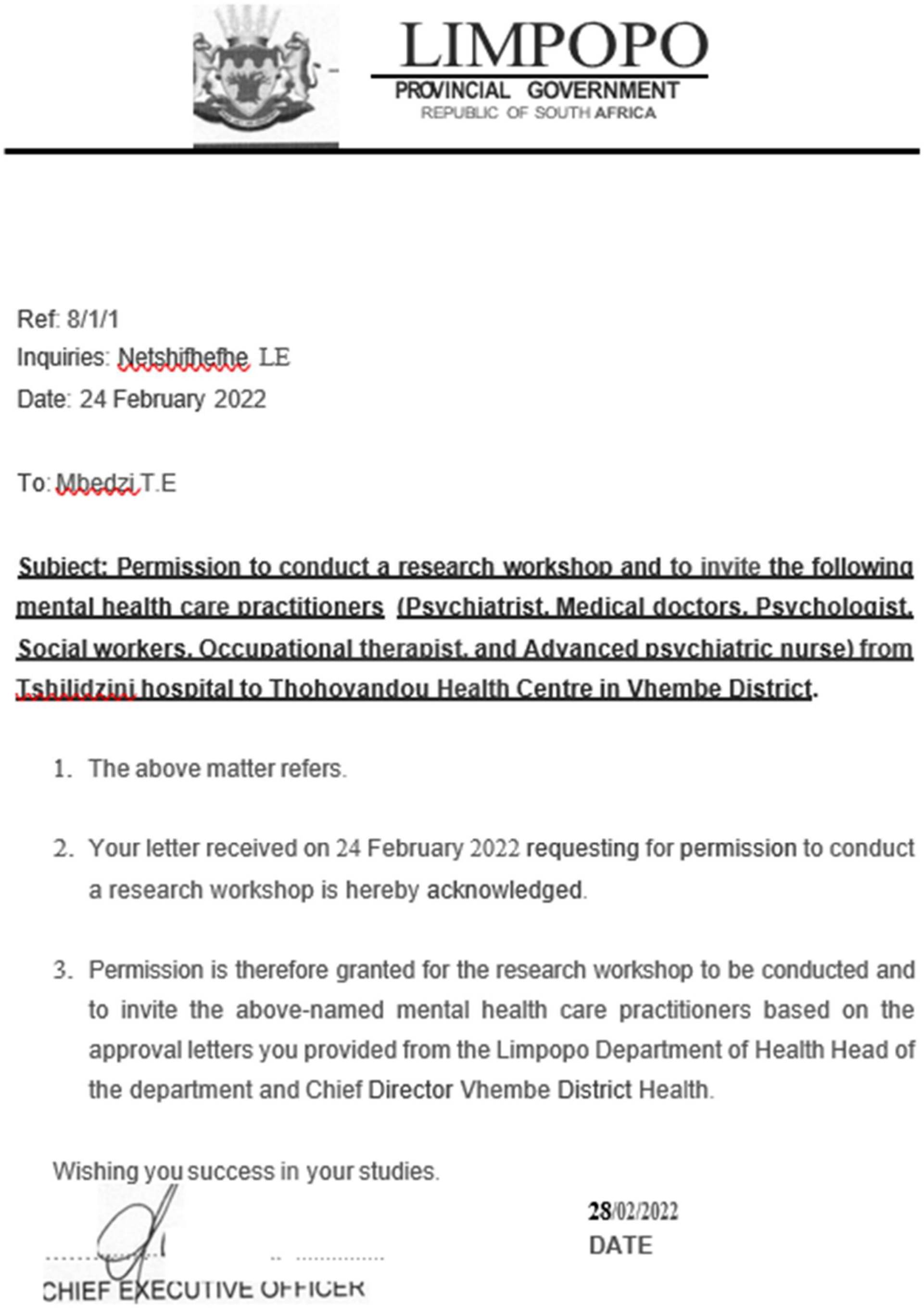


LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Ref: 8/1/1
Inquiries: Netshifhefhe. LE
Date: 24 February 2022

To: Mbedzi T.E

Subject: Permission to conduct a research workshop and to invite the following mental health care practitioners (Psychiatrist, Medical doctors, Psychologist, Social workers, Occupational therapist, and Advanced psychiatric nurse) from Tshilidzini hospital to Thohoyandou Health Centre in Vhembe District.

1. The above matter refers.

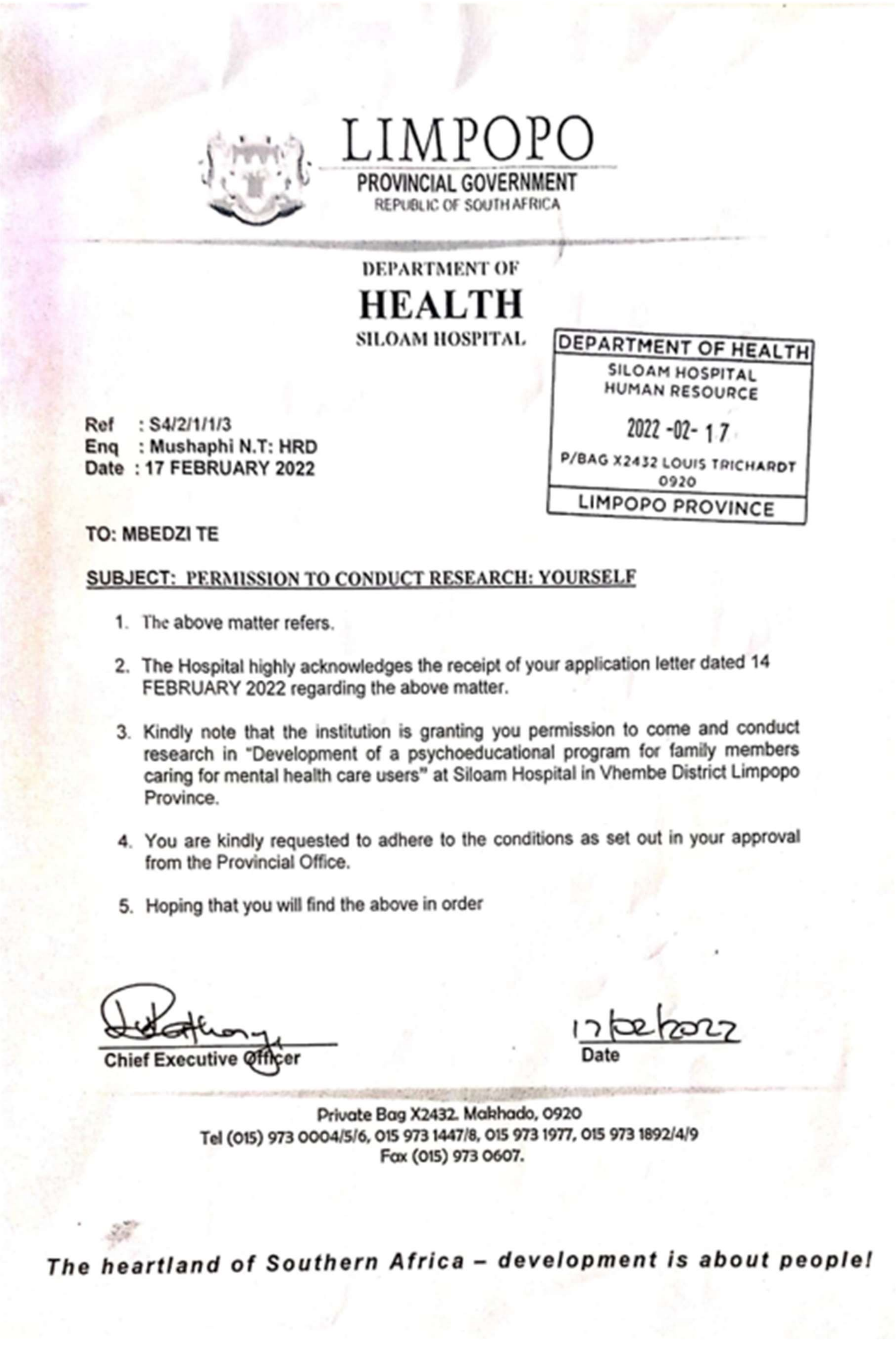
2. Your letter received on 24 February 2022 requesting for permission to conduct a research workshop is hereby acknowledged.

3. Permission is therefore granted for the research workshop to be conducted and to invite the above-named mental health care practitioners based on the approval letters you provided from the Limpopo Department of Health Head of the department and Chief Director Vhembe District Health.

Wishing you success in your studies.

CHIEF EXECUTIVE OFFICER

28/02/2022
DATE



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF
HEALTH
SILOAM HOSPITAL

DEPARTMENT OF HEALTH
SILOAM HOSPITAL
HUMAN RESOURCE
2022 -02- 17
P/BAG X2432 LOUIS TRICHARDT
0920
LIMPOPO PROVINCE

Ref : S4/2/1/1/3
Enq : Mushaphi N.T: HRD
Date : 17 FEBRUARY 2022

TO: MBEDZI TE

SUBJECT: PERMISSION TO CONDUCT RESEARCH: YOURSELF

1. The above matter refers.
2. The Hospital highly acknowledges the receipt of your application letter dated 14 FEBRUARY 2022 regarding the above matter.
3. Kindly note that the institution is granting you permission to come and conduct research in "Development of a psychoeducational program for family members caring for mental health care users" at Siloam Hospital in Vhembe District Limpopo Province.
4. You are kindly requested to adhere to the conditions as set out in your approval from the Provincial Office.
5. Hoping that you will find the above in order

Chief Executive Officer

17/02/2022
Date

Private Bag X2432, Makhado, 0920
Tel (015) 973 0004/5/6, 015 973 1447/8, 015 973 1977, 015 973 1892/4/9
Fax (015) 973 0607.

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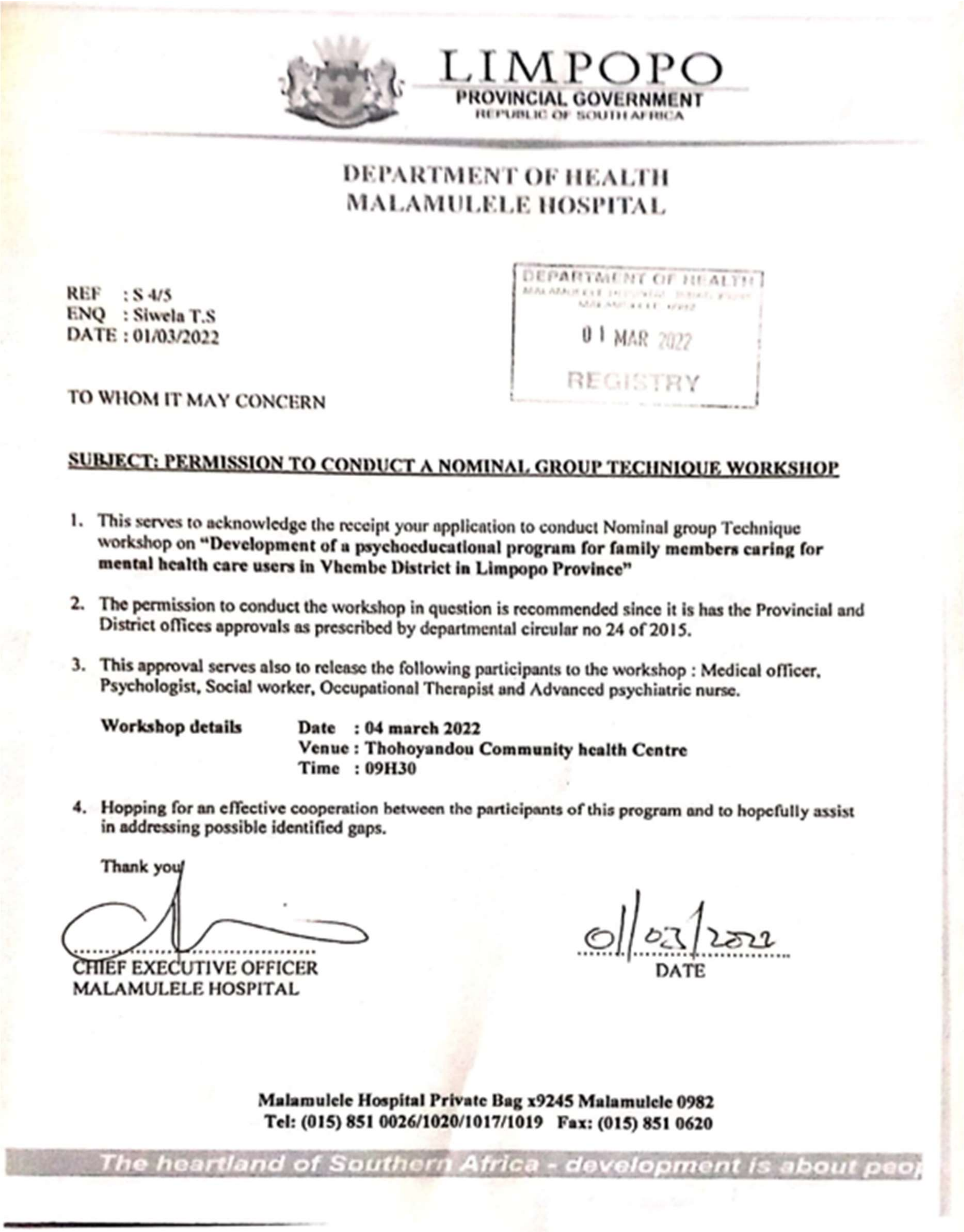

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
MALAMULELE HOSPITAL

REF : S 4/5
ENQ : Siwela T.S
DATE : 01/03/2022

DEPARTMENT OF HEALTH
01 MAR 2022
REGISTRY

TO WHOM IT MAY CONCERN

SUBJECT: PERMISSION TO CONDUCT A NOMINAL GROUP TECHNIQUE WORKSHOP

1. This serves to acknowledge the receipt your application to conduct Nominal group Technique workshop on **"Development of a psychoeducational program for family members caring for mental health care users in Vhembe District in Limpopo Province"**
2. The permission to conduct the workshop in question is recommended since it is has the Provincial and District offices approvals as prescribed by departmental circular no 24 of 2015.
3. This approval serves also to release the following participants to the workshop : Medical officer, Psychologist, Social worker, Occupational Therapist and Advanced psychiatric nurse.

Workshop details
Date : 04 march 2022
Venue : Thohoyandou Community health Centre
Time : 09H30

4. Hopping for an effective cooperation between the participants of this program and to hopefully assist in addressing possible identified gaps.

Thank you

CHIEF EXECUTIVE OFFICER
MALAMULELE HOSPITAL

01/03/2022
DATE

Malamulele Hospital Private Bag x9245 Malamulele 0982
Tel: (015) 851 0026/1020/1017/1019 Fax: (015) 851 0620

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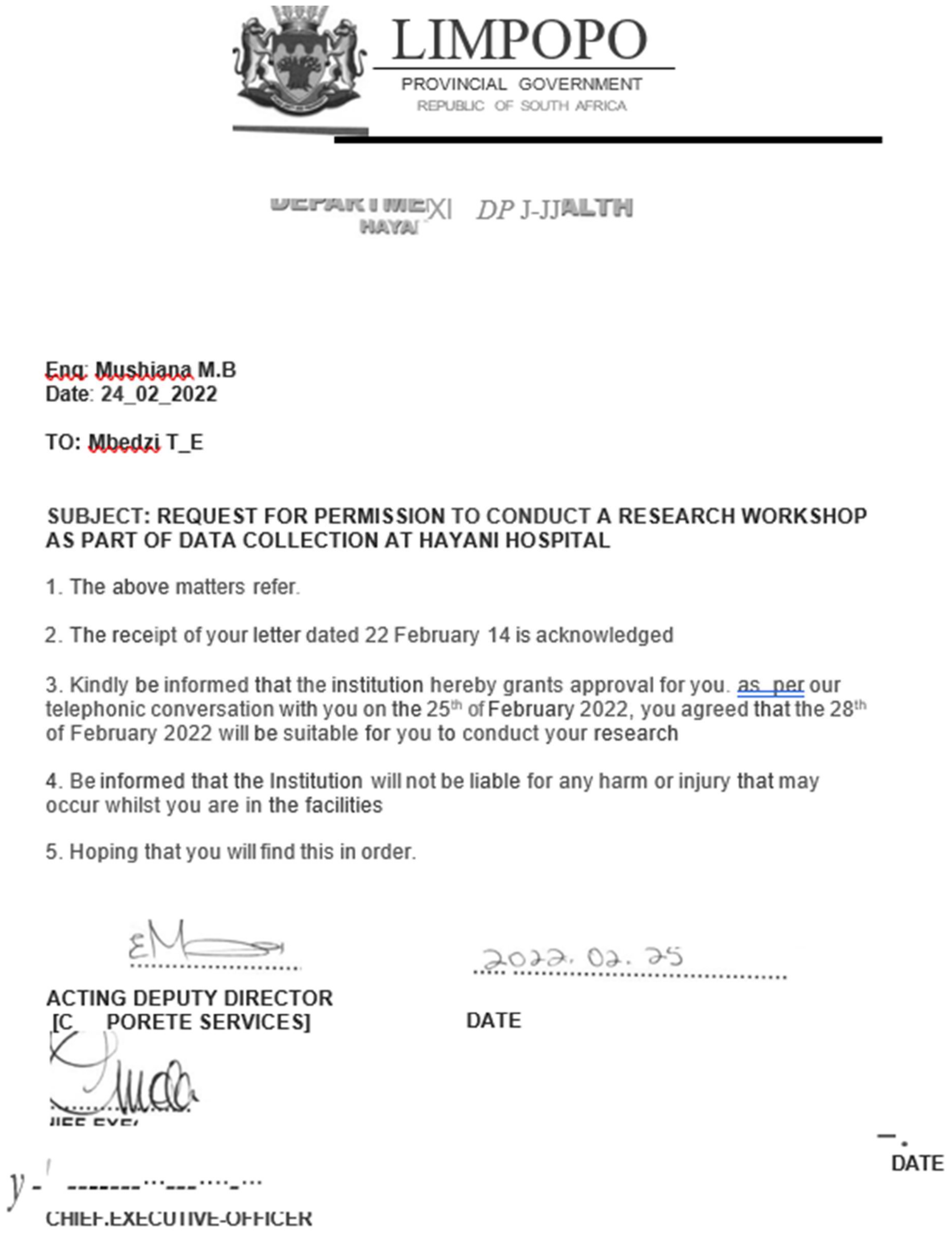


LIMPOPO

PROVINCIAL GOVERNMENT

REPUBLIC OF SOUTH AFRICA

DEPARTMEXI DP J-JJALTH

HAYAI

Enq: Mushiana M.B
Date: 24_02_2022

TO: Mbedzi T_E

SUBJECT: REQUEST FOR PERMISSION TO CONDUCT A RESEARCH WORKSHOP AS PART OF DATA COLLECTION AT HAYANI HOSPITAL

1. The above matters refer.

2. The receipt of your letter dated 22 February 14 is acknowledged

3. Kindly be informed that the institution hereby grants approval for you. as per our telephonic conversation with you on the 25th of February 2022, you agreed that the 28th of February 2022 will be suitable for you to conduct your research

4. Be informed that the Institution will not be liable for any harm or injury that may occur whilst you are in the facilities

5. Hoping that you will find this in order.

2022. 02. 25

ACTING DEPUTY DIRECTOR
[C PORETE SERVICES]

DATE

JIEF EXE/

DATE

CHIEF.EXECUTIVE-OFFICER

ANNEXURE G

ETHICAL APPROVAL

Institution: The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
- FWA 00002567, Approved dd 18 March 2022 and Expires 18 March 2027.
- IORG #: IORG0001762 OMB No. 0990-0278 Approved for use through August 31, 2023.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences

Faculty of Health Sciences **Research Ethics Committee**

13 August 2022

Approval Certificate Annual Renewal

Dear Mrs TE Mbedzi,

Ethics Reference No.: 674/2020 – Line 3

Title: DEVELOPMENT OF A PSYCHOEDUCATIONAL PROGRAM FOR FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS IN VHEMBE DISTRICT IN LIMPOPO PROVINCE

The **Annual Renewal** as supported by documents received between 2022-07-15 and 2022-08-10 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on 2022-08-10 as resolved by its quorate meeting.

Please note the following about your ethics approval:

- Renewal of ethics approval is valid for 1 year, subsequent annual renewal will become due on 2023-08-13.
- Please remember to use your protocol number (674/2020) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

On behalf of the FHS REC, Dr R Sommers
MBChB, MMed (Int), MPharmMed, PhD
Deputy Chairperson *of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria*

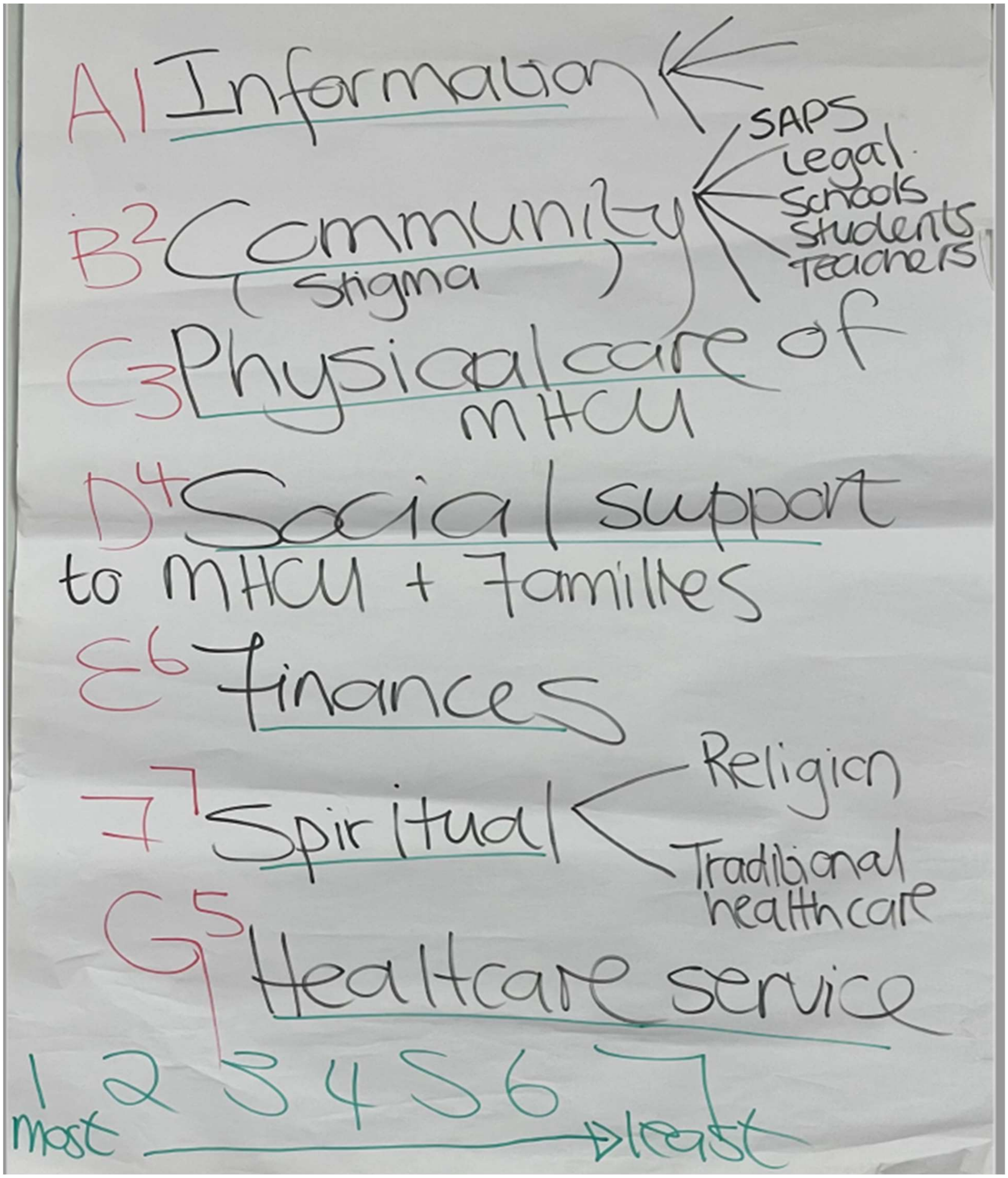
The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health)

ANNEXURE H

PHASE 2: NOMINAL GROUP TECHNIQUE

NOMINAL GROUP TECHNIQUE WORKSHOP PROGRAM
DATE: 2022/03/04
VENUE: THOHOYANDOU HEALTH CENTRE

1. OPENING PRAYER:
2. PURPOSE AND WELCOME:
3. INTRODUCTION: ALL
4. PRESENTATION OF THE RESEARCH FINDINGS:
5. NOMINAL GROUP TECHINIQUE PROCESS:
6. WAY FORWARD:
7. ANNOUNCEMENT:
8. CLOSING PRAYER:



A1 Information ←

SAPS
Legal
Schools
Students
Teachers

B2 Community
(Stigma)

C3 Physical care of MHCU

D4 Social support
to MHCU + families

E6 finances

F7 Spiritual

Religion
Traditional healthcare

G5 Healtcare service

1 2 3 4 5 6 7
most → least

	SECTION A: Demographic information				
1.	What is your gender	Male		Female	
2.	How old are you?	Years			
3.	What is your home language	Tshivenda			
		Xitsonga			
		Sepedi			
		Other			
	If other, please indicate				
4.	Indicate your current position	District manager			
		Clinic manager			
		Lecturer			
		Psychiatrists			
		Medical doctor			
		Psychologist			
		Social worker			
		Occupational therapist			
		Registered professional nurse			
		OTHER			
	IF other please specify				
5.	Indicate your highest qualification	Certificate			
		Diploma			
		Master's degree			
		Doctoral degree			
6.	Years of experience in provision of health care to the mental health care users and their families.	No. of years			

ANNEXURE I

PHASE 3: DELPHI TECHNIQUE

Dear Expert Participant

INVITATION TO PARTICIPATE IN THE STUDY: DEVELOPMENT OF A PSYCHO-EDUCATIONAL PROGRAM TO SUPPORT FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS IN VHEMBE DISTRICT, LIMPOPO PROVINCE, SOUTH AFRICA

I am a Ph.D. student in the Department of Nursing Science, Faculty of Health Sciences at the University of Pretoria. I am conducting the abovementioned study under the supervision of Profs A van der Wath, and M Moagi.

The objectives that formed the basis of this study are indicated in the table according to the three study phases:

PHASE 1	
Objective 1	To explore and describe the needs of family members caring for mental health care users (MHCUs) in Vhembe district, Limpopo province, South Africa.
PHASE 2	
Objective 2	To develop a psycho-education program to support family members caring for MHCUs in Vhembe district, Limpopo province, South Africa.
PHASE 3	
Objective 3	Refine and validate a psycho-educational program to support family members caring for MHCUs using an e-Delphi technique

Phase 1

A qualitative approach was adopted to explore and describe the needs of family members caring for mental health care users at home in Vhembe District in Limpopo Province. Semi-structured one-on-one individual interviews were used to collect data from 16 participants to address the first objective. The interviews with family members was directed by three broad questions followed by probing.

- What are your needs regarding caregiving to your family member with mental illness?
- What are your challenges with regard to care of your family member diagnosed with mental illness?
- What kind of support do you need to help you cope with the caregiving responsibility?

The findings revealed the essence of family members caring experiences, experiences of health care needs and the kind of support needed to meet their physical, social, psychological and social needs. The support needed from others was significant for all the participants and was considered to play a valuable role in the emotional, spiritual and physical functioning of families caring for MHCUs.

Phase 2

A range of stakeholders were invited to attend a one-day workshop. The researcher facilitated the nominal group technique workshop with the help of the supervisor of this research project, who played the role of a moderator. The researcher presented the findings of phase 1 first to familiarise the participants with the study. The groups generated ideas on the development of a psychoeducational program for family members caring for MHCUs. The analysis of data and used a combination of both qualitative and quantitative methods. The draft psychoeducational program was formulated from the empirical data of Phase 1 and Phase 2 and a literature synthesis.

Phase 3

You are invited to participate in Phase 3 which involves refining the psychoeducational program using a Delphi technique through gaining consensus among a group of mental health experts. The evaluation of the program requires three activities:

1. Section1: Complete the last page of the informed consent if you agree to participate in this study.
2. Section 2: Complete the biographical information by providing descriptive information on your professional and academic experience. This will enable the researcher to describe the sample.

No names or identities will be mentioned in the research report or publications.

3. Section 3: Evaluate the seven interventions of the program. You will be expected to read through the psychoeducational program and rate the interventions in accordance with the given criteria, using a Likert scale. Write comments in the space provided at the end of each intervention. Your ratings and comments will be compared with the evaluations of fellow experts.

The validation process should take approximately 1 hour to complete. The Delphi process will take at least two rounds; you will be expected to respond within a period of 1 – 2 weeks in each round. Your participation and comments will be highly appreciated. Comments received in round one will be collated and analysed for further validation in round two. For any clarification that may be required please contact me or my supervisors on the following:

Ms TE Mbedzi, Tel: +2715 962 8679 or cell: 0839876045/0722114780
Email: takalani.mbedzi@univen.ac.za
Professor MM Moagi Tel: +27(0) 183 892585 or cell: 0766754266,
Email: miriam.moagi@nwu.ac.za
Professor AE Van der Wath, cell: 0845063142,
Email: annatjie.vanderwath@up.ac.za

SECTION 2: BIOGRAPHICAL INFORMATION

Please complete the biographical information by describing your professional and academic experience. The biographical information will enable the researcher to describe the Delphi sample.

No.	Employer	Professional qualifications	Current position	Experience in the mental health field/ academic research /policy/ program development and implementation
1.				

ANNEXURE J

INDEPENDENT CODER CERTIFICATE

QUALITATIVE DATA ANALYSIS

PhD TAKALANI ELLEN MBEDZI
THIS IS TO CERTIFY THAT:

Dr Hester (Rina) Cathrina de Swardt has co-coded the following qualitative data:

15 Individual Qualitative Interviews

For the study

‘DEVELOPMENT OF A PSYCHO-EDUCATIONAL PROGRAM FOR FAMILY MEMBERS CARING FOR MENTAL HEALTH CARE USERS IN VHEMBE DISTRICT IN LIMPOPO PROVINCE’

I declare that the candidate and I have reached consensus on the major themes and categories and codes reflected by the data during a consensus discussion and that adequate data saturation was achieved as evidenced by the repeating themes and categories.

I agree that the shared data is to be kept confidential and that I may only discuss its contents with the researcher. Upon the student's graduation, I will remove the data from my computer and will not keep copies.

Dr HC de Swardt

HC de Swardt
D Litt et Phil: Nursing Education 3 August 2021 Rina.deswardt@gmail.com