FAMILIES AS PARTNERS IN THE PROVISION OF MENTAL HEALTH SERVICES: GUIDELINES FOR SOCIAL WORK PRACTICE

by

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DEDICATION

This thesis is dedicated to my loving mother, Kgadima Mashiane, whose hardships encouraged me never to give up in midst of adversities. Her presence is a pillar of strength for my tenacity.

DECLARATION

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I declare that the thesis, **Families as partners in the provision of mental health service: guidelines for social work practice**, is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I submitted the thesis to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

SMashiane

SIGNATURE

31 March 2021

DATE

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ABSTRACT

Mental illness remains one of the most devastating condition affecting the social functioning of individuals and families. The affected individuals and their caregivers expressed dissatisfaction in mental health service delivery. The mental health system is medically oriented and does not involve caregivers as partners in the provision of mental health services. Although the developmental approach has been adopted to guide the provision of services recognising human rights and social justice, the medical model remains a challenge in the provision of comprehensive mental health services. This is compounded by the Mental Health Care Act (Act No. 17 of 2002) that is silent on the role of families in the mental health system. Additionally, social workers are unable to provide adequate services due to lack of resources.

A qualitative study using the exploratory, descriptive and contextual designs was undertaken. Purposive sampling was used to select 28 participants from three groups, namely ten MHCUs, nine caregivers and nine social workers. The goals of the study were to understand the experiences of MHCUs, caregivers and social workers in mental health service delivery; and to proffer guidelines for social work practice to enhance partnership between the family and mental health care providers. Data was gathered through semi-structured interviews and analysed according to Tesch's (in Creswell, 2009:186; 2014) framework. Data verification was guided by Lincoln and Guba's (in Krefting, 1991:214-222) model to enhance trustworthiness.

The findings suggest that MHCUs and caregivers received inadequate psychosocial support which is attributed to lack of involvement in service delivery. Furthermore, social workers lack adequate training to provide effective mental health care. As a result, guidelines were developed for the establishment and enhancement of partnership between families and mental health service providers to offer comprehensive and sustainable mental health services. Future exploration of the role of the family in mental health services is required.

Key terms:

Family, mental health care users (MHCUs), caregivers, mental health care practitioners, partnership, social work, social workers.

ACRONYMS

ASASWEI:	Association of South African Social Work Education Institutions
CBOs:	Community-based Organisations
CPD:	Continuing Professional Development
CSG:	Child Support Grant
DoH:	Department of Health
DoJCD:	Department of Justice and Constitutional Development
DSD:	Department of Social Development
DSM:	Diagnostic and Statistical Manual of Mental Disorders
DSTV:	Digital Satellite Television
EPWP:	Expanded Public Works Programme
HIV:	Human Immunodeficiency Virus
HPCSA:	Health Professions Council of South Africa
IFSW:	International Federation of Social Workers
ISDM:	Integrated Service Delivery Model
MHCU:	Mental Health Care User
NASW:	National Association of Social Workers
NGOs:	Non-govermental Organisations
PHC:	Primary Health Care
PIE:	Person-in-environment
QLFS:	Quarterly Labour Force Survey
UK:	United Kingdom
UN:	United Nations
USA:	United States of America
RDP:	Reconstruction and Development Programme
SACSSP:	South African Council of Social Service Professions
SAFMH:	South African Federation of Mental Health
SANC:	South African Nursing Council
SASH:	South African Stress and Health Survey
SASSA:	South African Social Security Agency
SCIE:	Social Care Institute Excellence
SDGs:	Sustainable Development Goals

SITA: State Information Technology Agency

WHO: World Health Organization

WONCA: World Organization of Family Doctors

WPRPD: White Paper on the Rights of Persons with Disabilities

GLOSSARY OF TERMS[1]

1. General description of a MHCU with schizophrenia

Appearance is conveyed through posture, composure, clothing, and grooming. The appearance may present a healthy, sickly, young or old-looking, untidy, childlike and bizarre. Moist hands, perspiring forehead, tense posture, wide eyes, and may show signs of anxiety (Norris, Clark & Shipley, 2016:636)

Psychomotor behaviour will show restlessness, wringing of hands, pacing, agility, psychomotor retardation, other physical manifestations and any aimless activity (Wilcox & Duffy, 2015:576).

Attitude towards the clinician can be described as cooperative, friendly, attentive, interested, frank, seductive, defensive, contemptuous, perplexed, apathetic, hostile, playful, guarded, and the level of rapport established (Dziegielewski, 2015:71).

2. Delusions

A delusion is an unshakable, false idea, or belief that cannot be attributed to the patient's educational, social, or cultural background, which is held with extraordinary conviction and subjective certainty, and is not amenable to logic (Irmak, 2014:774). It is also described as fixed and bizarre belief held in spite of strong evidence to the contrary, which according to Dziegielewski (2015:158) involve:

Fixed belief delusions refer to the conviction that no matter the contrary to the evidence, what they believe is accurate. The most common fixed belief delusions include:

Persecutory delusion is a belief that one is the target of the malicious actions of others. The person is often desperate and overwhelmed with feelings of impending doom from which no escape seems possible.

Referential delusion is a belief that the actions of others have a special reference to oneself. The individual may express the fear that everyone is out to get them and so interpret normal everyday events as tied to their own life. The delusion can become so severe to stop the individual from performing daily activities and basic functioning.

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[1] The glossary contains explanations of concepts on the mental status examination of schizophrenia discussed in Chapter Two (item, 2.2.4.1 & 2.2.4.2).

Grandiose delusion relates to an inflated sense of self-worth, self-importance or self-esteem in which the individual sees himself or herself as a famous person or as divine.

Erotomanic delusion is a false belief that somebody loves them. The individual becomes completely absorbed in a fantasy relationship that is not reciprocated. The belief is so strong that it becomes difficult for the person to see what is real and what is not.

Nihilistic delusion refers to a major catastrophe will occur. The individual continually talks about it and prepares for the worst. This preoccupation may interfere with their normal functioning.

Somatic delusion relates to bodily concerns and images. The individual may focus on imagined body flaw and be unable to see themselves positively.

Bizarre thoughts are problems with basic cognitive processes involving thought content that seems strange to everyone, including those with similar beliefs in a similar cultural group. Such beliefs include:

Thought broadcasting is the belief that one’s thoughts are being revealed and others can hear the most personal and private thoughts.

Thought insertion is the belief that someone’s thoughts are being inserted into one’s mind from an outside source. The individual is convinced that the thoughts are not theirs but are planted in their head by someone or something.

Thought withdrawal is the belief that someone or something is removing ideas from one’s head and cannot be stopped from doing that.

Delusions of control is the belief that one is being controlled by an external force. The individual believes someone or something has mental control that is so strong that it can affect the individuals’ daily functioning and result in social or occupational behaviours.

3. Hallucinations

Individuals diagnosed with schizophrenia experience perceptual disturbances clinically known as hallucinations (Loue & Sajatovic, 2008:597; Baruah & Chaudhury, 2012:158). Studies characterise hallucinations as perception-like experiences which cannot be verified because they are not associated with a physical condition that can be used to corroborate them (Wong, 2014:133). Unlike observable external events, hallucinations have been found to occur without an external stimulus whereby non-real mental events are invested with reality (Wong, 2014:133; Behrendt, 2016:204).

Hallucinations are characterised by three main themes, namely religious themes, command hallucinations and unidentifiable voices (Loue & Sajatovic, 2008:597; Price, 2016:50) which individuals experience in the form of:

Auditory hallucinations are voices the MHCU might hear which are distinct from their own thoughts, conversing among themselves, often threatening, obscene, accusatory, or insulting and commenting on their life or behaviour (Behrendt, 2016:207).

Visual hallucinations involve seeing people or objects that others cannot see (Slocombe & Baker, 2015:137). MHCUs with these conditions often report seeing crawling insects, human-like figures having a supernatural quality of an angel, a snake or a massive man with wings and horns (Dudley, Collerton, Nicholson & Mosimann, 2013:130). These experiences may be triggered by other coexisting factors such as organic damage to the brain, substance use or abuse, or any other medical condition (Dziegielewski, 2015:156). Reactions to these visions can vary and include fear, pleasure, or indifference and can be distressing and disabling to people with psychosis (Dudley et al., 2013:127).

Tactile hallucinations relate to a condition an individual may experience feeling as if bugs are crawling on them. Tactile hallucinations may also be the result of substance misuse accompanied by a psychotic disorder.

Olfactory hallucinations relate to smell that does not actually exist in the environment.

Gustatory hallucinations relate to taste perception of unpleasant taste that others would not recognise, for example, a MHCU may report that the food they are eating is poisoned and therefore tastes rotten or bitter.

4. Disorganized thinking and speech

Disorganised thinking happens when the MHCU make loose associations, jumping from one topic to another, and making speech that is incoherent and vague, thus becoming difficult to understand what they are trying to say (Wong, 2014:133).

5. Negative symptoms

Negative symptoms are behaviours that should be present but are absent characterised by reduced appetite, lack of energy, lack of pleasure and inattention (Untu, 2015:26). The MHCU experiences of negative symptoms are outlined according to Barabassy, Szatmári, Laszlovszky and Németh (2018:46) as follows:

Diminished emotional expression is when an individual expresses flat or blunted affect which restricts facial expressions, initiation of speech and delayed movements.
Anhedonia is a decreased ability to experience pleasure.
Avolition is a lack of goal-directed behaviour.
Asociality is a lack of interest in social interactions and emotional withdrawal, decreased rapport, passivity, apathy, social withdrawal, difficulty in abstract thinking, lack of spontaneity, and stereotyped thinking patterns.
Alogia is characterized by a lack of speech, often caused by a disruption in the thought process.

6. Grossly disorganized or catatonic behaviour

This category refers to aspects of the MHCU's motor behaviour. Catatonia is a psychomotor syndrome which has historically been associated with schizophrenia, but has been found to feature in other disorders such as neurodevelopmental disorders, bipolar disorders, depressive disorders, and medical conditions (Dziegielewski, 2015:158; Wilcox & Duffy, 2015:577). According to Bellack (cited by Wilcox & Duffy, 2015:576) the term catatonia is derived from the Greek *kata* (down) and *tonas* (tension or tone). The diagnosis of catatonia requires three or more of the 12 identified psychomotor disorders as illustrated according to (Rasmussen, Mazurek & Rosebush, 2016:392):

Stupor is described as the most prominent catatonic symptom in which the individual displays limited psychomotor activity, is in a sleepy daze and does not responding appropriately to questions.
Catalepsy and waxy flexibility refer to a posture that is difficult for the individual to hold and it goes against gravity, for example, the individual may stand firm for long periods of time while refusing requests from relatives or clinicians to sit.
Stereotypy is repetitive movements that cannot be considered normal walking.
Posturing is unusual posture that looks uncomfortable.
Grimace displays an odd-looking face.
Mutism is a condition when an individual is capable of speaking and would not speak.
Echolalia is parrot-like representation of someone else's speech.
Echopraxia is parrot-like repetition of someone else's speech and movements.

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CHAPTER ONE

GENERAL ORIENTATION TO THE STUDY

1.1 General introduction and background

The family is a formidable partner at the forefront of the provision of mental health services to their mentally ill member. Mental illness is a complex condition that causes significant emotional and financial distress to individuals, families and society. However, families continue to provide caregiving to their relatives with mental illness. Studies demonstrate that the prevalence of mental health problems is on the rise worldwide (Kritzinger, Swartz, Mall & Asmal, 2011:140; Scott, Burke, Williams et al., 2012:483; Steel, Marnane, Iranpour et al., 2014:477; Mokwena, Madiba & Mokoena-Molepo, 2014:366). The World Health Organization (WHO) and World Organization of Family Doctors (WONCA[2]) report indicates that 16.5% of the South African adult population had experienced mental health problems (WHO & Wonca, 2008:147). Notably, the study conducted by the South African Stress and Health Survey (SASH) in 2004 found that 16.5% of South Africa's adult population suffered from some form of mental disorder (Herman, Stein, Seedat et al., 2009:2; Jacob & Coetzee, 2018:176; Meyer, Matlala & Chigome, 2019:25).

The South African Federation of Mental Health (SAFMH) 2009/10 annual report shows that the number of mental health service users reached 61,483. During that time, there were 4,702 mental health care users (MHCUs) admitted to 50 hospitals. A survey on the prevalence and burden of mental problems in South Africa happens every 10 years, while the national evaluation of mental health services is conducted every five years (National Mental Health Policy Framework and Strategic Plan 2013-2020, Department of Health [DoH], n.d:42). This suggests that the next report on the prevalence and burden of mental illness is expected in 2020. However, the records on the prevalence of mental illness reflect only the information on known cases of MHCUs

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[2] **WONCA** is an acronym comprising the first five initials of the *World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians*. Its short name is World Organization of Family Doctors.

obtained from hospitals. The MHCUs receiving mental health services from indigenous healers are not included in the report, thus revealing the magnitude of underreporting on this problem (Campbell-hall, Petersen, Bhana et al., 2010:611; Matlala, Maponya, Chigome & Meyer, 2018:46). Nevertheless, mental health problems are complex and can cause significant distress that interferes with the social functioning of individuals and their families (Corrigan, Mueser, Bond et al., 2008:3; Gullslett, Kim, Andersen & Borg, 2016:161).

The medical model remains the dominant model upon which the current conceptualizations of mental health are derived. The model considers the family as part of the problem that causes mental illness and not as a partner in the provision of mental health care (Beecher, 2009:267; Van der Sanden et al., 2015:401). Moreover, the exclusion of the family as an integral part of the mental health system is also revealed by its absence from the Mental Health Care Act (Act No.17 of 2002). Therefore, the challenges plaguing the health care system will persist as long as the social aspects of mental illness remain subordinated to the dominant medical explanations. It was on this basis that the social model of mental health (Beresford, Nettle & Perring, 2010:10) was proposed to provide an alternative conceptual framework for the provision of mental health services.

The social model attributes the causes of mental illness to social factors and not as a problem within the individual (Sorensen, 2012:2). Its proponents viewed the medical model as perpetuating the psychiatrisation or medicalisation of social problems (Chakravarty, 2011:275; Mills, 2015:213; Gullslett et al., 2016:169). However, the model does not deny the effects of physical or chemical processes on mental illness, but that the real problem is the way society reacts towards people with mental health problems (Sorensen, 2012:2). Furthermore, it provides a base that is oriented towards partnership in the provision of mental health services (Tew, 2011:2).

A social approach to mental health provides a context within which to practice partnership. The family plays a critical role in the provision of mental health care to the MHCUs. In most cases the family is the first to notice when a family member is not well. The family members communicate what they recognise as the problem in behavioural or situational terms (Watson, Kelly & Vidalon, 2009:1090, Coppock &

Dunn, 2010:18). Although the family members “may not necessarily use clinical terminology due to lack of clinical vocabulary, the descriptions they offer may suggest the interaction of biological, intra-psychic or interpersonal components of the illness” (Watson et al., 2009:1090). However, their descriptions may be used by mental health care practitioners for intervention. Therefore, the social model demonstrates the importance of the family in the provision of mental health care.

It has been noted that both medical and social models acknowledge the role of religious and indigenous descriptions of mental illness (Chakravarty, 2011:267; Burns & Tomita, 2015:867). Both religious and indigenous perspectives predate the current medical and social models of mental illness. The religious perspective views mental illness as a spiritual and moral problem while the indigenous or traditional perspective involves supernatural conditions (Mpono, 2007:17; Moodley & Sutherland, 2010:268). The religious explanations of mental illness replaced demonology which explains mental illness as caused by “supernatural forces that take control of the mind” (Chakravarty, 2011:267). Among South African communities, *mafufunyana* (spirit possession) are common indigenous descriptions of mental illness.

It should be borne in mind that various perspectives to mental illness evolve different treatment methods of mental conditions (Chakravarty, 2011:273). Mental health provides a context for describing both mental health problems and mental health services (WHO, 2009:1). The current provision of mental health services in the world is predominantly medical (Beresford et al., 2010:15). However, the South African government has adopted the WHO’s model on mental health that provides a framework for the provision of mental health services (Mavundla, Toth & Mphelane, 2009:357). The model is implemented in terms of the Mental Health Care Act (Act No. 17 of 2002) which provides a legal framework for the provision of mental health services (Ramlall, 2012:408). This has resulted in the Department of Health (DoH) developing the Policy Framework and Strategic Plan 2013-2020 (DoH, n.d:3) to advocate for the transformation of mental health services to be accessible, equitable, comprehensive and integrated at all levels of the health system. However, not much has been achieved regarding the provision of mental health services. A report by the Parliamentary Monitoring Group (2017) indicated that Limpopo Provincial

Departments of Health and Social Development did not have directorates focusing on mental health, lacked coordination of programmes, and provided no support to poor families of the MHCUs.

The WHO model on mental health contends that the provision of mental health services cannot be the responsibility of a single service setting (WHO & Wonca, 2008:21), but a collaboration between formal and informal systems. The formal primary health system refers to psychiatric services provided by professional health workers at various levels of treatment, namely primary, secondary and tertiary while the informal services refer to alternative healing practices, for example indigenous or traditional healing (WHO & Wonca, 2008:19; James, 2012:7). Regardless of the level of treatment, the WHO model on mental health promotes the involvement of individuals in their own mental health care and community-based practice (WHO & Wonca, 2008:21; Wong, 2014:242).

The WHO position suggests partnership in the provision of mental health services to meet the mental health care needs of the MHCUs. Although the literature is awash with the concept of partnership, there is a paucity of South African literature and policy relating to families as partners in the provision of mental health services to MHCUs. For instance, the provisions of the Mental Health Care Act (Act No.17 of 2002) focus on acute care (Ramlall, 2012:408). However, the family as an active player in the provision of mental health services is missing despite being acknowledged within the recovery literature (Georgaca & Zissi, 2018:81).

On the other hand, the policy on deinstitutionalisation was developed to integrate the MHCUs with families and communities (Mkhize & Kometsi, 2008:107; Vella & Pai 2012:222). Despite its noble goal of integrating the MHCUs with families, the deinstitutionalisation policy failed to recognize the family as a partner in the provision of mental health services (Mavundla et al., 2009:358; Tew, 2011:121; Ramlall, 2012:409). Moreover, deinstitutionalization is viewed as driven by political, economic and legal constraints with less regard for quality of life of MHCUs (Jonker & Greeff, 2009:860; Hudson, 2016:136). The inability of the policy to recognize the family has been attributed to constraints of working within the medicalised mental health system (Mkhize & Kometsi, 2008:107; Chakravarty, 2011:275; Mills, 2015:213).

However, studies on family caregiving reveal that families of MHCUs become the main providers of care to their members following deinstitutionalization (Mavundla et al., 2009:357; Chang, Zhang, Jeyagurunathan et al., 2016:2). Furthermore, Mavundla et al. (2009:357) describe family caregiving as an unpaid service to provide the MHCU with physical care and emotional support. This service makes family caregiving a compensation for the lack of services and resources within the mental health care system (Parker, 2012:418). Therefore, family caregiving has motivated the researcher to conduct this study and explore its participation as a partner in the provision of mental health services.

Families are not immune from the challenges of caring for their mentally ill relatives. Most families have rejected or abandoned the MHCUs (Moorkath, Vranda & Naveenkumar, 2019:307). However, the burden of caring for the MHCUs has been identified as a possible cause of families abandoning them because of either socio-economic problems or episodes of violence by some of the MHCUs (Koukia & Madianos, 2005:415; Mudau & Ncube, 2018:11600).

Nevertheless, a family remains the backbone in the provision of mental health care to their relative with a mental illness (Anokye, 2018:325). Most families regard caregiving for a family member as a moral obligation (Repper, Grant, Nolan & Enderby, 2008:433, Suro & de Mamani, 2013:301). Such an obligation is motivated by the principle of *ubuntu*[3] that characterises the value system of most South Africans (Siyabulela & Duncan, 2006:307; Chasi, 2014:495). Hence, the family takes over the responsibility of caring for its member upon discharge from mental health institutions.

The families' and mental health care professionals' participation in the provision of mental health services requires partnership. Partnership is not a new concept in South

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[3] *Ubuntu* is expressed as *'umuntu ngumuntu ngabantu' (in Nguni languages) or botho 'motho ke motho ka batho'* (in Sotho languages), literally translated as "a human being is a human being through other human beings". It is an expression of African philosophy of life that embraces humanness, interdependence, communalism and sensitivity towards others and caring for others (*Wanless, 2007;* Jensen & Gaie, 2010).

Africa, but has been a common practice known as *letšema*[4] among most rural African communities (Ramagoshi, 2013:50). In partnership, families share important information with mental health practitioners about their relative with mental illness (Beecher, 2009:271; Odegard & Bjorkly, 2012:100). Conversely, mental health service providers can offer support and information to families (Chen, 2008:1556; Macleod, Elliott & Brown, 2011:101) regarding medication, social benefits such as social grants, housing and social support networks (Martin, Hall & Lake, 2018:113). Both the family and the professional service providers play important roles in the provision of mental health care.

Partnership as a comprehensive approach to the provision of mental health services requires transformation of the South African mental health system. The government's commitment is required to ensure a transformed mental health system that provides a comprehensive, integrated and coordinated mental health services (Ramlall, 2012:408). Moreover, the family is a vital part in the transformation process through partnership. Partnership influences the functioning of multidisciplinary teams providing services to MHCUs and their caregivers. A multidisciplinary approach provides a context for collaboration, sharing and decision-making regarding the best way to provide mental health services and the involvement of families as partners (Kane & Luz, 2011:437) as well as religious and traditional leaders. The mental health practitioners share expertise for the benefit of the MHCUs and caregivers (Roncaglia, 2016:15). The psychiatrist prescribes medication, the psychologist involves the patient in individual psychotherapy, the occupational therapist offers social skills training, the psychiatric nurse implements and monitor treatment programme and the social worker provides psychosocial support and family intervention to MHCUs and their families (Swartz, 2004:80; Rogers & Pilgrim, 2010:138).

Partnership fits within the developmental approach that guides the practice of social work which embraces the principles of collaboration, empowerment, equity, trust, and respect to enhance social justice (Sewpaul, 2010:254; Patel, 2012:615; Blitz, Yull &

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[4] Letšema is a Sepedi and Setswana which "refers to a group of people who work towards a common goal" (Ramagoshi, 2013:50). It is a traditional practice in rural villages who the whole village would gather to plough the king's fields.

Lee, 2018:162). The role of social workers in the provision of mental health services was accentuated by a representative of the International Federation of Social Workers who, during a speech at the United Nations (UN), advocated for social workers to become more active in the field of mental health care in order to achieve the UN Sustainable Development Goals (Rudin, 2018).

1.1.1 Statement of the problem

Mental illness is complex and requires adequate provision of services to promote the wellbeing of MHCUs. The researcher observed that the current provision of mental health services is not comprehensive enough to improve the wellbeing of MHCUs. Caregivers are vital participants in the provision of mental health services, but their role is neglected within the mainstream mental health system. Caregivers do not receive adequate support from mental health care providers, thus make caregiving a burden.

The ineffectiveness of the mental health care system is due to mental health policies that are based on the traditional medical model which has medicalised social problems by using medical interpretations to explain mental illness (Gandi & Wai, 2010:324). Although the social model has long been introduced, it continues to be overshadowed by the medical orientation to the practice of mental health. The socially-oriented community-based healthcare system (Casstevens, 2010:385) and developmental approaches (Patel & Hochfeld, 2012:691) adopted as an alternative to the medical approach remain subordinated to the dominant medical orientation entrenched in mental health care. Furthermore, the WHO model on mental health (Ramlall, 2012:408) provided a medical template for the development of the Mental Health Care Act (Act No. 17 of 2002) which regulates the provision of mental health services. Unfortunately, this Act does not make provision for partnership with families in the provision of mental health services. Although the policy on deinstitutionalisation gave impetus to the needed transformation in mental health care which led to the release of the MHCUs from institutions into the care of their families and communities (Anokye, 2018:324), family caregivers experience inadequate support from the mental health service providers. Hence the need for a social model to challenge core assumptions of the medical model by recognising the role of social factors in mental illness (Aho, 2008:244; Beresford et al., 2010:7).

The involvement of the family as a partner in the provision of mental health services reflects a post-modern discourse which values lay knowledge and formal training alike (Whitley, 2008:359; Creswell & Poth, 2018:26). However, in terms of the Department of Social Development Manual on Family Preservation Services (2010:15), the involvement of families in programmes is tokenistic as it fails to acknowledge the complementary role that both mental health professionals and service recipients play in the provision of mental health care (Ray, Pugh, Roberts & Beech, 2008:79; Roscoe, Carson & Madoc-Jones, 2011:58). Therefore, family caregivers bear the burden of care due to lack of adequate support from the service providers.

In this study, the identified problem was minimal family involvement as a partner in the provision of mental health services. This makes access to services difficult, thus leaving families to struggle on their own as they care for their relatives with mental illness.

1.1.2 Motivation for the study

The researcher’s interest in undertaking this study emanates from nine years of working with people diagnosed with mental illness and their families in various communities and a psychiatric hospital in Limpopo Province. This study makes a case for comprehensive integrated mental health care service that involves the family as a partner. It was conducted with individuals diagnosed with schizophrenia based largely on the DSM-5 category and receiving treatment from Thabamoopo Hospital in Limpopo Province, their family caregivers and mental health care practitioners (social workers[5]). The researcher observed that mental health practitioners do not involve families of individuals with mental illness as partners in the provision of mental health services. Partnership could benefit families by facilitating access to resources,

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[5] The Mental Health Care Act, (Act No. 17 of 2002) includes a social worker within the definition of a mental health care practitioner as Mental health care practitioner who has been trained to provide prescribed mental health care, treatment and rehabilitation.

knowledge, information, and comprehensive service delivery resulting in improved quality of life (Kyzar, Brady, Summers et al., 2016:1).

Furthermore, social work as part of mental health practice is developmental (Van Breda & Addinall, 2020) in its approach to service delivery, and advocates for a collective approach to problem-solving to promote social inclusion (Newlin, Webber, Morris & Howarth, 2015:168). However, social workers experience myriad barriers that make partnership with families difficult to achieve (Webber, Reidy, Ansari et al., 2016:18). Although the Department of Social Development (DSD) introduced an Integrated Service Delivery Model (ISDM) in 2005 (Shokane, Makhubele, Shokane & Mabasa, 2017:279) which was followed by the Recruitment and Retention Strategy for Social Workers (DSD, 2007:36) that recognised social work as a scarce resource to improve service delivery, the shortage of social workers has remained endemic. This shortage of resources indicates a strong need for the involvement of families as partners to enhance the provision of mental health services. However, evidence on the application of partnership in mental health services is minimal.

The researcher has also noted that the Mental Health Care Act (Act No.17 of 2002) does not prioritise the family but focuses only on mental health practitioners as providers of services to MHCUs. Moreover, the White Paper on the Rights of Persons with Disabilities has made mental health a category of disability which priorities the physical than mental conditions despite the overwhelming research that shows the devastating effects of mental health problems to individuals, families, communities and the society at large. This is despite research showing that families are providing full-time care for their relative with a mental illness, with inadequate support from the mental health care providers (Flyckt, Fatouros-Bergman & Koernig, 2015:690; Yazici, Karabulut, Yildiz et al., 2016:99).

The South African Council for Social Service Professions' (SACSSP)[6] Professional Board of Social Work's statement on the 40th meeting has noted insufficient clarity on

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[6] South African Council for Social Service Professions' (SACSSP) is a statutory regulatory body for the profession of social work and other social service professions in South Africa (van Breda & Addinall, 2020).

the scope of practice in mental health for the social work profession (South African Council for Social Professions [SACSSP], 2018). The statement corroborates the research conducted by Olckers on social work in mental health (Olckers, 2018:34). Furthermore, a study by Van Breda and Addinall (2020) show that clinical social work, which is offered as a master's program, is now recognized as a specialization "to intervene in the mental health and other psychosocial consequences of psychiatric, health and other life challenges". However, most social workers have obtained Bachelor of Social Work which exposes students to generic practice including the field of mental health. Therefore, this suggests that social workers provide mental health services without appropriate training in mental health. Moreover, South Africa does not have specific guidelines for social work practice in mental health care in order to facilitate partnership with families. Hence, some of the participants expressed a need for further training. Guidelines are proposed to give structure to interventions.

Thus, there was a need to conduct this study to explore and describe the family as a partner in the provision of mental health services. The findings resulted in the development of guidelines for social work practice to promote partnership between the family and mental health care service providers. The developed guidelines will assist social workers to develop programmes that promote partnership with families to enhance the provision of a comprehensive, integrated, mental health services.

1.2 Research questions

Research questions are used in qualitative inquiry for exploration of the central phenomenon of study (Cummings, Browner & Hulley, 2007:18; Creswell, 2009:129). A research question is a broad statement of intent, encouraged by an idea or problem the researcher has generated (Bukvova, 2009:4; Ratan, Anand & Ratan, 2018:15; Mattick, Johnston & de la Croix, 2018:104) to guide the research process (Yin, 2011:67). It converts a research topic into a researchable problem (Mattick et al., 2018:105) that can be "analysed to provide useful information" (Aslam & Emmanuel, 2010:47). In this study, the research questions led to the exploration of family as a partner in the provision of mental health care. The research questions were narrowed to specific questions during the course of the research process so as to explain the research methods, including data gathering, analysis and verification. The research questions for the study were as follows:

- What are the participants' experiences of the family as a partner in the provision of mental health services?
- What are the participants' experiences of mental health care providers as partners in the provision of mental health services?

1.3 Goals and objectives

The term goal is often used interchangeably with terms such as "purpose", "objective" and "aim" as synonyms for one another (Fouché & De Vos, 2011:94). A goal or purpose describes the direction the researcher must follow in the study (Creswell, 2009:112; Marshall & Rossman, 2016:75). Research goals are regarded as the culmination of the problem statement and research question (Fouché & Delport, 2011:108) guiding the study. The goals of this study sought:

- To develop an in-depth understanding of the family as a partner in the provision of mental health services.
- To proffer guidelines for social work practice to promote and enhance partnership between the family and mental health care providers.

The research goals determine objectives which serve as a vehicle towards the realisation of the stated goals (Farrugia, Petrisor, Farrokhyar & Bhandari, 2010:280). Research objectives are more specific, achievable, take into consideration the available resources and relate to how the study is going to answer specific research question (Farrugia et al., 2010:280; Doody & Bailey, 2016:22). To achieve the goals of the study, the researcher formulated the following objectives:

- To explore and describe the advantages of partnership between the families of the MHCUs and the mental health care providers in the provision of mental health services.
- To describe partnership in the provision of mental health care from the perspective of MHCUs, caregivers and social workers.

- To draw conclusions and make recommendations about partnership between the family and mental health care providers in the provision of mental health services.

1.4 Theoretical framework

Every study requires a theoretical framework to explain the phenomenon being studied (De Vos & Strydom, 2011:37). The researcher uses literature to find a theoretical framework that can help formulate and refine the research topic, the overall aim of the research, the research problem and the research questions, thus determining the choice of methodology and methods (Fouché & De Vos, 2011:83).

Qualitative studies use theoretical frameworks to study the lived experiences of participants (Creswell, 2009:62; 2014). The ecological systems perspective is the theoretical framework that underpins the study. Its focus is on people and their environment, which Germaine (cited by Friedman & Allen, 2014:10) describes as providing a framework for analysing human interactions within a social environment (Neal & Neal, 2013:731). The ecological systems theory is often used interchangeably with the systems theory to explain human interactions which happen at different levels, among them microsystem, mesosystem and macrosystem within which individuals exist (Friedman & Allen, 2014:10; Makhubele, Matlakala & Mabvurira, 2018:99). Other related theories considered to enrich the study include family systems theories and developmental approach.

The ecological systems approach therefore fits in with the qualitative research as it explores the transactions between people and their environments (Makhubele, Matlakala & Mabvurira, 2018:99). It is a framework for understanding transactions between individuals, families, communities and institutions as systems working together in partnership within a social environment to provide comprehensive mental health care service to MHCUs (Michailakis & Schirmer, 2014:1; Lekganyane, 2018:119). The social model hinges on the ecological systems theory as it regards individuals as integral part of systems such as family, friends, support groups, stokvels[7] and social clubs, communities, institutions and the social environment. Moreover, the social environment suggests that lack of fit between the person and the systems may lead to a crisis (Friedman & Allen, 2014:5) which the individuals encounter as they move through their own unique life course (Masoga & Shokane, 2018:3). Nevertheless, ecological systems theory focuses on changing environments to ensure adequate resources that satisfy human needs (Masoga & Shokane, 2018:4).

Therefore, the adoption of the ecological systems theory as a theoretical framework places the study within a social model to ensure that the voices of participants are central to the qualitative research process. Qualitative researchers use these theoretical perspectives to guide the research process because “without theory there is nothing to research” (Silverman cited by Willig, 2009:9; Iurea, 2018:46). A detailed explanation of the theoretical framework adopted for the study is discussed in detail in Chapter Four.

1.5 Research methodology

Research methodology is defined as a systematic way used by researchers to solve a problem by describing, explaining and predicting phenomena (Rajasekar, Philominathan & Chinnathambi, 2013:5). Kumar (2011) defines research methodology as a collective term for the structured process of conducting research. Research methodology is underlined by a system of beliefs, philosophical assumptions and theoretical frameworks that determine the choice of research approaches, methods and strategies (Creswell & Poth, 2018:15). There are different research methodologies guiding research in social sciences. The main research methodologies include quantitative, qualitative and mixed methods (Creswell, 2009:11; 2014). The difference between these approaches is underpinned by their philosophy, methods, models and procedures used (Creswell & Poth, 2018:18). These approaches are used in various types of research on the understanding that the world is experienced differently and, therefore, there is no absolute truth (Bojuwoye & Sodi, 2010:283; Iurea, 2018:46). Therefore, the choice of methodology and methods allow the researcher to generate

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[7] Stokvels are saving schemes in South Africa where members contribute fixed sums of money to a central fund on a weekly, fortnightly or monthly basis.

an in-depth understanding of the social world of people by examining experiences, perceptions, meanings, attitudes and everyday practices using data gathering methods such as in-depth interviews and observation (Sant, 2019:40).

The quantitative approach is rooted in the physical sciences that follow the systematic, scientific and positivist approach (Kumar, 2011) that use statistical procedures or quantification in research. However, the difficulty in the quantification of emotions makes the use of quantitative research on human participants undesirable.

The mixed methods research refers to a combination of qualitative and quantitative approaches to provide a more comprehensive understanding of the research study (Creswell, 2014). It is based on the understanding that people experience a range of challenges in life, and therefore, one research approach may not be sufficient to answer every research question (Sant, 2019:38). The theoretical framework guiding both quantitative and qualitative inquiries are contained within the mixed methods research paradigm (Creswell, 2014). Although findings from both qualitative and quantitative data may complement each other, data analysis results may be difficult to compare as they are from two different methods (Creswell, 2014).

The qualitative inquiry was adopted for this study since its main purpose is to explore and describe phenomena. It is described as interpretative and naturalistic, as it seeks to understand and explain beliefs, experiences, behaviours, interactions and social contexts of research participants (Kumar, 2011; Melnikovas, 2018:40; Iurea, 2018:46; Creswell & Poth, 2018:22; Sant, 2019:38). It is inductive in nature, moving from specific observations and interactions to general ideas and theories (Creswell & Poth, 2018:20).

Qualitative research embraces a range of research methodologies that include grounded theory, phenomenology, discourse analysis and ethnography (Creswell & Poth, 2018:111; Sant, 2019:38). Hence, it has been described as an umbrella term that is difficult to define (Hennink, Hutter & Bailey, 2011:8-9). These research methodologies vary in their theoretical assumptions based on a set of beliefs, procedures and practices, but with a common goal of understanding the lived experiences of persons being studied (Henman, 2018:53). In this instance, a qualitative researcher brings along the theoretical assumptions that guide their view of reality, how they know reality, the value-stance and the methodology adopted for the study (Agee, 2009:437; Creswell & Poth, 2018:18). However, the methodologies share common strategies and methods to describe the lived experiences of the people (Polkinghorne, 2005:137; Willig, 2009:8; Kumar, 2011). Moreover, these methodologies hold for the existence of multiple realities that are created through interactions and relationships (Vandyk & Baker, 2012:350; Sant, 2019:38). Researchers use these multiple realities to gain an in-depth understanding of the phenomenon under study from the research participants viewed as having the ability to articulate and describe their experiences (Willig, 2009:9; Guest et al., 2013:47; Creswell & Poth, 2018:7).

Qualitative designs evolve throughout the research process to provide an overall plan that guides the researcher on how to go about, throughout the research process, conducting the study to achieve its purpose (Frith & Gleeson, 2012:56; Maree, 2012:35; Creswell & Poth, 2018:49). Common research designs in qualitative research include explorative, descriptive and contextual to establish how people experience their lives (Babbie & Morton, 2011:79; Harper & Thompson, 2012:5; Guest, Namey & Mitchell, 2013:47; Creswell & Poth, 2018:7). These designs are used to investigate how social factors influence relationships, patterns of behaviour, interactions and interpretations (Tweed & Charmaz, 2012:134). Their use is more appropriate especially when the understanding of problems is limited (Whiting & Sines, 2012:21; Mudau & Ncube, 2018:11593). Importantly, their use has a bearing on the application of the research methods such as population and sampling techniques, data collection, pilot testing, data analysis and data verification (Maxwell, 2013:3; Malagon-Maldonado, 2014:124) (cf. Chapter Four, items 4.5, 4.6 & 4.7).

1.6 Ethical considerations

Ethics is defined as moral principles and values which guide action (Thompson & Russo, 2012:33). Social science depends on humans to provide information relating to a research phenomenon. Qualitative research as a process of human interaction has potential risks that may arise due to conflict of interests (Creswell & Poth, 2018:149). The purpose of ethics in research is to protect research participants from harm that may result from the research (Robertson & Walter, 2007:411; Žukauskas, Vveinhardt & Andriukaitienė, 2018:149). This study focuses on vulnerable populations such as persons with mental problems and their families who have to share their personal vulnerabilities (Robertson & Walter, 2007:411; Elliott, 2016:12). It requires the researcher to be ethical by becoming aware of the struggles and experiences of the marginalised populations being studied (Hastings, 2010:307). Researchers, therefore, have an ethical obligation to protect participants from research harm. Ethical principles considered to evaluate potential risks and benefits of research include avoidance of harm, informed consent, confidentiality and management of information (Othman & Hamid, 2018:733). This section of the ethical considerations provides definitions of the main ethical principles as guidelines for undertaking qualitative research. The application of these ethical principles is discussed in Chapter Four (cf. item, 4.8).

1.6.1 Avoidance of harm

Researchers have an obligation to protect participants from harm that may result from the research process. The principle of avoidance of harm in social research intends to protect study participants from harm (Vaz & Srinivasan, 2014:191). Although researchers do not intentionally decide to cause harm, they have a responsibility to minimise the risk of harm on participants (Vanclay, Baines & Taylor, 2013:243). The purpose of this research is to understand the experiences of families in the provision of mental health services to MHCUs. MHCUs and their family caregivers may have been stigmatised, and as a researcher, it is important to be sensitive to the marginalisation afflicting the affected families. Social workers may experience disciplinary action from their employers for sharing privileged information. Therefore, in order to avoid harm social research requires researchers to obtain informed consent from participants, protect their anonymity and confidentiality, protect data, and provide participants with the right to withdraw from research (Vanclay et al., 2013:243).

1.6.2 Informed consent

Informed consent is defined as “an interactive process between subject and researcher involving disclosure, discussion, and a complete understanding of a proposed research activity, and which culminates in the individual freely expressing a desire to participate” (Huang, O’Connor, Ke & Lee, 2016:350). It is an ethical requirement in research to ensure that participants are not deceived for the purpose of securing their participation (Strydom, 2011:116). It suggests that participants can decide whether to share information with others or not (Iurea, 2018:50). However, informed consent may pose a dilemma for those afflicted with mental problems as they may not have the capacity to consent (Rogers & Pilgrim, 2010:244). Individuals in need of support may be deceived into believing that the research has material benefits for them. For example, some MHCUs and caregivers may be desperate to earn disability grant and grant-in-aid respectively. Moreover, the process of conducting research may be invasive as participants are required to recall their own experience of illness, caregiving and experiences of working with families. Participants may sometimes feel uncomfortable to share their personal experiences with the researcher.

The principle guides the conduct of the researcher to provide participants with the correct information about research requirements (Strydom, 2011:116). The provision of information about research is predicated on the consideration that participation should be voluntary at all times (Huang et al., 2016:351). This means participants should be adequately informed about the research, and decide whether to participate or decline (Arifin, 2018:30). Therefore, the researcher should ensure that MHCUs participating in this study are on medication to stabilise the severity of their psychotic symptoms. Moreover, MHCUs may need the assistance of their caregivers to consent on their behalf as they may be incapacitated to make informed decisions (Huang et al., 2016:350). The researcher should explain the purpose of the study to all participants and to get their consent for participation. The consent form should be thoroughly discussed with the participants in languages they understand. The participants shall have confirmed their acceptance by signing consent forms to participate in the research study. They shall also have signed consent forms as proof that they understood their role as participants in the research.

1.6.3 Confidentiality, privacy and anonymity

Social research may require disclosure of sensitive information about practices that impact on personal, family and work-related behaviour (Draneika, Piasecki & Waligora, 2017:216). Confidentiality refers to "information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure, without permission being given" (Hiriscau, Stingelin-Giles, Stadler et al., 2014:411). The concept of confidentiality is associated with anonymity and privacy which provides for the protection of the identities of research participants (Strydom, 2011:120; Vanclay et al., 2013:247; Oye, Sorensen & Glasdam, 2016:456). Participants may differ on cognitive, emotional and social capabilities (Thompson & Russo, 2012:39), and may therefore require protection from harm that may result from research. Vulnerable groups may not comprehend the consequences of participating in a research study. Moreover, their accounts may potentially expose them to retaliation or disciplinary action, especially social workers in policy related matters (Lancaster, 2017:99).

Therefore, it is the responsibility of the researcher to ensure that the principle of confidentiality, privacy and anonymity is applied to safeguard the acquisition, storage and transfer of information (Manti & Licari, 2018:146). Protection of the right of confidentiality and privacy should be declared in the consent process and protected during the research (Lancaster, 2017:98). Participants should be assured that their participation is anonymous and that they would not be identified by their answers to the research questions. Researchers should also confirm that participants' personal information is not divulged to third parties without their permission. Participants should be told that they have the right to share or withhold specific information depending on their willingness and that these decisions will not affect their benefits, such as disability grants, grant-in-aid and access to opportunities.

The researcher should ensure an appropriate setting that would not compromise participants' privacy and would also protect them from being interrupted and being listen to. However, attempts to maintain confidentiality, privacy and anonymity may be compromised especially in view of the fact that MHCUs may need the support of their caregivers during the interviews.

Furthermore, there were both advantages and disadvantages when interviewing MHCUs with or without the presence of their caregivers. MHCUs may freely share in the absence of their caregivers about concerns that they may not be willing to share with their caregivers. However, some MHCUs might feel uncomfortable talking to the researchers alone, thus preferring to share their concerns in the presence of their caregivers. Nonetheless, some caregivers could make the research process less productive by putting pressure on MHCUs to cooperate with the researchers or dominate the conversation (Huang et al., 2016:351).

1.6.4 Management of information

Management of information in relation to research refers to the organization, storage, preservation, and sharing of data collected and used in a research (Chigwada, Chiparausha & Kasiroori, 2017:2). Since the information may need to be regularly accessed for processing and analysis, it is the researcher's responsibility to protect participants from harm (Wolf, Patel, Williams-Tarver et al., 2015:595). This means decisions about how information will be preserved, and disposed of after the research is completed, is part of the researcher's responsibility. Anonymity is one of the steps that the researcher undertakes to protect the identity of participants by assuring them that the data collected is treated confidentially and stored anonymously by changing their names (Iurea, 2018:51). To ensure the protection of data the researcher should undertake the following steps:

- Research data is sensitive and requires that tools such as tapes, notes and transcripts of recordings should be securely kept in a locked cabinet that only the researcher had access to. The electronic information should be secured on the computer through a password. The use of passwords ensures that unauthorised individuals do not access the raw data. Therefore, access should be limited to the researcher, the promoter, and an independent coder.
- It is advisable that names of participants should be removed from notes and transcripts, and not used during the recording. Instead, alphabets should be allocated to participants to hide their identity.
- Consideration should be taken to have tape recordings and transcripts of the recordings destroyed after the researcher has completed his study.

A detailed discussion on the application of some of the aspects of research methodology will be discussed in Chapter Four.

1.7 Clarification of key concepts

Clarification of concepts helps to provide an understanding of the terms used in the study to avoid potential conflicts regarding their interpretation. It is a process that researchers use to identify and clarify concepts (Bojuwoye, 2013:1). Therefore, the definitions of concepts were those assigned to them for the purpose of the study (Iurea, 2018:46). Key concepts in this study are:

1.7.1 Family

The White Paper on families (DSD, 2012:16) indicates the difficulty in defining the concept, family, especially in diverse cultures as in South Africa and across the globe. It defines the concept family, as “a societal group that is related by blood (kinship), adoption, foster care or the ties of marriage (civil, customary or religious), civil union or cohabitation, and go beyond a particular physical residence” (DSD, 2012:3). The definition given by The Manual on Family Preservation Services (DSD, 2010:5) is shared by family theorists as “social groups related by blood (kinship), marriage, adoption, or affiliation, who have close emotional attachments and is integral to the well-being of individuals in relation to their psychosocial, emotional, physical, spiritual and economic needs”. Based on these definitions, a family appears to be an organized system functioning to achieve its own goals regardless of their structure (Becvar & Becvar, 2009:105).

The researcher has adopted the description of a family by Becvar and Becvar (2009:105) which states that “the family is organized to maintain the organization that defines it as a family thus functioning to achieve its own goals regardless of their particular structure”. Therefore, members of the family include a MHCU, siblings, parents, caregiver and extended family members.

1.7.2 Mental health

The mental health literature is saturated with definitions of mental health. The universally accepted definition provided by WHO defines mental health as “either negatively, as the absence of objectively diagnosable disease, or positively, as a state of well-being in which the individual realises their own abilities, can cope with the normal stresses of life, can work productively and fruitfully and can make a contribution to his or her community” (Coppock & Dunn, 2010:8). Rogers and Pilgrim (2010:17) view mental health as a multidimensional construct that describes a state of psychological, emotional and social well-being.

The Mental Health Care Act (Act No. 17 of 2002) does not refer to mental health but to mental health status which it defines as “the level of mental well-being of an individual as affected by physical, social and psychological factors and which may result in a psychiatric diagnosis". The latter definition introduces psychiatric diagnosis as integral to the conceptualization of mental health (Coppock & Dunn, 2010:8). It reflects what the former describes as the negative definition of mental health which implies the presence of mental illness. This way of describing mental health is consistent with the National Mental Health Policy Framework and Strategic Plan 2013-2020 (DoH, n.d:6) which defines mental health as an absence of a major mental health condition.

The researcher has adopted the description of mental health by WHO which refers to mental health as "a state of well-being in which the individual realises their own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to their community" (Meyer et al., 2019:25).

1.7.3 Mental health problem

The Mental Health Care Act (Act No.17 of 2002) refers to mental health problem as "a positive diagnosis of a mental illness in terms of accepted diagnostic criteria made by a mental health practitioner authorised to make such diagnosis". Mental health literature provides different descriptions of mental health problems showing the difficulty of arriving at a generally acceptable definition of mental illness as some definitions reflect a cultural dimension referring to abnormal behaviour as deviance from the norm (Rogers & Pilgrim, 2010:29). Schizophrenia is among common mental health conditions for people diagnosed with severe mental health problems (Wong, 2014:132). It is defined as "a chronic and severe mental condition that affects how a person thinks, acts, expresses emotions, perceives reality, relates to others", and is perceived as having lost touch with reality (Gulsuner, Stein, Susser et al., 2020:569). In this study the concepts mental health problems, psychiatric disorders and mental illness were used interchangeably to refer to people diagnosed with mental illness, particularly schizophrenia.

1.7.4 Mental health care user (MHCU)

The Mental Health Care Act (Act No.17 of 2002) refers to mental health care user (MHCU) as "a person receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status" of a MHCU. MHCU is a new term adopted in terms of the Mental Health Care Act (Act

No.17 of 2002) to replace the term patient which refers to mental illness as a disease. However, the term patient remains part of the current psychiatric literature and practice. The term patient was introduced in 1547 as an expression of a need for human care towards people with mental problems (Holmes, 1994:5). The current literature describes mental health as focusing on the disease ignoring the person afflicted with the condition (Tew, 2011:20). By replacing patient with MHCU the South African mental health establishment intended to promote caring within the mental health system. This change of terms was instituted in recognition of the rights accorded to every human being by the Constitution of the country. In terms of the Mental Health Care Act (Act No.17 of 2002), the determination for MHCU is based on the diagnostic criteria determined by a psychiatrist as an authorised official.

In terms of this research study, the term MHCU was adopted as used in terms of the Mental Health Care Act (Act No.17 of 2002) to refer to a person “receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user”.

1.7.5 Mental health care practitioner

Mental health care practitioner as defined in terms of the Mental Health Care Act (Act No.17 of 2002) refers to “a psychiatrist or registered mental health care practitioner, or nurse, occupational therapist, psychologist or social worker who has been trained to provide prescribed mental health care, treatment and rehabilitation”. Traditional healers include, among others, the diviner-diagnostician (or diviner-mediums) and healers (or herbalists) (Mpono, 2007:27) who are indigenous, endowed with special knowledge to treat mental illness (Ramgoon, Dalasile, Paruk & Patel, 2011:91). The professionals and indigenous healing practitioners often treat the same mental conditions from different viewpoints. However, their education and training, and scope of practice differ (Bartholomew, 2016:108). The main role of mental health care practitioners is to provide mental health services to improve an individual's mental health.

In this study, the concept mental health care practitioner was adopted in terms of Mental Health Care Act (Act No.17 of 2002) to refer to a psychiatrist or registered mental health care practitioner, or nurse, occupational therapist, psychologist or social worker who has been trained to provide prescribed mental health care, treatment and rehabilitation.

1.7.6 Social work

Social work is “a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing” (International Federation of Social Work [IFSW] & International Association of Schools of Social Work [IASSW], 2014). Social work utilises theories of human behaviour and social systems to intervene at the points where people interact with their environments (Friedman & Allen, 2014:10). The principles of human rights and social justice are fundamental to social work (2010:254).

Social work is about social change to improve the circumstances of vulnerable people (Baumann, 2007:132; Audu, Idris, Olisah & Sheikh, 2011:56) both by building on their personal strengths and by changing the social circumstances which have contributed to their mental problems (Coppock & Dunn, 2010:20). Coppock and Dunn (2010:20) further explain social work knowledge base as bringing together a range of social science perspectives, linked to an understanding of law and social policy as it affects users of social care services and their families or caregivers. This view is reflected within a bio-psychosocial model as a base for interdisciplinary collaboration in partnership with families in the provision of mental health services (Rogers & Pilgrim, 2006:19; Odegard & Bjorkly, 2012:100).

In this study the researcher has adopted the definition of social work by the International Federation of Social Workers (IFSW).

1.7.7 Social worker

A social worker as defined in terms of section 17 of the Social Service Professions Act (Act 110 of 1978) is “any person who holds the prescribed qualifications and satisfies the prescribed conditions, and who satisfies the council that he is a fit and proper person to be allowed to practise the profession of social work". The minimum requirements to be a social worker is a Bachelor of Social Work (BSW) degree, and registration with a regulatory body (Spolander, Pullen-Sansfacon, Brown & Engelbrecht, 2011:824). In South Africa, the statutory regulatory body is the SACSSP (cf. Item, 1.1.2).

1.7.8 Partnership

Partnership is defined as a process in which both service provider and service user work together to achieve common goals (Gandi & Wai, 2010:323). It is about a relation between two or more persons who join hands to achieve a common goal (Upvall & Leffers, 2018:228). The concept is practiced in different fields including communities, organizations, business and institutions (Ying & Loke, 2016:243; Shamsi, Amiri, Ebadi & Ghaderi, 2017:2) sharing complementary skills, resources, perspectives and shared knowledge for effective intervention (Meyer, Scarinci, Ryan & Hickson, 2015:536; Corbin, Jones & Barry, 2018:5). Furthermore, partnership is characterized by a collaborative commitment to a trusting relationship that brings mutual benefit to both partners (Austin & Seitanidi, 2012:943). African rural communities have always practiced partnership referred to as *letšema* where people in the village would be mobilised to work towards a common goal such as ploughing fields together (Ramagoshi, 2013:50). The increase in democratic principles of social justice (Upvall & Leffers, 2018:228) had influence in the fields of health and social development, thus abandoning the expert role to adopt partnership as "a shared commitment where all partners have a right and an obligation to participate" (Ying & Loke, 2016:243).

Partnership encourages families to be seen as part of the solution, not as part of the cause of mental illness (Bryan, 2009:507). Odegard and Bjorkly (2012:100) state that in partnership the mental health practitioner is part of the family system through interaction with the family. However, the partnership advocated within the current mental health practice is limited due to its preferred focus on the illness of MHCU to the exclusion of the family. It ignores the fact that in some instances the MHCU may be someone who is unable to function due to the severity of the mental illness, and needing the family to access the services offered.

In terms of this study, partnership is between the mental health care providers and the family (of the afflicted member) involved in the provision of mental health services. In simple terms, partnership means families and mental health care providers working together to share information and provide support needed about mental illness (Coppock & Dunn, 2010:20).

1.7.9 Recovery

There are numerous definitions of recovery reflecting features of mental health in various countries (Jacob, 2015:117). Antony (cited by Thomas & Rickwood, 2016:501) defines recovery as “a process of changing one’s attitudes, feelings, perceptions, beliefs, roles, and goals in life resulting in the development of new meaning and purpose in one’s life, beyond the impact of mental illness” (Carpenter-Song, Holcombe, Torrey et al., 2014:162). The UK definition of recovery states that “recovery comprises full symptom remission, full or part-time work or education, independent living without supervision by informal carers, and having friends with whom activities can be shared, all sustained for a period of two years” (Slade & Longden, 2015:3). Both definitions provide a common meaning of recovery as the ability to live a meaningful life.

In terms of the study, recovery is achieved through the process of partnership which provides for the mobilisation of resources to improve personal and social functioning of MHCUs and their caregivers.

1.7.10 Practice guidelines for social workers

Practice guidelines are defined as a set of systematically developed, evidence-based scientific recommendations intended to optimise the provision of services (Fischler, Riahi, Stuckey & Klassen, 2016:2). The aim of practice guidelines is to improve the quality and effectiveness of care by providing standards to reduce variation in the provision of care (Kredo, Bernhardsson, Machingaidze et al., 2016:123). Practice guidelines are effective in guiding the practice of mental health care practitioners in a culturally diverse context (Ratts, Singh, Nassar-McMillan et al., 2016:28) by standardizing intervention procedures (Fischler et al., 2016:2).

In this study, practice guidelines are recommended activities for social workers to promote the role of families and mental health practitioners as partners in the provision of mental health services to members afflicted with mental health problems.

1.8 Structure of the research report

The report provides a detailed composition of the study structured as chapters:

- Chapter One

An orientation and general introduction to the research report to provide a framework for the research. It focuses on the background to the study, the statement of the research problem, significance of the study, key research questions, goals and objectives, research approach and design, ethical considerations, clarification of key concepts, and the layout of the research plan outlining the research methodology for the study.

- Chapter Two

It focuses on the theoretical interpretations of partnership within the context of mental health. Theories pertaining to the mental health system have provided the framework for the conceptualisation and interpretation of partnership within the context of mental health care.

- Chapter Three

It focuses on the theoretical framework underpinning partnership. The ecological systems theory is explained as providing the theoretical framework for the study. Related theories include systems theories, family systems theories, person-in-environment approach, developmental approaches, indigenous perspectives, legal and policy framework and practice framework are discussed.

- Chapter Four

It is a comprehensive application of the qualitative research process. It focuses on the methods and procedures used to conduct the study, data collection, data analysis, and data verification.

- Chapter Five

It focuses on the presentation of the research findings, analysis and literature control regarding MHCUs and their caregivers as research participants. The qualitative data analysis will be highlighted and discussed. Emerging themes, sub-themes and storylines to underscore the themes will be presented. Literature will be used to support and/or contrast the themes.

- Chapter Six

It focuses on the presentation of the research findings which are presented and discussed, and thereafter literature control is applied to compare and contrast the findings regarding social workers as research participants. Emerging themes, sub-themes and storylines to underscore the themes will be presented. The findings are a reflection of the social worker's role in working with families and in collaboration with other service providers including doctors, nurses and psychologists, and indigenous healers in a multidisciplinary role.

- Chapter Seven

It focuses on guidelines on partnership practice for social workers and other practitioners involved in the provision of mental health services.

- Chapter Eight

It provides a summary of the research report outlining major findings, overall conclusions and recommendations derived from the research process and the research findings.

CHAPTER TWO

MENTAL HEALTH SYSTEM AND PARTNERSHIP PRACTICE IN THE PROVISION OF MENTAL HEALTH SERVICES

2.1 Introduction

The provision of mental health care has evolved through various stages, from magical through to religious and medical practices (Chakravarty, 2011:267). While these practices reflected an epistemological shift that informed the provision of mental health care, the family, to date, remained unrecognised. The provision of mental health care has remained the responsibility of experts involving prophets, priests and mental health care practitioners.

The current mental health system is dominated by the medical discourse despite evidence showing the effects of social factors in the aetiology of mental illness (Williams & Heslop, 2005:231; Bhattacahrjee, Singh, Rai et al., 2011:54; Uher & Zwicker, 2017:123). Although the medical approach may remain relevant, it may not adequately eradicate problems predating the magical, religious and scientific practices. None of these practices ever conceived the relevance of families as partners in the provision of mental health services.

This chapter conceptualises partnership within the context of mental health system. It explains the current practice of mental health based on the medical model. Partnership as a social process brings the social perspective of the mental health system reflecting an integration of multiple explanatory perspectives (Kendler, 2005:439; Beresford et al., 2010:18; Owiti, Palinski, Ajazet et al., 2015:23). The discussion of the chapter will focus on the background to the mental health system and conceptualisation of partnership.

2.2 Background to the mental health system

The mental health system is grounded within the systems theory. A system provides a framework for effective provision of mental health services (WHO, 2009:2; Jara, 2016:21). The mental health literature is saturated with myriad definitions of mental health reflecting different approaches to its conceptualization (Coppock & Dunn, 2010:8). Definitions of mental health are derived from different philosophical, theoretical and ideological perspectives relating to the medical and social paradigms (Coppock & Dunn, 2010:8). WHO defines mental health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" (Matlala et al., 2018:46). The Mental Health Care Act (Act No.17 of 2002) describes mental health as a condition affected by "physical, social and psychological factors which may result in a psychiatric diagnosis". In this context, different theories, perspectives, paradigms and models underlying the mental health system are utilized to conceptualise partnership as central to successful service delivery.

2.2.1 Models of the mental health system

There are currently two important models, namely, the social and medical explaining mental illness. These models are the main perspectives of the mental health system through which mental health is explained. However, they differ in how they explain the causes of mental illness, its basic classification and treatment. The models are discussed below to provide a background to the mental health system.

2.2.1.1 The medical model

The model is philosophically rooted in positivism which emphasises empirical knowledge (McCann, 2016:1) over magical thinking (Rogers & Pilgrim, 2010:2; Chakravarty, 2011:266). It emphasises biological factors as the cause of mental illness (Gullslett et al., 2016:169). In terms of this model, mental illness shares the same factors as the physical illness (Chakravarty, 2011:268) consisting of the physiological, biochemical, or genetic causes which can only be treated medically (Chakravarty, 2011:267). However, critics have described the model as a medicalisation of social problems to legitimise medical intervention and institutionalisation (Beecher, 2009:10; Chakravarty, 2011:277; Mills, 2015:217). The medicalisation of social problems suggests the exclusion of the mentally ill person and the family from participation in the treatment process (Williams & Heslop, 2005:232; Cottone, 2007:191; Aho, 2008:244; Chakravarty, 2011:275), thus aggravating social stigma and discrimination of MHCUs and their families. This has influenced the language used to describe mental illness. The description of mental illness has historically assumed negative terms involving insanity, mental impairment, deviant behaviour, mental or psychiatric disorder and mental disability (Siyabulela & Duncan, 2006:300; Martensson, Jacobsson & Engstrom, 2014:782). For example, in Sepedi, derogatory labels are used to describe the person with a mental problem as *segaswi* (madness, psycho, schizo, loony). These terms contribute to the alienation and discrimination of MHCUs. Family members are also not spared the stigma and social isolation as a result of being related to the MHCU. Hence some authors have referred to the medical perspective as a form of a cultural belief system that has conditioned the society to use medical diagnosis to explain social problems, thus obfuscating the social aetiology of mental illness (Aneshensel, 2005:222; Campbell & Long, 2014:49). Therefore, the focus of the model on the illness to the exclusion of the person makes the occurrence of partnership impossible.

The emergence of the biopsychosocial model was a reaction to the reductionism of traditional psychiatry (Borrell-Carrió, Suchman & Epstein, 2004:576; Pilgrim, Kinderman & Tai, 2008:1; Tew, 2011:23) within the medical model. The biopsychosocial model marked a shift from biological focus to consider a holistic perspective embracing the biological, psychological and social character of mental illness (Siyabulela & Duncan, 2006:300; Tew, 2011:23). This shift was informed by the view that most severe and persistent mental illnesses were due to biopsychosocial vulnerability involving environmental stress and substance abuse (Juvva & Newhill, 2011:179). The model considers the interactions of biological, psychological, and social factors in understanding mental illness and the provision of mental health services (Carey, Kinderman & Tai, 2014:1; Dziegielewski, 2015:72; Vargas, Clemente & Mayoral, 2016:492). This means mental illness is not only a medical problem, but also a psychosocial condition. Nevertheless, the biological aspects remain dominant despite the recognition of the psychosocial factors (Beecher, 2009:267; Deacon, 2013:847). Moreover, the model's affinity to the pharmaceutical industry continues to medicalise the treatment of mental illness (Pilgrim, Kinderman & Tai, 2008:20; Chakravarty, 2011:275). Hence, the emphasis is placed on the long-term use of antipsychotic drugs to control the severity of the psychotic symptoms of schizophrenia (Aho, 2008:247; Rogers & Pilgrim, 2010:161).

Similar to the medical model, the biopsychosocial focuses on the illness to the exclusion of the individual's ecological factors, relating to family, community, culture and environment despite its accommodation of multiple aetiological factors (Rogers & Pilgrim, 2010:2; Tew, 2011:25). Psychiatry remains the dominant profession responsible for diagnosis, prognosis, treatment, and aetiology (Williams & Heslop, 2005:232; Wall, Mirfin, White & Mezey, 2017:358). Although professionals including psychologists, nurses and social workers are mental health care practitioners, their role is secondary to that of psychiatrists. The indigenous healing practitioners, namely traditional and faith healers, are given less attention despite being trusted by the majority of families and community members (Campbell-Hall et al., 2010:611). However, the role of caregivers, family and the community as partners in the provision of mental health services remains excluded.

2.2.1.2 The social model

The social model focuses on the role that the society plays in mental health care. It is an embodiment of diversity of thoughts based on social theories to describe social problems involving mental illness and the role of society and the environment in mental illness (Bhattacahrjee et al., 2011:55). Furthermore, it derives its meaning from postmodern explanations which view human relationships as a socially constructed reality (Conrad & Barker, 2010:67). Problems relating to mental illness and the provision of mental health services are viewed as socially constructed (Counts, 2015:9). Such constructs influence society's perceptions and labeling of mental illness. It is for this reason that the medical model considers the socio-cultural, political, economic, and religious explanations that promote change in attitudes towards mental illness and mental health services (Becvar & Becvar, 2009:10; Tew, 2011:25; Chakravarty, 2011:281).

The model further suggests a social consensus reflecting values, beliefs, memories, fears, and desires about mental illness and the provision of mental health services (Walker, 2006:77; Gergen, 2011:111). The social consensus does not only incorporate medical and psychological knowledge, but reflects indigenous knowledge systems that enable MHCUs and caregivers to explain their understanding of mental illness (Mpono, 2007:16; Bojuwoye & Sodi, 2010:284). Culture, as a social perspective, influences perception, construction and experiences of mental illness and the provision of mental health services (Noiseux, St-Cyr, Corin et al., 2010:1; Pharr, Francis, Terry & Clark, 2014:2), for example, the African constructions of mental illness explains some psychotic episodes as resembling the calling to become a traditional healer. Most Africans who subscribe to this thinking believe that failure to comply with the calling will result in misfortunes involving, among others, mental illness, death of a relative, and joblessness (Bogopa, 2010:3).

The social theory regards mental health system as highly complex and challenging (Bailie, Matthews, Brands & Schierhout, 2013:1). It explains multiple factors relating to income, housing, stress, social exclusion, occupation, social support, lack of access to resources, and socio-economic pressures as determinants of mental illness (Matlala et al., 2018:47).

The social conceptualisations of mental illness reflect reactions to mental illness (Pescosolido, 2013:4). The society often reacts with stigmatisation, victimisation and discrimination towards the MHCUs and their families (Chang & Horrocks, 2006:435; Akinbode & Tolulope, 2017:241). Labelling as a social reaction has been linked to how the society has constructed mental illness (Quinn, 2007:176; Bhattacahrjee et al., 2011:55). Such reactions tend to exacerbate the severity of mental illness which further aggravates personal and family dysfunctions to MHCUs and their families (Perry, 2011:461). Both the MHCU and family members may struggle to access social amenities involving housing, employment, health and education (Kakuma, Kleintjes, Lund et al., 2010:122). The MHCUs may as a result resort to substance use and non-adherence to treatment, thus maintaining a life of mental illness (Perry, 2011:461).

The poor functioning of the mental health system may result from inefficient management, staff workload, inadequate support, poor infrastructure, limited funding and resources (Ramlall, 2012:408). These factors motivated different international forums including the WHO and the Alma Ata Declaration forums to call for the transformation of the mental health system to promote the rights of the MHCUs (Mkhize & Komatsi, 2008:103; DoH, n.d:3). Hence the adoption of a social model to mental health has become necessary as it recognises the involvement of families in the provision of mental health services (Tew, 2008:273; Counts, 2015:7). Therefore, the social model is appropriate for the conceptualisation of partnership.

2.2.2 Types of mental illness

The following list describes the main types of mental disorders impacting on the functioning of MHCUs.

- **Neurodevelopmental disorders** usually begin in infancy or childhood. Examples include attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder, and learning disorders (Ahn, 2016:1).
- **Schizophrenia spectrum and other psychotic disorders** include delusions, hallucinations, and disorganized thinking and speech (Untu, Moisa, Burlea et al., 2015:24). The disorders are discussed in detail in the glossary and item 2.2.4.1.
- **Bipolar disorders are e**pisodes of mania (periods of excessive excitement, activity, and energy) alternating with periods of depression (Matlala et al., 2018:48).
- **Depressive disorders are** characterized by feelings of extreme sadness and worthlessness, and reduced interest in activities (Matlala et al., 2018:46).
- **Anxiety disorders involve** excessively worrying about dangerous things that could happen (Dziegielewski, 2015:290). The disorders include generalized anxiety disorder (GAD), panic disorder, and phobias (extreme or irrational fears of specific things) (Peltzer, Pengpid & Skaal, 2010:10).
- **Obsessive-compulsive disorders** are usually experienced as repeated and unwanted urges, thoughts, or images (obsessions), and feeling driven to taking repeated actions in response to them (compulsions) (Dziegielewski, 2015:279). Common symptoms include hoarding disorder and hair-pulling disorder (trichotillomania) (Matlala et al., 2018:47).
- **Trauma- and stressor-related disorders** develop during or after stressful or traumatic life events. They include posttraumatic stress disorder (PTSD) and acute stress disorder (Steel et al., 2014:479; Dziegielewski, 2015:309).

2.2.3 Causes of mental illness

The explanations of causes of mental illness are derived from different models of mental illness. A general consensus is the attribution of causes to biological, psychosocial, environmental and supernatural factors across cultures.

According to the medical model mental illness is caused by biological factors involving genetics, prenatal damage, infections, exposure to toxins, brain defects or injuries, substance abuse and problem in the neurotransmitters (Teferra & Shibre, 2012:5; Hailemariam, 2015:35). Genetic or hereditary factors suggest that the person may have been born with mental illness (Wonpat-Borja, Yang, Link & Phelan, 2012:145). Moreover, an interaction of genetic and environmental factors including stress, abuse, or traumatic events can influence mental illness (Uher, 2012:1; Dziegielewski, 2015:309).

The biopsychosocial model explains the causes of mental illness as a combination of genetic dispositions and environmental stressors (Herzig, Mühlemann, Burnand et al., 2012:2). For instance, damage to the brain may cause cognitive changes regarding impairment of judgment and an inability to regulate behavior (Dziegielewski, 2015:431). Environmental or psychological causes include dysfunctional family life, poor relationships with others, substance abuse, low self-esteem and poverty (Scherr, Hamann, Schwerthöffer et al., 2012:108). Maternal exposure to psychosocial stress or infections may also trigger a change in the brain chemistry to cause autism spectrum disorder and dementia (Rode, Stricklin & Nicely, 2018:164). Abuse of dagga (cannabis), alcohol and caffeine can cause anxiety, depression, and paranoia (Hesse & Thylstrup, 2013:1). Alcohol abuse may damage the white matter in the brain and affect one’s thinking and memory (McEvoy, Fennema-Notestine, Elman et al., 2018:390).

The social model focuses on social contexts which attribute mental illness to different psychosocial factors relating to environmental stressors or traumatic life experiences and supernatural factors (Bhattacahrjee et al., 2011:58). The supernatural factors are associated with evil spirits, magic, demons, and witchcraft as causing mental illness (Zingela, van Wyk & Pietersen, 2019:147). The attribution of mental illness to supernatural factors is common among indigenous communities in different parts of the world. Some Africans and religious communities in South Africa, view supernatural factors as causes of mental illness (Sorsdahl, Flisher, Wilson & Stein, 2010:284). Supernatural factors are believed to be unleashed when individuals disobey social taboos and norms or disobeying culturally expected obligations of the society, a calling by ancestors or God.

2.2.4 The classification system

Classification is an activity that every human being performs to identify and differentiate objects (Berrios, cited in Uher & Rutter, 2012:591). In mental health, classification describes how mental health disorders are constructed and categorised (Flexer, 2015:35). Different diagnostic tools have been developed for the classification of mental illnesses. The most utilised tool in South Africa is the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Strand, 2011:273; Castillo & Guo, 2016:217). The current DSM-5 has adopted the spectrum approach which recognises environmental risk factors in mental illness (Castillo & Guo, 2016:217). The consideration of environmental risk factors is consistent with the ecological systems approach to explain the person-in-environment (PIE) associated with social work practice (Wakefield, 2013:131). Social work uses PIE for assessment and to promote common descriptions of service user situations to facilitate intervention. However, Wakefield (2013:131) contends that, the DSM-5 is usurping social work tasks to treat ‘‘brain-in-environment rather than person-in-environment”, thus entrenching the medical focus on mental health.

The common classification systems currently in use include the DSM-5 and the International Classification of Diseases (ICD-10) or the International Classification of Diseases (ICD-11) (Dziegielewski, 2015:4). The DSM-5 in particular has often been referred to as the bible of psychiatric diagnosis (Kupfer, Regier & Kuhl, 2008:2; Counts, 2015:2). Its main purpose is to provide efficient and effective communication among professionals, diagnosis and the formulation of treatment strategy, and facilitating empirical research in psychopathology (Dziegielewski, 2015:3).

However, the DSM-5 may not be objective since the observed behaviour is influenced by the practitioner’s orientation which includes personality, attitudes and expectations (Flexer, 2015:35). The MHCU’s experience believing that they are bewitched may be ignored in order to conform (or refute) a particular explanation relevant to the DSM-5 (Tew, 2011:23). This exclusion of the individual’s experience may not consider partnership with families as integral to the provision of a comprehensive mental health services (Beecher, 2009:10; James, 2012:17). Therefore, the practice of the medical approach is contrary to the principles of partnership. This suggests that partnership requires a social model which considers the social, economic, psychological and cultural aspects of mental illness (Beresford et al., 2010:16).

Nevertheless, to determine a diagnosis, a mental status analysis is conducted to gather biopsychosocial information which includes the biological, psychological and sociocultural factors of the person (Dziegielewski, 2015:72). Below is a discussion on schizophrenia as a diagnosis given to MHCUs who participated in this study.

2.2.4.1 Schizophrenia

The concept schizophrenia is a category of mental illness which was coined by Eugen Bleuler as a description of a split between thought, emotion and behaviour in affected individuals (Kaplan, Saddock & Grebb, 1994:457; Lysaker, Roe & Buck, 2010:36; Dziegielewski, 2015:150). Most Black South Africans use the term '*mafufunyana'* to refer to psychotic symptoms of schizophrenia, namely; hallucinations, delusions and aggressive behaviour (Mzimkulu & Simbayi, 2006:418; Campbell, Sibeko, Mall et al., 2017:2). Like the Western description of schizophrenia, *mafofonyana* is also a reflection of observed, but bizarre behaviour.

Schizophrenia is described as a mysterious illness as its causes have remained obscure despite being the most researched mental condition (Tandon, Keshavan & Nasrallah, 2008:1; Teferra & Shibre, 2012:1). The medical model of mental health attributes the causes of schizophrenia to biological factors relating to chemical imbalances (Aho, 2008:244; Grover, Davuluri & Chakrabarti, 2014:122); the genetic factors that explain the development of schizophrenia as 'running in family syndrome' (Tandon, et al., 2008:1; Dziegielewski, 2015:153); and environmental factors involving cannabis use, prenatal infection, malnutrition and seasonal onset (Tandon, et al., 2008:1; Scherr et al., 2012:107). Schizophrenia is a chronic and disabling condition associated with impairments in functioning including thought disorder, poor self-image, interpersonal relationships, family dysfunction, poor social functioning, and social isolation (Wong 2014:132) with a devastating impact on the quality of life (Chan, 2010:376; Sicras-Mainar, Maurino, Ruiz-Beato et al., 2014:1).

2.2.4.2 Diagnosis of schizophrenia

The purpose of diagnostic assessment is to improve diagnostic accuracy and appropriateness of treatment selection for MHCUs (Keepers, Fochtmann, Anzia et al., 2020:869). Diagnostic assessment requires the awareness of key features constituting schizophrenia. Such features are "inferred from behaviours performed or symptoms reported by clients" (Wong, 2014:132; Flexer, 2015:35). The symptoms or behaviours are organised in the form of diagnostic categories with the goal of assigning the MHCUs to these categories (Wong, 2014:132). A multidisciplinary team made up of psychiatrists, psychologists, psychiatric nurses and social workers participate in the assessment of the severity of the symptoms. Family members participate during assessment to give their views about the illness based on their observations and their interactions with the MHCU (Wong, 2014:133). Even though the current DSM-5 was meant to address the deficits in previous editions, it has also been "criticized for its limited cross-cultural applicability" (Singh, 2012:40; Grover et al., 2014:119). The DSM-5 diagnosis locates schizophrenia within a spectrum of disorders (Tiffin & Welsh, 2013:1155). The diagnostic categories of the DSM-5 are classified as criteria A, B, C, D and E described as criteria that must be met to fulfil the requirements of a particular category (Wong, 2014:133). Diagnostic Criteria A lists key features for schizophrenia with two (or more) symptoms, each presenting for one-month and continuous signs of disturbance persisting for at least six months (Wong, 2014:133). These features include delusions, hallucinations, disorganized thinking and speech (e.g. frequent derailment or incoherence); grossly disorganized or catatonic behaviour presenting as inappropriate behaviour indicative of abnormal control (e.g. dressing inappropriately, crying frequently); and negative symptoms showing blunted affect (decline in emotional response), alogia (decline in speech), or avolition (decline in motivation) (Wong, 2014:133). Such features are identified through an assessment process focusing on the following:

- Biomedical information involves the MHCU's general physical health or medical condition. Although social workers are not qualified to examine or diagnose biomedical information, they are expected to document their observations and provide referrals to medical practitioners to ensure comprehensive intervention (Dziegielewski, 2015:71).

- Psychosocial information involves the MHCU's cognitive, psychological, occupational and social functioning (Nordahl, Wells, Olsson & Bjerkeset, 2010:853). Relevant information is gathered during the mental status examination.
- Social, cultural and spiritual information is based on the assessment of the environmental factors impacting of the individual and family (Bojuwoye & Sodi, 2010:289; Dadlani, Overtree & Perry-Jenkins, 2012:177).
- Mental status examination describes the mental health care practitioner's observations and impressions of the MHCU's during the interview, focusing on the general descriptions, delusions, hallucinations, thinking and speech, and affect (Dziegielewski, 2015:71; Norris et al., 2016:635). The descriptions of mental status examination of a MHCU with schizophrenia are discussed in detail in the glossary.

2.2.5 Impact of mental illness on the functioning of MHCUs

Mental illness impacts on the functioning of MHCUs, family relationships and society at large. The impacted areas include health, economic and social domains of affected persons, their families, interpersonal and social functioning (Lund, Myer, Stein et al., 2013:845). Schizophrenia severely affects the capacity of MHCUs to perform their basic self-care and day-to-day functioning (Fekadu, Mihiretu, Craig & Fekadu, 2019:1). Lack of social interaction may exacerbate feelings of loneliness that may deteriorate to symptoms of hearing voices and paranoia, resulting in further isolation from social interactions (Connell, Brazier, O'Cathain et al., 2012:13). Family members may experience a variety of stress resulting from living with a MHCU. In some instances, employment opportunities, leisure time, mental and physical health including relationships are compromised. For caregivers, their roles change from being spouses, siblings and parents. MHCUs are not the only ones who experience social isolation. Their families carry the stigma of mental illness by virtue of their association with a MHCU (Nxumalo, & Mchunu, 2017:202). In most African communities, families with a MHCU are blamed for practicing witchcraft which they regard as the cause of mental illness.

Socio-economic impact affects social relationships and the economic activities of MHCUs, their families and society (Doran & Kinchin, 2019:43). MHCUs may not get employment due to the severity of the illnesses and the social stigma attached to mental illness. Some caregivers are forced to leave their employment to care for their ill relatives. Although MHCUs may earn disability grants, which is the main income in most families, the grant may not be adequate to meet the needs of all members of the household. The current R450.00 grant-in-aid earned by caregivers in South Africa is also not sufficient to meet the needs of the household which may include extended family members and the MHCUs' children. Even though feeding scheme programmes exist in South African schools, children's level of functioning may be adversely affected, resulting in poorer school performance, poor nutrition and social isolation (Fekadu et al., 2019:4). Rural communities are the most affected as they have to contend with transport costs, shortage of services and poor infrastructure. Although the Department of Rural Development and Land Reform in South Africa was established in 2009 for the development of rural communities, these communities continue to experience scarcity of water, housing, and social and health services.

The neglect in prioritising mental health in South Africa impacts significantly on the well-being of MHCUs and family caregiving (Mokwena et al., 2014:367). Inadequate allocation of budgets and human resources has consequently led to a staggering 75% MHCUs not receiving adequate services (Docrat, Besada, Cleary et al., 2019:708; Doran & Kinchin, 2019:43). Social workers, who are frontline workers in communities, have not been adequately trained to provide mental health services (Kourgiantakis, Sewell, McNeil et al., 2019:1; Van Breda & Addinall, 2020). Lack of a comprehensive integrated policy that include all mental health care providers and families in service delivery impact negatively on the recovery of MHCUs and the capacity of their caregivers to provide effective care (Lund, Petersen, Kleintjes & Bhana, 2012:402). Lack of support and resources has contributed to most families neglecting MHCUs. Moreover, the abilities of MHCUs and caregivers as part of the comprehensive integrated effort to provide services are not embraced and enhanced to improve their quality of life.

2.2.6 Mental health intervention for schizophrenia

The treatment of schizophrenia is usually lifelong and predominantly biopsychosocial involving the prescription of antipsychotic medications, psychotherapy, psychosocial and family intervention (Dziegielewski, 2015:187). It is a continuum of care involving individual therapy, case management, family support, and medication management (Dziegielewski, 2015:186; Baandrup, Rasmussen, Klokker et al., 2016:232). The treatment approach is multidisciplinary involving psychiatrists and psychiatric nurses who offer medical treatment, psychologists offering psychotherapy, social workers offering psychosocial intervention, and indigenous (traditional) and faith healers.

2.2.6.1 Psychiatric treatment

Psychiatric treatment provides antipsychotic medication as the treatment of choice (Wand, 2013:116; Danzer & Rieger, 2016:33; Keepers et al., 2020:869). Although antipsychotic medication alleviates the severity of symptoms, its potency is enhanced with the use of psychosocial interventions (Goff, Falkai, Fleischhacker et al., 2017:841). Therefore, the treatment of schizophrenia involves multidisciplinary approach to provide medical and psychosocial treatment to enhance the wellbeing of MHCUs.

2.2.6.2 Psychotherapy

Psychosocial interventions focus on psychotherapy and psychosocial support (Bhattacahrjee et al., 2011:54; Dziegielewski, 2015:302). Similar to the psychiatric treatment, psychosocial interventions are a component of psychiatric interventions. The two forms of treatment complement each other. Psychosocial interventions involve assessment to determine the nature of the problem, and develop appropriate intervention strategies.

Psychotherapy, which focuses mainly on the psychic aspect, explore thoughts and behaviours to improve the individuals’ well-being (Grover, Avasthi & Jagiwala, 2020:174). However, the intervention is effective when complemented with medication to promote recovery. As most MHCUs may lack awareness of the illness, psychotherapy helps them to learn about their illness and its effects, coping and stress management skills (Bojuwoye, 2013:80). The use of cognitive-behavioural therapy

(CBT) helps the MHCUs to manage hallucinations and delusions, and develop a better understanding of themselves (Lysaker, Glynn, Wilkniss & Silverstein, 2010:81).

2.2.6.3 Social work intervention

Social work recognises the relationship between people and their environments when assessing human behaviour and determining intervention strategies (Dziekielwski, 2015:33). Various responsive interventions are utilised to improve the functioning of individuals, families and communities. Therefore, the purpose of social work intervention is to develop capacity to cope, mobilise resources, and reduce stress. To accomplish this, primary methods of intervention guided by a broad range of knowledge, skills, values, ethics and techniques to enhance the social functioning of individuals are employed.

The values underlining social work intervention include social justice, dignity and worth of the person, importance of human relationships, integrity, and competence (Sewpaul, 2010:257). Common intervention techniques include counselling, family intervention, psychoeducation and psychosocial support (advocacy, raising awareness and empowerment in Table 2.1).

Psychosocial intervention is linked to the strengths-based perspective which emphasises the need to identify and to build on the strengths of individuals, families and communities, to recognise solutions to problems. The intervention is based on the understanding that problems in social functioning may result from stressful life situations, relationship difficulties or environmental factors (Ragesh, Hamza & Sajitha, 2015:166).

Table 2.1 Social work intervention techniques

Techniques	Purpose	Focus	Skills
Counselling (Drobot, 2013; Payne, 2014; Bolton, Hall, Blundo & Lehmann, 2017)	▪ To guide service users through interviews, gain insight into their problems. Their behaviour is thus modified and skills are developed to cope with situations.	▪ Identify events that precipitate the behaviour, identify maladaptive behaviour and consequences. ▪ Service users' experiences, perceptions, feelings and aspirations to grow and adapt to situations. ▪ Service users' strengths to build resilience and find solutions to current problems; resources and competencies to thrive in stressful situations	▪ Modelling, role-playing and training in assertiveness. ▪ Empathic response, active listening and reflecting. ▪ Clarifying the importance of their lives to increase awareness of the illness; the need for treatment and social consequences of the disorder. ▪ Cognitive restructuring through reframing their narratives to restructure perceptions and create new meaning of their experiences.
Family intervention (Giron, Fernandez-Yanez, Mana-Alvarenga et al.,	▪ Family restructuring. ▪ Family intervention strategies are used to promote family functioning by examining	▪ Family restructuring focusing on patterns of interaction including roles, boundaries and alliances among family members. Roles may change to accommodate caregiving for the MHCU and improve sharing of responsibilities.	▪ Applying systemic family therapies to focus on behaviours that lead to conflict, and altering patterns of interactions. Reframing techniques help the family to perceive the

2010; Makofane & Mogoane, 2012; Dziekielwski, 2015)	relationships and patterns of interaction in the family.	▪ Cultural competence (cf. Item, 2.3.3.3) to consider cultural aspects of family members as they may have a bearing on their understanding of the causes and treatment of mental illness (cf. Item 2.2.3 & Chapter Five, Item 5.3.1.2 Subtheme: 1.2).	situation differently and alter interactions. ▪ Mediating to resolve family conflict.
Psychoeducation (Kramers-Olen, 2014; Economou, 2015; Economou, 2015; McFarlane, 2016).	▪ To develop skills by providing relevant information to improve problem-solving, communication and assertiveness.	▪ Involves family-patient-professional partnership including family members as collaborators. Helps family members to understand the illness through their involvement in the intervention process.	▪ Using cognitive-behavioural therapy. ▪ Giving advice, identify and model alternative behaviour patterns and their consequences. ▪ Teaching problem-solving techniques and clarify perceptions.
Psychosocial support (Stavropoulou & Samuels, 2015)	▪ Provides a continuum of care and support which influences the	▪ Support offered to MHCs by caregivers, family members, friends, neighbours, professionals and community members on a daily basis.	▪ Advocating for access to information to promote knowledge about mental health and mental illness; education about stigma and discrimination; access support

	individual and the social environment.	▪ Provision of material support in the form of food parcels, shelter, and financial relief to alleviate distress.	services; social justice and the transformation of service delivery. ▪ Mobilising government support to address the plight of MHCUs and their families. ▪ Mobilising community resources through awareness programmes and linking MHCUs and families with social support networks (income generating projects, nutrition feeding schemes, employment and other essential amenities).

- Counselling technique

Counselling is an intervention technique used by social workers to assist service users find solutions to their problems. Service users experience stress arising from life transitions, interpersonal relations and environmental deprivation. Moreover, stress can interfere with personal, family and social functioning of individuals, caregivers and family members. Therefore, counselling requires the use of empathic understanding that encourages clients to share and release painful emotions, and to realise their own interpretations underlying their experiences (Murphy, Duggan & Joseph, 2013:708). Empathic understanding communicates unconditional love, tolerance and acceptance of the person, and commitment to provide help. Service users are thus enabled to mobilise their inner resources, gain an understanding of their experiences and identify personal abilities to overcome them.

- Family intervention technique

Family intervention technique is based on the understanding that MHCUs and caregivers may experience stressful family relations. Conditions relating to the onset of mental illness, in particular, may disrupt family stability which may be irreversibly changed. Family intervention strategies are used to promote family functioning by examining relationships and patterns of interaction in the family; and help family members to understand the impact of mental illness on the MHCUs and families (Constable, 2016:149). The intervention is based on the understanding that MHCUs and caregivers live with other family members or extended family members who serve as their support system. Therefore, family restructuring is appropriate to promote communication, problem-solving skills and family support (Kramers-Olen, 2014:506).

- Psychoeducation technique

The MHCUs are educated about the illness, engaged in problem-solving, communication and self-assertiveness training (McFarlane, 2016:468). Family members are also involved in the intervention process. Its focus is “multidimensional, including familial, social, biological and pharmacological perspectives, as well as providing service users and carers with information, support and management strategies" (Economou, 2015:259). The main emphasis is on education and raising awareness to improve the well-being and recovery from mental illness (McFarlane, 2016:467). Therefore, the outcome may improve compliance with medication, positive relationships, reduced burden of caregiving and reintegration of MHCUs into communities to improve their social and occupational functioning.

- Psychosocial support technique

This technique is important for people experiencing a crisis. It is a response to disruptions that may weaken personal, social and security safety nets for families (Palmer, 2013:148). Such families may need material, physical and educational support to improve their wellbeing. Thus, psychosocial support is employed to mobilise resources for families in distress. Related techniques include advocacy and empowerment which are used to promote human rights, access to resources, develop capacity of families to adapt and change their living conditions (Gray, 2010:82). Community development is one of the methods through which advocacy and empowerment are used as techniques to facilitate change in the lives of people (Gray, 2010:88; Chereni, 2017:408). Moreover, collective action may be mobilised to address basic psychosocial needs.

2.2.6.4 Indigenous interventions

Indigenous interventions involving traditional and faith healing are common practices providing community-based mental health treatment in most communities in Africa (Sorsdahl, Stein & Flisher, 2010:47; Burns & Tomita, 2014: 874). The interventions are aligned to the cultural and religious understanding of mental health problems and solutions (Zingela, Van Wyk & Pietersen, 2019:149). Assessment, diagnosis and treatment of mental illness is done through songs, dances, ceremonies, imagery, throwing of bones, dream interpretation and herbal remedies for psychological and emotional healing of MHCUs (Bojuwoye & Sodi, 2010:288). Moreover, family members may become part of the therapeutic process of the individual's healing (Bartholomew, 2016:109). However, MHCUs and their families continue to experience the effects of mental illness despite a plethora of interventions.

2.3 Partnership practice in the provision of mental health services

Partnership, is defined in chapter one Item1.7.7, as a practice among people who need each other to carry out tasks. Its conceptual definitions differ in scope and context (Gallant, Beaulieu & Carnevale, 2002:151; Ying & Loke, 2016:243). Partnership is synonymous with terms like colleague, ally and confederate, which "indicate one who is united or associated with another to enhance their mutual interest and success" (Määttä, Lützén & Öresland, 2016:2). It is a practice known to humanity since time immemorial through helping each other to improve the provision of services (O'Brien & Evans, 2017:1400).

The idea of partnership is premised on the understanding that no person has all the competencies or resources to address challenges (Henig, Riehl, Rebell & Wolff, 2015:27). The Sepedi idiom *"Tau tša hloka seboka di šitwa ke nare e hlotša"* (which literally means: lions which do not work as a collective will be defeated by a limping buffalo) has effectively captured the importance of partnership. This understanding reveals the social role of partnership befitting the social model (Rogers & Pilgrim, 2010:15). As a principle underlying the developmental approach (cf. Chapter Three, Item 3.2.4) that informs social work, partnership is a collective effort for the promotion of access to services (Lombard, Kemp & Viljoen-Toet & Booyzen 2012:180). Partnership with the caregivers of MHCUs is a shared responsibility to promote the wellbeing of those in need of care (Coyne & Cowley, 2007:901; Cook-Sather, 2013:1). Therefore, the main focus of partnership is the mobilisation of social relationships to improve the quality of life through the provision of services.

Partnership practice has been embraced by business and the public service with policy and ideological constraints. The current mental health system, in particular, is constrained by the medical framework which marginalises the social aspects of mental illness (Whitley, 2008:358; Leung & Lam, 2014:320). For instance, the revelations in the Life Esidimeni report[8] regarding the tragic deaths of 144 MHCUs have drawn attention to the marginalisation of families of the MHCUs in the decision-making

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[8] Life Esidimeni report is the outcome of an investigation that was commissioned by the state to establish the circumstances that led to the death of mental health patients after being transferred to some unlicensed non-government organisations (NGOs) as a result of the termination of a government-subsidised contract (Ornellas & Engelbrecht, 2018).

process (Makgoba, 2017:1; News24, 2018). This happened despite the concerted efforts by the South African Government to integrate democratic principles of *Bathopele*[9] (People First) to guide the provision of services. Partnership is an activity performed through a collective process to improve service delivery (Patel, 2012:607; Kidd, Kenny & McKinstry, 2015:39; O'Brien & Evans, 2017:1400).

2.3.1 Perspectives, assumptions and principles underlying partnership

Partnership contains a rich collection of perspectives, assumptions and principles for gaining a better understanding of the roles of individuals, groups and practitioners and organizations. Perspectives, assumptions and principles are sets of rules, ideas, or beliefs which are used to explain partnership.

2.3.1.1 Perspectives on partnership

The concept of partnership is applied in many contexts which assume different perspectives for its understanding. This suggests that no single perspective can capture the diversity of the concept of partnership. In the context of this study, perspectives provide insight into the process of partnership to create a common understanding in the provision of services (Mikkelsen & Riis, 2017:26). Partnership integrates insights from various theoretical frameworks including systems theory, ecological systems theories and developmental approaches, indigenous and practice frameworks from which the social model is derived (cf. Chapter Three). Therefore, partnership is an interaction of perspectives that participants bring based on their diverse believe systems.

2.3.1.2 Assumptions of partnership

The basic assumption of partnership is that the whole is greater than its parts (Brinkerhoff & Brinkerhoff, 2011:3). It suggests that people operate as part of wider

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[9] Bathopele is a Sotho word that literally means "people first". The term was adopted by the South African government guide the delivery of public services for the benefit of the people (Department of Public Service and Administration, 1997).

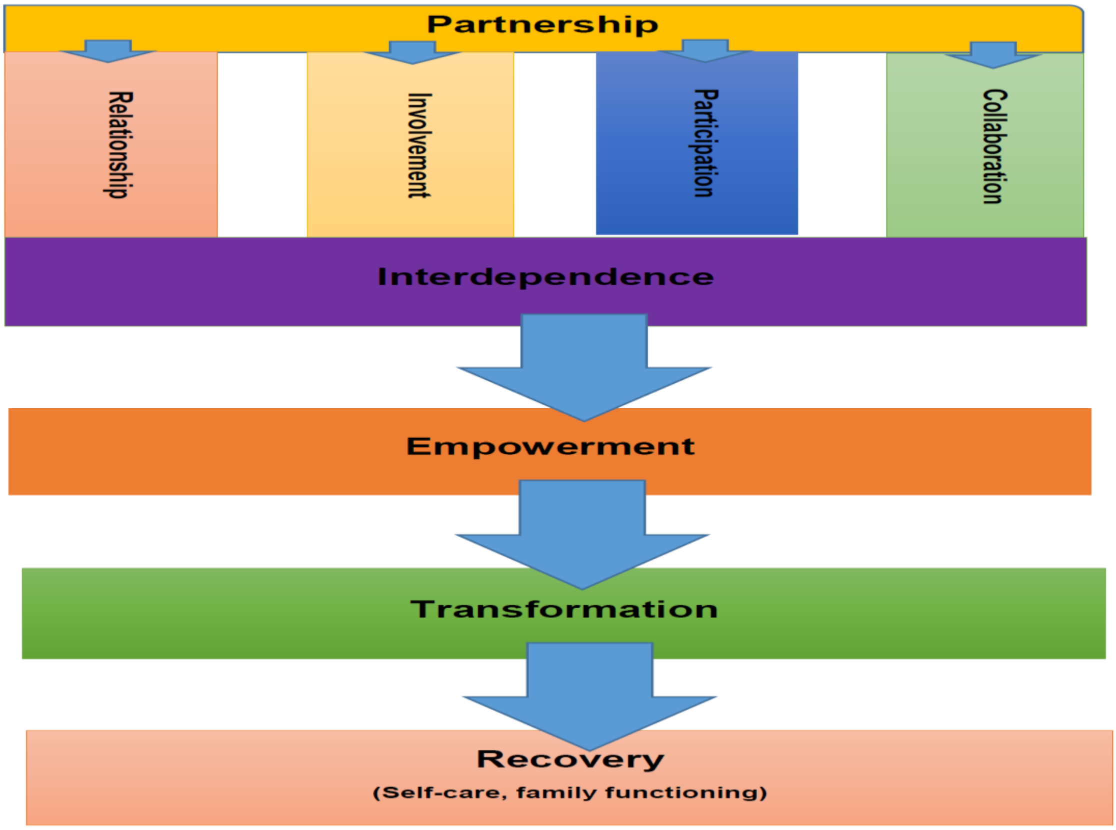
networks or systems involving families, friends, communities, institutions and culture, and MHCUs and families are part of these systems (Chu, 2018:357). People are viewed as participants in the construction of their own understanding of reality to influence relationships (Rogers & Pilgrim, 2010:15) within partnership. Therefore, partnership requires MHCUs to participate in shaping their recovery process to improve personal and social functioning. Moreover, there are shared values which evolve into interdependent, mature relationships characterised by each partner being equally valued, the ongoing exchange of ideas, and the equitable distribution of resources (Stringfellow, 2017:155). The interdependence of people on each other and their environment (stressors) helps them to draw resources from their environment and social networks in order to cope with their circumstances (Friedman & Allen, 2014:10). Partnership is inclusive of all social factors which interact with MHCUs and their families to transform their living circumstances and improve their well-being. There is emphasis on the relationship among individuals, families, groups, organisations and communities and their environments and their influence on each other.

This means in partnership individuals join hands with others to work together as a collective for mutual benefit. The participants work together as equals sharing a common vision, goals and objectives, information and resources for joint provision of services, problem solving and social justice. Partnership serves as a means through which individuals and families participate actively to improve their wellbeing.

2.3.1.3 Principles on partnership

Partnership is built on a foundation of shared principles or values to improve access to services (Bryan & Henry, 2012:409). The most important principles of partnership include relationships, involvement, participation, collaboration, cooperation, interdependence and empowerment (Carnwell & Carson, 2009:7; Bryan & Henry, 2012:409) and are illustrated in figure 2.1.

Figure 2.1: Key principles of partnership



These principles are interlinked to create reciprocal interactions influencing one another (Suchman, 2006:41; Perry & Pescosolido, 2015:117) to guide partnership practice. The relationship principle is a precursor for all other principles underpinning partnership (Carnwell & Carson, 2009:13). This means there is a relationship in partnership. Therefore, participants engage in relationship building to achieve partnership.

Although relationship can happen without partnership, there cannot be partnership without a relationship. This explains partnership as a relationship in which partners are equally valued and benefit from equitable distribution of shared resources (Reid, 2016:14). Importantly, communication is central to relationship building to convey the values of respect, trust, empathy, and commitment to the wellbeing of partners (Ngigi & Busolo, 2018:86). These values are important, especially for individuals and families faced with personal and social problems with little support from service providers. Equally, they guide social work intervention focusing on relationship building to improve the wellbeing of individuals, families and communities. Their expression in the context of a relationship creates a sense of hope and contribute to individual and family resilience. Importantly, families are able to build relationships at various levels of the ecological system to access networks of support services.

The principles of involvement, collaboration and participation are used interchangeably, and at times together, to explain the active role of partners in partnership (Carnwell & Carson, 2009:13; Bryan & Henry, 2012:409). As partners become involved through collaboration and participation, sufficient trust and respect develop, and partnership is enhanced (Solomon, Molinaro, Mannion & Cantwell, 2012:98) to improve mental health services.

The principle of collaboration is described as “a means of making partnership work” (Carnwell & Carson, 2009:12). It is a form of teamwork to respond to common needs. Groups or institutions agree on services they should provide together. Collaborating participants carry out activities that no individual, group or institution on its own can perform (Banerjee, Murphy & Walsh, 2020:1). For instance, most public institutions work in collaboration with private institutions to fight coronavirus pandemic (Goldman & Silva*,* 2020:1). Different types of collaboration are discussed in this chapter (item, 2.3.3) to explain partnership.

The principle of participation is defined as a voluntary process by which people participate in programmes to improve their quality of lives (Nijhuis, 2017:68). Granlund (2013:470) identifies two dimensions of participation, namely, “attending/doing and being involved/engaged while attending”. Individual participants, groups (family, friends), communities attend to activities that may involve information sharing, self-care, and decision-making as part of partnership building. For instance, MHCUs take medication which enables them to participate in decision-making processes at group and community levels regarding issues of social justice and access to services. Similarly, caregivers may participate at group and community levels to improve their capacity for caregiving. At the political level, individuals participate in processes that promise to promote political and social justice. Therefore, participation is an empowering process to improve the quality of lives of individuals, families and communities. Empowered individuals will have the confidence to participate in partnership processes.

The principles of interdependence, empowerment, transformation and recovery are the culmination of the function of a successful partnership (cf. 2.3.4.4), which marks changes in human behaviour and social systems (Gass, 2011:22), and improved quality of life for MHCUs, caregivers and their families.

2.3.2 Types of partnerships

There are different types of partnerships, namely collaborative partnership, community partnership and public-private partnership:

2.3.2.1 Collaborative partnership

Collaborative partnership explains partnership as involving participants from diverse contexts with different experiences and perspectives to improve the provision of mental health service. Partners participate in the decision-making process (Kin & Koukiadaki, 2009:389; Gole, 2018:14). This means caregivers as partners participate in the decision-making process regarding the provision of mental health services. However, the study shows caregivers are not participating in the decision-making process regarding the provision of mental health services. Professionals fail to share information with service users (MHCUs and caregivers) and indigenous practitioners (traditional and faith healers) regarding mental illness, treatment and access to services.

Collaborative partnership considers the capacity of partners working together as equals to improve the effectiveness of services (McCloughen, Gillies & O'Brien, 2011:47; Leung & Lam, 2014:320). Such a partnership is characterised by the values of sharing of information, commitment, equality, competence, trust and respect (Ngigi & Busolo, 2018:86). It is the willingness of partners to work together through the sharing of knowledge, experience, skills, expertise, risks and benefits to accomplish partnership goals not achievable by any one participant (Mitchell, 2005:127; Patel, 2012:607). Participants involved in collaborative partnership between sectors may include mental health professionals, community-based organisations, community network support structures, churches, traditional authority, indigenous and faith healers. Collaborative partnership is relevant and something to aspire for enhancing the capacity of caregivers.

2.3.2.2 Community partnership

Community partnership recognises challenges facing individuals and communities as interrelated (Bryan & Henry, 2012:417). Partnership is critical for community building and the promotion of social cohesion. However, communities are guilty for perpetuating the stigma and isolation of MHCUs and their families. Nevertheless, practitioners work with communities to fight stigma and discrimination towards MHCUs and their families through advocacy and awareness raising programmes. Furthermore, the integration of the MHCUs into the community can benefit from community partnership.

2.3.2.3 Public-private partnership

Public-private partnership involves government and the private sector collaboration in various functions including programme implementation (Visseren-Hamakers, Arts & Glasbergen, 2011:91; Tyshhenko, Bielikova & Ostapenko, 2017:294; Nikoliuk, 2018:18). The private sector, communities and government agencies participate in all stages of management: from information gathering, analysis, planning, decision-making, implementation and compliance (Pinkerton, n. d:160). Its focus on social problems plays an important role in placing the issues on the political agenda (Franczkiewicz-Wronka, 2013:127; Mikkelsen & Riis, 2017: xxiii). Notably, partnership replaces the expert role in the health and social care fields (Bryan, 2009:508; Ying & Loke, 2016:243). In the private sector, partnership serves as social responsibility to improve service delivery (McIvor, McHugh, McIvor & McHugh, 2006:n.d; Lichteuberger cited by Ying & Loke, 2016:243) and achieve sustainable development (Visseren-Hamakers, Arts & Glasbergen, 2011:91). However, the private sector may enter into partnership motivated by profit. For example, pharmaceutical companies profit from the occurrence of mental illness in order to provide medicines for its treatment. Nevertheless, the private sector has largely provided funding of programmes focusing on education and community development.

2.3.3 Partnership process

The approach to partnership reveals a structured process characterised by motivation, attributes and significance (Wiggins, 2008:633; Carnwell & Carson, 2009:12; Barley & Lawson, 2016:924).

2.3.3.1 Motivation for partnership

The motivation for the adoption of partnership is informed by events that happen before the occurrence of the concept, thus giving effect to the concept (Carnwell & Carson, 2009:18; Barley & Lawson, 2016:925). In this study, the circumstances of the MHCUs, caregivers and social workers motivated the adoption of the concept of partnership. Circumstances of MHCUs and caregivers as motivation for the adoption of partnership include mental illness and family caregiving.

Mental illness requires long-term care for MHCUs with schizophrenia who have become the sole responsibility of the caregivers. Caregivers may not cope with caregiving responsibilities, thus requiring support to enhance their caregiving capacity.

Family caregiving is care that is driven by a sense of kinship towards a relative with mental illness (Doutre, Green & Knight-Elliott, 2013:38). Family caregivers are often members of the family, namely parents, partners, siblings, adult children or an extended family member. Caregivers of MHCUs may experience a burden of caregiving resulting from including shortage of mental health practitioners and deinstitutionalisation due to increased mental health costs (Kopelowicz & Zarate, 2014:198; Hudson, 2016:137).

Although deinstitutionalisation provides a solution to the financial burden of the mental health institutions, the burden of care is shifted to families without providing them with resources and capacity for caregiving (Quah, 2015:2; Ahmed, Bruce & Jurcik, 2018:105). The costs of caregiving (Earle & Heymann, 2012:371) resulted in financial, psychological, health, work and social consequences (Ahmed et al., 2018:105). Caregivers in rural communities endure increased burden of responsibility with limited resources.

2.3.3.2 Attributes of partnership

An attribute refers to characteristics or qualities that uniquely “identify a phenomenon as differentiated from or similar to another” (Wiggins, 2008:635). Partnership is characterised by “shared responsibility, information and decision-making, which are supported by the attributes of communication, trust, respect and reciprocity; participation, commitment, coordination and interdependence” (Wiggins, 2008:635). These attributes suggest the ability for emotional intelligence for mature functioning relevant to effective partnership practice (Rode et al., 2018:165). In such a relationship, the social worker shows professional competence that expresses empathy in the service user-social worker relationship. Additionally, sharing of knowledge, decision-making and respect for the other’s expertise (Ying & Loke, 2016:243) are attributes of a partnership between the social worker who supports and advocates on behalf of caregivers. Therefore, the attributes enable MHCUs, caregivers and social workers to participate as equals in decision-making about partnership practice.

2.3.3.3 Partners’ roles and functions in practice

Partnership practice determines roles, values, attitudes, assumptions and practices that enhance competencies, strengths and capabilities of partners (Piper, 2005:3; Newlin et al., 2015:167). It ensures that services are provided efficiently at every level of intervention, namely individual, family and community forming a network of systems representing a social reality (Austin & Seitanidi, 2012:957). Practitioners perform roles that enable them to manage the implementation of partnership through case management.

Case management plays a key role in partnership practice. Its function is the coordination of services to develop collaborative efforts among all stakeholders through advocacy, mediation and facilitation (Austin & Seitanidi, 2012:929). A case manager engages in the assessment, planning, and implementation of programmes to improve the well-being of individuals and their families (Llenas & Gijarro, 2016:1). Among the key roles is facilitating collaboration to promote mutual respect, and harness differing but complimentary competences and teamwork to strengthen the capacity of family caregivers as partners (Wiggins, 2008:632; McCloughen et al., 2011:47; Kramers-Olen, 2014:504) to achieve goals effectively and efficiently.

Advocacy and cultural competence are central to case management. Advocacy embraces the values of *ubuntu* which are characteristic of partnership practice (Mahlangu, 2014:171). Service providers have to advocate for the rights of MHCUs and caregivers to cultivate a strengths-enhancing environment that alleviates discrimination and promotes access to services, social justice and empowers MHCUs and their families (Chereni, 2017:508).

Cultural competence is the ability to function and learn new patterns of behaviour and effectively applying them in appropriate settings (Good & Hannah, 2014:199). Writing from the US perspective, Davis and Donald (cited by The National Association of Social Workers [NASW], 2015:13) states that cultural competence ensures “the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of services, thereby producing better outcomes”. Similarly, the US standard of practice (NASW, 2015:4-5) and the *Bathopele* principles (consultation values, service standards, access, courtesy, information, openness and transparency, redress, and value for money) (Department of Public Service and Administration, 18 September 1997) require service providers to function in accordance with the ethics and standards that promote cultural competence through partnerships with families and communities to improve service delivery. These values require social workers to promote social justice by recognising the uniqueness of individuals based on cultural differences.

2.3.3.4 The significance of partnership

Partnership practice involves the application of the social model as significant to effective service delivery (Wiggins, 2008:635; Ying & Loke, 2016:243). The significance of partnership include recovery, family resilience, empowerment, and transformation of the service delivery system (Mikkelsen & Riis, 2017:38). The social model provides a context for partnership practice to facilitate an integrated and comprehensive mental health care. Its attribution of the causes of mental illness to complex and cultural factors suggests a social approach to the provision of comprehensive mental health services. The main concepts explaining the social model of partnership are presented in figure 2.2.

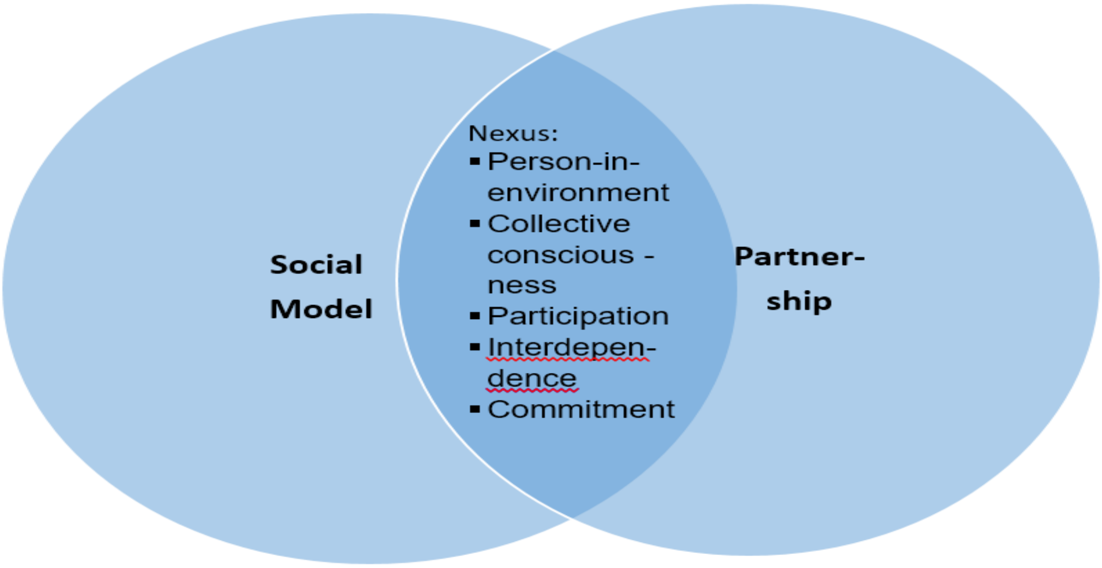
Figure 2.2 Partnership concepts

These concepts explain partnership in terms of the social model. Likewise, the social model and partnership recognises families as functioning within a social context that involves interaction among family members and within their environment. It suggests a need for relationships to enhance the capacity of the family to provide for its needs. The ecological systems theory views families as having the ability to share their experiences as participants in partnership. Families are able to integrate with social support networks to access the needed resources. While the family as a system contends with its dynamics, it must mobilise resources for the well-being of its members.

The social model has given the concept and practice of partnership increased importance as a key requirement of most community-based activities (Campos, de Sousa, da Costa Rodrigues et al., 2014:49) explained through social development, community development and developmental approaches. These concepts incorporate partnership practice as a means of promoting social justice through the redistribution of resources (Chereni, 2017:508), thus making the community the provider of resources to help individuals and families cope with their lives. The MHCUs, caregivers and families are part of the community and therefore participate as community members sharing a common understanding of mental illness, its causes and the choice of treatment.

Partnership interfaces well with the social model as a collective effort to improve the well-being of partners. The interface suggests a collaborative effort between service providers and families of MHCUs in the provision of mental health care. Figure 2.3 is an illustration of the social model-partnership nexus.

Figure 2.3 The social model-partnership nexus



Both the social model and partnership provide a person-centred, strengths-based, collaborative and empowering process to enhance capabilities through psychosocial support. They consider the person-in-environment (PIE) context of the individual as an ongoing transactional process that facilitates social functioning of individuals (Duggan, Cooper & Foster, 2002:7; Friedman & Allen, 2014:10). The PIE provides a comprehensive mental health system which recognises the family as a partner in the provision of mental health care (Payne, 2014:187; Dziekielwski, 2015:18). The experiences of MHCUs, caregivers and practitioners have motivated the adoption of partnership to provide an integrated and comprehensive mental health care.

Partnership, therefore, reveals a social model of practice characterised by participation, collective consciousness, interdependence, commitment, empowerment, transformation, recovery from mental illness and resilience.

Participation recognises the individual as possessing the knowledge, personal ability, and resources to participate in common programmes as an equal partner (Kleintjes et al., 2010:575) (cf. item 2.3.1.3). On the contrary, MHCUs may be affected by the effects of medication that can limit their participation. However, the level of their participation relating to household chores (washing dishes) or distributing leaflets to promote partnership programmes should be embraced.

Partnership contributes to collective consciousness based on the values and principles of *ubuntu*, trust, respect, compassion, empathy and accountability expressed towards fellow members. Members are able to share the vision, goals, objectives and commitment to partnership.

The main components of interdependence include teamwork, multidisciplinary collaboration, intersectoral cooperation, information sharing, trust and accountability. Interdependence happens when participation by stakeholders is based on common objectives (Stringfellow, 2017:155). However, impediments in the provision of services results from working in silos which is a form of functioning independent from the collective (Wood, Fulks & Taylor, 2014:42). Interdependence is an acknowledgement that no single individual can effectively address the complex nature of mental health. Hence the need for collaboration, cooperation, and interdependence among stakeholders involved in the provision of mental health care to promote partnership. All partners (caregivers, mental health care practitioners, indigenous practitioners, and various stakeholders) involved in the provision of mental health care share responsibilities based on knowledge, skills and abilities guided by the principles of respect for human rights and social justice in pursuit for social change on behalf of individuals, families, groups and communities by fighting poverty, lack of opportunities and discrimination; and cultural competence (Edwards, 2016:211). A culturally competent social worker is able to express a sense of community, connectedness, belonging and shared culture. The social, cultural and spiritual needs of MHCUs, families and caregivers are responded to by incorporating those differences into practice.

Partnership requires commitment to provide resources in terms of skills, knowledge, expertise and time to assist individuals, families, groups and communities, and address social needs and problems (Hoekstra, Talsma & Kaptein, 2016:169). Commitment is based on the values of *Ubuntu* which requires selflessness as practiced in most African communities through *letšema*. Furthermore, commitment to partnership should be motivated by the understanding that all human beings deserve access to the resource they need to improve their lives (Martens & Carvalho, 2016:1085). Partnership requires partners to work together as equals for a common course in improving service delivery. *Bathopele* principles as adopted by the South African Government, is recognition of the importance of commitment to service delivery. Service providers share information with MHCUs and caregivers about mental illness to enhance their ability to access support services to improve their well-being.

Transformation is a "profound, fundamental change, altering the very nature of something that can never go back to what it was before" (Gass, 2011:1). Partnership on the other hand, is a vehicle that drives transformation through empowerment of individuals and redistribution of resources (Chereni, 2017:515). Therefore, empowered individuals will participate actively in the transformation of the mental health system through knowledge and understanding or skills they have achieved (Mitchell, 2005:127; Cattaneo & Chapman, 2010:647). For transformation to take place, mental health care practitioners need to refrain from working in silos and embrace a collective empowering approach involving MHCUs, caregivers and the community. Such a strategy would promote justice, equity, participatory and an inclusive system that recognises the rights and roles of MHCUs, their families, and others involved in service delivery (Patel, 2012:615). However, transformation may not be easily accomplished in the short or medium term considering the lack of infrastructure and skilled practitioners in rural communities. To transform the mental health system, adoption of a social model that would encompass cultural competence of practitioners and the amendment of the Mental Health Care Act (Act No. 17 of 2002) is imperative. Changes in policies and attitudes are reflections of a transformed mental health system.

The social model provides a context for transformation to take place. When families have an influence as partners in the provision of mental health care, a social environment that is more prosperous, inclusive, sustainable and resilient to meet the needs of MHCUs and families will be created (Gass, 2011:1). Other important outcomes of transformation are the MHCUs' access to resources and services, improved quality of life and recovery from mental illness.

Recovery as defined (Chapter One, Item 1.7.8), suggests that individuals with schizophrenia can meaningfully recover over time (Lysaker et al., 2010:36). It is the outcome of interventions involving psychoeducation (McFarlane, 2016:461), counselling, group therapy and support groups (De Jong, 2011:31). Recovered MHCUs develop emotional intelligence (Rode et al., 2018:167), gain knowledge about disability benefits and social support services (Elbogen, Tiegreen, Vaughan & Bradford, 2011:224), even though this may pose a challenge in instances where there is limited social support.

Nonetheless, the recovery of MHCUs is the goal and culmination of the partnership process in mental health care. It involves not only symptom remission (Georgaca & Zissi, 2018:81) and achievement of psychosocial milestones (Heering, Janssens, Boyette et al., 2015:267) but also a sense of meaning (Farkas, 2007:69; Lysaker et al., 2010:75). MHCUs are able to perceive improvement in self-care and autonomy (Frost, Tirupati, Johnston et al., 2017:3) as they manage themselves more effectively in collaboration with others. They experience self-care at every service level, namely hospital, family and community (WHO & Wonca, 2008:18; Fekadu et al., 2019:1). For example, some of the MHCUs have stabilised and are able to perform tasks relating to bathing, making their beds and gathering firewood to prepare meals. Moreover, recovery from mental illness is what MHCUs, caregivers, family members and the community wish for, as it has the potential to release caregivers from the burden of caregiving.

However, the recovery approach has been criticised for its focus on individualised problems while it overlooks the “collective and structural experiences of distress, inequality and injustice” (Davidson, Brophy & Campbell, 2016:161). Besides its focus on the severity of psychotic disorders, it may be complicated by the community’s lack of understanding of mental illness, the attitudes of mental health care practitioners, namely social workers, and poor access to services (Stanton & Skipworth, 2005:155; Crowe & Averett, 2015:47). Hence, the argument that recovery paradigm has been “co-opted into the individual biomedical framework” to undermine the social factors influencing mental illness and social exclusion (Beresford et al., 2010:29; Kidd et al., 2015:39). Nevertheless, partnership as a developmental process of service delivery contributes to the recovery of the individual (Kidd et al., 2015:38). The individual is able to feel part of the society as he/she experiences acceptance and social integration (Westerhof & Keyes, 2010:111), and resilience thereafter.

Resilience is an expression of caregivers’ strengths that helps them to rise above adversity (Van Breda, 2018:3) (Cf. Chapter Three, item 3.5.1). It is important in the provision of mental health services. Social support, family relationships (Coleman & Wu, 2016:202) and the spirit of *ubuntu* contribute to resilience which enables caregivers to perform their caregiving responsibilities (Wilson & Williams, 2013:82). Additionally, partnership promotes resilience, reduces caregiver burden and improves capacity for caregiving (Moller-Leimkuhler & Wiesheu, 2012:157).

2.3.4 Partnership in social work practice

Social work plays a crucial role in the provision of mental health care to individuals, families and communities. Social work practice emphasizes ecological systems approach that is developmental, strengths-based and person-centred to provide a context for the practice of social work (Casstevens, 2010:386; Patel, 2012:607; Friedman & Allen, 2014:10). These theories provide a holistic approach to social work to examine the person-in-environment by considering family interactions, resources in the environment, cultural influences and community factors impacting on the person’s functioning (Friedman & Allen, 2014:11). Social workers consider the ongoing transactional process between individuals that affects their social functioning instead of classifying people as mentally ill.

Partnership is one of the aspects of the developmental approach that social workers use to ensure the involvement of individuals, families and communities in the provision of their own needs (Dennis, Baxter, Ploeg & Blatz, 2017:364; Ahmed et al., 2018:111). The strengths-based approach acknowledges the difficulties families face, regarding mental illness, isolation, unemployment, and poverty (Rani, 2015:446). The approach enables social workers to understand the families' strengths to overcome challenges.

Partnership can be facilitated through a multidisciplinary approach to provide mental health services. The provision of services to MHCUs involves multiple disciplines (e.g., medicine, nursing, social work and psychology) with each profession providing specialised knowledge and skills. A multi-disciplinary approach ensures a comprehensive provision of care for the mentally ill (NASW, 2015:9; Roncaglia, 2016:18). The social worker in a multi-disciplinary environment communicates information that may require other professionals to consider social factors when providing mental health services.

Social work intervention uses the case management process to apply the ecological systems perspective to partnership (Frankel & Gelman, 2012:12). Case management, which is central to social work practice, facilitates the provision of mental health services (Mohamed, 2016:10) in order to achieve goals more efficiently and effectively. The case manager facilitates collaboration to promote mutual respect, complimentary competences and teamwork that result in the recognition of family caregivers as partners (Wiggins, 2008:632; McCloughen et al., 2011:47). The strengths and vulnerabilities are identified to foster resilience and rebuild family and social relationships (Ahmed et al., 2018:109). In order to enhance partnership, reframing is used to promote strengths and improve family functioning (Gallant et al., 2002:869; Kleintjes, Lund, Swartz et al., 2010:568; Frankel & Gelman, 2012:73). Social workers are able to understand the cultural influences on perceptions, experiences and coping abilities of MHCUs and families regarding mental illness (Quinn, 2007:176; Frankel & Gelman, 2012:60). Both the social worker and caregiver work collaboratively to explore and identify resources to improve capacity for caregiving (Austin & Seitanidi, 2012:952). Therefore, caregivers as partners will feel worthwhile with unique needs and values, and the presence of support (Frankel & Gelman, 2012:73).

Community development facilitates advocacy, empowerment, transformation and partnership which enable family members to access resources through participation in community programmes (Ahmed et al., 2018:114). It is based on the developmental approach providing a form of social intervention within the mental health system focusing on social justice (Gray, 2010:75; Payne, 2014:228). The social development model recognises that caregivers may experience a burden due to lack of "support services and resources rather than the severity of the mental illness" (Grant, Sun, Fujinami et al., 2013:338). Among its roles is policy change in mental health care for the benefit of MHCUs, caregivers and families (McCabe & Davis, 2012:506; Sithole, 2017:303). Community development intervention for caregivers may happen through the use of support groups to empower and promote capacity for caregiving (Neal & Neal, 2013:726; Ahmed et al., 2018:112).

Social work intervention supports and empowers the MHCU and caregiver by linking them with social networks and resources (Carpenter & Raj, 2012:467) to improve the quality of their lives. The intervention provides for multidisciplinary collaboration between hospital-based social workers and community-based service providers through referral, meetings and imbizos (community gatherings) (Payne, 2014:238). Some of the service providers include community-based social workers, traditional and faith healers, and community-based care workers. The referral process link MHCUs and caregivers to community-based services for family and community integration and social network support services for partnership with caregivers and community-based service providers (Sorsdahl, Stein & Flisher, 2010:593). The family continues to be central to the integration of the MHCU within community to fight stigma and social isolation and promote recovery.

Support groups provide support to family caregivers to cope with their caregiving responsibilities (Ziliak, 2015:32). The support groups are usually made up of voluntary groups of family members that may include caregivers and community members (Gale, Kenyon, MacArthur et al., 2018:96). *Letšema* and church groups are examples of support groups in most communities in South Africa. They provide resources to caregivers as a form of support (Ahmed et al., 2018:112). The benefits of support to caregivers are expressed through “improved relationships with the MHCU, enhanced coping ability, acquired knowledge about MHCU’s condition, and enhanced utilization of mental health and social services” (Suro & De Mamani, 2013:309; Stevens & Thorud, 2015:35). Social workers facilitate the formation of support groups and promote access to those already established within the community (Powers, Webber & Bower, 2011:159) to improve the sharing of experiences and to enhance capacity for caregiving.

However, caregivers often find it difficult to access social work services. Therefore, both the social worker and caregiver should work as partners to explore the resources the caregiver may need for the recovery of MHCUs.

2.3.5 Barriers to partnership practice

The mission of the Mental Health Policy Framework and Strategic Plan 2013-2020 is to uphold human rights of people with mental illness; provide them with care and support; and integrate them into normal community life in partnership with providers, users, carers and communities (Stein, 2014:115). However, there are barriers that prevent partnership practice to realise the mission of providing effective mental health services (Kaas, Lee & Peitzman, 2003:742; Stanton & Skipworth, 2005:154; Outram, Harris, Kelly et al., 2015:174), thus contributing to violation of human rights (Mfoafo-M’Carthy & Huls, 2014:1). The barriers are summed up in the words of Leung and Lam (2014:320) who described partnership as a buzzword in contemporary mental health care. The dominant medical model of mental illness, labelling and social attitudes are common barriers to effective partnership practice.

The medical model of mental illness has made it difficult to incorporate the ecological systems approach into practice, thus rendering partnership practice ineffective (Webber, 2013:946). Family caregivers provide the care needed by MHCUs but are not recognised as essential components of the mental health system. They seldom receive adequate training and are almost never offered appropriate follow-up services, or referrals to community services.

However, social workers are increasingly adopting and implementing the principles of partnership (Ahmed et al., 2018:115) which acknowledge the expertise, skills and resources that families are already using to promote recovery of MHCUs (Sheridan et al., 2004:10; Payne, 2014:59). Their efforts are limited by lack of support in relation to resources to provide effective caregiving. Nevertheless, the practice of partnership requires significant policy shift within the formal mental health system (Ahmed et al., 2018:115).

Labelling is a social process through which mental illness is constructed as a form of social deviance (Thompson, 2014:460). Furthermore, labelling is regarded as an attachment of a deviant status to behaviour which does not appear normal to the observer (Thompson, 2014:460). Labelling is also a common form of reaction to the mentally ill by society. The individuals with mental illness may be perceived as sloppy, unpredictable, worthless and dangerous to others. Labels with derogatory connotations (‘*segaswi’* - mad person), are always used as scapegoat thus lead to the person assuming the identity (Bhattacahrjee et al., 2011:61). This phenomenon is referred to as self-fulfilling prophecy through which the individuals once defined and treated as mentally ill, may begin to see themselves, and act as such (Kroska & Harkness, 2008:193; Rogers & Pilgrim, 2010:36).

The diagnostic process has also been found to be complicit in perpetuating labelling (Perry, 2011:460). Such labelling may contribute to the development of stigma, stereotypes and prejudices against the persons with mental disorders (Gonzalez-Torres, Oraa, Aristegui et al., 2007:16; Akinbode & Tolulope, 2017:241). The MHCUs may be subjected to discrimination which may hinder their participation as partners in the provision of services.

Labelling does not only affect the person carrying the diagnosis of schizophrenia. The family members also become labelled by virtue of their relation with the MHCU. The mental health literature refers to this phenomenon as stigma by association (Van der Sanden, Bos, Stutterheim et al., 2015:401). Therefore, social workers need to be aware of the role of labelling in perpetuating mental illness and social isolation, and its negative effect on partnership practice.

Social attitudes perpetuate the stigma against individuals with mental illness and their families. The social causation hypothesis postulates that poor people are susceptible to mental illness due to adversities and stress (Rogers & Pilgrim, 2010:12; Bhattacahrjee et al., 2011:55; Ramlall, 2012:408). Mills (2015:217) explains this phenomenon as the “psychiatrization of poverty” which he argues, creates “a vicious cycle, where poverty may cause mental ill health, and mental ill health may lead to poverty”. This means one can only be mentally ill because of poverty. Similarly, the social selection theory postulates that genetically predisposed persons are vulnerable to mental illness due to genetic and environmental factors (Uher, 2009:1072; Rogers & Pilgrim, 2010:48). Both the social causation and social selection theories influence societal attitudes towards mental illness and the mentally ill. The theories tend to perpetuate social isolation, prejudice and discrimination of the mentally ill and their families.

2.4 Conclusion

This chapter has provided a background to the mental health system informing the conceptualisation of partnership within the context of mental health care. The medical and social models were identified as the main contenders in the field of mental health care. Partnership was presented as an alternative approach in the provision of mental health services. The information in this chapter will enhance the understanding of the family caregivers as partners with mental health care practitioners in mental health care. The information will also encourage others to pursue research in exploring and explaining partnership in the provision of services.

CHAPTER THREE

THEORETICAL FRAMEWORK UNDERPINNING PARTNERSHIP

3.1 Introduction

This chapter presents theoretical frameworks underpinning partnership. A theoretical framework is the use of a theory to explain a phenomenon of the study (Collins & Stockton, 2018:3). A theory is an organised and interconnected system of ideas, beliefs and values explaining the phenomenon being studied (Creswell, 2009:62; De Vos & Strydom, 2011:37). The use of theories is important in that it provides a framework for understanding the phenomenon of study and processes of intervention. In partnership practice, service providers use theories to explain partnership, plan partnership programmes, and predict the likely outcomes of their interventions. Thus, making the discussion of theories important in understanding partnership.

Partnership is explained to provide insight into its effectiveness in improving service delivery. The social perspective of partnership embraces a number of related and overlapping theoretical perspectives committed to issues of equity, social justice and human rights (Collins & Stockton, 2018:5). The theoretical framework considered for this inquiry include systems theory, ecological systems theory (Westerhof & Keyes, 2010:111; Bhattacahrjee et al., 2011:55), developmental approaches (Patel & Hochfeld, 2012:694) and indigenous perspectives (Matoane, 2012:107), which are common in social work. Legislative and policy framework, and practice framework are also discussed to explain partnership practice.

3.2 Ecological systems perspective

The ecological systems theory is the theoretical framework for the study. Its origin is within the systems theory as a framework for studying individuals in their contexts (Neal & Neal, 2013:722). The theory affirms the interdependence of people with their environment at different levels (micro, meso and macro) for the understanding of mental illness (Smith, 2011:478; Neal & Neal, 2013:728). The microsystem represents a setting (home or hospital) or set of people (individual and family members) regarding their experiences of mental illness and their social interaction; a mesosystem describes the interconnections among these systems as affecting the MHCUs through relationships, and communication patterns; and the macrosystem involves social conditions (cultural influences, resources, social support networks) affecting the wellbeing of the MHCU and family (Neal & Neal, 2013:728). The MHCU and family participate at every level of the ecological system involving family, cultural, communal and societal relationships. These levels are critical to social work and the application of partnership. Social workers examine social factors affecting individuals and families at various levels of interaction and determine the care and resources needed to improve their functioning.

The ecological system assumes that people experience stressors as they interact with their environment, and therefore acquire resources from their environment, social networks and inner resources to cope with stressors (Masoga & Shokane, 2018:4). Partnership fits the ecological systems theory as it focuses on relationships among individuals, families, communities and their environment as different forms of systems working together to ensure access to services. The understanding that behaviour is ever-changing as people adapt to their surrounding (Barley & Lawson, 2016:924; Ngigi & Busolo, 2018:84) suggests that the circumstances of MHCUs and their caregivers can change for the better.

The ecological systems theory is often used interchangeably with the systems theory to provide a multidimensional interconnected network of social interactions for the understanding of phenomena (Smith, 2011:478; Neal & Neal, 2013:728). In this study, the theory is ecological systems theory applied together with the systems theory, family systems theory, person-in-environment approach and developmental approach.

3.2.1 Systems theory

This theory views individuals as part of wider networks or systems in interaction with each other and influencing one another, in a specific relationship (Neal & Neal, 2013:728; Friedman & Allen, 2014:7). Although the ecological systems theory views people as part of their environment, the systems theory focuses on the relationships between systems. It provides a framework for understanding the role of society and social factors in the development of problems such as mental illness (Friedman & Allen, 2014:4). The main assumption of the systems theory is that people interact with each other (Karakurt & Silver, 2014:81). The family, in particular, is such a system of interactions linking its members with larger systems such as institutions, communities and the society at large (Von Bertalanffy, cited by Karakurt & Silver, 2014:81). It further explains the interdependence among systems which function as a coordinated partnership (Stringfellow, 2017:155). Partnership, therefore, plays a role in linking the family with different systems (Masoga & Shokane, 2018:4) providing comprehensive mental health services to MHCUs. Diverse stakeholders such as professionals, institutions, traditional and religious healers, and communities become part of the mental health system through the provision of mental health services (Bailie, Matthews, Brands & Schierhout, 2013:1). However, the current practice to service delivery is disjointed, thus making the application of systems theory to partnership difficult.

Furthermore, the systems theory provides a framework for change. Social workers are regarded as part of the system of change collaborating with other systems such as individuals, families, professionals and civil society to bring about change. They focus on the relationships between people and other systems to strengthen the social support network in order to bring about the required change. However, change within the system, such as mental health, is not possible as it is constrained by the policies, rules, values and attitudes to keep the very system intact (Becvar & Becvar, 2009:286; Yilmaza & Kilicoglu, 2013:16). This means, the current mental health system based on the medical model will make partnership practice involving families of MHCUs difficult to achieve. However, the theory of change advocates changing the context within which mental health is practiced (Becvar & Becvar, 2009:287; Barley & Lawson, 2016:924) in order for partnership practice involving families of MHCUs to occur. Such a change will require changing the current medical model and replacing it with a social model that embraces partnership practice.

3.2.2 Person-in-Environment (PIE)

Person-in-environment (PIE) approach is a component of the ecological systems theory for understanding the context within which MHCUs and their families function (Sheridan, Warnes, Cowan et al., 2004:7; Friedman & Allen, 2014:10). The approach posits that multiple influences, namely biological, psychological, social and spiritual interact as aetiological factors for the development of mental illness (Dziegielewski, 2015:72). It is a combination of all factors impacting on the wellbeing of individuals. MHCUs, caregivers and families live within an environment affecting their functioning.

The rural environment, especially, is the most stressful for MHCUs, caregivers and families due to the dearth of resources.

As a multilevel, multisystemic, and interdisciplinary approach, the PIE perspective enables mental health practitioners to incorporate the perspectives of the MHCU, family, service providers and the society (Kaslow, Bollini, Druss et al., 2007:279; Doutre et al., 2013:34) to provide services. For social systems like families of MHCUs, PIE provides a context for adaption, growth and integration (through socialisation processes) to function within the social environment (Scott, 2008:405; Friedman & Allen, 2014:6). The families of MHCUs are thus able to access a network of resources to improve the wellbeing of their members.

Social work has appropriated the PIE approach as a model of intervention to attend to problems affecting people at various levels of functioning, namely, individual, family, social and environmental aspects that impact on their wellbeing (Makhubele, Matlakala & Mabvurira, 2018:99). The attributes of PIE include adaptation, life stress, coping, power and human relatedness (Germain cited by Friedman & Allen, 2014:12). These attributes have the potential to facilitate partnership between families and service providers to improve service delivery to MHCUs.

The attribute of adaptation involves “reciprocal interactions and exchanges between the system and its environment, which ultimately results in both being changed” (Friedman & Allen, 2014:6). The concept assumes that the PIE provides a context which allows for the MHCUs and their families to adapt in the midst of mental illness. Adaptation, in this context, means that the MHCUs understand that they are experiencing mental illness and need to adhere to treatment, while the family accepts that their relative has mental illness and requires caregiving. The family should identify someone within to become the primary caregiver of the MHCU. Community and institutional support may be sought to complement efforts undertaken by the family in providing for the needs of the MHCU. Therefore, such adaptation enables the family to participate in partnership programmes to improve their wellbeing.

The attribute relating to life stress and coping suggests that individuals experience life stress and opportunities during the course of their lives. Mental illness creates an environment of stress affecting the social lives of MHCUs and their families. Mental health problems may arise from a stressful life situation such as inability to access resources. In this study, caregiving for the mentally ill person has been linked to caregivers experiencing stress which is referred to as the caregiver burden (Moller-Leimkuhler & Wiesheu, 2012:157).

Nevertheless, the PIE may provide a context to cope with life stresses (Gullslett et al., 2016:161) and the development of problem-solving abilities (Germain cited by Friedman & Allen, 2014:13). The family is strengthened to participate in social networks as a partner to mobilise resources for improved functioning (Pescosolido, 2013:116). The MHCU and the family, in particular, become integrated within the community, thus resulting in adherence to social norms and values, increased self-esteem and diminished burden of caregiving.

The PIE provides a context within which individuals develop the attributes of human relatedness, competence, self-direction, and self-esteem which are interdependent (Friedman & Allen, 2014:14). Such a context is applicable within the social model and partnership for building social relationships. In African communities, the attributes of human relatedness are expressed through the principles of *ubuntu* and *Bathopele* created within their social context.

However, power relations may affect human relatedness due to their influence on transactions in families, communities and institutions (Friedman & Allen, 2014:14). At the family level, caregiving roles may be allocated arbitrarily to a family member on the bases that the caregiver is young, a sibling, or woman. The caregiver may feel abused when expected to perform other responsibilities which can be assigned to other family members. At the community level, caregivers may be excluded from community activities due to their association with the individuals with mental illness who may also be treated with disdain. The institutional level determines how resources are distributed. The mental health system is the context in which legislation and policies are developed to regulate relationships among various role players. Mental health care practitioners have the power to provide or withhold services to MHCUs and caregivers by invoking confidentiality and lack of insight. The Life Esidimeni tragedy shows how denial of services can result in the death of MHCUs (Makgoba, 2017:2) (cf. Chapter Two, Item 2.3). However, the PIE can provide an enabling context for empowerment of MHCUs, caregivers and family through human relatedness. The empowerment will enable the caregiver to participate in partnership with mental health care practitioners and community members. Therefore, PIE is a context of relationships which are fundamental to the practice of partnership in the provision of mental health services.

3.2.3 Family systems theory

The theory provides a theoretical framework for understanding the interactions within the family. According to this theory, the family is described as a social unit consisting of members made of sub-systems such as parents, siblings and other members (Sooryamoorthy & Makhoba, 2016:309). In most African communities, the extended family form part of the family system that goes beyond the limitations of the western descriptions of the nuclear family. However, the description of family as "most timeless, central and enduring of all social institutions" (Lubbe, cited by Sooryamoorthy & Makhoba, 2016:309) fits the role of the family of ensuring the healthy functioning of individuals, families and communities.

Therefore, the definition of the family should focus on the interaction between family members including the mentally ill member (Benjamin & Wendel, 2016:782). Such a definition should describe the family in terms of roles, functions and abilities rather than the symptoms afflicting the individual. The family as system is paramount in the recovery of the MHCU (Carpenter-Song et al., 2014:163). Common approaches used to explain the family as a system include strategic, structural and systemic approaches describing a quid pro quo (who is doing what to whom, where, when, and in what way) form of interaction focusing on the roles performed by different members of the family (Odegard & Bjorkly, 2012:99; Benjamin & Wendel, 2016:782).

Family members are connected by kinship expressed through a great sense of *ubuntu* for each other (Moodley & Sutherland, 2010:271; Webber, Reidy, Ansari et al., 2016:17). Kinship determines the distribution of roles to perform caregiving tasks. This description of the family suggests that family members work interdependently (Friedman & Allen, 2014:7) to improve their physical, emotional, intellectual, social and moral functioning. The family is responsible for identifying another family member as a caregiver of the member with mental illness. The MHCU also has a role to play in the family according to his/her abilities.

The ecological function of the family system links the family with the larger social systems such as culture, religion, communities, societal attitudes, resources and environment that interact with the family and its individual members (Neal & Neal, 2013:723). The function of the family is to mobilise resources for family members and facilitating participation of members in social support network programmes. Among the resources that the family mobilises is the extended family which plays a key role as a support system that provide emotional and material support to members of the family (Makiwane, Gumede, Makoae & Vawda, 2017:50).

The systemic model, emphasizes the role of a practitioner as part of the system through interaction with the family. The model recognises families as partners suggesting that they need to be included in the provision of mental health services to their relative with a mental illness. Therefore, the family systems approach enables the family to participate in partnership processes focussing on the interactions between the family and service providers to improve the provision of services to a MHCU.

The family systems theory informs social work practice. Its family focus enables social workers to use family-centred care in which the family is recognized, respected and supported as a partner within its social environment of caregiving and decision-making (Devaney, McGregor & Cassidy, 2017). Social workers use family systems theory to understand the family interactions impacting the members' wellbeing. Furthermore, social workers utilise the strengths of family members to derive intervention strategies to improve family functioning. Intervention focuses on strengthening and supporting family functioning to improve the quality of life for its members.

3.2.4 Developmental approach

The developmental approach applies “theories, perspectives, frameworks, models and methods” to guide service delivery (Gray, 2010:97; Greenfield, 2011:529). The approach has been adopted as a social work practice in South Africa to mark a shift from the medical model to the social model (Lombard et al., 2012:180; Van Breda & Addinal, 2020) in order to enhance the wellbeing of individuals, families, and communities within their social context. The values that underline the developmental approach are based on *ubuntu* and *Bathopele* principles (cf. Chapter Two, Item 2.3.4.3) to promote equality, human rights and social justice (Patel & Hochfeld, 2012:691; Van Breda & Addinal, 2020). The developmental approach provides a context that considers the strengths of people across their biological, psychological, and social environments (Greenfield, 2011:532). However, the implementation of the developmental approach has faced impediments in its attempt to empower the vulnerable people and improve their circumstances (Lombard et al., 2012:181) (cf. Chapter Two, Item 2.3.6).

Nevertheless, community-based programmes, are central to the promotion of the developmental approach (Lombard et al., 2012:181). They involve the integration of MHCUs for acceptance by community members, and linking them with the social support network to enhance their wellbeing. The community-based programmes are based on the principles of partnership which involve collaboration of different stakeholders to improve the provision of services (Lombard et al., 2012:181). Their main focus is community integration to facilitate recovery through the development of skills and access to resources to promote social integration (Anthony & Farkas, 2009:9; Collins, Ward, Snow et al., 2017:684). MHCUs are able to build a meaningful life, become self-managing and taking more active control over their lives even when they experience recurring symptoms (Thornton & Lucas, 2011:24).

One of the key aspects of developmental approach is empowerment. Empowerment is a principle of intervention based on the belief that change is possible and that people are able to exercise control over their own lives and circumstances (Lombard et al., 2012:180). Its central role in partnership is to address power differential between professionals and MHCUs and their families, with the aim of improving their living circumstances (Bryan, 2009:508; Patel, 2012:605).

Empowerment is central to the practice of social work (Cattaneo & Chapman, 2010:64). Social work practice in South Africa has adopted the developmental approach with the goal of empowering the vulnerable individuals and communities. Advocacy is a skill used by social workers to empower individuals and communities by promoting access to services, human rights and social justice. Additionally, social work practice work ‘with’ than ‘for’ the clients to promote partnership practice that recognises the value of service users in the provision of services. However, the domination of the medical orientation on the provision of mental health services constraints the empowerment project that the social work practice advocates.

Participation in community activities may enable both the MHCU and caregiver to realise their strengths and to feel empowered. Caregivers may participate in support groups to advocate for human rights and social justice. Moreover, their participation empowers them to access resources to improve their living conditions. As empowered individuals, they recognize their strengths in order to strive for positive change and wellbeing (Cattaneo & Chapman, 2010:646), and show the ability to work as partners in empowerment programmes. Additionally, they become active participants in decision-making as advocates of social justice regarding their own lives (Cattaneo & Chapman, 2010:649; Chereni, 2017:507). However, the findings show that some caregivers and family members live in fear of violence by the MHCUs and struggle to receive police help (cf. Chapter Five, Item 5.3.4.2. Subtheme 5.2). Caregivers get help from neighbours and relatives who may help restrain a violent MHCU to take him/her to hospital. Nevertheless, as they become empowered, they perceive themselves as having knowledge, skills and resources to build their own support networks and to make their own choices.

Therefore, partnership practice fits well with the developmental approach to enable families to participate in the provision of mental health services. It promotes community-based programmes to facilitate access to mental health care and other social amenities. Although social work practice is based on the developmental approach, their ability to intervene is limited due to lack of adequate services and skills, especially in rural communities. Caregivers are thus left with the responsibility of providing for the needs of MHCUs with limited support.

3.2.5 Indigenous perspectives

Indigenous framework provides an epistemological and ontological worldview of knowledge systems to inform the understanding of fundamental aspects of day-to-day life (Grant & Osanloo, 2014:17). Indigenous knowledge systems are practiced among indigenous communities worldwide for classification and naming of systems such as illness and treatment methods (Letseka, 2012:47). In Africa, much has been written about the Afrocentric philosophy that reflects the indigenous principles involving the

South African notion of *botho* or *ubuntu* (a person is a person through persons) to explain the interconnectedness in humanity (biological and spiritual or mental being) (Chasi, 2014:495). In South Africa, the spirit of *ubuntu* was used as a battle-cry to mobilise the oppressed masses to unify against oppression. Therefore, the indigenous framework seems to be grounded within the social model to ensure the wellbeing of all humanity. However, although the African perspective perceives humanity as unitary, human beings experience separation especially in the event of “a dream, trance or some other altered state of consciousness” and mental illness (Bojuwoye, 2013:75). This means the unitary state of humanity is susceptible to disruptions which may be due to physical and mental dysfunction.

The social perspective of the indigenous framework is consistent with the ecological systems framework which explains humanity in interaction with its context. However, there seems to be divergence regarding the attribution of causes of mental illness. The indigenous framework explains mental illness from a cultural perspective of the individual and the family. It suggests that the experience of mental illness is specific to the cultural context of the individual. The cultural perspective of the family guides the classification, causes and interpretation of the experiences and the explanations used to make sense of their sociocultural context (Campbell-Hall et al., 2010:617). Moreover, the indigenous framework views the illness afflicting the person as a family illness than the individual (Bartholomew, 2016:106). Therefore, the indigenous understanding regarding mental illness guides the help-seeking behaviour and the provision of mental health services.

The indigenous framework is consistent with the social model approach to service delivery guided by the values of *ubuntu* and *Bathopele* principles to dispensing services to those in need. Like the western classifications (cf. Chapter Two, Item, 2.2.4) the indigenous communities have explanatory models of classifying problems and provide appropriate interventions (Bojuwoye, 2013:74). Furthermore, this correspondence between traditional and western classification systems is seen as having the “potential for collaboration between traditional and biomedical practitioners” (Burns & Tomita, 2015:875) to provide comprehensive integrated mental health services through partnership practice.

The diagnosis and treatment of mental illness does not only involve the individual, but the whole family (Bogopa, 2010:2). The ancestors communicate themselves through a family member in various forms including illness, bewitchment or cursing (Bogopa, 2010:1). The family will, thereafter, approach traditional or faith healers to understand what could be bothering the family member. The role of the indigenous healing practitioner is to interpret the hidden message behind the illness in order to find the cure (Nwoye, 2015:305). The treatment may involve the use of herbs, performing of rituals and cleansing the MHCU and family of evil spirits to rid them of bewitchment (Sorsdahl et al., 2010:284; Campbell, Sibeko, Mall et al., 2017:2). Furthermore, the kinship spirit mobilises family members, including the extended members to participate in the healing of the MHCU.

Indigenous framework provides a cultural context for a culturally competent intervention that integrates cultural experiences to improve the quality of care (Good & Hannah, 2014:198). Its developmental orientation fits the practice of social work that challenges the medical view of mental health care (Khumalo, Temane & Wissing, 2012:419). For example, the family participate in the healing process to cleanse them of the curse that may be contributing to illness afflicting their family member.

Social workers use different intervention approaches reflecting indigenous knowledge systems to provide culturally competent services. Partnership as a principle of service delivery guides the practice of social work in the use of indigenous knowledge systems to give a voice to the indigenous communities reflecting their norms and practices (Patel et al., 2012:13). In South Africa, the collective spirit of cooperation and collaboration is expressed through the indigenous philosophy of ubuntu (Mabvurira & Makhubele, 2018:12) to respond to social needs and promote the wellbeing for all.

This approach explains the collective nature of the indigenous framework as developmental in its approach to the provision of services. It finds resonance in the eloquent expression of Mwalimu Julius Kambarage Nyerere’s philosophy of Pan-Africanism and African Socialism stating that "traditional African values and principles of communalism, collective production, egalitarian distribution, and universal obligation to work” (Otunnu, 2015:18) where everything is connected, interrelated and interdependent. The ability to mobilise support for the MHCU is not limited to the family, but to the community to work together for the benefit of all. It is an expression of *ubuntu* to emphasise the importance of the collective over that of the individual.

One of the techniques of indigenous framework is *letšema* through which indigenous communities apply the principles of partnership to extent a hand to those in need. *Letšema* is a common collective practice among indigenous communities that is used to help individuals and families to accomplish tasks. In *letšema* the affected family members participate directly. Hence, indigenous communities are considered the social capital of the poor (Gibbs, Campbell, Akintola & Colvin, 2015:110). MHCUs and their families benefit from the assistance they receive from communities in various forms such as transport to take them to hospital and to keep an eye on MHCUs.

Furthermore, communities help each other in various activities such as agriculture, cooperative harvesting, food preparation, construction of houses, and mutual-aid activities. They can work in partnership with families to persuade the government to improve access to services. They also work in collaboration with mental health practitioners to facilitate the provision of services that respond to social needs and help vulnerable individuals and their families (Patel et al., 2012:13). Therefore, indigenous framework has the ability to promote partnership as a practice principle that organises collective provision of services.

3.3 Legislative and policy framework underpinning partnership

South Africa approved a legislation, namely; the Mental Health Care Act (Act No. 17 of 2002), to align with international trends with special emphasis on improving mental health care and the protection of human rights (Szabo & Kaliski, 2017:69). The development of the National Mental Health Policy Framework and Strategic Plan 2013-2020 placed emphasis on the social factors such as stress, lifestyle, poverty, unemployment, violence and substance abuse, as contributing to mental illness (DoH, n.d:3). These developments prompted the World Health Organization and Assessment Instrument for Mental Health Systems (WHO-AIMS) to find South Africa as complying with international conventions regarding the provision of mental health care in respect of human resources, facilities and psychotropic medication (Ministry of Health South Africa, 2007:25-27). However, the mental health policy is still rooted in a medical model which fails to recognise the role of family in provision of mental health services. Moreover, the country is still plagued with widespread inequalities in the distribution of resources (Lund et al., 2009:393; Ramlall, 2012:408). The current mental health system is unable to provide quality care (Semrau, Lempp, Keynejad et al., 2016:2), especially to rural communities who are largely African. Deinstitutionalisation has added a huge burden of care to families who have assumed the caregiving responsibilities despite lack of resources (Kotzè, van Delft & Roos, 2010:83).

Other legislations associated with the provision of mental health services include the Traditional Health Practitioners Act (Act No. 22 of 2007), Social Assistance Act (Act No. 13 of 2004) and the Local Government Municipal System Act [Act No. 32 of 2000]). The Traditional Health Practitioners Act (Act No. 22 of 2007) regulates the practice of traditional healers (herbalists, diviners, traditional surgeons those who do circumcision) and traditional birth attendants, but faith healers have been excluded (Keikelame & Swartz, 2015:662). Nevertheless, The National Mental Health Policy Framework and Strategic Plan 2013-2020 offers to facilitate “links between mental health services and traditional healers and faith healers at local district levels, including appropriate referral pathways in both directions” as part of its implementation of The Traditional Health Practitioners Act (Act No. 22 of 2007) (DoH, n.d:41). In terms of the Social Assistance Act (Act No. 13 of 2004) the MHCUs and their families are able to access social grants in the form of disability grants for the MHCUs and the grant-in-aid for family caregivers. The Local Government Municipal System Act (Act No. 32 of 2000) facilitates the availability of services such as housing, water, transport and clinics. Partnership with families can help to lobby the respective authorities to facilitate access to these services in order to promote quality of life for the MHCUs, caregivers and families.

3.4. Practice framework underpinning partnership

Practice framework provides a conceptual map that guides intervention based on a set of principles and values to support best practice (Ahmed et al., 2018:117). The challenges that communities face need a practice framework that can respond to their social context. Mental health is a specialised practice that requires advanced therapeutic competence (Van Breda & Addinal, 2020). Social workers are trained in clinical social work to provide specialised psychosocial interventions (cf. Chapter Two, Item 2.2.6.3). However, the cultural and religious factors which exert a significant role in the lives of MHCUs are usually ignored (Grover et al., 2014:119) due to the influence of the medical model over treatment of mental health. The practice framework critical to partnership include strengths-based and community-based care perspectives based on the developmental approach which are discussed below:

3.4.1 Strengths perspective

The current mental health practices are based on the disease or medical model which relies on pharmacology and psychosocial treatments (Conrad & Barker, 2010:68) to the exclusion of family whose role is regarded as insignificant. However, the emergence of a strengths-based approach marked a shift in perspective from the medical approach to the social perspectives, emphasising human capacities, empowerment, and recovery (Sheridan et al., 2004:7; Taylor, 2006:2; Gass, 2011:1). As MHCUs and families experience challenges due to mental illness, the strengths approach views them as having the capacity for resilience, growth and change (Rani, 2015:445; Van Breda, 2018:11). However, resources are required to complement caregivers’ capacity and enhance their resilience (Rani, 2015:445). The strength-based approach implores social work intervention to support families to enhance their resilience and better their situations. Such support promotes the involvement of caregivers as partners in identifying needs, establishing social support and partnerships, and developing skills than passively receiving services (Sheridan et al., 2004:7; Hadley & Rouse, 2018:50). This recognition of the family strengths provides a process leading to partnership between practitioners and families of MHCUs. Partnership as a principle of the developmental approach recognises families as experts having the capacity to participate in the transformation of their lives. Families in rural communities have shown such capacity by evolving their own systems of care to cope with daily caregiving challenges.

The strengths-based practice is characterised by capacity for growth and change, self-awareness and resilience (Pulla, 2017:111). The capacity for growth and change suggests that humans have the ability to solve their own problems (Rani, 2015:445). This capacity for growth and change is based on the understanding that humans have the ability to define their problems and seek solutions (Friedman & Allen, 2014:14;

Michailakis & Schirmer, 2014:11). For example, caregiving is a difficult and demanding responsibility. However, caregivers have the knowledge of providing care despite the burden they endure as they undertake their caregiving responsibilities. Furthermore, the MHCUs and caregivers may participate in community programmes to link with support networks to enable their access to services. It is this knowledge and understanding of their roles that create a conducive environment to work in partnership with mental health care practitioners. Therefore, their ability to solve their own problems suggests their resilience.

Resilience is a process of positive adaptation within the context of adversity (Afifi, Merrill & Davis, 2016:663; Wong, Liamputtong, Koch & Rawson, 2017:4392). Resilient individuals show a healthy psychological development with the ability to bounce back or recover from adverse conditions (Bolton, Hall, Blundo & Lehmann, 2017:1). Such individuals show determination, endurance, adaptability, and recovery from adversity (Taormina, 2015:37). Caregivers can achieve resilience in a partnership context which is supportive. Unfortunately, this is not the case in the current mental health service delivery system. The scarcity of support services has contributed to family caregivers assuming the role of a social worker, nurse, advocate, and crisis worker to manage MHCUs (Chan, 2010:376). Deinstitutionalization without adequate community resources has also contributed to family members assuming these roles (Chan & O'Brien, 2011:386). Caregivers have nonetheless remained steadfast in their obligation to provide care to MHCUs.

3.4.2 Community-based mental health care

Community-based mental health care involves the provision of comprehensive services that include medical treatment and psychosocial support to promote recovery and improve the quality of lives. The term community-based care suggests that services are initiated within the community, by the community, for the community. Furthermore, the services offered are accessible, sustainable and cost-effective to promote the principles of equity and social justice (Boesten, Mdee & Cleaver, 2011:41). The mental health services relating to diagnosis, treatment and care, rehabilitation, health promotion and access to social services (Hansson, Ovretveit, Askerstam & Brommels, 2010:2) are provided within a multidisciplinary and intersectoral context closer to the service users. There is collaboration among service providers involving mental health care practitioners and indigenous healing practitioners.

Community-based mental health services are based on the social model to promote the involvement of families in programmes to address the effects of mental health problems (e.g. stigma and social isolation) on MHCUs and their families. Additionally, it promotes collaboration and social cohesion based on the philosophy of *ubuntu* and *Bathopele* principles (Letseka, 2012:48) to enhance caring capacity and acceptance of vulnerable people. Community perceptions, values, and networks promote understanding of family challenges and strengths and determine intervention. MHCUs and caregivers participate in programmes as equal partners in programmes designed to identify the causes, treatment, prevention of mental health programmes, and address their needs.

Networking happens within the scope of community-based mental health care to mobilise resources and provide a support structure to MHCUs and their caregivers. Community structures such as the local and international NGOs, civic organisations, government services, churches, traditional authorities and municipalities are mobilised to provide a network of support services. Networking also facilitates referral to connect MHCUs and caregivers to existing services to receive practical support that promote their integration into the community.

Community mental health promotion programmes are conducted in public facilities such as clinics schools, churches and community centres. The purpose is to educate the public about the causes and effects of mental illness on the functioning of individuals and their families. The programmes are used to raise awareness about the stigma attached to mental illness, and the effects of drugs and alcohol use contribute to mental illness. They are also used to advocate for human rights and social justice promote access to services and for social integration of the MHCUs and their caregivers. However, communities have also been found to be the source of stigma and social isolation for the MHCUs and their families through labelling (cf. Chapter Two, Item 2.3.6). Moreover, some community members have been found to be the source of illicit drugs and alcohol that are harmful to the wellbeing of MHCUs as well as the community. One of the reasons for the neglect of MHCUs and their families is due to negative attitudes of the community.

Nevertheless, community members are often responsible for identifying and referring families to treatment centres, respite services and skills training centres. Treatment centres in communities are used for the treatment and rehabilitation for those addicted to drugs and alcohol. The MHCUs and their caregivers can participate in skills training programmes such as vocational skills, learnerships, internships, and apprenticeships, which are provided by the Sector Education and Training Authority (SETA) in South Africa. Their participation may promote integration into the community that may have rejected them due to mental illness.

One of the main functions of community-based mental health services is the integration of the MHCUs into the community and facilitating access to mental health services, disability grant, grant-in-aid and community services. The participation of MHCUs and caregivers in community-based mental health care empowers them to become resilient and cope with the effects of mental illness. Partnership with various stakeholders involved in the provision of mental health care is facilitated through participation in community-based care. Partners contribute their expertise to promote partnership for the benefit of the MHCUs, caregivers, their families and members of the community involved.

3.5 Conclusion

This chapter has provided an understanding of the theoretical frameworks informing the conceptualisation of partnership. The theoretical frameworks placed partnership within social model as an alternative approach in the provision of mental health services. Theories informing the practice of partnership included systems theory, ecological systems theory, person-in-environment approach, family systems theory, developmental approach, indigenous framework, legislative framework, and strengths perspectives. The information in this chapter enhanced the understanding of various theories explaining partnership. The information will also encourage those interested in research on partnership in mental health services.

CHAPTER FOUR

RESEARCH METHODOLOGY

4.1 Introduction

Research methodology provides a theoretical foundation for the researcher to conduct a study (Whittaker, 2012:30). Some studies have used terms such as strategies of inquiry or approaches to inquiry as synonymous with research methodology (Creswell, 2009:11; Melnikovas, 2018:29). Research methodology includes the scientific foundation the researcher employs to conduct a study and guides the selection process of the research methods (Long, 2014:428). This chapter is about the application of the research methodology which describes how the process unfolded. The research paradigm, research approach, research designs and the research methods will be discussed.

4.2 Research paradigm

Every research is based on philosophical assumptions about reality underlying the approaches involved in studying social problems. The assumptions provide the researcher with a paradigm to employ correct methods, principles and frameworks for the research (Mabvurira & Makhubele, 2018:18). Rehman and Alharthi (2016:51) define a paradigm as “a basic belief system and theoretical framework with assumptions about ontology, epistemology, methodology and methods”. Researchers use paradigms to articulate beliefs about the nature of reality, knowledge and values underlining the phenomenon of study (Creswell & Poth, 2018:18). Rehman and Alharthi (2016:51) describe positivism, interpretivism, and critical theory as the major research paradigms. Qualitative inquiry is identified with the interpretivist paradigm which describes reality as arising from interactions between people and their social environment (Creswell & Poth, 2018:18). The interpretive paradigm subsumes different paradigms including phenomenology, hermeneutics, critical theory, symbolic interaction and ethnomethodology (Dean, 2018:3). It describes experiences of people as happening in a continuously changing environment, and therefore, subject to multiple interpretations of reality (Kivunja & Kuyini, 2017:34). The paradigm views people as active participants in the construction of meaning about their experiences and the need for social justice respectively (Rehman & Alharthi, 2016:55). Importantly, the paradigm guides the qualitative research approach to explore and describe the interpretations of individuals about their experiences (Dean, 2018:1). The researcher makes inferences from the interpretations (Kivunja & Kuyini, 2017:34) of participants to discover and describe the involvement of families as partners through their interactions with service providers.

4.3 Research approach

This stage of the research process refers to the decision to adopt a research approach for the study. The choice for an approach is between a quantitative, mixed methods and qualitative research approaches (cf. Chapter One, item 1.5). This study followed the qualitative approach to explore the natural and real-life lived experiences of the participants in order to gain an understanding of the meaning they ascribe to mental illness and caregiving (Willig, 2009:9; Guest et al., 2013:47; Creswell & Poth, 2018:7).

In this study, the researcher interacted with participants to explore their experiences, perceptions, attitudes and beliefs (Conrad & Barker, 2010:67; Neuman, 2014:48) regarding the the provision of mental health services. The approach afforded the participants an opportunity to share their lived experiences relating to mental illness, caregiving, and the provision of mental health services. Moreover, the researcher was able to reflect on the impact the research process has on the participants and himself. This sense of reflexivity was used to mitigate the contamination of the participants' narratives during semi-structured interviews including the presentation and interpretation of the findings (Probst, 2015:37). The participants' reflections on the involvement of families as partners in the provision of mental health services, are discussed in Chapter Five.

4.4 Research designs

The study applied an exploratory, descriptive and contextual research designs to determine how MHCUs, caregivers and social workers make sense of, and interpret, experiences of mental illness. The application of the research design is discussed below.

4.4.1 Exploratory design

It was selected and used for the researcher to develop a better understanding of the phenomenon under study (Anokye, 2018:325). Little is known about the value of partnership in the provision of mental health services; particularly the contribution that families could make towards the promotion of mental health and well-being of MHCUs; the needs or support services that MHCUs and their caregivers require; and the challenges social workers encounter that hamper their efforts to involve and engage MHCUs and their caregivers as partners in the provision of mental health services (Adams, Kahn & Raeside, 2014:43). Additionally, limited research was done in South Africa on the involvement of families as partners in the provision of mental health services. Nevertheless, the exploratory research design helped to identify issues that influenced the participants' subjective meaning and understanding of mental illness and its impact on the personal, family and social functioning. It also facilitated the exploration of the need for partnership with mental health care practitioners in the provision of mental health services (cf. Addendum G).

4.4.2 Descriptive design

The descriptive accounts of the participants' lived experiences are important in qualitative studies (Willig & Billin, 2012:120; Harper, 2012:89) as they provide a better understanding of the "what" and "how" the phenomenon of study is experienced. The researcher used the descriptive research design in the study to gain a better understanding of the family in the provision of mental health care. Additionally, the use of the design enabled the researcher to describe challenges experienced by social workers in the provision of mental health services with a view to formulating practice guidelines for the involvement of families as partners in the provision of mental health services (cf. Chapter Six, item 6.3). Open-ended questions were asked to facilitate the descriptions of their experiences (cf. Addendum G). The researcher was able to provide descriptions of the participants' experiences that were revealed during the interviews. Literature control was conducted to compare and contrast the descriptions with previous findings (cf. Chapter Five & Six).

4.4.3 Contextual design

The contextual dimension of research focuses on the immediate context or environment in which the phenomenon occurs (Saukko, 2005:346). The context or environment includes the physical or socio-cultural context influencing the identity and social meaning shared by the individuals about the phenomenon (Dibley, 2011:16). The contextual design takes into consideration the experiences of the research participants within their environment, namely the familial, physical, geographic, social context, political, cultural, economic, and religious aspects as the focus of research (Malagon-Maldonado, 2014:121). This study was conducted in the environment where the participants experienced stressful live situations for MHCUs and their caregiver due to mental illness, shortage of services, unemployment, and poor working conditions for social workers.

South Africa is a multicultural society with dynamic experiences of families and individuals experiencing mental illness. Such experiences are influenced by their varied socio-cultural backgrounds. The participants who received mental health services from Thabamoopo Hospital come from diverse rural and township communities with diverse understanding of mental illness. Their perceptions, experiences and feelings attached meaning to their understanding of mental health services (Corbin & Straus, 2015:155). It also became evident that the participants' experiences of the provision of mental health services were influenced by their social context that limited their access to services. The participants were able to share their lived experiences within their social, religious, personal, economic, cultural context. For example, lack of income affects the caregivers' ability to provide care and support to MHCUs. Additionally, lack of resources account to the social workers' ability to provide adequate services to MHCUs, caregivers and families.

The context of participants guided the researcher in employing the research design techniques for population and sampling, data collection, data analysis and data verification as presented in the next section.

4.5 Population, sample and sampling procedures

Population refers to individuals, families, groups or organisations, communities and events that could contribute to a research topic (Leedy & Ormrod, 2013:152). The participants as components of a population shared their lived experiences with the researcher to facilitate the accomplishment of set goals (Yin, 2011:15). The researcher specified clearly who constitutes the study population, in order to select the appropriate participants to answer the research questions. Therefore, to have a broad understanding of the families' involvement in the provision of mental health services, three populations were identified, namely; MHCUs receiving medical treatment and social work services within catchment areas serviced by Thabamoopo Psychiatric Hospital in Lebowakgomo, Limpopo Province; caregivers of MHCUs receiving mental health and social work services within the catchment areas specified above; and social workers rendering mental health services to MHCUs living with their families within the catchment areas specified above.

Sampling was conducted as it was not possible to study the entire population of MHCUs, their caregivers and social work practitioners providing mental health services (Strydom, 2011:224). A sample means a small group of individuals drawn from the entire population from whom a researcher gathered information (Townsend & De la Rey, 2011:39). There are two forms of sampling, namely probability and non-probability.

Non-probability sampling is commonly used in qualitative research to study new areas of research and targeting subjects characterising the issue to be studied (Kumar, 2011; Acharya, Prakash, Saxena & Nigam, 2013:330). This means the probability that participants will be selected is unknown (Acharya et al., 2013:330). Moreover, the study cannot be generalised beyond the sample. Nevertheless, researchers employ purposive sampling to select participants for inclusion in the study (Mack, Woodsong, MacQueen et al., 2005:6; Strydom & Delport, 2011:392). The use of purposive sampling suggests deliberate choice of participants who can provide relevant information to the study (Acharya et al., 2013:330). It is based on the researcher's judgment to select a sample that satisfy some criteria such as accessibility, availability and less costs (Acharya et al., 2013:330).

In this study, a non-probability purposive sampling was utilised as the total number of MHCUs, their caregivers and social work practitioners providing mental health services in the population could not be identified. The researcher used his judgement in selecting the sample based on information obtained from the health professionals who identified MHCUs, their caregivers and the social workers. Records of MHCUs were used to select the MHCUs who have been discharged from the hospital and are on treatment in the care of their relatives. Each caregiver of the MHCU was sampled to participate in the study. Caregivers were identified by MHCUs and family members. Social workers were identified by the health professionals to participate in the study. The sampling ensured that the participants would provide rich information about their families' role in the provision of mental health services (Holloway & Wheeler, 2002:122; Gibbs, Kealey, Willis et al., 2007:540; Yin, 2011:88). The researcher's experience of nine years in rendering mental health services at the institutional and community levels was to his advantage when identifying potential participants who met the criteria for inclusion and exclusion presented in Table 4.1 and 4.2 below.

Table 4.1: Criteria for inclusion in the sample

Mental health care users (MHCU)	**Caregivers of MHCU**	**Social workers in a mental health setting**
▪ The MHCU must live with the family.	▪ The caregiver must be living with the MHCU in the same household.	▪ Social worker must have two or more years of experience in rendering services to MHCUs.
▪ The MHCU must be diagnosed with schizophrenia and receive mental health services.	▪ The caregiver must be responsible for taking care of the MHCU.	▪ The social worker must be providing mental health services to MHCUs receiving treatment from Thabamoopo Psychiatric Hospital.
		The social worker must be willing to participate in the study.
	▪ The caregiver must be willing to participate in the study.	

Table 4.2: Criteria for exclusion from the sample

MHCUs	Caregivers	Social workers
▪ Who were not diagnosed with schizophrenia. ▪ Who lived on their own.	Who does not live with the MHCU in the same households.	▪ Who worked outside stipulated areas

One of the tasks of the researcher in purposive sampling involves the selection of a setting located within a particular geographic area for conducting research (Onwuegbuzie & Leech, 2007:244; Nicholls, 2009:640; Yin, 2011:244). For the purpose of this study, the selected population came from the communities receiving mental health services from the Thabamoopo Psychiatric Hospital within the Capricorn District Municipality in Limpopo Province. The province is predominantly rural and made up of four district municipalities, namely Capricorn, Mopani, Vhembe and Waterberg. Capricorn District Municipality consists of three local municipalities, namely Blouberg, Molemole, Polokwane and Lepelle-Nkumpi. Thabamoopo Psychiatric Hospital is located in Lebowakgomo within Lepelle-Nkumpi municipality. It is one of three psychiatric hospitals in the province. Maps showing Limpopo district and municipalities, and Lepelle-Nkumpi municipality in which the hospital is located are included in the addendum of this study (Addendum J).

The municipality is located in the southern part of Capricorn District. The major part of the municipality is approximately 95% rural and under the Traditional Authorities. It has 30 wards, one of them is a township called Lebowakgomo where the hospital is located (Capricorn District Municipality Annual Report 2016-17: Lepelle-Nkumpi Municipality).

Thabamoopo psychiatric hospital is the only mental health hospital in the district. It also serves neighbouring districts, namely Sekhukhune and Mokopane, which lack mental hospitals. However, general hospitals in these districts have psychiatric wards for assessment and, thereafter referral to the Thabamoopo psychiatric hospital. Lepelle-Nkumpi Municipality has 96 primary health care clinics.

4.5.1 Sample size

The sample size in qualitative research cannot be planned at the onset of the study. Qualitative research requires a smaller sample size than quantitative research. The sample size is dependant on what researchers want to know, “the purpose of the inquiry and availability of time and resources” (Strydom & Delport, 2011:391). On the contrary, small sample has disadvantages, especially in relation to the transferability of findings to other situations (Vasileiou, Barnett, Thorpe, & Young, 2018:15). However, the sample sizes should be enough to gather data to sufficiently address the research questions. There were 10 MHCUs, 9 caregivers and 9 social workers who were sampled to participate in the study. Thus, sampling ensures the participation of those who will yield the most relevant and plentiful data (Yin, 2011:88) relating to the provision of mental health services.

4.5.2 Data saturation

Data saturation on the other hand, occurs when new information is no longer emerging during data collection (Corbin & Straus, 2015:134). This view suggests that data saturation is a way of determining the sample size (Creswell & Poth, 2018:158). Therefore, saturation of data emerges when additional data collected no longer elicit new themes for the study (Saunders, Sim, Kingstone, et al., 2018). The researcher reached data saturation after the ninth interview with the MHCUs and proceeded to conduct the 10th and final interview. Data saturation was reached during the eighth interview with the caregivers and social workers, respectively. A final additional interview was conducted with a caregiver and social worker to ascertain that no new information was forthcoming. This brought the total number of interviews to nine for both groups.

4.5.3 Preparation of participants for data collection

After obtaining ethics approval from the Department of Social Work at Unisa, the researcher submitted a letter requesting permission to conduct research (Addendum B), accompanied by the research proposal and ethics approval letter (Addendum B & C) to the Limpopo Provincial Department of Health for consideration. Permission was granted to the researcher to conduct the study (Addendum D).

The researcher's choice of the problem, its formulation and objectives of the study provided the impetus for the preparation of data collection. A pilot test of the interview guides was conducted with was conducted with two MHCUs, two family members of the MHCU and two social workers using semi-structured interviews. Potential participants were thereafter identified with the assistance of the mental health professionals and social workers, and the researcher met with them individually to build rapport as a way of creating a conducive environment to share information (Majid, Othman, Mohamad et al., 2017:1076).

The contact enabled the participants to know the researcher and to understand the purpose of the research (Kemparaj & Chavan, 2013:94). The researcher explained the purpose as understanding the family as a partner in the provision of mental health services and the procedures of the research related to the study and established the participants' willingness to engage in the study. The ethical requirements in relation to participation in the study and the use of information gathered were explained to them. The consent form was explained to ensure that they understand their role in the study (Addendum E & F).

4.6 Data collection method

Data collection is a process of gathering information in order to answer research questions (Kabir, 2016:202). The main approaches to data collection in qualitative research include interviews, focus groups and observation (Barrett & Twycross, 2018:64). Although qualitative inquiries use different forms of data collection techniques, semi-structured interviews were regarded as appropriate for this study (Kabir, 2016:212).

Semi-structured interviews are a method of data collection used for data collection to generate contextually rich data, from participants, to gain an understanding of the phenomenon from their perspective (Malagon-Maldonado, 2014:131; Sant, 2019:40). Researchers use semi-structured interviews to facilitate personal contact between the researcher and the participants in order to make it easier for the latter to share their views, experiences and challenges. However, methods of data collection may not provide accurate and reliable information due to constraints such as lack of resources or required skills (Kabir, 2016:221). In such situations the researcher should be aware of the problems that these limitations impose on the quality of the data (Kabir, 2016:211).

Nevertheless, successful data collection requires building rapport with the participants as the first task for every researcher (Gibbs et al., 2007:541; Kabir, 2016:203). Face-to-face interviews allowed for personal contact which promoted rapport (Creswell, 2014). Its interactive approach presented the researcher as expressing interest in the participants' stories. However, face-to-face interviews may limit communication as some participants may feel uncomfortable to share personal information (Hiriscau et al., 2014:410). However, rapport improved and participants increased their interest in giving rich qualitative data. Additionally, face-to-face interviews allowed the researcher to gather non-verbal data from observing body language and facial expressions.

Interview guides were used as appropriate research instruments containing sets of predetermined questions (Greeff, 2011:352). An interview guide is a list of questions which directs conversation towards the research topic during the interview (Kallio, Pietila, Johnson & Kangasniemi, 2016). The researcher developed an interview guide for each of the three groups of participants, namely MHCUs, caregivers and social workers (Addendum G & H). The use of the interview guide has ensured that the collection of information was the same for each participant (De Clerck, Willems, Timmerman & Carling, 2011:12). It provided the researcher with an opportunity to explore the participants' views and opinions (Field & Morse cited by Greeff, 2011:348). The researcher was able to focus on the questions while allowing the participant decides to provide new information (Nicholls, 2009:640). Note-taking was limited as the researcher avoided disrupting the flow in the participants' storytelling (Yin, 2011:156).

Furthermore, qualitative interviews require the application of interviewing skills to engage the participants. Interviewing skills enabled the researcher to build rapport with the participants in order to get deeper understanding of their experiences (Agee, 2009:437; Campbell & Scott, 2011:6). The researcher was able to clarify how the participants were selected for the study. This was followed by the compilation of their biographical information as part of the interview process. Furthermore, the researcher was able to ask for a full description of the participants' experiences related to the topic and allow them to talk in an open-ended manner (Hill, 2012:9). The researcher was able to ask appropriate questions in order not to miss critical information (Yin, 2011:27). The open-ended questions were asked with a wide range of probing questions to engage participants until the topic was exhausted (O'Reilly & Parker, 2012:192). The questions enabled the researcher to understand the meaning of the what the participants were saying. Another advantage of semi-structured interviews is that this method of data collection is compatible with several methods of data analysis (Willig, 2009:23). However, qualitative interviews have been criticised for being time-consuming and lacking generalisability (Queirós, Faria & Almeida, 2017:378).

Additionally, interviews were audio-taped with the permission from the participants (Addendum E & F). In preparation for the interviews, the researcher tested the recording equipment to ensure that it was in good working condition. The researcher familiarised himself with the content of the consent form, the concepts used, the purpose of the research, and who to contact for further information (Jamieson, Sambu & Mathews, 2017:13), in order to address the questions that the participants might have had. A simple everyday Sepedi language spoken by MHCUs and their family caregivers was used to break the barriers of communication that are usually caused by the use of technical jargon. Probes and follow-up questions were used to influence the richness of the information that the participants provided (Yin, 2011:132). The participants were also encouraged to give as much information as they possibly could to elaborate on their answers without being judgmental or feeling judged. However, audio-taping may discourage the participants from sharing personal information as they may fear that the information might be used against them (Creswell, 2014). Additionally, the audio-tape might malfunction and cause the loss of valuable information.

4.6.1 Pilot testing

Pilot test is used by researchers to assess whether the quality of the interview guide will illicit the sought data in preparation for data collection (Chenail, 2011:257; Burkard, Knox & Hill, 2012:87). An assessment was made as to whether the questions were clearly understood by the participants (Majid et al., 2017:1074). The pilot test of the interview guides was conducted with two individuals per population group (MHCU, a caregiver and social worker) who met the criteria for inclusion. These participants were not part of the final sample (Hill, 2012:87). Positive feedback was obtained from them regarding the structure of the questions, their clarity and their sequence and therefore no changes were made. The assessment of the data collected from the pilot testing interviews yielded rich information which confirmed that the questions elicited the required responses.

4.6.2 Method of data analysis

Qualitative data analysis refers to the process of organising and interpreting data for the researcher “to see patterns, identify themes, discover relationships, develop explanations, make interpretations or generate theories” (Vaismoradi, Turunen & Bondas, 2013:398) (cf. Chapter Five & Six). Qualitative data analysis includes “reviewing, synthesising and interpreting data to describe and explain the phenomenon of the study” (Henning, van Rensburg & Smit, 2013:101). It is an ongoing process that enables the researcher to continually reflect on the data, ask questions, and write memos throughout the study (Creswell, 2009:183; Silverman & Patterson, 2013:24). The process allowed the researcher to constantly interact and immerse in the collected data in order to familiarise himself with it (Clarke, Braun & Hayfield, 2015:230), and develop an in-depth understanding that enabled ongoing analysis that guided the next stage of data collection and interpretations grounded in the data (Maher, Hadfield, Hutchings & de Eyto, 2018:3). The researcher applied the eight steps of Tesch (1990) proposed by Creswell (2009:186; Creswell, 2014) for purpose of analysing the collected data to understand the participants’ views. Tesch’s steps provided the researcher with a useful analysis of the process of the study as follows:

- The researcher listened to and transcribed each of the 28 audio-taped interviews involving three groups of participants, namely MHCUs, caregivers and social workers. The transcription involved repeated listening to every word uttered by the participant.
- Each transcribed interview was thoroughly read to derive the underlying meaning of the responses.
- The researcher wrote ideas down as they came to mind in order to identify common and unique responses.
- The previous step was repeated for all 28 transcriptions from three groups to derive common themes emerging from the interviews.

- After repeating this exercise, the researcher listed the themes that emerged. They were grouped together according to their commonalities and categorised into themes, sub-themes and categories.
- The list of themes was compared with the data and were abbreviated into unique codes which were written alongside the appropriate portion of the text. The coding was reviewed paying close attention to the emergence of new themes.
- The most descriptive words were identified for the themes and similar ones were placed into categories.
- The final codes were decided upon and wrote in alphabetical order.
- The data for each category was written and a preliminary analysis of the data motivated the start of the process of reporting the findings.
- Data gathered from each group of participants, namely MHCUs, caregivers and social workers were compared to look for complementarity and differences in the descriptions of phenomena.
- A discussion between the independent coder, and the researcher in consultation with the supervisor was conducted to compare and consolidate the themes, sub-themes and categories which emanated from the data.

4.7 Trustworthiness

Every researcher strives for the scientific rigour of the data informing the outcome of their study. Qualitative research is described as a “messy, non-linear and often unpredictable undertaking” (Sinkovics & Alfoldi, 2012:827). Hence data verification is required to make sense of it. The researchers utilise data verification to subject research data to rigorous scrutiny to ensure its trustworthiness (Bulpitt & Martin, 2010:7). This process ensures that the findings of the research accurately represent what is being studied to bring about credible conclusions (Williams & Hill, 2012:175). The criteria for trustworthiness or rigour of qualitative research include credibility, dependability, confirmability and transferability (Houghton, Casey, Shaw & Murphy, 2013:12), and the discussion below is based on how they were applied in this research inquiry.

4.7.1 Credibility

Credibility of research is about the confidence in the truth of the study findings (Hussein, Jakubec & Osuji, 2015:1182; Connelly, 2016:435). Although the concept of truth has affinity with the positivist research approaches, in qualitative research the concept focuses on meaning of findings rather than seeking to prove or disprove the truth (Sinkovics & Alfoldi, 2012:830), thus determining the credibility of the study (Houghton et al., 2013:13). Furthermore, credibility is dependent on the skill and competence of the researcher (Tuckett, 2005:30; Connelly, 2016:435) presenting truthful experiences that participants would immediately recognize as their own (Hussein et al., 2015:1183). To ensure credibility of the study, the researcher ensured that the data was properly collected, analysed and interpreted to accurately reflect the experiences of the participants (Yin, 2011:78). To achieve credibility, Lincoln and Guba’s strategies of triangulation, peer debriefing and member checking were employed (Houghton et al., 2013:13).

Triangulation is a process of collecting and comparing information from multiple sources to interpret and corroborate the truth value of information derived from data sources (Tuckett, 2005:38; Yin, 2011:81). The methods of triangulation include triangulation of data methods, triangulation of data sources and triangulation of researchers for checking out the consistency of findings and to increase confidence in the credibility of findings (Amankwaa, 2016:122).

Triangulation of data sources involves the gathering of multiple perspectives from a variety of sources to have a possible complete picture of phenomena (Loh, 2013:9). Data gathered from three sets of participants, namely; MHCUs, caregivers and social workers ensured congruence and complementarity of the data (Addendum G). Interviews were repeated with the same participants to verify the authenticity of data. Information gathered from recordings and observations was used to establish consistency of data gathered from the interviews and to maximise the credibility of the study. The researcher has repeatedly listened to the audio-taped interviews and readings of transcripts focusing on critical narratives. Data gathered from each group of participants were compared to look for convergence or divergence. Therefore, the approach generated detailed description of the participants' experiences (Nicholls, 2009:590) regarding the provision of mental health services.

Triangulation of researchers uses multiple analysts or observers to review findings to seek multiple meanings to add depth to the analysis (Hays, Wood, Dahl & Kirk-Jenkins, 2016:176). The process of triangulating analysts occurred when the independent coder, and the researcher independently analysed the same qualitative data and compared findings (Cope, 2014:90). A discussion between the independent coder, and the researcher in consultation with the supervisor was conducted to compare and consolidate the themes, subthemes and categories which emanated from the data.

4.7.2 Transferability

Transferability involves a criterion for assessing the applicability of findings in another context of study (Schurink, Fouche' & De Vos, 2011:420). Thick descriptions of data facilitate sufficient detail to evaluate the extent to which the conclusions drawn from interviews are transferable for future research, other settings and people (Tuckett, 2005:38; Schurink et al., 2011:420; Cope, 2014:19). The researcher provided rich data to enhance transferability of the findings to similar contexts (Vandyk & Baker, 2012, 351; Creswell, 2014; Amankwaa, 2016:122), and to allow others to check the degree of the transferability of the findings.

4.7.3 Dependability

Dependability is concerned with whether the findings, interpretations and conclusions are an accurate reflection of the participants' experiences (Amankwaa, 2016:122). It is achieved when findings are replicated with similar participants in similar conditions and still achieve the same findings (Cope, 2014:89). Therefore, to ensure dependability the researcher provided a dense description of the exact research methods of data collection, analysis and interpretation. The researcher used the iterative process of coding to return to earlier data in order to achieve consistency of data (Elliott, 2018:2859). Another approach used to achieve dependability is referred to as the inter-coder reliability (O'Connor & Joffe, 2020:4). Inter-coder reliability is achieved when another researcher concurs with every stage of the research process (Cope, 2014:89) to achieve dependability. The independent coder's services assisted the researcher to compare analysed data in order to produce shared interpretations regarding the phenomenon of study (Cope, 2014:90; Connelly, 2016:435).

4.7.4 Confirmability

Confirmability refers to accurate reflection of participants' experiences (Hays et al., 2016:174). Amankwaa (2016:122) suggested that confirmability can be demonstrated through audit trail, triangulation, and reflexivity. The recordings and verbatim transcripts formed part of evidence of the participants' lived experiences. The researcher kept a diary to record and reflect on how personal experiences, observations, thoughts, feelings and assumptions (Houghton et al., 2013:14) affect the interview process.

4.7.5 Reflexivity and bracketing

In qualitative research, the researcher affects and is affected by the research context (Darawsheh, 2014:561; Probst, 2015:37). Researchers bring to the research context their value systems, philosophical orientation, background and previous experience on the phenomenon which can influence the research process (Amankwaa, 2016:122; Galdas, 2017:1). Hence, the need for researchers to be aware their personal and professional experiences in implementing the research process through the principle of reflexivity. Reflexivity is defined as "a conscious process of unmasking hidden conflicts and assumptions/ideas/beliefs with a goal of emancipating thinking and action of self, others, reality and context" (Kalu, 2019:97). It is a response to researcher bias which can impact on the research process and its outcome. The fact that the researcher was once involved in the provision of mental health care as a social worker, has the potential to introduce bias. Therefore, he should maintain a reflexive attitude to reflect on thoughts and feelings to keep out perceptions and subjectivity (Cope, 2014:90).

Alongside reflexivity is the concept of bracketing through which the researcher maintain neutrality to eliminate bias (Probst, 2015:38). The researcher's constant interaction with the supervisor assisted him to constantly examine how his preconceptions, beliefs, values, assumptions and experience interfere with the research process (Rolfe, 2006:309; Amankwaa, 2016:122). A diary was used to note one's thoughts and values to determine that they do not interfere with the data gathering process. Relevant literature was consulted to reflect and engage in continuous self-critique and self-appraisal to maintain awareness throughout the research process.

4.8 Application of ethical considerations

The explanation of the ethical considerations provided in Chapter One (Item, 1.6) guided their application during the research process. They provided guiding principles for protection of participants from harmful research practices. The human rights and social justice approaches were adopted to guide the ethical conduct of the researcher through the process of data collection, data analysis and interpretation of data. The researcher followed professional ethics, values and practice standards which are established arrangements for governance of professional practice (Robertson & Walter, 2007:411; Fulford & Woodbridge, 2008:82; Mooney-Somers & Olsen, 2017:129). During data collection, the researcher noticed that his encounter with participants was not only physical, but involved emotional reactions that influence the interview process (Creswell, 2009:87; Vanclay et al., 2013:243). The researcher, therefore, conformed to the standards of conduct through ongoing communication and observing his obligations to participants (Swauger, 2011:500). Data analysis and interpretation of data are carried out to ensure that the research findings reflected the participants' experiences (Arifin, 2018:31). Therefore, the researcher applied the ethical principles such as avoidance of harm, informed consent, confidentiality and management of information to the study as follows:

4.8.1 Avoidance of harm

Avoidance of harm is minimised through proper planning of the research process to conduct an ethically sound research (McKellar & Toth, 2016:2). The most important aspects for protecting the participants from harm involves obtaining approval and permission to conduct research. The researcher obtained approval from the Department of Social Work Research and Ethics Committee at Unisa which ensured that the research would be conducted under an experienced, qualified and competent supervisor (Addendum A). The approval provided the first step in ensuring the protection of participants from the risk of harm. It also provided an opportunity to request permission from the Department of Health in Limpopo to conduct research

(Addendum C). The request for permission was granted (Addendum D). The permission allowed the researcher to identify gatekeepers who facilitated access to participants, namely MHCUs, caregivers and social workers. a meeting was arranged with the management of Thabamoopo Hospital as gatekeepers to discuss the purpose of the study and the content of the informed consent forms that the participants would be requested to sign. The hospital management facilitated access to information on participants. The researcher was allowed access to the MHCUs folders to identify those who fit the profile for research. Those identifies were diagnosed with schizophrenia, still on treatment to control the severity of their symptoms and living at home with caregivers. The social workers were identified according to the areas where the MHCUs lived and received mental health services. The identifying particulars such as names, address and telephone numbers of caregivers and social workers were obtained to establish contact. The researcher visited MHCUs and their caregivers, and contacted social workers telephonically to prepare them and secure appropriate dates and time for the interviews. Furthermore, participants were advised to approach social workers to receive debriefing for emotions that might have been aggravated by the sharing of information during the interviews.

4.8.2 Informed consent

The informed consent principle guided the conduct of the researcher through the research process (Strydom, 2011:116). The researcher approached potential participants individually to seek consent for participation in the study. He ensured that MHCUs participating in the study were on medication which stabilised the severity of their psychotic symptoms. Thorough explanation of the research process was given to seek the participants' agreement to participate in the study (Arifin, 2018:30). The information about the research was offered in language appropriate for participants to ensure better understanding of general purposes, procedures and possible consequences of the research. Both the consent form and interview guide for MHCUs and caregivers were translated into Sepedi language (Addendum E & H) for better understanding. The forms for social workers were in English which is the employer's medium of communication. The consent form and interview guides were thoroughly discussed with the participants in Sepedi (for MHCUs and caregivers) and English (for social workers) as languages they understand. All participants were given an appropriate time to ask questions and address any concerns, and to decide whether or not they wanted to be involved in this study. Consent to record the interview was also sought and secured from them. Furthermore, the potential participants were informed that their participation was voluntary, and they had a right to withdraw from the study at any time even after the informed consent had been signed. They were also given the contact details of the research coordinator to report any breach of ethical conduct by the researcher. The participants confirmed their acceptance by signing consent forms to indicate their permission to participate in the study. However, MHCUs were assisted by their caregivers to complete the consent forms.

4.8.3 Confidentiality, privacy and anonymity

The researcher is a registered social worker and is bound by the oath of confidentiality, privacy and anonymity. The research promoter ensured that the researcher conduct the research according to the ethical requirements of the university. The right of confidentiality, anonymity and privacy was declared during the consent process and protected during the research. The anonymity and confidentiality of the participants was maintained by not revealing their names and identity in the data collection, analysis and reporting of the study findings (Arifin, 2018:30-31). The researcher informed the participants that their participation is anonymous and that they would not be identified by their answers to the research questions. Furthermore, the researcher informed the participants that their personal information would not be divulged to third parties without their permission. Additionally, the participants were informed about their right to share or withhold information and that their decisions will not affect their benefits, such as disability grants, grant-in-aid and access to opportunities. An appropriate location for conducting the research was identified with the consent of the participants to protect them from being interrupted and overheard, and ensure their confidentiality and privacy. The advantage of MHCUs being interviewed alone, may enable them to talk freely about some concerns that they may not willing to share with their caregivers. However, some MHCUs who felt uncomfortable talking to the researchers alone, were interviewed in the presence of their caregivers to ensure a sense of safety and well-being.

Privacy and confidentiality were managed carefully during telephone communication, interview sessions, transcription of data, data analysis and data interpretation. The transcription of data was conducted in a private room using earphones to avoid the possibility of recordings being heard by other people. The identities of the participants were removed during data transcription, including their names or any significant aspect of identity. In presenting the findings of the study, the participants were referred to by their pseudonym names in the verbatim quotes. Written consent or any document which contains the participants' personal detail was kept in a locked cabinet with no access to anyone other than myself. Data were shared with the other two qualitative researchers for the purpose of reaching agreement of the interpretation without exposing the participants’ details at any interim stage. The access of the supervisors to the data was explained to the participants and their consent regarding this matter was obtained (Arifin, 2018:31).

4.8.4 Management of information

Management of information is part of the researcher’s responsibility to protect participants from harm (Wolf, Patel, Williams-Tarver et al., 2015:595). The researcher transcribed data during the course of data collection. Data collected was treated confidentially and stored anonymously by using pseudonyms (Iurea, 2018:51). Names of participants were removed from notes and transcripts, and were not used during the recording. Instead alphabets were allocated to participants during transcription to hide their identity. The transcripts were shared with one qualitative researcher and independent coder for the purpose of cross checking in data analysis. Important tools such as tapes, notes and transcripts of recordings were securely kept in a locked cabinet that only the researcher had access to. The information storage on personal computer and laptop, hard disk and memory sticks were protected by the use passwords held only by the researcher. The use of passwords ensured that unauthorised individuals did not access the raw data. Access was limited to the researcher, the promoter, and an independent coder.

The University of South Africa (Unisa) policy on the management of information requires that research records be preserved for a minimum of five years (or as required by policy or legal frameworks) after the submission of the report or the results. Both written and electronic data from this study will be stored for five years. However, the interview recordings and transcripts will be disposed after the researcher had completed their studies.

4.9 Conclusion

This chapter focused on the application of the qualitative research methodology to the study. A qualitative approach was used to discover and describe an understanding of the experiences of the participants in the provision of mental health services. This was achieved through the use of exploratory, descriptive, and contextual research designs. Additionally, the methods of data collection, analysis and verification were applied to demonstrate the credibility of the study. Furthermore, the application of ethical considerations demonstrated the researcher’s professional obligation to protect participants was achieved. The participants’ accounts of their experiences are discussed in chapters five and six.

CHAPTER FIVE

RESEARCH FINDINGS ON THE EXPERIENCES OF MENTAL HEALTH CARE USERS (MHCUS) AND CAREGIVERS

5.1 Introduction

The presentation of the findings is divided into two chapters. The findings in this chapter are based on the MHCUs' and their caregivers' experience of the provision of mental health services. The findings emerged from the storylines of ten MHCUs diagnosed with schizophrenia and nine caregivers obtained from semi-structured interviews. The MHCUs were on medication which stabilised the severity of their psychotic symptoms and were cared for by their caregivers who were family members who lived with them.

To increase credibility of the study, data was independently analysed by the researcher and an independent coder. Themes and subthemes were identified, discussed and consensus on the outcomes was reached by the researcher, the independent coder and the promoter. Storylines from transcripts were subjected to a thorough literature control to establish the credibility and trustworthiness of the study.

The chapter focuses on the profiles of the MHCUs and their caregivers, and the presentation of themes, subthemes and conclusion. The findings on the social workers' experience are presented in Chapter Five.

5.2 Demographic profiles of the MHCUs and caregivers

This section presents the demographic profiles of the MHCUs and their caregivers. Caregivers were made of three mothers, five siblings and one cousin. Alphabets were used to identify and link MHCUs to caregivers, for instance, the family member linked to MHCU A is coded as AA. However, as F and J were cared for by their mother, they both shared FF as a code for their caregiver. The demographic data presented on Table 5.1 below reflect gender, age, year of onset of illness, duration, relations and source of income.

Table 5.1: Demographic profiles of the MHCUs and caregivers

Mental Health Care Users (MHCUs)						**Caregivers**						
MHCU	Gender	Age	Year of onset of illness	Period in years since first diagnosis (duration)	Source of income	Caregivers	Gender	Age	Marital status	Relations	Duration of caregiving since first diagnosis	Source of income
A	F	72	1972	42	DG[10]	AA	F	74	M[11]	Sister	42	DG
B	M	46	2002	12	DG	BB	F	52	S[12]	Sister	12	Self-employed
C	F	34	2014	7 months	No income	CC	F	38	S	Sister	7 months	Employed
D	M	32	2004	10	DG	DD	F	30	S	Sister	10	Child Support Grant
E	M	31	2000	14	DG	EE	F	44	S	Cousin	14	Mother of MHCU is a pensioner
F	M	31	2009	5	DG	FF	F	58	M	Mother	5	Unemployed - depends on her son's DG

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[10] Disability Grant

[11] Married

[12] Single

G	F	30	2013	1	No income	GG	F	55	M	Mother	1	Unemployed - depends on donations
H	M	29	2011	3	Casual jobs	HH	F	58	M	Mother	3	Mother’s husband receives old-age pensioner
I	M	28	2000	14	DG	II	F	26	S	Sister	14	Mother employed
J	M	26	2005	9	DG	FF	F	58	M	Mother	9	Unemployed - depends on her son’s DG (Same caregiver for MHCH F)

The demographic profiles of the participants are based on age differences, gender, sources of income, relationships and age of onset of mental illness and caregiving.

5.2.1 Age differences of the MHCUs and caregivers

Age is an important predictor of causal factors and severity of mental illness (Svensson, Lichtenstein, Sandin et al., 2012:43; Untu, 2015:25) and the ability to perform caregiving responsibilities (Rodríguez-Sánchez, Pérez-Peñaranda, Losada-Baltar et al., 2011:2). It takes into consideration the developmental needs of participants and the provision of age-appropriate resources.

The biographic profiles of MHCUs reveal that ten participants were between 25 and 72 years of age with an average of 36 years at the time of the interviews. The number of years since the MHCUs were diagnosed with mental illness ranged from seven months to 42 years with an average of 21.1 years. The biographical profiles of caregivers reveal that nine participants were between 26 and 74 years. The average age was 44 years. Three mothers of MHCUs were aged between 55 and 58 years and were within the developmental stage of generativity versus stagnation. The MHCUs in their care were aged between 26 and 31. A 58-year-old caregiver was caring for her three mentally ill sons. However, two sons were eligible to participate in the study as they were formally diagnosed with schizophrenia. The third was excluded on the basis that he was not receiving treatment even though he was deemed mentally ill by the family.

- Age of the MHCUs

Mental illness knows no age and can affect everyone (WHO & Wonca, 2008:26; SA Mental Federation of Mental Health, 2014-2015:5). However, each person experiences the onset of mental illness at a particular age of his/her life. The age of onset in mental illness refers to the first appearance of positive psychotic symptoms (Eranti, MacCabe, Bundy & Murray, 2013:160) including hallucinations, delusions (especially persecutory delusions), thought disorders, negative symptoms and affective symptoms (Scherr et al., 2012:108).

According to Eric Erikson's epigenetic stages of psychosocial development, the age of an individual shows their achieved biological, psychological and social milestones (Westermeyer**,** 2004:29; Becvar & Becvar, 2009:110; Marcia & Josselson, 2012:617). However, the condition of the MHCUs may make their mastery of their respective and subsequent stages of psychosocial development difficult and at times impossible to achieve (Becvar & Becvar, 2009:110; Capps, 2012:281). The MHCUs' developmental phases are discussed in terms of Erikson's three stages of human development (Westermeyer**,** 2004:29; Becvar & Becvar, 2009:110; Wilt, Cox & McAdams, 2010:156).

- Intimacy versus self-absorption or isolation (21- 40 years)

Eight MHCUs fell within the intimacy versus self-absorption or isolation stage of development wherein they are expected to form long-term intimate relationships. All MHCUs were single at the time of the interviews. Two female participants had children but were not involved in intimate relationships. Claims by one of the male participants of being romantically involved could not be confirmed by his caregiver. However, the claim may be interpreted as showing the presence of erotomatic delusions, which often causes MHCUs to believe that they are in love with someone (Dziegielewski, 2015:155). The opposite of intimacy is self-absorption or isolation which may result from stigma usually experienced by individuals with mental illness. The MHCUs may face isolation and rejection because the society view them as lacking the ability to engage in normal intimate relationships (Rogers & Pilgrim, 2010:29).

- Generativity versus stagnation (40 - 65 years)

Only one male MHCU's age fell within this stage of development. He was 46 years old. At this stage, expectations are that the individual can provide for a family, have close friendships, engage in community activities and enjoy overall good mental health. Although the MHCU had a wife and children who unfortunately left him because he was physically abusive, he however expressed the intention to safe money towards payment of lobola (bride price) to marry another wife. The onset of mental illness at the age of 34 diminished his perception of reality (Maj, 2012:65) which disrupted his personal and social functioning, thus causing stagnation in his social life (Becvar &

Becvar, 2009:110; Malone, Liu, Vaillant et al., 2016:4). He was unable to provide for his family or play a meaningful role in the community.

- Integrity versus despair and isolation (over 65 years)

One female MHCU was 72 years and became mentally ill from the age of 30. Due to her condition, she never married, did not have children, and was never employed. Her mental condition affected her ability to reflect on the past, present, and anticipated future (Wilt et al., 2010:156).

- Age of the caregivers and MHCUs

The age of the caregivers has an impact on their caregiving roles due to their varied personal needs (Bailey & Gordon, 2016:225). Caregivers, irrespective of their age, perform multiple responsibilities as carers of MHCUs. These responsibilities require the ability to address challenges, for example financial responsibility, disruptive behaviour and reduced quality of life (Wong, Lam, Kit, Chan & Chan, 2012:1). In most instances, caregiving is the responsibility of family members such as parents, siblings and cousins.

Although, tradition dictates that adults should provide for themselves and have families of their own, those who are mentally ill are unable to do so. Unfortunately, mothers find themselves reduced to perpetual caregivers of their ill adult children for most of their lives (Gunderson, 2004:37; Johansson, Anderzen-Carlsson, Åhlin & Andershed, 2010:692).

Siblings are also involved in caregiving, especially in the absence of a parent or older relative. Of the six (four males and two females) MHCUs aged between 25 and 75 were cared for by their sisters and one by a cousin. In African communities, a cousin is regarded as a sibling and therefore part of the family. The parents of the four MHCUs siblings are deceased, the fifth MHCU has a mother who is employed, and the other’s mother was suffering from a chronic illness. The age difference between the three MHCUs and their sisters (caregivers) was two, whilst the other two were four and thirteen respectively.

Three caregivers who were in the intimacy versus self-absorption or isolation stage of development were involved in relationships with partners and friends. Usually, family caregiving dictates that the available family member becomes the caregiver (Sanders, Szymanski & Fiori, 2014:257; Githaiga, 2016:2). The siblings as caregivers sacrifice their personal needs and give preference to the needs of their relative with a mental illness (Daire, Torres & Edwards, 2009:67; Sanders, Szymanski & Fiori, 2014:257). Their sacrifice may be informed by the African values of *Ubuntu* - *umuntu ngumuntu ngabantu* (in Nguni languages) understood as *motho ke motho ka batho* (in Sotho languages). Literally, the dictum means one's humanity is better fulfilled within the collective.

The younger caregivers may, however, experience challenges when supervising older male MHCUs to attend to their personal needs and to enforce adherence to medication (Chang et al., 2016:6). As caregivers, they are expected to provide support, resources and nurturing as part of their responsibilities to their older siblings (Lohrer, Lukens & Thorning, 2007:129; Sanders, Szymanski & Fiori, 2014:258). However, their attempts at fulfilling their caregiving responsibilities may interfere with their personal lives (Bailey & Gordon, 2016:226), resulting in the development of psychosocial problems, among them, poor quality of life and interpersonal stress (Usita, Hall & Davis, 2004:22; Iseselo, Kajula & Yahya-Malima, 2016:2).

On the other hand, the 44-year-old cousin was in the generativity versus stagnation developmental stage, with expectations to be able to provide for a family, have close friendships, engage in community activities and enjoy overall good mental health. Likewise, a 74-year-old caregiver cares for a 72-year-old sibling and are both in the last developmental stage of integrity versus despair and isolation. Although the caregiver was married, like her sibling, she did not have children of her own. She cared for her sibling despite certain tasks that require physical strength to perform (Osborne, 2009:296; Capps, 2012:274). Old age may impact negatively on one's caregiving abilities resulting in decline in health (WHO & Wonca, 2008:193; Iseselo, Kajula & Yahya-Malima, 2016:2).

5.2.2 Gender of MHCUs and caregivers

Gender is a social construct explaining the demographic characteristics of individuals (Andermann, 2010:505) that influence the social behaviour of individuals. Mental illness and caregiving have gender characteristics as well.

- Gender of MHCUs

Mental illness affects every person irrespective of gender. However, in mental health gender is one of the defining attributes of mental illness. Although gender was not the determining factor in deciding who should participate in this study, there were seven males and three female participants. The highest number of men confirms the general view that men are more vulnerable to mental illness than women (Beauchamp & Gagnon, 2004:1021; Rogers & Pilgrim, 2010:74). Studies show that male MHCUs have “earlier age of onset, a poorer premorbid history, more negative symptoms, a higher relapse rate, a worse outcome, a poorer response to neuroleptic drugs, and a lower family morbidity risk for schizophrenia” than female MHCUs (Eranti et al., 2013:155). However, studies show that more women than men receive psychiatric diagnoses and psychiatric services (Rogers & Pilgrim, 2010:69) which is attributed to the fact that women are more inclined to consult mental health care practitioners at the onset of an illness than men.

- Gender of caregivers

Literature on caregiving indicates that women constitute the majority of caregivers (Tramonti, Bongioanni, Leotta et al., 2015:44). All nine caregivers were females (cf. Table. 5.1). This seems to confirm the assertion that caregiving is largely a gendered responsibility confined mainly to women (Robinson, Bottorff, Pesut et al., 2014:409; Githaiga, 2016:2). Gendered responsibility is often determined by society which has predominantly conferred caregiving responsibilities to female members of the family (Møller, Gudde, Folden & Linaker, 2008:157; Perrone-McGovern, Wright, Howell & Barnum, 2014:21) particularly in African communities (Tarimo, Kohi, Outwater & Blystad, 2009:66; Githaiga, 2016:2). Most women endure the burden of caregiving by sacrificing their schooling, employment and marital homes to care for their mentally ill family members (Githaiga, 2016:2).

5.2.3 Source of income of the MHCUs and caregivers

Studies have found that mental illness has negative effects on the socio-economic functioning of the MHCU and the family (Lund, Myer, Stein et al., 2013:845; Ysseldyk, Kuran, Powell & Villeneuve, 2019:169). Mental illness contributes to social isolation and deprivation of both the mentally ill and their caregivers from access to social services, employment opportunities and other income-generating activities (cf. Chapter Two, Item 2.2.5).

- Source of income for MHCUs

Only one MHCU was involved in some intermittent income generating activity as a casual worker at a brickmaking and building construction factory. Two were unemployed and had no other source of income. Seven MHCUs were receiving a monthly disability grant of R1 600.00 that the state provides through the South African Social Security Agency (SASSA, 2016). Disability grant is accessed in terms of the Social Assistance Act (Act No. 13 of 2004) Section 9 (b) on the basis that the person is “unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance”. The disability grant is recommended by a medical doctor. However, not every MHCU described in terms of this provision of the Social Assistance Act (Act No. 13 of 2004) received disability grant on the basis that they were stable to find employment.

The cost of living is high in South Africa, and the disability grant is far from adequate (Graham, Moodley & Selipsky, 2013:328) to cater for beneficiaries’ needs. StatsSA (2019:3) report shows three levels of poverty in terms of expenditure per person per month in rands as at April 2019:

- **Food poverty line (extreme poverty)** was R567.00 (in April 2019 prices) per person per month. This refers to the amount of money that an individual will need to afford the minimum required daily energy intake.
- **Lower-bound poverty line** was R810.00 (in April 2019 prices) per person per month. This refers to the food poverty line plus the average amount derived from non-food items of households whose total expenditure is equal to the food poverty line; and

- **Upper-bound poverty line** was R1 227.00 (in April 2019 prices) per person per month. This refers to the food poverty line plus the average amount derived from non-food items of households whose food expenditure is equal to the food poverty line.

Although MHCUs earn a disability grant of R1 600.00 which is rated at the upper-bound poverty line, the grant is usually the only income in a family of about five to eight members. In such a family the grant takes care of the following needs: travelling costs to and from the clinic and hospital for the MHCU and the caregiver; the grant also buys a bag of mealie-meal (staple food) which cost about R776.00, electricity and water about R600.00. Six families live in rural areas where there are limited health and social services. In some instances, caregivers and MHCUs travel long distances to access health care facilities.

The results of the Quarterly Labour Force Survey (QLFS) for the third quarter of 2019 released by Statistics South Africa (2019), reveal that the national unemployment rate is at 29, 1%, and Limpopo Province is at 21.1%. Statistics South Africa Poverty Trends Report shows that the Eastern Cape and Limpopo have remained among the poorest provinces since 2011 (StatsSA Poverty Report, 2019)**.** Therefore, the disability grant is the only income in most families caring for the MHCUs with the expenditure exceeding the income.

- Source of income for caregivers

Of the nine caregivers, one was employed, and another received the government old age pension. The income from disability grants received by MHCUs supplemented the overall family income. However, six families relied solely on the disability grant of their mentally ill member as no other family member was employed. One family had no source of income. Although the MHCU was diagnosed with schizophrenia and was on medication, the medical doctor had not recommended her to receive a disability grant. She was also unable to apply for a child support grant because to her missing identity document. The caregiver was also unable to apply for a child support grant on behalf of the MHCU's because of the lost identity document. In addition, the caregiver could not apply for a grant-in-aid because the MHCU was not recommended for a disability grant. Unfortunately, the caregiver could not look for employment because she had the MHCU to care for 24 hours. Therefore, the family relied on donations from relatives for basic needs. This is evidence of the difficulties endured by families when caring for the mentally ill.

Caregivers qualified for R450.00 grant-in-aid offered on condition that the MHCU receives a disability grant. The amount is payable to caregivers as provided by the Social Assistance Act (Act No. 13 of 2004, Section12). Unfortunately, the caregivers were not aware of this provision, neither were they informed about it by the social workers and other mental health care practitioners.

5.3 Empirical findings

This section presents six themes and fourteen subthemes (Table 5.2) that emerged from data analysis of accounts of MHCUs and caregivers. The identified themes, subthemes and storylines are presented, compared with literature to establish credibility and trustworthiness (Morrow, 2005:250; Cope, 2014:89). The findings are interpreted through the ecological systems approach.

Table 5.2 Themes and subthemes

Themes	**Subthemes**
1: Descriptions of mental illness by the MHCUs and their caregivers	1.1 Understanding of mental illness at its onset 1.2 Understanding of the causes of mental illness 1.3 Reactions to the onset of mental illness
2: Experiences of services provided by the mental health professionals	2.1 Experiences of mental health services provided by doctors 2.2 Experiences of mental health services provided by nurses 2.3 Experiences of mental health services provided by social workers

	2.4 Experiences of mental health services provided by indigenous healing practitioners 2.5 Lack of information sharing by the mental health care practitioners
3: Family caregivers as support systems in the provision of care to their relative with a mental illness	3.1 Caregivers take responsibility to care for MHCUs
4: Caregiving challenges experienced by caregivers	4.1 Non-compliance with treatment 4.2 Violent behaviour by MHCUs 4.3 Burden of caregiving
5: MHCUs' and caregiver's perceptions of the community regarding mental illness	
6: MHCUs' and caregivers' expectations of mental health service providers	

5.3.1 Theme 1: Description of mental illness by the MHCUs and their caregivers

Mental illness is a complex condition for MHCUs and caregivers to understand and describe. They both derive their understanding from their observations and experiences of the illness (Bhattacahrjee et al., 2011:56). The participants explained their understanding of the onset, causes, reactions, treatment, needs, social relationships and recovery relating to mental illness.

5.3.1.1 Subtheme: 1.1: Understanding of mental illness at its onset

The onset of mental illness suggests MHCUs behave in ways not consistent with behaviour that may be deemed normal (Kebede, Alem, Shibre et al., 2003:629; Sigrúnarson, Gråwe, Lydersen & Morken, 2017:1). It may cause confusion to both the MHCU and the caregiver as they may not know what is happening. However, the

MHCUs' and the caregivers' description of the onset of mental illness reflect their awareness, observations and interpretations of behaviour. Five MHCUs were unaware of their unusual behaviour at the onset of their illness. Another two reported having been aware of the discomfort but did not associate it with mental illness. Caregivers, on the other hand, provided different descriptions of the onset of the MHCUs' mental illness as unusual behaviour of someone who may be talkative and destroying property.

MHCU-D	**Caregiver-DD (Sister)**
My sister realised I was unusually talkative without running out of breath, but I was apparently not making any sense. I don't know what else she saw in me, but I was not aware of my actions. She decided to call an ambulance for me, saying "my brother is not well" – I just found myself talking and having a lot of energy. I could see that people were afraid of me. I guess they were afraid I could hurt them (Male, 32 years)	*He started in 2002 showing signs of* [mental] *disturbance by burning his bed and bedding. My understanding is that a normal person will not do such things. I was shocked and asked myself what could be the problem? I was scared – he walked out as I was falling asleep and started cleaning the yard after 3h00. I kept asking myself if he had lost his sleep. He returned and started burning his bed and bedding.* (Female, 30 years)

The accounts show differences in the descriptions of behaviour which suggests differences in their level of awareness. The MHCU's account of the onset of his mental condition seems to support the widely-held notion that people who suffer from mental illness lack awareness of their illness (Rogers & Pilgrim, 2010:243). Although they may be on medication to stabilise the severity of the illness, medical side-effects may maintain the severity. Typically, their behaviour is not always deliberate but influenced by the effects of mental illness on their cognitive functioning (Lysaker, DiMaggio, Daroyanni et al., 2010:304; Dunn et al., 2014:760; Dziegielewski, 2015:158). They are unable to associate their behaviour with mental illness. However, some authors argue that MHCUs may deny their condition (Haslam, Ban & Kaufmann, 2007:135; Sarge & Gong, 2019:446) due to its general association with shame and stigma (Coppock & Dunn, 2010:10). This suggests that the MHCUs may know what mental illness is, and the social effects it has on them. Consequently, the MHCUs are at the mercy of their caregivers to fill their memory gaps regarding the nature of the onset of their illness.

The role of caregivers in filling the memory gaps of MHCUs regarding the onset of mental illness confirmed their awareness based on observations, interpretations and understanding of normal and abnormal behaviour (Fuchs & Steinert, 2004:375; Haslam et al., 2007:130; Coppock & Dunn, 2010:18). Although caregivers may not immediately associate the behaviour with mental illness, they usually suspect that the behaviour is not normal (Hsiao, Klimidis, Minas & Tan, 2006:59; Mayberry & Heflinger, 2013:105). Moreover, the abnormal behaviour is frightening to family members. The caregiver communicated with the MHCU as a family member, and not as a sick person, as she (caregiver) established reasons for his behaviour despite the danger he (MHCU) posed to the family.

Such an observation confirms the view that behaviour is a form of communication (Sharif, Basri, Alsahafi et al., 2020:1) to understand the functioning of individuals and family interactions. It is only when the MHCU consulted with mental health care practitioners that a proper diagnosis was made. However, the MHCUs and the caregivers' accounts of the onset of mental illness remain a key diagnostic requirement for the mental health care practitioners to make a diagnosis (Makgoba, 2017:50).

The onset of schizophrenia is a gradual experience of odd feelings, thoughts, perceptions and a gradual loss of reality for a period of a few months before the actual breakdown (Untu et al., 2015:25; Kafali, Bildik, Bora et al., 2019:315). However, the MHCUs' descriptions of their experiences of the onset of mental illness seem to reflect the active phase of psychosis.

MHCU-E	**Caregiver-EE (cousin)**
The illness started when my neck turned and would not return to its normal position. I was unable to walk; my feet were swinging and my tongue hanging…I started seeing frightening things which attacked me … I was struck by lightning as I entered the gate. I thought they were sending things to me as I saw a lizard touching me. While still shocked, asking myself where the lizard	*I have been with the family since January 2014 (caregiver has been caring for the MHCU for eight months. She does not have the background relating to the onset of the illness).* (Female, 44 years)

came from, the snake in the water wanted to kill me…I saw things, ancient departed people I know. Things crawling on me entering through my nostrils during the night. I heard strange voices saying I must die. One voice belonged to my maternal uncle. I felt pain in my head, an attack inside my nose and heard someone saying I must die. (Male, 31 years)	

The MHCU's account of the onset of his mental condition suggests the ability to perceive, think and articulate experiences of the onset of disturbed behaviour (Scherr et al., 2012:107). The account confirms the cognitive functions of MHCU's to make sense of social processes (Lysaker, Dimaggio, Daroyanni et al., 2010:304). Nevertheless, mental health care practitioners also consider the MHCU's personal accounts when conducting the mental status examination to determine the level of personal and social functioning of the MHCUs (Dziegielewski, 2015:72). Moreover, Feigin (2013:126) advise that hallucinations and delusions may reflect the social and cultural context influencing his perception of illness and health behaviour. However, Wong (2014:133) cautions practitioners against over-reliance on the MHCU's versions as they may be influenced by hallucinations and delusions that are often common among individuals who are diagnosed with schizophrenia. Therefore, the onset of mental illness impacts on the personal and social functioning of individuals.

One of the MHCUs who experienced hallucinations in the form of voices described how she responded to the voices, while the caregiver explained how she responded to her reactions.

MHCU-G	**Caregiver-GG (mother)**
I don't know what mental illness is…I was hearing voices, saying people are going to kill me. I then ran away from home. (Female, 30 years)	*When my daughter jumped through the window with her three months old baby at 01h00 (early hours of the morning), shouting a praise 'masione maila kolobe' (meaning Zionists do not eat pork) as she ran down the road, I realised that she was mentally ill. We* [caregiver and one of the MHCU's siblings] *followed her to*

	my uncle's home… she was just restless and pacing up and down not wanting to sit down. We got a taxi to take her to hospital where she was admitted. (Female, 55 years)

The voices that the MHCU hears seem threatening (Reynolds & Scragg, 2010:122; Mawson, Berry, Murray & Hayward, 2011:256), thus forcing her to escape. The MHCU's experiences are consistent with Merleau Ponty's theory of embodiment that explains the hearing of voices as happening in a context, thus having a meaning to persons experiencing them (Thomas et al., 2004:13; Mawson et al., 2011:257). The illness followed the birth of her child, thus suggesting a postpartum psychosis (Castro et al., 2014:92). Postpartum psychosis is described as representing schizophrenia which is characterised by hallucinations (Bucci et al., 2013:163; Castro, 2014:92; Behrendt, 2016:204). However, the caregiver was not able to link child birth (postpartum psychosis) with the illness. Her immediate reaction was to mobilise family members into action to establish the nature of the problem and provide support.

Although schizophrenia is derived from the predominant medical interpretations of mental conditions (Moagi, 2009:118), Black South Africans use the term 'amafufunyana' or 'mafofonyana' to designate hallucinations, delusions and aggression (Mzimkulu & Simbayi, 2006:418; Bogopa, 2010:1). Moreover, studies caution about the danger that hallucinations may pose to the family and the society at large as they require compliance that may involve violence (Hugdahl, 2009:554; Bucci et al., 2013:163). Just as anyone would react to threats, the MHCU had to run away (Dezecache, 2015:210). However, her escape prompted the caregiver to suspect mental illness especially as the MHCU shouted religious praises for the church leader. Interestingly, the symptoms are consistent with mental illness which Ngubane (cited by Mzimkulu & Simbayi, 2006:418; Bojuwoye, 2013:75) referred to as spirit possession. Both the MHCU and the family were overwhelmed by their experiences which forced them to seek help from the mental health care practitioners. The family reaction is consistent with the assertion by Blanchard, Sayers, Collins and Bellack (2004:106) and Spaniol (2010:485) about the onset of the mental illness as a motivation for mobilisation of family support and other relevant services to ensure the well-being of the MHCU. Similarly, the MHCU's shouting of praises of the church leader, was a cry for help, as she ran through the night to seek refuge at the extended family home. This ability of the family to mobilise support is consistent with the ecological systems framework which views individuals as part of a network of social relationships and resources (Neal & Neal, 2013:722).

In other instances, the MHCUs may not regard themselves as mentally ill despite their behaviour being considered by others as strange (Rogers & Pilgrim, 2010:26). This was evident when one participant did not notice anything wrong with his behaviour but his family associated the same behaviour with mental illness.

MHCU-J	**Caregiver-FF (mother)**
I did not realise I had mental illness. I was not aware of what I was doing. It was only when I arrived here at home from boarding school that family members were able to notice that I was sick (Male, 26 years)	*He started being sluggish and he is still in that condition. It is what bothered him. If anyone talked to him, he would just remain in one place like a statue – just standing still… I then suspected that he was mentally ill* (Female, 58 years)

The findings reveal that a mentally disturbed person is "disconnected from habitual ways of perceiving, thinking, judging and acting" (Soles, cited by Dupret & Quere, 2015:314). The caregiver observed the behaviour of standing still as unusual and indicating that something was wrong with the family member. Although, under normal circumstances, standing still may not necessarily reflect mental illness, the behaviour is a common diagnosis in schizophrenia as catatonia (Wilcox & Duffy, 2015:576; Dupret & Quere, 2015:313). Catatonia refers to a psychomotor disorder characterised by the presence of three of the following symptoms: stupor; catalepsy; waxy; flexibility; mutism; negativism; posturing; mannerisms; stereotypy; agitation; grimacing; echolalia; echopraxia; motor resistance to simple commands; rigidity and repetitive movements (Wilcox & Duffy, 2015:577) (cf. Glossary). The symptoms that the caregiver identified are a stupor, mutism and posturing fit the description of catatonia. This shows that the caregiver knows how family members should conduct themselves under normal circumstances. Therefore, the behaviour was foreign, and prompted the caregiver to start asking questions to ensure that the family stability is maintained.

The 58-year-old mother had to come to terms with the fact that her third son was afflicted with mental illness. The son reported to have experienced the symptoms of the onset of mental illness which was corroborated by the caregiver.

MHCU- F	**Caregiver- FF(Mother)**
I was about 24 years old in 2009 when the illness started. I realised that I had mental illness because of my habit of checking the surroundings before doing anything. I was aware of my behaviour, but I was unable to understand why I was so vigilant. It was only when I felt like I could fly … that I realised that I was suffering from mental illness. I was taken to the hospital for treatment. (Male, 31 years)	*I realised that he was smoking dagga…When he relapses, we call the police without making him aware. If he sees you holding a phone, he would charge at you. We would hide. He was also not sleeping in the house because he was afraid that the police would pounce upon him while asleep.* (Female, 58 years)

A study in the UK found an association between the age of initiation of cannabis use and the age of onset of schizophrenia (Donoghue, Doody, Murray et al., 2014:528). The age of onset of schizophrenia in men has been found to be between 16 and 45 years (Donoghue et al., 2014:528). Unfortunately, the mother of the MHCUs was unable to provide the ages of the onset of their illness. However, her account differs from theirs regarding the onset of the illness. This account confirms the assertion that most individuals with mental illness are cared for in their own homes by lay caregivers with lay understanding of mental illness (Pickard, Jacobs & Kirk, 2003:82; Semrau et al., 2016:2). While acknowledging the professional role as guiding clinical theory, practice, and policy, some authors also describe lay understanding as determining how mental health system, clinicians, and clients interact (Levi & Haslam, 2005:117; Furnham & Telford, 2012:4). Therefore, lay understanding of caregivers influences their help-seeking behaviour for intervention (Haslam, Ban, & Kaufmann, 2007:129; Teh, King, Watson & Liu, 2014:5), thus confirming the assertion of the current study that the family plays an important role in the provision of mental health care. The interdependence of both approaches is confirmed as central to the provision of mental health care.

Mental illness may lead to depression which is common among individuals experiencing the onset of schizophrenia (DSM-5, 2013:102). One MHCU who did not have insight into her condition thought that she was suffering from depression.

MHCU-C	**Caregiver-CC (Sister)**
Initially I did not realise that I was mentally ill, I believed I had depression. I was also telling those I interacted with that I had depression, as I did not accept that I was mentally ill… No, I just saw myself as normal, also controlling traffic in town. I thought I was praying for all those people who were driving cars. Directing those going to Satan to go to him, and those going to God to do so… I did not understand myself. I was doing things, not trusting anybody, regarding my sister as an enemy, wanting to pray for people, and going to pray for them, always screaming fire! fire! I saw her as the one responsible for the things I was doing, as the cause of my illness… (Female, 34 years)	*The day she was sprinkling water in the yard, I got worried…She ran to the street shouting fire! fire! fire! She was saying many things - about people following her, that there are others waiting outside and watching her as she goes to the shops, that they have poisoned her toiletry, and she then asked me to pray. She started telling me she was burning inside her body. That's when we realised there was a problem.* (Female, 38 years)

The excerpts confirm the view that MHCUs with schizophrenia exhibit religious delusions and hallucinations (Grover et al., 2014:119). In such cases, the MHCUs' insight is greatly affected (Woo & Keatinge, 2008:480; Dziegielewski, 2015:155). However, the MHCU's reference to depression may have given her a sense of hope as depression is less stigmatising than mental illness (Bhattacahrjee et al., 2011:58). The denial of mental illness also shows the negative impact the condition has on people especially in a society that perceives and labels such individuals as social deviants. However, people's understanding of mental illness may reflect traditional and religious practices within communities, thus shifting the focus of understanding from the medical model to the social construction of mental illness (Quinn, 2007:175; McCann, 2016:3); for example, certain communities sprinkle water on their homes or places of worship as a traditional or religious practice for protection against evil spirits and witchcraft. Nevertheless, the social stigma of mental illness makes it difficult for the MHCU to accept the diagnosis for fear of social isolation. Denial has thus become a strategy to maintain social acceptance in the midst of suffering from mental illness.

Nevertheless, both the MHCU and caregiver used their common-sense interpretive competence to recognise that there was something wrong with the former's behaviour (Thomas et al., 2007:177; Milbourn, McNamara & Buchanan, 2015:274). This indicates their ability to differentiate between normal and abnormal behaviour. Furthermore, their interaction with the community and mental health care practitioners provided a better understanding of the mental condition.

5.3.1.2 Subtheme: 1.2. Understanding of the causes of mental illness

The understanding of mental illness is still dominated by the medical framework with its emphasis on chemical imbalances as the cause of the illness (Williams & Heslop, 2005:232; McCann, 2016:3) (cf. Chapter Two, Item 2.2.1.1). However, the social model, which considers the experiences of individuals, emphasises the use of cultural and religious perspectives to gain understanding of the causal factors of mental illness (Coppock & Dunn, 2010:8) (cf. Chapter Two, Item, 2.2.1.2). The understanding of mental illness is seen as the outcome of shared experiences and belief systems about health and illness (Swartz, 2004:15; Bojuwoye & Sodi, 2010:283). Such an understanding reflects social narratives that are personally and culturally derived (Castillo & Guo, 2016:225). The participants were able to identify the causes of mental illness, among them, stress, dagga and alcohol, supernatural factors and interpersonal relations. Although stress has become a common expression of normal relations, its extreme form leads to the individual's development of mental illness (Rogers & Pilgrim, 2010:28; Coppock & Dunn, 2010:17) as was articulated in the narratives of both the MHCU and caregiver.

MHCU-C	**Caregiver-CC (Sister)**
I was under a lot of stress, and that made me believe I had depression due to many things that happened to me in life…I started to understand that the stress I experienced had contributed to mental illness. (Female, 34 years)	*I thought it was a personal issue involving the father to her children. She also told the psychologist that I laid a charge with the police against her and this seemed to have hurt her a great deal. It is true that I had laid a charge against her, with the support of the*

	family, because she had severely assaulted a child. (Female, 38 years)

Both excerpts reflect a relationship between stressors and symptoms displayed by individuals diagnosed with schizophrenia (Nordahl et al., 2010:852). Studies found have that exposure to psychosocial stressors contribute to the development of mental disorders (Herzig et al., 2012:2). With regard to the MHCU, the problem was her experience of stress which she attributed to her life experiences. The caregiver, on the other hand, understood the problem to be strained family relations which she attributed to the MHCU's behaviour. Of course, the stress that the MHCU was experiencing could have been the result of strained personal and family relationships (Nordahl et al., 2010:852). Both the MHCU and caregiver have identified psychosocial stressors as responsible for their experiences. Their experiences fit in with the ecological systems approach to understand the impact of the problem on family interactions (Wang, 2011:425; Marek & D'Aniello, 2014:444). They reveal complex and dynamic interpersonal relationships in interaction with their social environment as sources of their psychosocial stresses (Smith, 2016:782). The onset of the MHCU's mental illness was the culmination of their stressful circumstances. Although mental illness is an interaction of biopsychosocial factors, both the MHCU and caregiver attributed the cause to psychosocial factors.

The human immunodeficiency virus (HIV) is another condition that has been associated with the aetiology of mental health problems (Gostin, 2015:687; Adams, Zacharia, Masters et al., 2016:56). The MHCU who became psychotic three months after the birth of her child attributed the cause of her illness to HIV which she discovered following a mandatory test during pregnancy to prevent mother-to-child transmission of the virus (Coetzee, Hilderbrand, Boulle et al., 2005:489; Shirindi & Makofane, 2015:944; MSF International AIDS Working Group, 2017:2). The caregiver heard for the first time about the diagnosis during the course of the research interview.

MHCU – G	**Caregiver – GG (Mother)**
Yes, I'm sick because of HIV. The mental illness started after giving birth to my child. I only knew about HIV when I received the blood test results. (Female, 30 years)	*I will be lying if I should confirm what the cause is. The family just saw her as secretive because she would never tell anything…She was just someone difficult to talk to or advise, but would always complain that I did not love her, that I only loved her two sisters…* (Female, 55 years)

Mental health problems are the most common among people living with HIV (Adams et al., 2016:26). A study in China shows that people living with HIV are vulnerable to mental health problems (Niu, Luo, Liu et al., 2016:2). Additionally, most people become aware of their HIV status following a testing procedure (Sen, Nguyena, Kima & Aguilar, 2017:12). This is consistent with the finding which reveals that the MHCU knew about her HIV status following a blood test. Moreover, the blood test is part of the antenatal procedures to prevent mother-to-child transmission of HIV (MSF International AIDS Working Group, 2017:2). Additionally, the corollary is the MHCU becoming symptomatic on knowing her HIV status, thus aggravating fear of living with an incurable disease, dying from the illness, and transmission of the illness to the child (Burchardt, 2010; Stinson, & Myer, 2012:37). These traumatic experiences may have developed to the level of a post-traumatic stress disorder (Hobfoll, Gaffey & Wagner, 2020:76) at the time of child birth, which she understood as the onset of mental illness.

Moreover, the experiences may have contributed to poor communication within the family. Thus, confirming the view that some individuals diagnosed with HIV tend to experience difficulties in disclosing their status to others (Tayo & Makofane, 2015:487). Additionally, the fear of rejection may have caused her to accuse her mother for not loving her (Ganzer, 2018:14). Therefore, resulting in the deterioration in family relationships as individuals struggle to manage a behaviour they consider as difficult.

MHCU-E	Caregiver-EE (Cousin)
Others say it is dagga…It was dagga, but I have stopped using it when I got sick…The causes of my illness, eeh… is the lizards that I have been talking about. The doctor says it is dagga. I got sick, after I had stopped it (dagga)…I discovered that I can smoke it today and not feel any effect. I'll only start feeling the effects two days later. (Male, 31 years)	*Just the way he (MHCU) explained earlier that he had been seeing things.* (Female, 44 years)

Substance abuse is another factor contributing to the development of mental illness (Resnick, Walsh, Schumacher et al., 2013:2074). Seven male MHCUs confirmed to have used dagga before, during and after being diagnosed with schizophrenia.

MHCU-F	Caregiver-FF (Mother)
They [family members] *were saying "I eat a lot and I'm troublesome. When I find them cooking, I want to have all the food to myself so that others have nothing to eat". That made me think it was dagga because I was smoking dagga. This made me realise I had mental illness…It was when I stopped smoking dagga that I realised my behaviour was an indication of mental illness.* (Male, 31 years)	*He was not born with mental illness. I realised that he was smoking dagga. His father smoked dagga heavily and together with his brother this boy took after him.* (Female, 58 years)

The responses are consistent with a study in North America revealing that the majority of male MHCUs have misused substances before the onset of psychosis (Kamali, McTigue, Whitty et al., 2009:198). Literature also shows that substance use is a common factor in the aetiology of mental illness (Swartz, 2004:227; DSM-5, 2013:105), particularly schizophrenia (Uher & Zwicker, 2017:121). Studies show that the effects of mental illness may impair the MHCUs' cognitive functioning, thus making it difficult for them to link the illness with substance use (Anderson, Frissell & Brown, 2007:71; Albertella & Norberg, 2012:386).

The excerpts show the participants' views about the role of dagga in the development of mental illness (Kamali et al., 2009:198; Albertella & Norberg, 2012:381; Lev-Ran, Imtiaz & Le Foll, 2012:531). The MHCU experienced withdrawal symptoms in the form of hallucinations following cessation of dagga use (Hesse & Thylstrup, 2013:4). Additionally, withdrawal symptoms could predict failure in quitting, thus aggravating a relapse (Maarof, Ali, Bakry & Taha, 2018:156).

However, individuals with mental illness create narratives to explain their experiences that are real to the individual (Price, 2016:3). Wong (2014:133) has found self-reports regarding experiences of mental illness to be unreliable. In support of this view, the findings of this study show that some caregivers were unable to corroborate the MHCUs' experiences. This implies that the caregivers may rely on the information that MHCUs relate regarding their experiences.

Belief systems determine the understanding of mental illness and society's reactions (Quinn, 2007:175; Bartholomew, 2016:110). They determine how mental conditions are defined and the choice of treatment. Most African communities prioritise traditional healing to connect with one's deceased kin in order to get an understanding regarding the causes of mental illness (Bartholomew, 2016:109) as the following storylines illustrate:

MHCU-D	**Caregiver-DD (Sister)**
I don't know what the illness was about, whether it was stress or dagga. In my mind I told myself that maybe it was because we were a family of traditional doctors. I also thought it could be because of the stress I had in relation to people. It could be stress or the ancestors. I just thought maybe my deceased father was complaining about me wherever he was; the way I was struggling as this house was getting dilapidated… I started to understand that the stress I was experiencing had contributed to mental illness. (Male, 32 years)	*He returned from hospital and burned his bed and bedding… during the time he was smoking dagga… Maybe they* [traditional healers] *would be able to tell us if it were the ancestors and what they wanted.* (Female, 30 years)

The MHCU expresses a desperation in trying to understand the cause of the illness. His speculation about the possible causes of his illness points to dagga, stress or ancestors. Both the MHCU and caregiver place their hope on the traditional healers to explain the causes and find the solution to their problems. Interestingly, none of them looks at behaviour change in relation to the environmental factors (use of dagga and stress). The responsibility is left to the ancestors to address the problem. Nevertheless, the MHCU's concern about his condition may be a promising help-seeking behaviour setting him on the road to recovery (Teh et al., 2014:5). Traditional healers are thus sought to provide psychosocial support (Campbell-Hall et al., 2010:612) to promote personal, family and social functioning. This is an affirmation of the role of traditional healers as an integral part in the provision of mental health care.

Environmental factors contribute to the MHCU's mental disturbance (Dziegielewski, 2015:426). All seven male participants reported that they had used dagga prior to the onset of mental illness.

MHCU-B	**Caregiver-BB(Sister)**
It is caused by dagga… When I was building a house with another boy, he placed me under his spell [controlled his mind through witchcraft]. (Male, 46 years)	*On his return home from hospital, he continued to smoke – ooh, he smokes dagga my mother's child!* (Female, 52 years)
MHCU-H	**Caregiver- HH(Mother)**
In fact, I was smoking dagga. We (with friends) were smoking during the day we would smoke four times and, in the evening…I was always cool after smoking…The problem is that somebody mixed dagga with something, or I don't know, that caused my disturbance [mental illness] … It means they (friends) are responsible for my disturbance… (Male, 29 years).	*…as the family, we thought people have done bad things to him - like, bewitching him. When we investigated, we found that witchcraft was not a factor.* (Female, 58 years)

Several studies show an association between psychosis and substance use (Pierre, 2010:598; Mullin, Gupta, Compton et al., 2012:826). However, in some instances, the onset of mental illness is associated with witchcraft thus denying the role of dagga. The supernatural argument is an explanatory model used among most African communities to explain the illnesses (Mpono, 2007:17; Reis, 2013:622; Bartholomew, 2016:109) in relation to "causation, precipitating events and initial symptoms, expected course of the illness as well as treatment options" (Campbell-Hall et al., 2010:612).

According to the authors, “indigenous explanatory models of illness in South Africa incorporate spiritual understanding of causation, including upsetting the ancestors through witchcraft and failing to perform rituals” (Campbell-Hall et al., 2010:612) (cf. Chapter Three, Item 3.2.5).

The MHCUs were able to describe witchcraft as the casting of spells and through poisoning. This attribution of the causes of mental illness to supernatural factors characterised most of the MHCUs and their caregivers’ responses. In support of the explanatory model of illness, Ntsan’wisi (cited by Baloyi, 2014:1) asserts that Africans believe the cause of illness, dying or misfortune is the result of having been bewitched. Larkings, Brown and Scholz (2017:207) show how beliefs may impact on the perceptions of MHCUs about mental illness. A study conducted in Northern Uganda by Reis (2013:622) reveals how the belief in spirit possession and witchcraft strengthen perceptions about mental illness. Therefore, the attribution of causes to supernatural forces tends to exonerate the MHCUs from being an accomplice in causing mental illness through the use of dagga.

The social construction of mental illness as witchcraft has shaped the health perception and behaviour of some individuals, their families and communities (Feigin, 2013:125). This view suggests that witchcraft is a socially acceptable and plausible explanation for illness (Thomas, 2007:279; Campbell, Sibeko, Mall et al., 2017:5). The danger with this narrative is that it tends to shift personal responsibility of MHCU regarding the use of dagga as contributing to the development of mental illness. Moreover, the narrative may interfere with individuals’ logical explanation of mental illness and could inadvertently encourage the continued use of dagga (Trimble, 2010:241).

However, some caregivers confirmed the use of dagga as having contributed to the onset and course of mental illness, thus refuting the supernatural argument held by MHCUs. The caregivers’ understanding of the role of dagga in mental illness shows that support for supernatural factors may not be universal. This means the caregivers may not support the behaviour of MHCUs being perceived as contributing to the development of mental illness.

However, the use of dagga has found universal acceptance for its social and medical benefits and has been legalised in two states of the USA, Spain, Italy, Portugal, Switzerland, the Netherlands, Belgium, Canada and Uruguay (Barry, Hiilamo & Glantz, 2014:207; Warf, 2014:433; Firger, 2017:34). Moreover, in Southern Africa dagga has traditionally been used among Zulu, Sotho and Swazi warriors who smoked “before battle in order to gain energy and self-confidence” (Kepe, 2003:607). In addition, praise singers and diviners believe that the use of cannabis clears the user’s mind (du Toit cited by Kepe, 2003:607). South Africa has gone ahead to legalise the private use or possession of dagga for own consumption (Constitutional Court of South Africa, 2018:52). However, its use has been found to trigger the onset of a psychotic episode in some of the users (Donoghue et al., 2014:528). The availability of dagga may complicate caregiving for the MHCUs who are likely to relapse after its use (Slocombe & Baker, 2015:132; Danzer & Rieger, 2016:31). Interpersonal and family relations as well as social functioning may be disrupted due to the effects of dagga. Although the availability of dagga may serve public interest, its effects may be detrimental to the well-being of some MHCUs. Nevertheless, the caregivers in the current study have confirmed that the use of dagga by the MHCUs exacerbates the development of mental illness.

5.3.1.3 Subtheme 1.3: Reactions to the onset of mental illness

The diagnosis of mental illness can be a devastating experience for an individual and his or her family (Dziegielewski, 2015:151). Schizophrenia is associated with substantial personal and interpersonal distress and life disruptions for the MHCU and the family (Milbourn et al., 2015:271), hence the expressions of shock and surprise as reactions to the realisation of mental illness. The storylines below present the participants’ reactions following their realisation that the MHCUs were mentally ill.

MHCU-B	**Caregiver-BB (Sister)**
I have just found myself among mad people at the hospital. I didn’t ask why I’ve been admitted – I was just shocked to hear that I was mad. (Male, 46 years)	*When he fell off his bed, we* (caregiver and husband) *thought he was drunk as she was taking alcohol. That’s how the illness began.* (Female, 52)

MHCU-H	Caregiver-HH (Mother)
I was just shocked to find myself in the hospital… I never thought I would find myself there. I asked nurses and psychiatrist why it is that others were not right [referring to fellow MHCUs in the ward] and they said because they were patients. I asked myself how I got there, among these types of patients, aah …that meant I was a patient like them… (Male, 29 years)	*We were surprised; we also didn't know what the problem was. He was on duty when he got disturbed.* (Female, 58 years)

The MHCUs may lack awareness of their condition as mental illness (Lysaker, France, Hunter & Davis, 2005:140; Larkings et al., 2017:206). Research shows that most individuals with mental illness are admitted while in an acute phase of the illness and lacking awareness of their circumstances (Oud, Schuling, Slooff et al., 2009:2; Callaly, Trauer, Hyland et al., 2011:221). Hence, the participants were surprised and shocked to find themselves among people they regarded as "mad" in hospital. Although Fitzgerald (2010:229) has found little understanding of the relationship between how individuals comprehend and react to their illnesses, the reactions of the participants suggest their awareness of mental illness. Their awareness that they were among fellow MHCUs might have triggered the reactions and the subsequent awareness of the mental condition (Perkins, Cooper, Abdelall et al., 2010:1072; Schlehofer & Thompson, 2011:194).

Caregivers, like any person including members of the family, may not expect to have a family member suffering from mental illness. Such realisation may be reacted with emotional and psychological disruption of family functioning. The findings relating to caregiver reaction to mental illness are consistent with those from a study by Chang et al. (2016:2) suggesting that caregiver's fear of mental illness has a negative impact on their caregiving responsibilities and social functioning (Conrad & Barker, 2010:67). Such fear may lead to mobilisation of support for the MHCU. Conversely, both MHCUs and family members may find themselves isolated from friends and the public. One MHCU reacted by withdrawing from church activities as he felt stigmatised by church leaders. Equally, the caregiver reacted with shock and disbelief at the behaviour of the MHCU.

MHCU-D	Caregiver-DD(Sister)
I stopped going to church because those prophets [preachers] *go to the hospital to tell me that was sick. When I'm supposed to tell them my real experiences in the church, they are not listening to me, instead they tell me that I'm crazy and sick.* (Male, 32 years)	*I was scared. My understanding was that a normal person would not burn their bed. I was shocked. My mother was still alive at the time and working in Johannesburg (Gauteng) and when she came to see me the damage was already done.* (Female, 30 years)

Mental illness may inadvertently contribute to social isolation (Larkings et al., 2017:206). MHCUs experience public stigma, reflecting negative attitudes, beliefs and discriminatory behaviour (Pescosolido, 2013:1; van Zelst, van Nierop, van Dam et al., 2015:2) leaving them with a devalued social identity (Rogers & Pilgrim, 2010:243). For instance, in Sepedi (indigenous language of the participants), the term *bogaswi* (psychosis, madness) invokes negative reactions due to social perceptions of mental illness. Instead of referring to the illness as *bolwetši bja monagano* (mental illness), the public refers to it as *bogaswi*. The term *bogaswi* (madness) carries derogatory connotations, is disempowering and stigmatising to the ill person (Thomas, 2014:495). Hence, the MHCU withdrew from the public as a way of defending himself from perceived threat (Perkins et al., 2010:1072; Sullivan, Herzig, Mohr et al., 2013:221). However, the caregiver was shocked by the behaviour which she perceived as not normal. Her fear is consistent with the assertion that families of MHCUs "live in constant state of uncertainty due to the unpredictability of the illness" (Stiles, 2013:139). The fear may be exacerbated by the fact that families and community members may not know what harm the person may inflict on them. The worst fear could be the realisation by the family that the person, who is most feared by everybody including the community, need their care. Therefore, the fear of mental illness goes beyond the family system into society.

Some MHCUs experience seasonal outbreaks of mental illness. Seasonal outbreaks of mental illness suggest that the individual enjoys social functioning and better quality of life for a period, and thereafter experiences psychotic symptoms during subsequent seasons (Heering et al., 2015:266). As a result, some MHCUs are subjected to seasonal hospitalisations. One of the caregivers observed and explained seasonal occurrences of her son’s mental illness.

MHCU-J	**Caregiver-FF(Mother)**
I was surprised to find myself at a mental hospital. I didn’t say anything. I was just shocked to find myself there and I asked myself ‘what do I want here?’ I was not able to get the reason why I was in hospital. (Male, 26 years)	*What surprises me is that there is a period (during which) – he was born in May – every year April/May, he starts displaying signs of mental disturbance…* (Female, 58 years)

Environmental factors have an influence on the seasonal occurrence of schizophrenia (Goldinger, Shakhbazov, Henders et al., 2015:2). Such occurrences are labelled differently in different cultures. In Sepedi, seasonal episodes are euphemistically labelled *ditlhare di a khukhuša*[13] which associates the occurrence of mental illness with the budding of trees. However, the descriptions tend to show the occurrence as abrupt and without clear precipitating factors. Seasonal explanations may provide families with cues of an imminent psychotic episodes and help them to observe the MHCU closely for any sign of a relapse. Caregivers may also be able to mobilise resources in anticipation of the MHCU’s relapse. Therefore, the seasonal occurrence plays a significant ecological role in the treatment and management of mental illness.

5.3.2 Theme 2: Experiences of services provided by mental health professionals

Studies show that mental illness is a condition that is difficult for MHCUs and caregivers to comprehend and manage (Wang, 2011:428). Hence a need for the provision of comprehensive services that are accessible, affordable, available, efficient and effective (Hopkins, Loeb & Fick, 2009:927; Nxumalo, Goudge & Thomas, 2013:219). Comprehensive provision of services should consider the ecological systems approach to understand the social environmental needs and strengths of the service users. Both MHCUs and caregivers require the support from mental health

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[4] “*Ditlhare di a khukhuša*” is a Sepedi metaphor which literally mean ‘trees are flowering’ referring to a MHCU who shows the re-emergence or the worsening of psychotic symptoms.

professionals to provide required services. The provision of mental health care is multidisciplinary to provide a continuum of care from admission to discharge and aftercare (Mcneil, Mitchell & Parker, 2013:291). Professionals involved in the provision of mental health services include psychiatrists who diagnose and prescribe medication, psychologists who offer psychotherapy, occupational therapists who offer vocational skills training, psychiatric nurses who implement and monitor treatment programmes, social workers who offer individual and family intervention with the MHCUs and their relatives, and traditional and religious practitioners who offer healing (Rogers & Pilgrim, 2010:138). This section focuses on how the MHCUs and caregivers experienced services provided by mental health care practitioners.

5.3.2.1 Subtheme 2.1: Experiences of mental health services provided by doctors

MHCUs are usually referred to hospital by their caregivers for treatment of mental illness. Medication is offered as the treatment of choice for schizophrenia to reduce the severity of the symptoms (Wand, 2013:116; Danzer & Rieger, 2016:33). Psychiatrists determine the diagnosis, prognosis and prescribe treatment to alleviate the severity of the symptoms and to some extent relieve caregivers of the burden of caregiving. They work with medical practitioners and psychiatric nurses who conduct preliminary assessments, prescribe medication and recommend admission in the absence of the psychiatrist during admissions (Rogers & Pilgrim, 2010:145; Wong, 2014:136). It must be noted that MHCUs and caregivers are not able to differentiate between medical practitioners and psychiatrists.

Psychotherapy is provided by psychologists when the MHCU has recovered from the acute state of the illness. Family intervention and support services are offered by social workers to help caregivers to fulfil their caregiving responsibilities (Reed, Apedaile, Hughes & Ormerod, 2013:33). However, chronic under-resourced facilities may compromise effective provision of mental health care, thus leaving both MHCUs and caregivers dissatisfied with the services offered (Lund, Kleintjes, Kakuma & Flisher, 2010:393). Moreover, the quest to provide the person-in-environment comprehensive services is thus compromised (cf. Chapter Three, Item 3.2.2). Seven MHCUs and their caregivers shared their experiences of services provided by doctors. Six MHCUs and their caregivers were informed by medical doctors that they had mental illness, while one and her caregiver consulted a private medical doctor (in a private practice) who informed them that the body pains and stroke caused the illness.

Some MHCUs experience co-occurring physical health conditions caused by multiple factors: substance abuse, poor diet, and side effects of medication. Historically, individuals with mental illness have described themselves as suffering from nervous breakdown (Gove, 2004:358; Carpenter-Song, Chu, Drake et al., 2010:232). Schizophrenia as a diagnostic construct inferred from behaviours performed or symptoms reported by clients, conjures up the belief of a condition existing in reality, more exactly, a physical disease occurring in people (Wong, 2014:132). MHCUs have to undergo physical assessment to determine the effect of physical ailments on the mental condition. The mental disorders that result from physical ailment are elements of a comprehensive and holistic biopsychosocial assessment to establish the existence of physical causes including infection, autoimmune response, injury, or other potential causes (Harkness, 2011:227). Hallucinations and delusions as major features of schizophrenia are limited to thought processes with no physical association that can be used to corroborate them (Wong, 2014:133). Therefore, assessment of physical conditions provides the mental health professionals an opportunity to determine causes of mental disorders and suitable interventions to mitigate the problem. Nevertheless, the MHCU and caregiver seemed to support the diagnosis that the doctor provided.

MHCU-A	**Caregiver-AA (Sister)**
The doctors told me the problem was my body. (Female, 72 years)	*She was always numb and I took her to a private doctor who performed X-Ray on her and found that she suffered an internal stroke which caused her disorientation and weakness when talking to her - you see, it is how the doctor explained.* (Female, 74 years)

Individuals with mental illness tend to report their experiences as physical conditions affecting their social and occupational functioning (Onyeka, Høegh, Eien et al., 2019:192). Although some mental conditions may happen without the existence of a physical condition, physical conditions may exacerbate them (Dziegielewski, 2015:171). As the findings show, the caregiver observed the MHCU as suffering from a physical condition which was medically confirmed as a stroke. Moreover, the mental status examination (MSE) includes physical assessment to determine any interaction between the mental and the physical conditions (Norris et al., 2016:640). The MHCU and caregiver play a role during the MSE by sharing the history of the illness with a team of practitioners (Dziegielewski, 2015:172). In certain instances, the symptoms resulting from a physical condition (e.g. stroke) may be similar to mental conditions in the form of delusions and hallucinations (Gras, Swart, Slooff et al., 2015:299). This explanation supports the MHCU's and caregiver's observations of the physical aspects of the illness. Therefore, the importance of interactions between professionals and caregivers in determining the diagnosis and treatment of mental illness was made apparent.

MHCU-B	**Caregiver-BB (Sister)**
I was told at the hospital by the doctor that I am mad. (Male, 46 years-old)	*As he got sick* (mentally ill), *the doctors said to my mother the way this person behaves, he is sick* (has mental illness). (Female, 52 years)

Caregiver-CC (Sister)
The doctors said she was mentally ill. (Female, 38 years)

MHCU-G
It was the doctor at the hospital that said I had mental illness. (Female, 30 years)

The findings reveal that the MHCUs and caregivers have interacted with the medical practitioners during the treatment process. Doctors communicate a diagnosis of schizophrenia to MHCUs and their caregivers once a diagnosis had been established based on the ill person's behaviour (Outram, Harris, Kelly et al., 2014:552). Outram et al. (2014:551) are of the view that the sharing of diagnostic information helps individuals with schizophrenia to "adapt to their illness, providing explanations for symptoms experienced, facilitating access to medical resources and enabling them to participate knowledgeably in their health care”. Moreover, the MHCUs will be able to comply with medication and caregiving to strengthen and promote recovery (Chen, 2008:1556; Mahaye, Mayime, Nkosi et al., 2012:611). Thus, caregiving becomes enhanced while promoting partnership between doctors and caregivers in the provision of mental health services (Baillie, 2016:42). Therefore, the interaction between the doctors and families confirms the importance of the latter in fostering information sharing about the illness and caregiving.

5.3.2.2 Subtheme 2.2: Experiences of mental health services provided by nurses

Nursing care is the first service that MCHUs receive in hospitals, clinics and communities, and is available around the clock. Historically, nursing has been experienced as a ‘jack of all trades’ profession due to the multitasking roles of providing medical care, counselling, rehabilitation programmes and community-based health services (MacNeela, Scott, Treacy & Hyde, 2010:1299; Fung, Chan & Chien, 2014:698). Hence, nurses form part of the multidisciplinary mental health team involved in the provision of mental health care. The MHCUs and caregivers shared their experience of the services provided by nurses.

MHCU-C	
The nurses at the hospital told me that I had mental illness while I continued to deny it. (Female, 34 years)	
MHCU-F	**Caregiver-FF (Mother)**
Those who have been helpful with their encouraging words were sisters (nurses) who wished to see me one day buying grocery for my mother, having a wife and my mother having a daughter-in-law. (Male, 31 years)	*Nurses advised me to call the police to help me restrain him (MHCU) without making him aware.* (Female, 58 years)
MHCU-G	**Caregiver-GG (Mother)**
I only knew about it (HIV status) *when I received the results of my blood test. The test was done by a nurse at a clinic. I was*	*The nurses at the clinic confirmed she had mental illness…They gave us a date to visit, we are taking her (MHCU) for injection on 08/04/2014 and pills*

required to do a blood test as I was pregnant. (Female, 30 years)	*(medication) on 17/04/2014. She (MHCU) goes to the clinic every month.* (Female, 55 years)

Nurses are among professionals assisting MHCUs and families to receive the required mental health care (Scott, 2008:405; Fung, Chan & Chien, 2014:698). Such a role is clearly articulated at the primary, secondary and tertiary level of nursing care. In the United Kingdom (UK) community mental health nurses providing primary health care are said to be the largest professional group providing mental health care at the community level (Coffey & Hewitt, 2008:1592). This is also the case in South Africa which has integrated community mental health services within the primary health care system to monitor MHCUs' compliance to medication (WHO, 2008:146; DoH, n.d:8). Rural communities in South Africa benefit from services offered by the primary health care nurses who, due to lack of general practitioners, function as mini doctors responsible for diagnosing and treating common illnesses, and monitor compliance with medication (Mavundla, Toth & Mphelane, 2009:358; Braathena, Vergunsta, Mjic et al., 2013:41). Their primary health nursing care enables them to identify relevant referral professionals as well as the police, social workers and psychologists for the MHCUs and families to receive required services.

The provision of mental health care requires mental health professionals to conduct themselves with integrity towards those they serve (Wahl & Aroesty-Cohen, 2010:49). However, not all caregivers were satisfied with the services provided by some nurses. One caregiver was unhappy with the fact that some nurses implicated her brother (MHCU) in criminal activities within the hospital.

Caregiver-II (Sister)

After he was admitted at a mental hospital, some nurses gave him dagga to sell, and he was thereafter accused by the hospital authorities while the nurses, who are supposed to be the main culprits, were not accused. (Female, 26 years)

MHCUs are vulnerable and may be taken advantage of by professionals who "tend to use their power to blame MHCUs for transgressions they may not have committed" (Rogers & Pilgrim, 2010:234). They become helpless and refrain from involvement in shared decision making (Berry, Danaher, Beckham et al., 2017). Studies conducted in South Africa have found that “a significant number of nurses held negative and stereotyped perceptions of mental health care users” (Kakuma et al., 2010:117). The misconduct of the professionals may increase the MHCUs’ risk of relapse which is contrary to their professional training that they should promote recovery from mental illness (Kazadi, Moosa & Jeenah, 2008:52; Wahl & Aroesty-Cohen, 2010:49). Nevertheless, not all nurses behave in ways contrary to their ethical code of practice. The *Bathopele* principles require practitioners to enter into and strive for partnerships when offering services to the public. However, the influence of the medical model on mental health care tends to perpetuate power differentials of the expert-patient type relationship, thus rendering the practice of *Bathopele* principles and partnership impossible. Therefore, the MHCUs are placed in a paradoxical relationship demanding them to willingly accept behaviour that is forced on them, as they are blamed, and are not believed, because ‘they are mentally ill’.

5.3.2.3 Subtheme 2.3: Experiences of mental health services provided by social workers

Social work services are based on integrated systems approaches focusing on individuals, families, communities and their social environment (Payne, 2014:185). The approaches that guide social work assessment and intervention include ecological, bio-psychosocial, cognitive, family-centred, developmental and strengths-based to promote recovery, resilience and social justice (Pillai & Parsatharathy, 2014:71; Jenson, 2014:564; Rani, 2015:445). Social work practice examines the transactional relationships among individuals, families, communities and their social environment (Tew, 2011:123; Friedman & Allen, 2014:17). The understanding is that problems in social functioning result from stressful life situations. The intervention should be comprehensive to address the rights and social justice involving individuals (MHCUs) and families (MHCU, caregiver and family members) to strengthen interpersonal relationships and family functioning (Parikh, 2015:244).

Social workers are part of the mental health professionals providing social work services to MHCUs and their families. They provide services in both hospital and community settings. The services involve conducting psychosocial assessment of concerns about and the impact of mental illness to determine the personal, family and social needs of MHCUs, caregivers and families in order to guide intervention (Davidson et al., 2016:160). The intervention may include referral for more specialised services in consultation with other mental health care practitioners (Webber, Reidy, Ansari et al., 2016:14; Llenas & Gijarro, 2016:1). The intervention may happen within the hospital and at the homes of the MHCUs strengthening their capacity through building relationships, gaining community access and acceptance, and creating networks and resources (Jenson, 2014:564). MHCUs and caregivers shared different experiences of social work services. Of the ten MHCUs four had contact with social workers when they were admitted to hospital. Of the ten MHCUs four had contact with social workers. The storyline below illustrates the point expressed:

MHCU-F

> *I had a meeting with social workers in the presence of family members. We were discussing the type of life I'm living which was not the right one – taking money forcefully from people, is causing trouble. The social worker told me to become an exemplary in the community, and that a person with mental illness is able to become stable if he behaves and take medication".* (Male, 31 years)

MHCUs and their families benefit from social work practice that provides psychosocial interventions to promote family functioning and access to social services (Lombard, 2008:167; Moloto & Matsea, 2018:143). Social work uses case management to ensure that the services provided are comprehensive to address the challenges experienced by individuals, families and communities (cf. Chapter Two, Item 2.3.5). Case management as a form of interprofessional practice brings together a range of specialities for effective comprehensive delivery of services (Mcneil et al., 2013:291). The researcher worked in a mental health hospital and within communities where case management principles were not applied. For example, MHCUs, caregivers and families were rarely referred for social work services. However, for social workers to provide services, referral between mental health care practitioners must take place. In this study five MHCUs reported to have had contact with social workers. Their caregivers had no contact with the social workers and, therefore, could not corroborate the claims made by MHCUs.

MHCU-E	**Caregiver-EE (Cousin)**
Social workers were also there [hospital] *assisting me. We were just talking, talking, talking…I can’t remember what we were discussing.* (Male, 31 years)	*There has been no contact with social workers at the hospital and here at home.* (Female, 44 years)
MHCU-H	**Caregiver-HH(Mother)**
I can’t remember who, among the health practitioners - nurses, doctors, social workers, helped me. (Male, 29 years)	*There has been no contact between the family and the mental health care practitioners - nurses, doctors and social workers. None of the mental health care practitioners has visited our home.* (Female, 58 years)
MHCU – J	
It was when my mother visited me in hospital that she would take me to social workers to talk to them… I can’t remember what we discussed. (Male, 26 years)	

The findings are consistent with those from the study conducted in Turkey titled “theory of mind and unawareness of illness in schizophrenia: is poor insight a mentalizing deficit?” to examine cognitive functions of MHCUs which found that cognitive deficits affect their ability to comprehend what was communicated to them (Bora, Sehitoglu, Aslier et al., 2007:104). Studies have found different factors affecting the cognitive dysfunctions for instance, aging (Bailey & Gordon, 2016:225) and severe mental illness (Ho, Moore, Davine et al., 2013:882) which affect attention/information processing, problem-solving, and insight (De la Torre, Perez, Ramallo et al., 2016:221). Moreover, even though the information might have been shared with MHCUs, they would not comprehend and may therefore not remember the information due to the severity of their conditions. However, it was worrying that some caregivers did not have contact with social workers. One possible explanation for the lack of contact could be inadequate staffing which has dogged the social work profession for many years and resulting in huge caseloads (Lombard, 2008:164; Shokane, Makhubele, Shokane & Mabasa, 2017:279). For instance, the WHO-AIMS Report on Mental Health System in South Africa shows that the total number of social workers is 0.4 per 100,000 of the population (WHO & Department of Psychiatry and Mental

Health, 2007:6). Another possible explanation could be poor case management within the mental health system as a barrier to the provision of comprehensive mental health care due to lack of coordination, collaboration and cooperation among the mental health care practitioners (Outram et al., 2015:352). Hence, the need for the involvement of caregivers through partnership to serve as the link between the MHCUs and the social worker.

Social workers apply the PIE approach in different settings including hospitals and communities. Community-based services include psychosocial interventions focusing on direct services to individuals and family, and promotion of social support networks. However, the services are inaccessible to caregivers. Two caregivers explained their interaction with hospital-based social workers who visited their homes.

Caregiver-GG(Mother)
The hospital-based social worker visited us once to know the home while she (MHCU) was still at the psychiatric hospital. She wanted to know how the family is managing. She took notes like you (researcher) are doing now. (Female, 55 years)

MHCU-I	Caregiver-II (Sister)
I only met them (social workers) while I was still admitted in hospital- The reason for seeing me was because I was not going to the hospital for treatment, but now I go. (Male, 28 years)	*We had to go to the social workers (hospital-based) to complain that whenever we brought the MHCU to hospital, doctors would refuse to admit him claiming he was not sick.* (Female, 26 years)

The findings suggest that hospital-based social workers have an opportunity to interact with the MHCUs in and outside the hospital settings to address problems affecting the personal, family and social functioning. Such problems may include defaulting on medical treatment which is a common contributor to relapses and social dysfunctions. The common techniques used include case management, individual and family intervention and networking to enhance the social functioning of the affected (Ward, Smith, James et al., 2011:4; Pillai & Parsatharathy, 2014:71). Additionally, the social worker advocates for the interests of MHCUs by serving as a link between the family and other practitioners to improve the provision of mental health care.

Social workers apply the PIE to interact with individuals within their social environment (Shor & Shalev, 2014:69; Makhubele, Matlakala & Mabvurira, 2018:99). Hence, they conduct home visits to establish their circumstances, clarify the diagnosis of the MHCUs and address their psychosocial needs (Rapp, Van Den Noortgate, Broekaert & Vanderplasschen, 2014:606; Dziegielewski, 2015:72; Mohamed, 2016:13). Strengths and challenges of the MHCU, caregiver, family and community are assessed and recognised (Seloilwe, 2006:262; Tung & Hu, 2010:479). Families in rural communities may need assistance with transport to take the MHCU to hospital, but transport costs may be a barrier. However, not all caregivers were satisfied with the services offered by hospital- and community-based social workers.

MHCU-B	**Caregiver-BB (Sister)**
Hospital social workers said they were going to phone home…. (Male, 46 years)	*One day I went to the social worker at the hospital to request transfer of my brother* (MHCU) *at a psychiatric hospital. She would not assist me because I lived outside her area of work. She suggested I go to the local* (community-based) *social worker in my area. I then told her that I had approached her office as the records of the MHCU were in the hospital …You will wait for social work services while the girls (referring to social workers) are just sitting and not attending to us. You just say I guess this is how things work here. I felt discouraged when they referred me to the local social workers.* (Female, 52 years)

MHCU-B	**Caregiver-BB (Sister)**
Hospital social workers said they were going to phone home…. (Male, 46 years)	*One day I went to the social worker at the hospital to request transfer of my brother* (MHCU) *at a psychiatric hospital. She would not assist me because I lived outside her area of work. She suggested I go to the local* (community-based) *social worker in my area. I then told her that I had approached her office as the records of the MHCU were in the hospital*

	…You will wait for social work services while the girls (referring to social workers) are just sitting and not attending to us. You just say I guess this is how things work here. I felt discouraged when they referred me to the local social workers. (Female, 52 years)
MHCU-D	**Caregiver-DD(Sister)**
The social workers wanted to have a family interview with me and my sister…The doctors had informed me they were waiting for my sister for a family consultation with social workers. They never told me what we were going to discuss with social workers. They just said our problem required social workers. I think this was because I had told them that my sister was impatient with me. She just called an ambulance without establishing what the problem was with me. That hurt me a lot. It is the one that made me stay long in hospital. *My younger brother went to a circumcision school without me. I was supposed to take him to circumcision school. I was not able to participate in his circumcision rituals as I was in hospital. I was not there when he came back from the circumcision school. Anyway, the meeting with social workers never happened. I never had an opportunity to talk to my sister, and I'm now back at home. Local social workers never visited me at home.* (Male, 32 years)	*We never met with social workers as family (MHCU and myself). I only heard from MHCU that we were required to meet them. None of the mental health care practitioners visited the family…I don't think of approaching the mental health care practitioners for assistance because the MHCU once consulted a social worker who was never available. I went to the hospital as I had received a letter inviting us to see the social worker, he or she was not there to see us. But things had remained stable since then. The last time we had disagreements was in January (2014).* (Female, 30 years)

The dissatisfaction of MHCUs and their relatives about social work services have been expresses in the study by Mills (cited in Rogers & Pilgrim, 2010:243) who found that users of services preferred non-professional services to social and health professionals. Families approach social workers when they need assistance with access to services (Ahmed et al., 2018:106). They expect social workers to understand their circumstances and to provide relevant information and assistance (McFarlane, 2016:461). The findings therefore suggest that social workers for some reason failed to offer required services which should be accessible, affordable, comprehensive and acceptable to MHCUs, their families and communities (Gergen, 2015:409). Their services should be guided by the PIE approach and the *Bathopele* principles (that are consistent with those of social work) to improve caregiving capacity.

The fact that families feel unsupported may increase caregiver burden and cause family dysfunction in certain situations (Yusuf, Nuhu & Akinbiyi, 2009:43; Outram et al., 2014:10). However, a study by Dlamini and Sewpaul (2015:469) show that in South African social workers contend with lack of resources, poor working conditions, high caseloads, bureaucratic control, lack of professional autonomy, political interference in practice and the erosion of the legitimacy of the profession which may contribute to provision of poor services. While acknowledging these constraints there is an appeal to social workers to depart from doing "what they're trained to do and serve on the basis of the needs of people with mental health problems" (Sawyer, Stanford & Campbell, 2016:129). The plea requires social workers to address the impact of stressors on family functioning, support networks and their social consequences by targeting family interactions and larger psychosocial systems to bring relief to the family (Faust, 2008:294; Becvar & Becvar, 2009:281; Greenfield, 2011:531).

5.3.2.4 Subtheme 2.4: Experiences of mental health services provided by indigenous healing practitioners

MHCUs consult indigenous healing practitioners, with the help of their family caregivers to establish the nature of the problems they are experiencing. Indigenous healing practitioners (including diviners, herbalists and faith healers) provide alternative culturally embedded system of healing (Campbell-Hall et al., 2010:611). In South Africa, indigenous practice is legally recognised and is regulated in terms of the Traditional Health Practitioners Act (Act No. 22 of 2007). Most African families consult indigenous healing practitioners for a variety of health conditions, including mental disorders (Sorketti, Zainal & Habil, 2011:209; Bartholomew, 2016:111). Research conducted in South Africa in 2009 reveals that MHCUs with DSM-IV diagnosis consulted Western (29%) or (20%) alternative practitioners (9% traditional healers and

11% faith healers) (Sorsdahl et al., 2010:592). Indigenous healing systems form part of the environment however, the MHCUs and the families may or may not use them.

In this study, both MHCUs and caregivers consulted traditional or faith healers prior or when they were suffering from different illnesses. Of the ten MHCUs, four reported to have been taken to traditional healers, two consulted both traditional and faith healers, one consulted only a faith healer while another contemplated seeing a traditional healer.

Caregiver-AA(Sister)

As a family, when my father was still alive, we took my sister to traditional and faith healers so that she got better. Other family members said it had to do with ancestors, but she did not get better. Things got better when she started going to the hospital after three years of treatment by traditional and faith healers. (Female, 74 years)

The finding confirms the outcome of studies suggesting that most African families in South Africa use both indigenous and public sector Western systems of healing for mental health care (Quinn, 2007:175; Campbell-Hall et al., 2010:611). Studies have found that people consulting traditional healers attribute the cause of mental illness to supernatural forces (Quinn, 2007:175; Laher, 2014:193). Traditional healers in South African are the first contact for treatment and are readily available to communities in need of mental health services (Meissner cited by Campbell-Hall et al., 2010:612). Although MHCUs may not choose their preferred practitioners, they are always accompanied by a caregiver to consult a healer (Rogers & Pilgrim, 2010:243).

The role of indigenous healing may suggest the influence of socio-cultural factors and belief systems which are consistent with the social model to mental illness (McCann, 2016:4). In terms of this model, social factors contribute to the aetiology of mental illness, and families use their belief systems to explain such causes in supernatural terms, thus requiring intervention from traditional and faith healers (Zingela et al., 2019:149).

The MHCUs share the views with members of the society regarding the role of traditional healers as mediators between the family and ancestors to establish the reasons for mental illness (Bogopa, 2010:1).

Caregiver-DD(Sister)

I always wish that we could take him somewhere - to the indigenous healing practitioners for healing, to hear what the problem is. If it is the ancestors, then explain to us what they want. …Even the hospital doctors are not saying what the problem is, and this creates a feeling that the traditional doctors would be able to tell us what the problem is. (Female, 30 years)

MHCU-H

The family took me to a Pedi doctor [traditional healer] *who told my sister that the zol* [cannabis cigarette] *I smoked was poisoned by someone and that is the reason I got mentally ill.* (Male, 29 years)

Traditional healers mediate between the ancestors and families regarding the latter's challenges (Burns & Tomita, 2015:867). The findings show that families consult traditional healers when they believe supernatural factors are involved in the aetiology of mental illness and deteriorating family conditions (Grover et al., 2014:120). Families may consult traditional healers prior to the relative with mental illness receiving hospital treatment, while some would consult if they are not satisfied with hospital treatment. They invoke the role of ancestors on the understanding that they (ancestors) may unleash supernatural powers when angered by the behaviour of the person or family (Mzimkulu & Simbayi, 2006:419; Bogopa, 2010:1). However, the diagnosis by traditional healers may support or dispute the family's understanding of the causes of mental illness.

Reference to supernatural factors reflect belief systems attributed to mental illness and reveal their socio-cultural constructions (Thomas, 2007:279; Conrad & Barker, 2010:69) which both MHCU and caregiver share to make sense of their experiences (Coudin, 2012:25). However, in the Western diagnostic system, the MHCU would have been described as showing persecutory delusions for suggesting that witchcraft is the cause of his mental illness (Dziegielewski, 2015:155).

One of the components of indigenous healing is faith healing (Burns & Tomita, 2015:867). Religion and spirituality shape peoples' perspectives and guide the development of values, moral reasoning and conscience (Chandler, 2012:577).

Families consult faith healers for the treatment of their relative with mental illness as they belief that they could be helped through prayer as illustrated below.

MHCU-C	**Caregiver-CC(Sister)**
I just regarded myself as normal and visualised myself controlling traffic in town. I thought I was praying for all those people who were driving in their cars, those going to satan to go to him, and those going to God to go to him, separating them from one another. (Female, 34 years)	*[On my way back from a friend's home*] *my sister, phoned to inform me that the MHCU ran to people's houses, shouting fire! fire! ... I went to the house (where she had run to) and the street was full of onlookers staring at her with shock. That's when we realised there was a problem. We then brought her home. On arrival, she was saying many things, that people are escorting her, there are people waiting outside and watching her as she goes to the shops, they make sure she gets home; that they have poisoned her toiletry with their things, and asking me to pray for them which I promised to do. I prayed with her, and she started telling me she was burning inside her body… I then said we should go to church as there was a marquee hoisted in the vicinity...* *It was an all-night prayer service. We entered the church and they prayed for her, then we came back home to sleep… She demanded that we should go back to the church so that they could pray for me to get married and have a child; and saying "things that are on earth, are not real but fake. I want to get real things for the family".* (Female, 38 years)

Caregiver-HH(Mother)
We were always taking him to church, and the congregation would pray for him. He also understood that he was going to church for prayers regarding his mental condition. He is no longer going to church. (Female, 58 years)

The findings resonate with those from a study by Grover et al. (2014:119) explaining the role of religion and spirituality in mental illness. However, their convictions were divergent in that the MHCU's were characterised by delusions (Grover et al., 2014:120). Although research shows the difficulty of distinguishing between religious and psychotic experience (Grover et al., 2014:120; DeHoff, 2015:22), the caregiver could notice the delusional character of the MHCU's religious expressions (Swartz, 2004:87; Chandler, 2012:580): wanting to pray for her to get married, have a child and wealth. The caregivers regard the church as a support system and that prayers may heal those who are mentally ill.

Apparently, not all individuals with mental disorders are satisfied with the treatment administered by indigenous healing practitioners as the following excerpts reveal.

MHCU-E	**Caregiver-EE(Cousin)**
The family secured R3 500 to take me to a Pedi (traditional) healer who failed to help me. He told me to take medication that was prescribed by a doctor (medical) at the hospital to recover… *He gave me muthi which rendered me ineffective when I had sex. I was not cured, I just felt better. Those things (lizards) cannot be cured…he (traditional healer) came to treat me in my bedroom on his last day. He placed 'muthi' all around the house (to remove spells). …. he continued to throw his bones on the floor to diagnose my condition. He said it was 'nzonza' (a snake) - that makes me mad. That it is going to make me fight with people… It is true I fight everybody. I'm no longer sure when I'm going to recover… The traditional healer could not stop the lizard. He gave me muthi and instructed me to use it. The following day, I just found myself turning things around, and hurting my mother.* (Male, 31 years)	*The family has trust in medication and the church (Roman Catholic church); his mother took him there most of the time.* (Female, 44 years)

MHCU-J	**Caregiver-FF(Mother)**
My father took me to a Shangaan traditional doctor to confirm that I was sick. He told my	*It is the time when their father was still alive. He was smoking dagga and*

father that I was not seriously sick and that it was because I smoked dagga and cause trouble. He said he could help me…I just said no I couldn't see what I was doing…My father wanted to abandon me at traditional healer's home. (Male, 26 years)	*these children took after him.* (Female, 58 years)

Individuals with schizophrenia can provide "verbal accounts of the sensations they claim to have experienced" (Wong, 2014:133). However, their report may be riddled with denials of the illness or a muddled psychotic narration of their experiences (Wang, 2011:426; Wong, 2014:133; Cella, Hamid, Butt & Wykes, 2015:233; Sarge & Gong, 2019:446). Although such narratives may suggest poor insight (Nederlof, Muris & Hovens, 2013:188), they are an expression of a social narrative explaining the traditional healers and supernatural factors as an integral part of the mental health system (Thompson, 2013:220). However, the caregivers were unable to corroborate their claims. The only caregiver who confirmed the use of dagga by the MHCUs claimed that the children (MHCUs) learnt the behaviour from their heavy dagga-smoking father. The narratives explain social environment (Friedman & Allen, 2014:10) influencing the MHCU's behaviour. It appears that communities that sanction the use of dagga for medicinal purposes may not be convinced that it (dagga) causes mental illness. Unfortunately, some caregivers have to endure the burden of caregiving as a result of the MHCU's abuse of dagga, which has been found to be among the leading causes of mental illness.

5.3.2.5 Subtheme: 2.5: Lack of information sharing by the mental health care practitioners

MHCUs and their caregivers are entitled to information from mental health care practitioners regarding the nature of the illness, diagnosis and treatment (Makgoba, 2017:64). Information sharing is a basic human rights requirement through which the MHCUs consent to treatment in terms of the Mental Health Care Act (Act No. 17 of 2002). Partners involved in information sharing are regarded as experts among themselves (Shepherd, Shorthouse & Gask, 2014:1). This means practitioners must share information about the illness and the type of treatment offered. However, MHCUs may lack the capacity to follow explanations about the nature of their illnesses due to the severity of symptoms. Therefore, such information can be shared with caregivers as they have the responsibility to consent on behalf of their mentally ill relatives. Seven MHCUs and their caregivers reported that practitioners did not share information with them regarding the illness, while the remaining three and their caregivers shared the information.

MHCU-D	**Caregiver-DD(Sister)**
There were so many doctors and they didn't even tell me what the problem was… all they did was to change my treatment everyday – 8 or 9 times…They warned me to never smoke, even my siblings will tell you I no longer smoke dagga, I hate it a lot – it is not good for me. (Male, 32 years)	*Doctors, even those at the mental Hospital, did not say what the problem is. So, I don't know what his problem is. They only asked questions about whether he was still smoking dagga, or tobacco or drank alcohol. I told them that he was longer doing that, and they kept quiet... I asked doctors what they had found to be the problem. They said I must ensure that he took his medication. I kept on asking what the problem was, but they did not respond. They are supposed to say what the problem is, but they are unable to do so. This is the problem we experience with doctors.* (Female, 30 years)

Caregiver-FF(Mother)
The doctor did not explain the cause of their illness to me but only asked whether there was any family member who suffered from mental illness... I explained that those I grew up with did not have mental problems. (Female, 58 years)

MHCU-J	**Caregiver-FF(Mother)**
The doctors never explained to me about my illness. I never asked. (Male, 26 years)	*His main problem was not explained but another doctor would always reprimand him saying "you don't want to go to school, you must be in jail to be with your friends there, then you will come to your senses".* (Female, 58 years)

Similar findings were reported by Outram et al. (2014:551) in Australia showing the reluctance of practitioners to share information with MHCUs and their caregivers. This reluctance was explained by Rogers and Pilgrim (2010:243) based on the view that MHCUs lack insight into their condition and, therefore, incapable of giving a valid view.

However, the MHCUs may have been in an acute state of illness that made communication and understanding difficult (Dunn, Sinclair, Canvin et al., 2014:760; Dziegielewski, 2015:158). Hence it would be difficult to determine whether the mental health professionals explained the diagnosis to them or not (Wong, 2014:137).

Moreover, the caregivers have also corroborated the claim that the practitioners have not provided information to them and the MHCUs about the nature of the illness. Although family caregivers may have the ability to understand the diagnosis, practitioners may perceive them as sharing the same pathology as MHCUs (Rogers & Pilgrim, 2010:244). In addition, Lebow's (cited by Rogers & Pilgrim, 2010:243) has observed that medical doctors tend to dismiss families as naïve about treatment of their relatives with mental illness. Such negative attitudes were found to create a barrier to effective communication with caregivers (Marquez & Garcia, 2011:63; Rowe, 2013:24), thus discouraging caregivers from approaching service providers for support.

The traditional doctor-patient relationship can also be a constraint that can limit the interaction with relatives of MHCUs (Chen, 2008:1556; Solomon et al., 2012:98). Equally, practitioners are bound by the principle of confidentiality which restricts the sharing of information without consent (Chen, 2008:1556; Chan & O'Brien, 2011:387; Rowe, 2012:22). Although confidentiality is beneficial in protecting and respecting the constitutional rights of MHCUs, Chan and O'Brien (2011:387) caution that it may adversely diminish caregivers' ability to manage the daily problems associated with caregiving thus create tension between themselves and the MHCUs. Caregivers may feel ignored. For example, this point is illustrated by the Life Healthcare Esidimeni tragic incident in which the Gauteng Provincial Department of Health (South Africa) failed to share information and to obtain consent of families about the transfer of MHCUs to other treatment facilities (non-government organisations), thus resulting in the death of 143 MHCUs (Makgoba, 2017:25). This happened despite the South African Mental Health Care Act (Act No.17 of 2002, Section 13) allowing for disclosure of "information if failure to do so would seriously prejudice the health of the MHCU or other people". Importantly, the sharing of information is not confined to a diagnosis and the use of medication, but should include interactions with family and community members. The sharing of information is central to the ecological systems approach which encourages communication across the micro, meso and macro levels to promote interdependence.

5.3.3 Theme 3: Family caregivers as support systems in the provision of care to their relative with a mental illness

Literature describes caregiving as a form of support provided to a family member irrespective of the condition (e.g., mental illness) (Milliken & Northcott, 2003:109; Chang et al., 2016:2). Individuals with serious mental illness worldwide for example, have traditionally been the responsibility of mental health institutions (Chow & Priebe, 2013:1). However, in South Africa, advances in medical treatment have shifted caregiving from institutions to families through the deinstitutionalisation process (du Plessis, 2004:4; Lund & Flisher, 2009:1040; Hamden, Newton, McCauley-Elsom & Cross, 2011:274). Deinstitutionalisation was premised on the understanding that medication would stabilise the severity of the symptoms and encourage family caregiving. However, studies show that families have become the main providers of caregiving despite the burden they endure (Yusuf et al., 2009:43; Moller-Leimkuhler & Wiesheu, 2012:156; Wong, Lam, Chan & Chan, 2012:1). Family caregiving is further discussed in the following subtheme.

5.3.3.1 Subtheme 3.1: Caregivers take responsibility to care for MHCUs

The mental health literature describes mental illness as a devastating condition affecting cognitive, perceptual and social functioning of MHCUs (LeVine, 2012:58). MHCUs need care from onset and throughout the course of the illness. Caregivers are usually at the forefront to notice changes in the conduct of a family member and assess the severity before they seek help. MHCUs require family support for basic needs, including food, shelter, medication, hygiene and admission in hospital (Mavundla et al., 2009:361; Dziegielewski, 2015:191). Hence, families become the primary sources of support for the day-to-day management of their mentally ill relatives (Petrowski & Stein, 2016:2873). All ten MHCUs were cared for by family caregivers as illustrated in the following excerpts.

MHCU-A	**Caregiver-AA(Sister)**
My sister reminds me to take medication because I forget… I sweep, wash dishes	*I think it was our sister-in-law that took her to the hospital. I was working in the*

and do laundry; I spend disability grant on grocery (caregiver interjecting – also when she travels). (Female, 72 year-s)	*city at the time. I only returned to live here in 2003. I moved her (MHCU) to our other sister in another village, because I was living with my mother-in-law here. She lived with boys who could not look after her …I think I started caring for her in October 2013… She agreed, and I can see she is in good spirit and she is now a year with me…* (Female, 74 years)

MHCU-B	**Caregiver-BB(Sister)**
She [my sister] looks after me. I stay with her children at home, and they cook. (Male, 46 years)	*I have ensured that my son and my nephew sleep at home with him* [MHCU] *and look after him…If he is about to get a seizure, we hold him before falling to the ground, and then help him to sleep. I loosen his clothes and he normally wake up within five minutes.* (Female, 52 years)

Family members are the primary source of care and support for their mental ill relatives (Petrowski & Stein, 2016:2873). Although caregiving responsibility is designated to a member in the family such as a parent, sibling, cousin or spouse, the study shows that family members are assisting each other in providing care to the MHCU, thus making family caregiving a collective responsibility (Chang & Horrocks, 2006:435; Crowe & Brinkley, 2015:286). In this study, caregivers were always assisted by other family members in carrying out their caregiving responsibilities especially when the primary caregiver is either overwhelmed or unavailable due to other responsibilities. Both MHCUs and their caregivers corroborated each other's accounts regarding the responsibilities that caregivers performed as illustrated in the following excerpts.

MHCU-C	**Caregiver-CC(Sister)**
My sisters visited me several times in hospital, once a week or fortnightly bringing me food and fruits. They accepted me and helped me to recover from stress. They would take me to town and movies to get some fresh air. They	*I was accompanied by our eldest sister when we took her* [MHCU] *to the hospital for admission. We wished the hospital could sedate her to induce sleep. The doctor asked for background information and we gave him all the*

cooked and did my laundry. They love me and encourage me to take medication. My children were also visiting me in hospital. They looked sad, but wanted to see me discharged from the hospital… I sat down with my children and explained the nature of my illness to them. (Female, 34 years)	*information…She is my younger sister and I understand I would not abandon her even if she rejects me. I understood she needed help.* (Female, 38 years)
MHCU-G	**Caregiver-GG(Mother)**
My mother and my younger sisters are looking after me. They cook, do laundry for me and remind me to take medication. You will hear them saying to me it is time for medication. (Female, 30 years)	*I jumped through the window (to follow her) as she ran into the streets in the middle of the night. I took along her younger sister and one of our relatives, to search for her. Since her return from the mental hospital, she can sit with family, converse and laugh. She washes dishes and sweeps the floor. Those are her main tasks for the day. Her siblings are taking good care of her and they are supportive. They cook for her and give her food. We also take care of her child* as a family. (Female, 55 years)

Caregiving has become a family responsibility for individuals with mental illness (Seloilwe, 2006:263; Quah, 2014:598; Petrowski & Stein, 2016:2873). It is embedded within the following multiple ecological systems: family, community, social and cultural norms and social policy (Cash, Hodgkin & Warburton, 2019:710) to ensure effective provision of care to MHCUs. Family responsibility suggests that caregiving is an obligation towards a family member despite the burden of responsibility associated with it (Chang & Horrocks, 2006:436; Chang, 2016:6). The MHCU is depended on the caregiver to improve personal and social functioning. In most African communities' caregiving has become a kinship function for the caring of the individuals with mental illness (Githaiga, 2016:2). Kingship may suggest that the caregiver may not abandon her own kin due to blood relation and shared beliefs (Githaiga, 2016:2).

However, sharing of caregiving, also regarded as collective caregiving is not applied universally but it is specific to certain communities especially of African and Asian ancestry (Wong, Lam, Chan & Chan, 2012:1). Collective caregiving shows an understanding of the abilities of the MHCU to perform tasks that enhance their ability to function independently (Saunders, 2003:190; Becvar & Becvar, 2009:104; Iseselo et al., 2016:2). The allocation of caregiving responsibilities to the MHCUs may be informed by sociocultural factors and demographic status: gender, age, physical and mental abilities to perform a task. As the study shows, caregiving still remains the responsibility of women irrespective of the gender of the person being cared for (Seloilwe, 2006:265; Githaiga, 2016:2).

The family manages caregiving to determine how responsibilities are allocated to siblings, parents, aunts, spouses, cousins or other extended family members. At times, younger siblings care for older siblings (Sanders, Szymanski & Fiori, 2014:261). Although younger siblings are also involved in caregiving due to the unavailability of an adult, the practice may contradict certain cultural values which require a younger sibling to be subordinated to the oldest (Hernandez, Barrio & Yamada, 2013:698) as the following excerpt illustrates.

MHCU-D	**Caregiver-DD (Sister)**
I'm in the care of my sister. She does everything for me. She and John (cousin) took me in 2014 – John is the one who took me to Lebowakgomo Hospital because my sister could see that I was not well. …It is my sister who takes me to the hospital and no other person. She is the one who understands my problem. She also sees that I don't smoke dagga and I don't drink alcohol. Family members cook for me, and clean my room. (Male, 32 years)	*I live with the MHCU and there is no problem. He washes dishes, sometimes he does his own laundry, and cooks when he is hungry…* (Female, 30 years)

As with a study by Yang, Hsieh, Lee and Chen (2017:410) in China, the findings suggest that siblings take the caregiving role especially in the absence of their parents. As a result, some siblings (caregivers) may be obliged to adjust their roles to cope with the burden of caregiving demands: disruptions in household routines, dysfunctional family relationships, financial constraints and neglect of other family members (Sanders et al., 2014:257).

Family caregiving takes care of all the needs of the MHCU, but within the means. This means the care is not limited to physical care but involves emotional support as well. The individuals with mental illness experience emotional problems during the course of the illness (Rogers & Pilgrim, 2010:40) as the following excerpt illustrates.

MHCU-E	**Caregiver-EE (Cousin)**
When I explain what I was feeling to my mother she always tells me to take it easy and that everything will be okay. It is now three years that I have been like this…My girlfriend is aware of my mental illness. If I am disturbed, my girlfriend cries. She also prays for me. (Male, 31years)	*Sometimes he wakes up and not say a word to anyone. He will only stare with protruding eyes. I would ask what is going on and he would say "Aah! auntie, eish, these witches – lizards." He likes jokes. When I'm with him I make sure I chat with him so that he does not engage in deep thought because when he is quiet, he looks miserable, and I get scared. I will then share a joke and we will both laugh. He does not want an impatient person.* (Female, 44 years)

Literature describes emotional responses of individuals with schizophrenia as showing diminished emotional expression, decreased ability to experience pleasure, lack of goal directed behaviour, lack of interest in social interactions and emotional withdrawal (Dziegielewski, 2015:157). Caregivers often find the behaviour frightening thus making it difficult to engage such individuals (Seloilwe, 2006:266; Price, 2016:1). However, caregivers have lived with the MHCUs long enough to know when they experience mood changes. Their reactions show their ability to observe changes in the MHCUs' emotions, thoughts and behaviour, and to react appropriately (Wong, 2014:133).

Caregiving, as discussed above, is a collective responsibility in most families, regardless of the nature and impact of the illness on both the MHCUs and the family. The family members take turns to supervise MHCUs to perform self-care tasks, among them, bathing, eating, clothing or preparing for sleep (Hou, Ke, Su et al., 2008:509; Rogers & Pilgrim, 2010: 239). Most recovering MHCUs can perform minimal tasks:

brushing teeth, bathing, eating and laundry. All ten MHCUs were engaged in self-care tasks as illustrated in the following excerpts.

MHCU-D	**Caregiver-DD (Sister)**
Although the medication tends to render my body ineffective. I also try to wash dishes, cook and help here and there with my disability grant – I buy meat and toiletry. I do this together with my sibling (caregiver). I buy electricity and clothes for myself so that I don't wear worn-out clothes. I also smoke tobacco - boxer and Stuyvesant are my preferences. (Male, 32 years)	*We share tasks among ourselves…He washes dishes, sometimes he does his own laundry, and cooks when he is hungry… He uses his disability grant to buy meat and I buy other things. He keeps the rest of the money for himself for use when he goes to the hospital for treatment.* (Female, 30 years)
MHCU-I	**Caregiver-II (Sister)**
I clean the yard by removing weed. I also fix the kraal. I then bath and relax… I'm now paying an instalment for a bed; I buy clothes and food - only buy meat. My mother buys mealie-meal… (Male, 28 years)	*As the main carer I prepare food for him and clean his room for him. He always waits until food is prepared and ready. He does laundry, makes his bed and bath himself.* (Female, 26 years)

MHCU-A	**Caregiver-AA (Sister)**
I sweep, wash dishes and do laundry; I spend the disability grant on grocery (Female, 72 years)	*She sweeps the courtyard and when she is done, I will ask her to rest. I don't want her close to the fire. I do not allow her to cook. She just sweeps, that's what she helps me with. She also does laundry and I can see that she can manage, and she does it well. I don't make her clean the house. I do it myself.* (Female, 74)
MHCU-E	**Caregiver-EE (Cousin)**
I pay DSTV (digital satellite television – monthly subscription), monthly funeral subscription, buy grocery and spend the rest on buying clothes for me and girlfriend. You know guys must engage in romantic relationships. I helped my	*I clean his bedroom. Sometimes he does his own laundry. When I prepare a meal and dish up for him, I remind him to take his medication, but most of the time he takes it by himself.* (Female, 44 years)

sister with the construction of her house. I was keeping myself busy. You see it was to get some piece job [temporary jobs]. (Male, 31 years)	
MHCU-G	**Caregiver-GG (Mother)**
I clean and wash dishes. (Female, 30 years)	*Those are the dishes she washes and that is her main task for the day.* (Female, 55 years)

Studies conducted in New Zealand have explained the MHCUs as having the ability to perform self-care tasks (Broadbent, Kydd, Sanders & Vanderpyl, 2008:148; Capone, 2014:2). Self-care is a skill that MHCUs develop to take care of their own needs (WHO, 2009:22; Grady & Gough, 2018:S431). The ability for MHCUs to develop self-care skills is an affirmation of the important role that families play within the mental health system as a support system (James, 2012:7; Hernandez et al., 2013:697; N'gambi & Pienaar, 2013:99). The self-care approach gets support from the strengths-based perspective which recognises opportunities, hope, solutions to problems that MHCUs experience (Rani, 2015:445). Additionally, MHCUs have physical and psychosocial needs which can be met with the support of family members (Mavundla et al., 2009:257; Pakenham, 2011:186).

The support that caregivers provide complements self-care tasks to meet the MHCUs' physical and psychosocial needs (Mavundla et al., 2009:257; Anokye, 2018:324). Family support involves food preparation and provision of shelter, supervision of medication, personal hygiene, and engaging them in social activities to protect them from loneliness and hopelessness (Mavundla et al., 2009:360; Pakenham, 2011:190). The treatment of schizophrenia is long-term and requires long-term use of medication. Family support is therefore tantamount to assuming the role of mental health professionals in managing and supervising the use of treatment (N'gambi & Pienaar, 2013:99). The family home serves like a hospital ward manned by a medical team composed of family members providing a refuge for the physical, emotional and social support for their family member with mental illness (Du Plessis et al., 2004:4; Anokye, 2018:324).

Nevertheless, families are sometimes blamed for worsening the MHCUs' mental condition despite being the main support system (Rogers & Pilgrim, 2010:239). This view creates a paradox for the family whose caregiving responsibilities is usually an obligation and not a choice by being related to the MHCU (Petrowski & Stein, 2016:2876). Equally, like many families, those with MHCUs experience interactions that involve disagreements and conflicts which may require outside intervention.

Caregiving may be constraint by inadequate support from the social environment. Thus, caregivers are left with the responsibilities to seek services from alternative practitioners (Irazabal, Pastor & Molina, 2016:8). A Sepedi idiom *"mmago ngwana o tshwara thipa ka bogaleng"* which literally translated states that 'the mother of a child holds the sharp blade of a knife to protect her child' captures the role of the caregiver as someone who fights for the rights of the person in their care. It suggests that caregivers have the potential to influence policy for the transformation of the mental health system in order to improve conditions of people with mental illness (Gee, McGarty & Banfield, 2015:231). The protection of the rights of MHCUs is also supported by the Mental Health Care Act (Act No. 17 of 2002). Caregivers can, therefore, advocate for partnership to enhance the provision of better mental health care as the following excerpts illustrate.

Caregiver-AA(Sister)

The hospital medication was not good for her. She walks as though she was about to fall to the ground. She appears stiff. I asked hospital doctors to stop the injection and replace it with another injection, but they were not in agreement. As she was receiving a social grant, I decided to take her to a private doctor. She is no longer giving me problems. As I now understand what her illness is, I asked God to give me patience. I now know what the problem is. (Female, 74 years)

Caregiver-BB(Sister)

My hope was always with the doctor who promised to find a social worker for me to have my brother transferred to a mental hospital, but never did. I left the hospital without seeing my brother and those social workers… One day I felt this doctor is no longer hearing me. I went straight to the social worker right there. The social worker told me that they only attended to those from a specific area and suggested that I should go to the local social worker where the family lived. I thought we will receive help from the hospital. I had to find another doctor who helped me to take him to a mental hospital. (Female, 52 years)

The caregivers have the ability to influence decisions by authorities to provide required services. As advocates of the rights of MHCUs to access service, caregivers showed competence and abilities to perform their responsibilities by insisting to be heard (Pakenham, 2011:188). Moreover, MHCUs are usually in a state that they may not rationally challenge injustice, and caregivers become their voice (Given et al., 2008:116; National Academies of Sciences, Engineering, and Medicine, 2016:277) which demonstrates their ability to influence treatment decisions for better services (Stanton & Skipworth, 2005:155; Lloyd, Lloyd, Fitzpatrick & Peters, 2017:1). Therefore, MHCU-caregiver-doctor relationship developed (Bland & Foster, 2012:517) with MHCUs accessing the services the caregivers have been advocating for.

5.3.4 Theme 4: Caregiving challenges experienced by caregivers

The WHO estimates that “one out of four families worldwide have at least one member suffering from a mental disorder” (Shamsaei, Cheraghi & Esmaeilli, 2015:1). The MHCU becomes the responsibility of their family members who have to provide care. Schizophrenia is a long-lasting condition with no known prevention or cure (Insel & Scolnick, 2006:11; Lloyd et al., 2017:1) and contributes to stress experienced by both MHCUs and their caregivers. Although antipsychotic medication is available, it can only reduce the severity of psychotic symptoms without completely returning the MHCU to the initial normal functioning (Rogers & Pilgrim, 2010:196; Lloyd et al., 2017:1). Families must endure the social effects resulting in their social isolation and rejection (Opare-Henaku & Utsey, 2017:1; Lloyd et al., 2017:1). Therefore, the effects are systemic in that the mental condition is not only affecting the MHCU, but the family in that family functioning becomes affected.

The challenges resulting from the effects of mental illness as experienced by caregivers are further discussed in the three subthemes below.

5.3.4.1 Subtheme 4.1: Non-compliance with treatment

Mental health literature describes schizophrenia as a severe and chronic condition that requires prolonged medical treatment, mainly with antipsychotic drugs (Yusuf et al., 2009:43; Mahaye et al., 2012:608). Studies show that individuals with schizophrenia are prone to recurring relapses that may be due to their defaulting on treatment (Ascher-Svanum, Zhu, Faries et al., 2010:1; Bener, Dafeeah & Salem, 2013:279). One of the responsibilities of caregivers is to supervise and monitor medication compliance by MHCUs. The caregivers expressed non-compliance with treatment by the MHCUs.

Caregiver-BB (Sister)

He does not take medication. He is always smoking dagga and drinking alcohol except when his disability grant is finished. He will start shaking (having withdrawals symptoms). (Female, 52 years)

Caregiver-II (Sister)

When he starts to show signs of illness [relapsed], he stayed away from home, not having supper with us, always pacing up-and-down and going in and out of the house. He had stopped taking medication demanding money from my mother to buy dagga (marijuana)… I then called the police who took him to hospital… (Female, 26 years)

Caregiver-GG (Mother)

She was not taking her medication. She was roaming the streets and it became difficult for us to manage her. It was always a struggle when she was told to take medication. (Female, 52 years)

A study in KwaZulu-Natal by Mahaye et al. (2012:608) that assessed adherence to treatment in MHCUs living with families has found moderate to high levels of non-adherence. The use of substances was a dominant factor among those defaulting treatment; the severity of symptoms with disruptive behaviour, forgetfulness, and lack of insight and motivation (The American Pharmacists' Association, 2013:70). Other studies identified fear of stigma, and inadequate knowledge as contributing to default on treatment (Kazadi et al., 2008:56; Ray & Dollar, 2014:720). This suggests that psychosocial factors are involved in defaulting on treatment.

Non-adherence to treatment is particularly concerning given its strong association with relapse (Townsend, 2009:513; Bener et al., 2013:273) as the following excerpts illustrate.

MHCU-D	Caregiver-DD (Sister)
I did not know what caused my mental disturbance. Although the doctor had told	*I was present in 2004 when he relapsed. He relapsed again in 2009…He was*

me it was dagga, I am still disturbed even after I have stopped smoking. (Male, 32 years)	*disturbed. He was just talkative; we could hardly hear his incoherent speech. He rarely leaves home when he is well, but when he is mentally disturbed, his movement changes, you can see his eyes protruding that he is no longer the same. I saw him change, he will start making noise, being talkative, becoming restless and wandering the streets aimlessly, then I know that he is not right.* (Female, 30 years)
MHCU-F	**Caregiver-FF (Mother)**
I was discharged, but defaulted on treatment when I arrived home. I then started snatching cigarettes and money from people to buy dagga. But I went to the hospital, and the doctor said I had mental illness. I went to a tavern with my cousin who drank beers and some friends who gave me dagga to smoke. While smoking, I was also drinking alcohol. I came home in a bad state, but I did not want my mother to see how I was because my mother thought I had gone to buy eggs. I did not listen when I was asked [by mother] to behave. (Male, 31 years)	*He would be better, but relapse again. He comes back from hospital in a good state just like when he returns from prison. The problem is he defaults on treatment. He smoked dagga immediately after his discharge from the hospital. When he is home or relaxing at the tavern, friends keep offering him cannabis. But he is no longer smoking as before. He was advised by fellow MHCUs to stop smoking during his last discharge from the hospital. He promised to stop but expressed a craving for it. I told him to stop using dagga because it would destroy his future.* (Female, 58 years).

The findings confirm that relapsing individuals are more likely to experience the re-emergence of psychotic symptoms resulting from non-adherence to treatment (Kazadi et al., 2008:53; Bener et al., 2013:274). Consistent with the findings is a study conducted in the US indicating that MHCUs have often used substances following their discharge from a mental health hospital (Anderson et al., 2007:68; Lev-Ran, Imtiaz & Le Foll, 2012:531) resulting in non-compliance with treatment and relapses (Hernandez, Barrio & Yamada, 2013:669). However, a relapse may not only be due to substance use but could also relate to withdrawal symptoms that are usually experienced by individuals who have stopped the use of substances (Smelson, Dixon Craig et al., 2008:904; Hesse & Thylstrup, 2013).

The use of dagga and alcohol in South Africa has cultural benefits in spite of the adverse effects contributing to poor adherence to treatment and exacerbation of relapse (Kazadi et al., 2008:53; Saban, Flisher, Laubscher et al., 2013:201). Peer pressure and the availability of dagga in the community also influence the use of substances (Anderson, Frissell & Brown, 2007:66; Chorlton & Smith, 2016:324). The economic benefits that most communities derive from the sale of dagga and alcohol encourage substance use with its adverse effects (Shamsaei et al., 2015:1). Therefore, caregivers are left with no choice, but the responsibility of managing relapses, frequent re-hospitalisations and the costs of caregiving.

The defaulting of treatment is not only a medical problem, but impact on the social functioning of the person and the family (Kazadi et al. 2008:52; Sorsdahl, Stein & Myers, 2012:3). For example, in the US defaulting on treatment resulted in high cost of outpatient interventions and frequent rehospitalisation (Ascher-Svanum, Zhu, Faries et al., 2010:1). Families may need restructuring of roles (Sundar, Fox, & Phillips 2014:752), especially as the MHCU will require extensive caregiving. Some members of the family, may be forced to leave their employment to take care of the MHCU, thus placing a strain on the financial and the general well-being of the family.

Other factors contributing to non-adherence may be beyond the control of the MHCU as was the case with a MHCU who was incarcerated.

Caregiver-E

I was placed in police custody. I spent another month again sick, in pain and having a headache. I was taking medication when I was in police custody. As you know, prison inmates fight a lot and they soaked my pills in water. So, I was out of medication. I asked for treatment and no one helped me… I relapsed four times. (Male, 31 years)

Studies conducted in London, Canada and the US confirm that the incarceration of the individuals with mental illness in police custody interrupted the use of medication (Gur, 2010:227). Individuals with mental illness encounter the criminal justice system as offenders and not as MHCUs (Gur, 2010:220; Short, MacDonald, Luebbers et al., 2012:336). However, lack of training in mental health intervention has been found to contribute to police officers' inability to provide the mentally ill with the necessary care

(Martinez, 2010:167; Clayfield, Fletcher & Grudzinskas Jr., 2011:742; Watson & Fulambarker, 2012:72). Hence, the MHCUs in the care of the police are likely to experience a relapse due to lack of access to medication.

The challenges that caregivers experience relate to the MHCUs' defaulting on their treatment. The behaviour of the MHCU may lead to relapses and increase the burden of care. Additionally, lack of access to social support network makes caregiving difficult and has an adverse effect on family stability. Moreover, lack of skilled practitioners in facilities providing services to MHCUs may disadvantage caregivers. Therefore, caregivers need a supportive social environment that provides coordinated and comprehensive services (Horspool, Drabble & O'Cathain, 2016:2) to improve the MHCUs' adherence to medication.

5.3.4.2 Subtheme 4.2: Violent behaviour by MHCUs

Mental illness has historically been associated with violent behaviour (Nederlof et al., 2013:183). This association of mental illness with violence continues to be the subject of debate both within the mental health professions and the broader public (Rogers & Pilgrim, 2010:228). However, it must be noted that any discussion on violence by MHCUs must consider the social nature of violence among members of the public. Moreover, MHCUs are also affected by the general violence experienced by members of the public. Common types of violence include domestic, sexual, physical assault, murder and destruction of property which can be directed at children, adults, animals and property. Although the prison population worldwide is made up of normal people who have committed violent crimes, violence committed by MHCUs receives a curious attention to "legitimise institutionalisation of society's unfounded prejudice and fear regarding mental illness" (Rogers & Pilgrim, 2010:234). Violence, irrespective of who perpetrates it, is frightening. However, caregiving suggests that caregivers occasionally encounter the violence of MHCUs as they perform their caregiving responsibilities. Therefore, the ecological systems approach is invoked to provide a holistic understanding of the violence committed by MHCUs on the caregivers.

A study in the US shows the rates of violent behaviour among people with mental disorders irrespective of gender (Scott & Resnick, 2006:600; Steinert & Whittington, 2013:169). Violent behaviour influences how mental health care and caregiving responsibilities should be provided (Lidz, Banks, Simon et al., 2007:23; Copeland &

Heilemann, 2011:521). For example, the Mental Health Care Act (Act No. 17 of 2002) provides a legal basis for involuntary admission in hospital. Nevertheless, caregivers continue to perform their caregiving responsibilities despite the violence or threat of violence they may face (Nordström & Kullgren, 2003:326; Copeland & Heilemann, 2011:520). MHCUs reported their violent behaviour towards family members, while caregivers experienced violent behaviour from their relative with a mental illness as the following excerpts illustrate.

MHCU-E
I was aggressive, beating everybody in the family. It means I was angry… I have to say, it is mental illness. …I just saw myself beating my mother with an empty kettle and a cup of tea, as I was in pain - hearing the voices of people. … I ended up hurting her on her head and she bled…The police explained to the magistrate that this is a sick person and he receives disability grant. (Male, 31 years)

MHCU-I	**Caregiver-II (Sister)**
I just saw myself doing bad things, I was just harassing people – beating papa. Yes, I was just harassing everybody in the family – beating mama with my hands. I was not aware of what I was doing. Yes, my mother was in pain because she ran away to the neighbours… (Male, 28 years)	*He was smoking dagga and we noticed that he was disturbed. He was troublesome, demanding money, and issuing threats of throwing children in a pit-toilet and burning the house. Sometimes we slept at our neighbours' house and he would lock us out. We called the police, and he threatened us in their presence claiming that they were his friends. They arrested him, and he returned after three days claiming to have been discharged and showing no change in behaviour. When we asked the police to take him to hospital, the doctors discharged him saying he is not sick. We explained to them what he does at home. One day he demanded money from my mother and when she told him she did not have it he strangled her. He also demanded that my mother pay back the R500.00 bail money (that he paid). My mother laid a charge with the police against him and he spent 6 months in prison.* (Female, 26 years)

Popular perception of mental illness regards individuals with mental illness as prone to violent behaviour than persons who are not mentally ill (Nederlof et al., 2013:183). The society is suspicious of persons with mental illness to be inclined to violent behaviour. Some MHCUs inadvertently confirm the perception. In this study, MHCUs were able to recognise their violent behaviour towards family members. For them to recognise their behaviour suggests that they are ready to change and start behaving normally (Barley & Lawson, 2016:924). Although Wong (2014:133) warns against trusting self-reports from MHCUs, Lidz et al. (2007:23) and Brenner & DeLamater (2016:349) are of the view that any report of a violent incident from any source be treated as true. In support of this view, family members have also corroborated reports of MHCUs regarding the violent behaviour they displayed towards their family members.

Caregiver-AA (Sister)

She started in 1972, before our father died in 1975. She just started by saying a lot of things she did not understand and fighting with family members. She was violent towards other people. She has assaulted our brother who comes after her. She was aggressive. (Female, 74 years)

Caregiver-BB (Sister)

My mother kept saying that she did not know what to do when he was aggressive. He is always fighting… we don’t even clean his bedroom. He says we are taking the wisdom that his father left for him in his bedroom. No one enters – he leaves his room when he wants to. Should he find out that you have cleaned the room, he complains about things missing…He slapped me two days ago… but denied having hit me when my husband confronted him and demanding that he must ask for forgiveness. He just said, “I never hit her”. (Female, 52 years)

Caregiver-CC (Sister)

It is true that I had laid a charge against her, with the support of the family, because she had severely assaulted her child. (Female, 38 years)

Caregiver-GG (Mother)

The thing with her is that she would fight everyone in the family...She uses anything that she could lay her hands on. Her sister has a scar as she (MHCU) hit her with a rock. (Female, 52 years)

The findings suggest that family members are victims of violence by their relative with a mental illness (Douglas, Guy & Hart, 2009:680; Johansson et al., 2010:692; Volavka, 2013:65). They experience violence in the form of routine threats culminating in physical assaults, rape, murder and burning of property (Woo & Keatinge, 2008:85; Copeland & Heilemann, 2011:520). Violence by MHCUs is seen as caused by the severity of psychotic symptoms than a conscious act of malice (Volavka, 2013:66; Nederlof et al., 2013:183). Findings seem to contradict some research that dismisses the association of violence with mental illness (Lidz et al., 2007:24; Rogers & Pilgrim, 2010:230; Brenner & DeLamater, 2016:349). However, MHCUs and caregivers corroborate each other regarding the experiences of violence meted out against family members. This view is supported by Mental health legislation which provide that such individuals be considered for involuntary assessment and treatment (Scott, 2008:408; Rogers & Pilgrim, 2010:226; Elbogen, Dennis & Johnson, 2016:2). Consequently, caregivers have sought intervention from the police and mental health care practitioners for protection (Mclean & Marshall, 2010:63; Brennan, Warren, Peterson et al., 2016:453).

Caregivers, especially in rural communities, who experience inadequate services may resort to extended families and neighbours for protection from the violence of their relatives with mental illness (Robinson, Springer, Bischoff et al., 2012:308; Braathena et al., 2013:41). Nevertheless, family members still feel the obligation, responsibility, and moral duty to care for the MHCUs despite the violence they endure (Tung & Hu, 2010:479; Szmukler & Rose, 2013:137).

The MHCUs' aggressive and violent behaviour is not limited to family members but extends to members of the public as well (Elbogen et al., 2016:1), as the following excerpt illustrates.

Caregiver-BB (Sister)

According to my brother, everybody in the neighbourhood is a witch. Villagers are fighting with him, even the village chief knows. A chicken would not be seen in our yard as he would threaten to kill and eat it. One day he slaughtered a neighbour's goat. Neighbours are also scared of him; they do not speak to him because he calls them witches. We took him to the village chief where he was reprimanded. On arrival at the police station, I told them that he was troublesome and that he took peoples' properties. When children come to my restaurant, he takes their money,

buys beer and drinks while the children are watching. One day he assaulted a customer, and no one intervened because he was wild. She was bleeding (victim) right here in the restaurant. People kept shouting at me to stop him. How do I take care of a MHCU who fights others? We are afraid to stop him. I then called the police who instructed me to call an ambulance… He is violent when he relapses, beats people without provocation. I can't handle him… (Female, 52 years)	
MHCU-F	**Caregiver-FF (Mother)**
Police took me from home into custody because I had taken R11-00 from another man to buy dagga. I remember smoking dagga. While in police custody, the captain said that they were taking me to hospital regarding a crime I committed at a Drop-in-Centre, where my mother worked. I had entered through the window and stole food to cook where I was staying since I was no longer staying at home… I was arrested in June 2010 during the soccer world cup and remained in police custody for a month. I was released and appeared in court on 4 August which I failed to honour. On 28 December, just as we were about to celebrate new year, I got arrested again and taken to a mental hospital. On 13 of January 2011 while there, I was found in possession of dagga and got arrested for smoking it…I always escaped from the mental hospital - about three to four times. I would come home after escaping. I started sleeping at my friends' houses to evade the police. (Male, 31 years)	*When he is accompanied to hospital, one police car is not enough. Seven police cars are required because he can run. When he escaped from the hospital, he came home changed clothes, took his siblings' clothes, got blankets from friends and slept in the church opposite our home. He would move on in search of another place…* (Female, 58 years)

Violence by MHCUs is not only confined to family members, but affect community members as well (Douglas et al., 2009:680; Rogers & Pilgrim, 2010:230). Reports of a family member having a stomach ripped open by a MHCU show the public the danger of a person with mental illness (Scott & Resnick, 2006:659; Braathen et al., 2013:39). Nevertheless, MHCUs interact with others at every level of the ecological system (micro, meso and macro) (Cash, Hodgkin & Warburton, 2019:712). Unfortunately, neighbours, friends and acquaintances may become victims of their violent behaviour which may reinforce the public perception of the mentally ill as dangerous (Szasz, 2003:377; Douglas et al., 2009:679; Rogers & Pilgrim, 2010:230). Community members may also provide support to the family by physically restraining the person to control the behaviour (Quinn, 2007:177; Sangeeta & Mathew, 2017:104). Hence families seek intervention from the police and mental health care practitioners. The findings, therefore confirm the perceptions regarding the relationship between mental illness and violent behaviour. In addition, they are consistent with the fact that the social environment has an influence on the people's perceptions of mental illness.

5.3.4.3 Subtheme 4.3: Burden of caregiving

Caregiving is not a career, but a sacrifice that family members make towards their relatives with mental illness. Some caregivers sacrificed their careers, jobs and dreams to provide for the needs of their relatives with mental illness (Wilson & Williams, 2013:80; Bartholomew, 2016:106). Caregivers contend with the daily effects of mental illness which may be difficult to manage (Moller-Leimkuhler & Wiesheu, 2012:157). The burden they endure is enormous as they have to care for people that the society regard as dangerous. Moreover, they have to resist the stigma and social isolation associated with the MHCUs. However, the burden of caregiving may result in despondency among caregivers due to disruptions in their personal and family functioning, and social relationships, loss of income and lack of professional support (Hou et al., 2008:508; Chang et al., 2016:4). Experiences of despondency are discussed below.

Caregiver-BB (Sister)
When he has money (disability grant), he does nothing for his children. The money will be finished within two days. Whether payments are made for the burial society, it is not his problem. He will say "dogs and donkeys are dying, and their souls go to heaven". I have decided to do my best and save money on his behalf. The other day, he was wearing underwear walking along the road, beating people's cars with open hands and kicking them while coming towards us at the restaurant. He became a spectacle and when I told him to move away from where he was (near the speed hump), he continued to move around cars. When approached he got violent. I called an ambulance and we took him to hospital. There he told them that we are tying him up when we are supposed to tie goats. He said I tie him so that I can use and destroy the dishes our mother left him to dish-up for men (customers) at the taxi rank. (Female, 52 years)

Caregiver-II (Sister)
Mother always gave him money to appease him without success. We were afraid of him and would call our sister (living in another village) as he was afraid of her. One day, while threatening us, my sister suggested we cut him with an axe. We all got up - my two sisters, myself and my mother, and he screamed for help. Our neighbours heard the screams and came to investigate, only to find us beating him. The reason for beating him was that he had threatened to throw my two sister's children in the pit-toilet and telling us to leave his home demanding money from us. We took him back to hospital where he escaped with a fellow inmate after three months together. They sustained injuries when they scaled the hospital fence. The hospital staff followed him and took him back to the hospital where he spent three years. He stopped taking his medication in 2012/13 and started giving us problems, demanding money from my mother. He would ask for R50.00, and later ask for more to buy dagga and something to mix it with. My mother asked about his disability grant because he never give anyone money. He would promise to payback when he receives his disability grant, but he never did. He was receiving R1 270.00, now it is R1 600.00. He claims to have a wife and demand that my mother should buy baby milk and nappies for his child. We do not know about the wife and child he is referring to. He took R400.00 from my mother and spent it on airtime. (Female, 26 years)

Caregivers endure MHCUs' behaviours that make them feel treated with disrespect and hostility instead of gratitude (Chien, 2008:28; Sen & Nath, 2012:153) despite being their (MHCUs) main support systems. They experience the MHCUs as unpredictable disruptive and not conforming with family norms and difficult to manage (Flyckt et al., 2015:684). The experiences are overwhelming, challenging, distressing and affecting their abilities to cope (Endrawes, O'Brien & Wilkes, 2007:432; Hou et al., 2008:513; Hernandez et al., 2013:669).

Nigeria and China have found that caregiving responsibilities have profound psychosocial, physical and financial burdens on caregivers (Yusuf et al., 2009:43; Moller-Leimkuhler & Wiesheu, 2012:156; Wong et al., 2012:1). Caregiver burden is further exacerbated by the scarcity of services especially for families in rural communities who must travel long distances to receive professional support (Du Plessis et al., 2004:4; Given et al., 2008:115; Moller-Leimkuhler & Wiesheu, 2012:157). The consequences may be family dysfunction, unemployment difficulties leading to emotional instability including fear, sadness, anger, guilt, stigma and rejection (Yusuf, Nuhu & Akinbiyi, 2009:43; Yazici et al., 2016:96). To mitigate caregivers' burden, resilience enables them to continue to provide care despite lacking adequate knowledge, experience and resources (Seloilwe, 2006:263; Kopelowicz & Zarate, 2014:198). Resilience also enables families to restructure household routines by allocating roles to other family members (Mavundla et al., 2009:358; Stiles, 2013:140).

5.3.5 Theme 5: MHCUs' and caregivers' perceptions of the community regarding mental illness

MHCUs are not only members of their own families, but are part of communities within which they live, sharing common norms, values, identity and a social environment (Goodsell, Colling, Brown & England, 2011:283). They experience their social environment through their immediate and extended families, friends, neighbours and institutions (Coppock & Dunn, 2010:42; Graham, Moodley & Selipsky, 2013:332). As a social system, the community's expression of mental illness is premised on the understanding that social factors contribute to its aetiology and progression (Whitley & McKenzie, 2005:72; Akinbode & Tolulope, 2017:241). It is through social structures that the community expresses its attitudes towards mental illness (Sickel, Seacat & Nabors, 2014:204). For example, every community has a label for a mental condition and react differently towards the illness, the person with mental illness and their family. The community also facilitates a context for the provision of services to families and their relatives with mental illness (Campbell & Burgess, 2012:381). This suggests that the community interacts at every level of the ecological systems (micro, meso and macro) to ensure access to social support network.

Community support is a social activity provided through networks to improve the social functioning of the MHCUs and their families (Rogers & Pilgrim, 2010:55; Nee & Witt, 2013:677) (cf. Chapter Three, Item 3.5.2). Although some MHCUs and caregivers have not required community support, they however experienced acceptance from community members as illustrated by the following excerpts.

Caregiver-AA (Sister)
As a family we have not required assistance from the community. We have always been able to assist each other as the family, with our father still alive, to manage her especially when she was aggressive. At least she is back in the church - we support each other and go together [to church]. (Female, 74 years)

MHCU-C	Caregiver-CC (Sister)
I'm not aware of their reactions [community members] *as I was sick. I'm not involved in any activities in the community. We only meet at funerals, weddings and parties (mainly birthday parties).* (Female, 34 years)	*As the family we were not concerned about what people [community reaction] thought of us. We only wanted to help her (MHCU). Ooh! They interacted with us as before. [Church reaction towards family and MHCU] we only went together the day I took her to the marquee for an all- night prayer. I never took her to the church again as you know in every family each person follows their own belief. My eldest sister said we must not pressurise her into church. She belongs to Roman Catholic and I'm a born again. The members of the Roman church [MHCU's church] never visited (MHCU). I met one of the church members who told me they had visited but there was no one at home.* (Female, 38 years)

Community members vary in their understanding and perceptions of mental illness based on their experience of the mentally ill (Sangeeta & Mathew, 2017:97). Their perceptions may manifest as social stigma thus limiting integration of MHCUs, caregivers and their families into communities (Kasow & Weisskirch, 2010:547). For example, some community members may avoid contact with the MHCUs. Likewise, the MHCUs and caregivers have varied experiences of the community (Collins, Ward, Snow et al., 2017:678). This confirms views suggesting that the MHCUs and their families may internalise stigmatising ideas and believe that they are less valued (Corrigan, 2007:32; Conrad & Barker, 2010:71). Consequently, a self-fulfilling prophesy may result as both the MHCUs and caregivers may expect negative reactions including stigma, prejudice, discrimination and social isolation (Kotadia, Walton, Webster et al., 2018:12) thus impacting on their social interactions. On the other hand, family members may resort to family support to enhance their caregiving abilities. Hence, they may see no need for community support because their kinship obligation ties them together to provide collective caregiving.

On the other hand, some community members acknowledge the role of caregivers in providing for the needs of MHCUs. They may be motivated by the ethos of *ubuntu* promoting indigenous welfare to respond to the family needs and promote their well-being (Patel, Kaseke & Midgley, 2012:13). Indigenous welfare is a support system embracing a moral system that values the family as part of the community (Chasi, 2014:496). Community members are able to interact with MHCUs and their caregivers.

Caregiver-AA (Sister)

The community, what will they say, they will just say you are taking care of your sister as she is no longer like when she was living alone at the family home – it is what they tell me. In fact, most community members are thankful… You can ask her as they always say to her "you look really good, you look good". …

Caregiver-II (Sister)

They [community members] *do come* [visit the family]. *They used to be afraid of him the time when he was still having severe psychotic symptoms. He would chase them away accusing them of being witches. They have now realised that he has recovered, and they are now able to visit the family.* (Female, 30 years)

The support that the community offers seems to suggest its understanding of the negative effects of mental illness on both the family and the MHCUs (Wong, Sands & Solomon, 2010:655; Pernice-Duca, Biegel, Hess et al., 2015:446). In African communities the support offered to the family may be influenced by *ubuntu* (Wanless, 2007:117; Letseka, 2012:47) that regards MHCUs as "blameless for the mental condition which is seen as beyond their control" (Quinn, 2007:176). This view of mental illness suggests a social perspective that focuses on correcting the social environment for the benefit of all including the individual.

Deinstitutionalisation has also contributed to the reintegration of the MHCUs whose care has been placed in families and communities (Chan, 2010:375). Communities, therefore, have the responsibility to afford the MHCUs an enabling environment for their social functioning. For instance, the church as a social institution is a source of support and a moral watchdog in the society, and not a bearer of stigma and prejudice (Chandler, 2012:577). The role of the church is important in the treatment of mental illness by providing an enabling environment for the support and provision of mental health services. They provide a context for resilience to enable the family to bounce back from the burden of caregiving (Payne, 2014:206) and to see itself (family) as the main resource in the provision of mental health service. Even though churches provide social services including food, clothes, shelter and counselling to the vulnerable individuals and their families, one of the MHCUs expressed dissatisfaction with the way the church stigmatised him.

MHCU-D

I stopped going to church because those prophets went to the hospital to say I'm sick. When I'm supposed to tell the prophets my real experiences in the church, they are not listening to me, instead they tell me that I'm crazy and sick, and that I must tell a family member to be the one to heal me. There is a relative of ours who attends the same church. He won't help me with anything because he is a priest and not a prophet. Even the priests, when I ask them to tell me my real problems, they are unable to do so. They tell people in the church that I'm sick and thing hurts me because people laugh at me. This is what made me leave the church, which I liked before. (Male, 32 years)

The finding shows that victims of public stigma experience rejection and social isolation (Pescosolido, 2013:10), and may withdraw from public involvement (Wong et al., 2010:654) and church activities. The use of derogatory language is stigmatizing (Van der Sanden et al., 2015:400), and may negatively influence the individual's self-image (Casstevens, 2010:385). For instance, it may promote prejudice by suggesting that "the person is forever mentally ill even when there is no longer a trace of mental illness" (Rogers & Pilgrim, 2010:36). Negative labels towards l individuals with mental illness may become a barrier to them accessing employment, housing, interpersonal relationships, including physical and mental health care (Sickel et al., 2014:204). Thus, the environment that the MHCUs and their families find themselves can be a source of support or stress.

5.3.6 Theme 6: MHCUs' and caregivers' expectations of mental health service providers

Most people experiencing challenges have expectations for a good quality of life. Mental illness has adverse effects on the social functioning of individuals (Wittmann & Keshavan, 2007:157; Spaniol, 2010:482). The MHCUs may become unable to provide for their needs and those of their children. Caregivers may not be able to provide for the needs of their families as they provide a 24/7 a week care to MHCUs (Quah, 2014:600). As a result, both the MHCU and family would require support from mental health service providers to meet their needs as the following storylines illustrate.

MHCU-G

I need a disability grant. I asked the doctor who treated me at the mental hospital to approve a disability grant for me, but he did not tell me that I do not qualify. Instead, he said he would be arrested if he recommended a disability grant for me. (Female, 30 years)

MHCU-F

I want the mental health care practitioners to visit us frequently, maybe weekly or bi-monthly to see how we are struggling to get employment and to assist when we need help regarding mental illness. *The mental health care practitioners must check with my mother if I am taking medication and whether I attend review sessions.* (Male, 26 years)

The findings suggest an association between the presence of mental illness with a loss of income resulting in poor quality of life (Lund et al., 2013:847). Consistent with the findings are the outcomes of a study conducted in Canada which established that the MHCUs expressed a need for support services (Fleury, Grenier, Bamvita & Tremblay, 2013:365). The expression of expectations suggests self-awareness regarding their unmet needs (Broadbent et al., 2008:148; Tomita, Burns, King et al., 2016:13). The expectations also show their awareness of the role of mental health care practitioners as providers of services to themselves and their families. Although doctors determine eligibility, not every MHCU qualify for a grant. However, social workers as advocates for social justice (Chereni, 2017:509) are instrumental in ensuring that MHCUs and caregivers access social grants (Hall & Sambu, 2018:137), and rehabilitation programmes (Parliamentary Monitoring Group, 2017) and support services (McFarlane, 2016:463). Caregivers have also expressed frustrations and dissatisfaction with services from mental health care practitioners.

Caregiver-BB (Sister)

The police came and were worried that he may smash the state's vehicle. I did not know where else to go for help. … The ambulance arrived, and the paramedics said they could take him in his condition. It was a bioscope (show) - here at the rank (taxi rank), *I'm a bioscope, I'm no longer afraid of the people. On another day, while he*

> *went to get medication from the clinic, I received a call from someone who live around the clinic saying, "come and see your brother is walking naked to the clinic". One of our relatives had to give him a trouser and asked him to return home. He refused and proceeded to the clinic - still naked. At the clinic he was given medication and sent home still naked. The clinic staff did not call the ambulance. I thought it was a joke, I just said "we will remain the bioscope of the world – what can I say?" …At the hospital I told the doctor that "I tried many times to call the ambulance and the police who never came – I don't know what to do, or do I have to suffer like this for being his sister? – when the hospital says I must care for him, does that mean I must tie or carry him on my back or what? I don't know."* (Female, 52 years)

Studies that examined the needs of caregivers revealed that caregivers needed support to provide for the needs of MHCUs (Shankar & Muthuswamy, 2007:303; Anokye, 2018:327). They contend with difficult and aggressive behaviour of the MHCUs due to lack of information regarding the cause, treatment and prognosis (Chan & O'Brien, 2011:386; Robles-García, Fresán, Berlanga & Martínez, 2012:812) including the stigma resulting from being relatives and carers of the person with mental illness person (Quinn & Knifton, 2013:554; van der Sanden, Bos, Stutterheim et al., 2015:400). However, Makgoba (2017:2) encourages service providers to listen and address caregivers' expectations. Moreover, mental health service providers should be accessible and empowering to caregivers. Although there are other competing human needs that must be fulfilled (Gorman, 2010:28), recovery for the MHCUs is the caregivers most desired outcome. Mental health care practitioners together with caregivers need to ensure that the MHCUs recovery from mental illness is achieved.

However, other studies have found that some mental health care practitioners do not accord MHCUs and caregivers an opportunity to express their expectations, but rule out their explanations as unreliable, irrelevant or difficult to verify (Velpry, 2008:241; Rogers & Pilgrim, 2010:2; Wong, 2014:133). They tend to perceive the needs of MHCUs, in particular, as influenced by hallucinations and delusions, and are therefore ignored as not genuine (Rogers & Pilgrim, 2010:242; Wong, 2014:133). Family members are also ignored as they are perceived as sharing the same perspective as the MHCUs (Rogers & Pilgrim, 2010:244). However, Tew (2011:123 &125) argues that recovery is not about becoming symptom-free, but the ability to resist problematic symptoms, for instance, internal voices or irrational beliefs. Therefore, the families' expectations are for the mental health care providers to render support for the recovery of MHCUs.

5.4 CONCLUSION

The chapter explores MHCUs’ and their caregivers’ understanding and experiences of mental illness, its causes, treatment and the role of mental health care practitioners in the provision of mental health services. It also explores interpersonal and family relationships, and how MHCUs and caregivers perceive their personal, family and community roles. The social perspectives are considered to explain the effects of mental illness on their functioning and the role of caregivers in the provision of mental health services to promote recovery of MHCUs.

The MHCUs explained their experiences of the onset of the symptoms of mental illness and its causes. Male MHCUs had used dagga which aggravated mental illness. Stress, depression and supernatural forces are included as causes of mental illness. All the MHCUs were previously admitted to hospital for treatment. Some had consulted traditional and religious healers before hospitalisation. The hospital treatment was provided by mental health care practitioners (doctors, nurses, psychologists, social workers and occupational therapists) and indigenous healing practitioners (traditional and faith healers). Some received disability grants following their discharge from hospital.

The MHCUs received a 24-hour care from caregivers who lived with them. This arrangement, facilitated their responsibilities of ensuring that MHCUs take medication regularly, eat properly, accompany them to hospital, provide information to mental health care practitioners and to request information regarding diagnosis and psychosocial interventions. Moreover, the caregivers did not abandon the MHCUs despite being victims of their violent behaviour or threat thereof. Support from some relatives coupled with caregivers’ resilience have sustained their caregiving responsibilities. This has enabled them to endure the negative burden of caregiving which was exacerbated by, among other things financial constraints, high cost of living, limited professional support, and disruptions of their personal and social development.

CHAPTER SIX

EMPIRICAL FINDINGS ON THE EXPERIENCES OF SOCIAL WORKERS IN MENTAL HEALTH SERVICES

6.1 Introduction

As part of the multidisciplinary team, social workers shared their experiences through semi-structured interviews. The data were independently analysed by the researcher and an independent coder for credibility. The findings are also compared with the literature to establish their trustworthiness (Morrow, 2005:250; Ngulube, 2015:7).

6.2 Demographic profiles of social workers

This section presents the demographic profiles of the participants.

Table 6.1: Demographic profiles of social workers

Participants	**Age**	**Gender**	**Years of experience**	**Place of work**
K	46	F	14	Community-based (CB[14])
L	43	F	13	Psychiatric hospital (PH[15])
M	42	M	5	Community-based (CB)
N	40	F	9	General hospital (GH[16])
O	40	M	7	Psychiatric hospital (PH)
P	33	M	4	Psychiatric hospital (PH)
Q	33	F	7	General hospital (GH)
R	30	F	4	Psychiatric hospital (HP)
S	26	M	3	Psychiatric hospital (HP)

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[14] CB stands for community-based
[15] PH stands for psychiatric hospital
[16] GH stands for general hospital

6.2.1 Age and gender of social workers

The biographic profiles of social workers reveal that nine social workers were between 25 and 47 years of age with an average of 33 years. Six were females and three males. Their ages suggest that they are matured to understand their roles as providers of mental health services (Wilt et al., 2010:156). Six participants were in the intimacy versus self-absorption or isolation (21 to 40 years) stage of development and the expectation is that they form long-term intimate relationships and have children. Three were in the generativity versus stagnation (40 to 65 years) stage which required that they should have close friendships, provide for their families, engage in community activities and enjoy overall good mental health.

6.2.2 Qualification of social workers

All the participants had a Bachelor of Social Work (BSW) degree which enabled them to register with the SACSSP to practice as stipulated in the Social Service Professions Act (Act No. 110 of 1978). None had received or enrolled for any post-graduate qualification. Their average work experience was seven years.

In Australia, a suitable social worker in mental health should attain a postgraduate qualification (Martin, 2013:280). Unlike Australia (Martin, 2013:280) and Britain (Coppock & Dunn, 2010:35), South Africa does not have postgraduate qualification in mental health for social workers. Previously, the University of South Africa (Unisa) offered a coursework master’s degree in mental health which was phased out in 2010 and the last students completed at the end of 2013. A study by Olckers (2018:34) reveals that the SACSSP does not have a scope for social workers to train and practice mental health. Although clinical social work has a focus on mental health, it is only offered as a master’s programme (Van Breda & Addinall, 2020). However, the Professional Board of the SACSSP, in collaboration with the Association of South African Social Work Education Institutions (ASASWEI), has conducted a review of the scope of practice for social work which culminated in the approval for specialisation in clinical social work (SACSSP, 2018; Van Breda & Addinall, 2020).

Social workers participate in needs-based training organised by employers or Continuous Professional Development (CPD) workshops offered by independent trainers to acquire knowledge and skills in assessment and intervention in mental health. However, some MHCUs, caregivers and family members were not happy with their services.

Mental health is one of the fields of practice in social work (Gray, 2010:87). In South Africa, mental health services are offered at both hospital and community levels. The White Paper on Social Welfare (DSD, 1997) identifies mental health as a sub-category of disabilities and outlines the functions for social workers providing mental health services. In support of a multidisciplinary team, the Mental Health Care Act (Act No. 17 of 2002 section 1: xvii) includes a social worker as a mental health care practitioner “trained to provide prescribed mental health care treatment and rehabilitation services”. However, a concern is that the White Paper on the Rights of Persons with Disabilities (WPRPD, 2015) and the White Paper on Social Welfare (DSD, 1997), makes no mention of mental health care.

General hospitals provide psychiatric services and social workers based in hospitals in collaboration with those in communities are expected to address the needs of MHCUs, their families and communities. In the Capricorn district where the study was conducted, the MHCUs with severe mental conditions are transferred to Thabamoopo Psychiatric Hospital. In some instances, hospital-based social workers visit the MHCUS’ families to explain the nature of the illness and/or prepare them for the imminent discharge of the MHCUs from the hospital; identify community resources to support the MHCUs and their families; offer family psychoeducation on the importance of the MHCUs’ adherence to medication to minimise relapses and improve the MHCUs’ social functioning.

6.3 Presentation of themes, subthemes and categories

Four themes, seven subthemes and five categories (Table 6.2) emerged from the data analysis, as stipulated in the table below.

Table 6.2: Themes, subthemes and categories

Themes	Subthemes	Categories
1: Social workers' experiences in working with families of MHCUs	1.1 Families' lack of understanding of the role of social workers in the provision of mental health services	
	1.2 Social workers' perceptions of family experiences	1.2.1 Social workers' accounts of families' lack of understanding of mental illness 1.2.2 Social workers' accounts of challenges experienced by families in caring for MHCUs 1.2.3 Social workers' impressions on caregivers' lack of support from other family members within the household 1.2.4 Social workers' perceptions of families' coping abilities 1.2.5 Social workers' perceptions of the families' understanding of the treatment of mental illness
2: Services provided by social workers to MHCUs	2.1 Psychosocial support to MHCUs and their families 2.2 Use of case management in the provision of services to MHCUs and their families 2.3 Facilitation of the provision of social assistance to MHCUs and their families 2.4: The working relationship between the	

	hospital and community-based social workers	
3: Social workers' views on partnerships with families of MHCUs		
4: Social workers' opinions on who should form part of the mental health care team to work with families of the MHCUs		

6.3.1 Theme 1: Social workers' experiences in working with families of MHCUs

Social workers interact with families as they provide services to MHCUs. Their practice is developmental in approach focusing on the social context of mental illness to understand the experiences of MHCUs and their families (Jeon, Chenoweth & McIntosh, 2007:6; Moller-Leimkuhler & Wiesheu, 2012:157; Ennis & Bunting, 2013:1). Their PIE orientation (Gray, 2010:80) encourages forging partnership with caregivers and families of MHCUs to create a responsive social environment. Therefore, partnership suggests involvement of the family as a primary support system working with social workers to enhance the provision of effective and sustainable mental health services.

Social workers' experiences of working with families of MHCUs are further discussed in the following two subthemes and five categories.

6.3.1.1 Subtheme 1.1: Families' lack understanding of the role of social workers

Historically, the mental health institutions were homes for the mentally ill (Chow & Priebe, 2013:1) as families were perceived as lacking the capacity to care for them. Hence, the provision of mental health services was associated with nurses and doctors only (Na, Yim, Lee et al., 2015:298). This phenomenon seems to have perpetuated the belief among family members that treatment and care for their relatives with mental illness was the responsibility of the mental health professionals. Social workers, who are a part of the mental health professionals (Jaworowski, Barel & Gropp, 2003:338; Faust, 2008:293; Coppock & Dunn, 2010:20) are not perceived by families as involved in mental health care. Therefore, family caregivers show lack of understanding of the role of social workers regarding the provision of mental health services.

> *I don't know if it is because they* [family members] *have been living with these MHCUs for a long time, they are exhausted. It becomes difficult, because when social workers try to reunite the MHCUs with their families, no one volunteers to take care of them. Others would just come to the office* [social workers' office] *thinking that Thabamoopo Psychiatric Hospital is an institution where MHCUs stay forever. They do not understand that it is where patients are treated and, when they get better, they should go back home. They often argue that they do not want the patient anymore and that they should be transferred to Thabamoopo Psychiatric Hospital. When it is explained to them that a social worker is not responsible for transferring patients to Thabamoopo and that only the doctor could do that, they find this unacceptable. According to them a social worker is responsible for the uninterrupted care for the MHCU.* (Female, 46 years, CB)

> *Based on my experience, mental illness in many communities remains stigmatized. When MHCUs are brought to the hospital, families tend to believe that they are coming for good and they no longer want them. They do not realise that our role as professionals and government is to rehabilitate them and return them home.* (Male, 40 years, HB)

> *They think Thabamoopo Hospital is a permanent home for MHCUs. They do not accept that MHCUs are admitted for treatment and should be discharged and go back home when they feel better.* (Female, 30 years, HB)

The findings suggest that institutionalisation of MHCUs was the service that families required as a form of relief from the burden of caregiving. Families seem to believe that the mentally ill belong to mental institutions away from families (Chow & Priebe, 2013:1). Moreover, institutionalised care is still one of the main services offered worldwide including South Africa (Irmiter, McCarthy, Barry et al., 2007:279; WHO cited by Lund & Flisher, 2009:1040). Furthermore, stigmatisation of mental illness, MHCUs and their families (Ray & Dollar, 2014:720), makes it difficult for some family members to care for their ill relatives. Additionally, the families' need for institutionalisation of the MHCUs may also suggests their lack of capacity to care for them. For instance, the MHCUs' repeated relapses and aggressive behaviour may be a motivation for caregivers to seek their institutionalisation (Mowbray, Collins, Bellamy et al., 2005:7; Chow & Priebe, 2013:8). Moreover, a request for institutionalisation could serve as a help-seeking behaviour by caregivers struggling to manage severe episodes of the illness (Irmiter et al., 2007:279; Starnino, 2009:823; Pickard, Inoue, Chadiha & Johnson, 2011:248). Therefore, institutionalisation may benefit families as a relief from emotional and physical strain of caregiving and social stigma (Wong, 2014:243).

However, institutionalization does not suggest anything wrong with deinstitutionalization. The latter offers MHCUs an opportunity to reintegrate in the community and to function with minimal support (Ahmed, 2018:105). Family members can maintain closeness and acceptance of the MHCU as a family member. It also enables social workers to interact with families in their home environment to understand their experiences and challenges in caring for the MHCUs. Families will, in turn, develop a better understanding of the services offered by social workers in mental health.

6.3.1.2 Subtheme 1.2: Social workers' perceptions of family experiences

In mental health, social workers engage families to understand their caregiving experiences and develop intervention plans (Milbourn et al., 2015:217). Caregivers often experience a burden that affects their social, physical and emotional functioning (Heru, Ryan & Vlastos, 2004:67; Pickard et al., 2011:248). The social workers' perceptions of caregivers' experiences are articulated in the following categories.

Category 1.2.1: Social workers' accounts of families' lack of understanding of mental illness

Social workers are often approached to intervene at the point where families are experiencing caregiving challenges (Nathan & Webber, 2010:23). However, such challenges may be due to the caregivers' lack of understanding of mental illness.

> *The problem* [lack of understanding] *is that the family members as they do not understand mental illness, for instance, when the MHCU touches an item (something) in the house, they tell them not to break it or that the item belonged to another member of the family. As a result, the MHCU feels unwelcomed. Family members offend the MHCUs and when they express their feelings regarding the treatment, they are ignored and labelled "segaswi" (mentally ill).* (Female, 46 years, CB)

> *They* [family members] *would usually say that the MHCU is destroying things and they cannot cope with that behaviour anymore. Most of the time, when* a social worker *makes a follow-up, they discover that the incident actually had happened three years before. The family did not give them the support they required. They only see the MHCU as causing problems for the family. There could be - different ways of handling the situation. They should share their previous efforts before asking for intervention.* (Female, 43 years, HB)

The findings are consistent with those of previous studies blaming families for contributing towards the MHCU's illness (Jones, 2004:962; Beresford, 2005:60; Lidz, Cornelison, Fleck & Terry cited by Muhlbauer, 2008:100; McCann, 2016:2). Notably, the participants did not mention the fact that family reactions might have been due to the impact of mental illness on their functioning (Gutierrez-Maldonado, Caqueo-Urizar & Ferrer-Garcia, 2008; Crowe & Lyness, 2014:186) than the purported lack of understanding of mental illness. Moreover, families might not have known that the MHCUs' behaviour could have been influenced by psychiatric conditions (Rogers & Pilgrim, 2010:242; Wong, 2014:133). Furthermore, their reactions could have been informed by their experiences of the unpredictability of the behaviour of the MHCUs (Stiles, 2013:139). Notwithstanding their limited understanding of mental illness, families continue to provide care to the MHCUs.

Mental illness is a challenging condition experienced in societies. Caregivers may be fearful that once afflicted the MHCU would "forever be mentally ill even when there is no longer a trace of mental illness" (Rogers & Pilgrim, 2010:36). The literature on caregiving has largely associated such reactions with a burden of caregiving (Crowe & Lyness, 2014:186) and not with caregivers' lack of understanding of mental illness. Such families struggle to come to terms with the presence of a person with mental illness (Jones, 2004:962; Rowe, 2010:437). Hence, the need for social work intervention to help them understand the complexity of mental illness and caregiving responsibilities (James, 2012:19). Social workers should assess the social environment of families in order to derive the reasons for their lack of understanding of mental illness.

Category 1.2.2: Social workers' accounts of challenges experienced by families in caring for MHCUs

Literature shows that one out of four families worldwide has at least a member suffering from a mental disorder (Shamsaei et al., 2015:1). Families experience mental illness as a complex, mysterious, disruptive and distressing condition (Opare-Henaku & Utsey, 2017:1; Lloyd et al., 2017:1), and therefore, difficult to manage. The fact that schizophrenia has no known prevention or cure (Insel & Scolnick, 2006:11; Lloyd et al., 2017:1), contributes to the stress experienced by caregivers whose caregiving responsibilities may never end. Antipsychotic medication only reduces the severity of psychotic symptoms without completely returning the MHCU to the initial normal functioning (Rogers & Pilgrim, 2010:196; Lloyd et al., 2017:1). Families find themselves having to contend with relapses which have become common among individuals with schizophrenia (Earle & Heymann, 2012:359). Participants explained the challenges that families experienced as involving the MHCUs' defaulting medication, substance abuse, psychotic symptoms, violent and disruptive behaviour.

> *….Actually, the main challenge they present is the defaulting of treatment by the MHCUs.* (Male, 42 years, CB)
>
> *The major problem is that the patients default on treatment. It is a major problem because when they are home nurses, social workers and other professionals are based in hospital. The families are able to notice that the MHCUs' behaviour is no longer the same as when they left the hospital following their discharge or before the onset of the illness. Most families say they would observe a person laughing alone, working extremely hard, starting fights in the family, spending money unreasonably, another just giving away money; that is how they notice that the person is not well.* (Female, 30 years, HB)

Social workers confirmed the negative experiences of families after the MHCUs had stopped using prescribed medication (Burbacha & Stanbridge, 2006:41; Bener et al., 2013:278). The findings have also been confirmed by family caregivers (cf. Chapter Five, Item, 5.3.4.2). The violent behaviour of the MHCUs defaulting on treatment may destabilise family relations and their normal functioning. Lack of amenities for the MHCUs may contribute to their boredom which may increase the deterioration of their functioning (Flyckt et al., 2015:684), hence, the need for social work intervention to strengthen family relations and adherence to treatment, and improve access to services (Webber, Reidy, Ansari et al., 2014:14). Substance abuse by some MHCUs aggravates violent behaviour that leads to non-adherence to medical treatment.

> *The families would say the MHCU was fighting. Most of the time it is the problem of substance abuse, for instance, when the MHCU returns to drinking alcohol and/or smoking dagga, they assault family members. In most instances the MHCUs would have defaulted on their medication and started using substances.* (Female, 46 years, CB)

Social work practice requires social workers to conduct assessments to understand the experiences of families of violent individuals with mental illness (Faust, 2008:296; Ahmed-Mohamed, 2011:9; Moore, 2012:105). The assessment that social workers conduct enable families to discover that the violent behaviour of MHCUs is due to the default on treatment and the use of substances. Supporting this view is research conducted in the UK, Canada, Australia, Sweden and the United States (Chorlton & Smith, 2016:325) regarding the effect of defaulting from treatment and the use of substances which trigger the violent behaviour of MHCUs. Social work assessment may involve the PIE which focuses on the bio-psychosocial, cognitive and social environment through which social workers interact with families to identify risk factors that exacerbate social problems (Webber, 2014:176; West, 2018:63). Therefore, social workers are able to use the information provided by families to understand their experiences and advocate for their access to social justice.

Category 1.2.3: The social workers' impressions on caregivers' lack of support from family members within the household

Caregiving is generally described as a family role allocated to a specific member (Pharr et al., 2014:1). Caregivers need support to carry out caregiving responsibilities (Pharr et al., 2014:1). However, most caregivers perform their caregiving responsibilities with minimal or no support from other family members. In most African communities, caregiving is a gendered responsibility allocated mainly to women (Aga, Nikkonen & Kylmä, 2014:149; Petrowski & Stein, 2016:2873). Nevertheless, the allocation of responsibilities can also depend on the availability of a family member (Githaiga, 2016:2). Participants noticed lack of family support to caregivers.

> *Another thing that I have noticed is lack of support for caregivers by other family members within the household. Some family members do not participate in the*

> *caring of the MHCU and that becomes a challenge that makes the MHCU to feel unwanted.* (Female, 40 years, HB)

> *Most of the time it was a challenge where caregivers lacked support because their experiences would be so overwhelming. This is the reason why on many occasions they would struggle to get assistance.* (Female, 43 years, HB).

The findings show that caregiving and the functioning of the MHCUs are closely linked and impact on one another. According to Friedmann (cited by Sanders et al., 2014:257) the impact is on “the psychosocial dynamics and adaptation among the entire family as a unit”. Both the caregivers and MHCUs may experience social isolation, stigmatisation, feeling unrecognized and undervalued (Jeon et al., 2007:6; Kellett, Shugrue, Gruman & Robison, 2010:143) by other family members.

Although lack of family support is a common practice within the individualistic western culture (Wanless, 2007:117; Nagengast, 2015:82), the findings seem to suggest the emergence of a similar practice among African families that have traditionally provided collective caregiving (Seloilwe, 2006:263; Wilson & Williams, 2013:83). However, lack of family support may also be influenced by social environmental factors concerning the high rate of unemployment (Statistics South Africa, 2017), poverty, financial problems and/or problematic interpersonal relationships (Nordahl et al., 2010:852). Families lose their spirit of *ubuntu* when they can no longer be there for one another (Jensen & Gaie, 2010:297). Lack of cooperation within the family leaves caregivers to contend with disruptive behaviours of MHCUs on an ongoing basis thus prompting them to seek professional support to bolster their caregiving capacity (Muhlbauer, 2008:99; Lloyd et al., 2017:1).

Category 1.2.4: Social workers’ perceptions of families’ coping abilities

Social workers intervene to enhance the coping abilities of caregivers by providing information regarding the behaviour of MHCUs and promoting access to support networks (Iseselo et al., 2016:2).

> *Yes, we do ask them* [caregivers] *about the things they do when the MHCUs shout, swear and break windows. At the hospital we are told that when the MHCUs start shouting they call neighbours and restrain them. ...Some MHCUs arrive here at the hospital assaulted. Other caregivers would call the social worker who would in turn call the police. Others would say when the MHCU starts shouting, they do not talk to them. They just keep quiet, for instance, if the MHCU*

> *refuses to eat or to bath they do not force the person. Their understanding is that the following day the MHCU would be alright and no longer displaying anger. Other family members have a way of avoiding them and remaining quiet and then they would realise that a particular family member was the best person to deal with the MHCU, then they would call on them to intervene. They would talk to the MHCU's favourite person who would only engage them when ready to do so.* (Female, 33 years, HB)

> *The* [coping abilities] *would depend on the severity of the condition affecting the person, but the one that is fighting, destructive and everybody can't face them, family members would seek refuge with their neighbours. But with the one that is not fighting the family would organise transport to take them wherever they felt they would be helped.* (Female, 30 years, HB)

Coping suggests the ability of families to respond to the behaviour of the MHCU (Huang, Sun, Yen & Fu, 2008:818; Grover et al., 2015:5). A study conducted in Tanzania by Iseselo, Kajula and Yahya-Malima (2016) on the coping abilities of families affected by mental illness explains the burden of caregiving as affecting the caregivers' coping abilities (Iseselo et al., 2016:2). The study shows that families endure aggression in the form of assaults, threats, intimidation, violent behaviour and destruction of property (Iseselo et al., 2016:2). However, factors relating to age, duration of illness, living arrangements and other contextual factors enabled caregivers to develop coping abilities.

Additionally, coping involves the ability to solve problems with regard to managing stress and regulate negative feelings (Friedman & Allen, 2014:13). Caregivers have shown the ability to mobilise resources within their social environment. They have used support from relatives, communities, the police, mental health care practitioners and indigenous healing practitioners to cope with the disruptive behaviours of the MHCUs (Grover et al., 2015:5). Their abilities to mobilise resources ensured that the MHCUs received the required services. Some caregivers were able to develop communication techniques to contain the MHCU's disruptive behaviours (Crowe & Lyness, 2014:186). However, their experiences may be so overwhelming that they seek intervention from social workers. Social workers apply the PIE approach to understand the experiences of caregivers.

> *My experience when working with the families of the MHCUs is that most of the time they are complaining. You realize that they are in fact tired. When they come to you is because they need some relief. They will be tired because of the MHCU*

> *doing the same thing [*disruptive behaviour*] time and time again. So, when they are with you, they are in a different environment where they experience some relief.* (Female, 40 years, HB)
>
> *Some, will tell you that they swear at them, break windows, destroy property – we no longer want them here at home, we would like you (social worker) to take them to a place for people like them. Even families that are well-informed and educated still disown them. We had a case whose family member's sister is a social worker, and it was the very social worker who said, "we don't want him in the family because he hurts us emotionally, he destroys property and he is the only son in the family, but we don't want him in the family". As many people lack information about mental health, they just disown the MHCUs without reservation. It is only when you* [social worker] *give them education on what mental illness is about that the MHCU does something they see things that others may not see, hearing voices of people that others may not hear* [hallucinations] *– that some understand while others remain unyielding*. (Female, 33 years, HB)

The study shows that families endure challenges in caring for their relatives with mental illness, and need support to enable them to cope with the demands of caregiving (Seloilwe, 2006:263; Macleod et al., 2011:101). A study conducted in Taiwan on the impact of caregiving of the mentally ill with schizophrenia reveal that caregivers experienced emotional distress resulting from caregiving responsibilities (Lee, Yang, Chen et al., 2006:546). The distress may result in some families rejecting their relatives with mental illness (Feldman & Crandall, 2007:138; Larkings et al., 2017:206). Consequently, the stigma of mental illness leads to disharmony within the family and social rejection in the community (Feldman & Crandall, 2007:137; Pescosolido, 2013:8).

While participants attributed lack of understanding of mental illness by family members as the source of rejection of the MHCUs, they also acknowledged that rejection is not only limited to family members who may lack knowledge but those with advanced formal education may not welcome the MHCUs too. Additionally, low socioeconomic status and lack of support may affect caregivers' understanding of mental illness (Schulz & Sherwood, 2008:109 &111; Switaj & Wciorka, 2012:53). However, the association between socioeconomic status and understanding of mental illness could not be substantiated in this study. Hence, caregivers have always approached social workers for support in relation to the care of their relatives with mental illness (Lee, 2006:546; Ahmed et al., 2018:106) to improve their coping abilities (Gray, 2010:80).

Social workers are guided by the ecological systems framework, developmental approach and strengths-based approach to interact and understand the experiences of caregivers (Ahmed-Mohamed, 2011:13), and provide intervention services and improve the coping abilities of caregivers.

Furthermore, some families may become overwhelmed to the point of helplessness and despair.

> *Generally, social workers find that families are not coping with the MHCUs. Sometimes the MHCUs just stop taking medication and they relapse. Following the relapse, depending on the severity of the illness, some burn houses, others kill siblings. It becomes difficult for family members to live with such a person. At some point they need some relief, and the only relief is taking the person to the hospital where they can be taken care of.* (Male, 40 years, HB)
>
> *Families get tired of the person* [MHCU] *because of their disruptive behaviour. So, when the MHCUs are admitted into hospital, families feel relieved and get a bit of a respite from caregiving responsibilities.* (Female, 40 years, HB)

The findings confirm the understanding of social workers regarding schizophrenia as affecting not only MHCUs but also their caregivers (Huang, Sun, Yen & Fu, 2008:817; Anokye, 2018:321). Caregivers interact with the MHCUs regularly as their support system (Muhlbauer, 2008:100; Grover et al., 2015:5) while exposed to their aggressive and disruptive behaviour (Yazici et al., 2016:97). The findings illustrate the caregivers' traumatic experiences of living with people who suffer from mental illness which requires intervention. Hence, families show help-seeking behaviour for support and relief from the burden of caregiving (Pickard et al., 2011:251). The involvement of social workers at the micro, meso and macro level will muster required resources to mitigate the caregiving challenges.

Category 1.2.5: Social workers' perceptions of families' understanding of treatment of mental illness

The complexity of mental disorders makes it difficult for families to "know what to do about them, independent of professional guidance" (McFarlane, 2016:462). Family caregivers turn to social workers for assistance. Social workers assist families to enhance their understanding of mental illness (McFarlane, 2016:462) and its treatment. Participants reported on how families sought help for the treatment of MHCUs.

> *When a family member talks alone, the family may conclude that the person has been bewitched. They will take the person to church or to traditional doctors depending on their beliefs.* (Female, 30 years, HB)

> *The family will indicate the person has mafofonyane* [mental illness] – *but not admitting that they are sick. They believe the person has been bewitched. They do not believe it could be hereditary. They may blame other families as responsible for causing the illness. Some would go to traditional healers who would reassure the family that the person's condition was caused by so and so and they would ensure that the illness infected the person who caused it.* (Female, 42 years, CB)

> *But others will not tell you. Most of them are afraid because, according to our* [participant] *culture* [African] *people are afraid to reveal that they are consulting traditional healers, especially when they are in hospital. But they do consult traditional healers. When you probe further, you find they have been to traditional healers where you will find that the MHCU was chained. The MHCU might have committed an offence due to anger as a result of been chained by the family that was only trying to help. He wants to be treated like a human being but family members are also not aware that they are ill-treating them.* (Female, 33 years, HB)

Families have their own construction of mental illness and its treatment influenced by belief systems (Swartz, 2004:92; Poirel, Corin & Del Barrio, 2011:88; McCann, 2016:2). Studies on the use of traditional healing in South Africa reveal that most families prefer indigenous healing (traditional and faith healing) as the treatment of choice for mental illness (Campbell-Hall et al., 2010:612; Zingela et al., 2019:146). Indigenous healing is used as a treatment of choice especially in rural communities where the services of mental health care practitioners are scarce (Campbell-hall et al., 2010:611; Pouchly, 2012:66).

Research has linked preference for traditional and faith healing to their availability and accessibility to families as compared to services offered by the mental health care practitioners and social workers (WHO, 2009:23; Campbell-hall et al., 2010:611; Bojuwoye & Sodi, 2010:283). Although social workers are critical of the methods of treatment used by traditional healers, their services are not always accessible as those of traditional healers. In most cases the traditional and faith healers are the first people that most families consult because their treatment is in keeping with their belief systems (Crawford & Lipsedge, 2004:131; Bartholomew, 2016:115). In ecological terms, traditional healers offer treatment that is compatible with the social environment and expectations of families. Their involvement helps reduce shortage of mental health providers by providing psychosocial support to MHCUs and their families (Mzimkulu & Simbayi, 2006:419; Bartholomew, 2016:113). This is despite perceptions within the mainstream western context of mental health system that traditional healers lack the capacity to provide mental health services (Campbell-Hall et al., 2010:613; Keikelame & Swartz, 2015:659). Even though families continue to trust traditional and faith healers, some are fearful to reveal to the mental health practitioners that they had consulted traditional and faith healers due to the negative perceptions of the latter.

However, lack of appreciation of the role of traditional practice by mental health practitioners shows the inability to apply the PIE strategy to address the challenges posed by the mental health system. Hence social workers must be culturally competent to appreciate the diversity of the families' lived experiences (Good & Hannah, 2014:198). This means social workers must understand that families may associate mental illness with supernatural factors involving witchcraft and would seek traditional or faith healing (Nwoye, 2015:310). Such understanding should reflect the ecological systems approach which requires social workers to recognise, understand, and support families within their sociocultural context (McCann, 2016:6) and to work with the family in ensuring appropriate methods of intervention.

However, participants have observed that families would seek treatment from the western-trained health care practitioners and social workers should indigenous healing fail. The findings indicate that the use of hospital treatment does not suggest the abandonment of the traditional and religious healing. Most families would ensure that the MHCUs adhere to the hospital and traditional or faith healers' treatment. One of the participants who had similar cultural beliefs with families of the MHCUs, shared her preference for traditional and faith healing.

> *Another thing is religion where the MHCU would belong to a church that uses religious rituals. I'm afraid of mentioning them. Let us assume the church uses tea, and the MHCU is not defaulting on medication and they adhere strictly to the*

> *medication but because they use tea as prescribed by the church or medicine from a traditional healer, the tea would dilute the effect of the medication causing them to relapse and become violent.* (Female, 46 years, CB)
>
> *Families reported that when the MHCU was on treatment from the hospital and traditional or religious healers, they tended to believe the dosage would speed-up recovery, only to cause overdose. The families would refer them to the church or healers where they got the medicine or even to the social workers, or the doctor; as most MHCUs listen to the doctor's instructions, if the doctor tells them "don't drink too much tea or don't ever drink tea because it causes damage", the doctor may be the one they understand.* (Female, 43 years, HB)

Mental health care practitioners are aware of the importance of being culturally competent. The findings articulate their recognition of cultural and religious factors influencing the choice of treatment in families. It is also a recognition of the role of traditional and religious healers as providers of mental health services (Sorsdahl et al., 2010:592). Therefore, social workers do not discourage the MHCUs from using traditional medicine (Campbell-Hall et al., 2010:619). This recognition reflects their (social workers) ability to notice their (families) strengths and support their resilience (Aarti & Sekar, 2006:127; MacFarlane, 2011:56). Such an approach is consistent with the social model of intervention which requires social workers to be culturally competent in their practice (Ahmed-Mohamed, 2011:6; NASW, 2015:4). Like traditional and religious healers, social work intervention is non-medical but family-focused and promotes the integration of both medical and social approaches to mental illness (Bojuwoye & Sodi, 2010:284).

Social workers have expressed concerns regarding the concurrent use of both traditional and hospital medicine causing side-effects to MHCUs. This concern highlights the contradictions that persist between traditional and hospital forms of treatment. Additionally, the concern seems to reveal the social workers' pessimism regarding the effectiveness of indigenous healing (Campbell-Hall et al., 2010:612). Moreover, the concerns that social workers express seem to highlight families' lack of information regarding the side-effects resulting from the concurrent use of traditional and hospital treatment. Therefore, lack of information may limit the ability of families to access social work services (McFarlane, 2016:463). Some participants have found that families lacked information regarding mental illness and caring for the MHCUs.

> *As the family lack information or knowledge of how to work with MHCUs they experience problems that require us as service providers to assist them in dealing with the patients. Sometimes, when a person develops mental illness, families may not understand that it is mental illness. Instead, they may see it as a behavioural problem in the case of a young person while an adult would be said to have changed or attribute it to witchcraft. If the mental health condition develops when the person is employed and productive, they may attribute that to witchcraft or others' jealousy of their success.* (Female, 30 years, HB)

> *The issue is that families lack information regarding mental illness hence, they want to have the person placed somewhere. …Most of the time, especially in communities, families treat MHCUs as people who cannot make decisions for themselves.* (Male, 42 years, CB)

A study in Botswana on experiences of families with people with mental illness shows that caregivers provide care despite their lack of adequate knowledge, experience and resources of caring for such a person (Seloilwe, 2006:263; Giron et al., 2010:75). Research shows that caregivers need information regarding mental illness to carry out their caregiving responsibilities which require insights, judgment and critical thinking (Given, Sherwood & Given, 2008:120; Ahmed & Baruah, 2015:43). However, caregivers experience barriers that deny them adequate information regarding mental illness. Practitioners' attitudes, beliefs and stigma have been identified as contributing to discrimination against caregivers thus serving as a barrier to the sharing of information on mental illness (Knifton, 2012:287; Quinn & Knifton, 2014:554) and access to social support network (Kotadia, Walton, Webster et al., 2018:13). The implication resulting from lack of information is the inability of caregivers to access support network services to improve their caregiving responsibilities for MHCUs. It also makes caregiving difficult as they may not know how to manage the effects of the illness. This calls for social workers' initiative to develop networks for caregivers.

6.3.2 Theme 2: Services provided by social workers to MHCUs

Social work practice advocates for a social rather than medical perspective focusing on the socio-cultural context of individuals and families (Casstevens, 2010:385; Payne 2014:185; Sawyer et al., 2016:129). It is guided by the ecological systems approach that examines the transactional relationships between systems involving individuals, families, communities and their social environment in order to enhance understanding of the PIE interactions to promote recovery (Tew, 2011:123; Friedman & Allen, 2014:17). Social work is predicated on the understanding that most people with mental health problems experience social problems in the form of poverty, unemployment and lack of access to resources (Conrad & Barker, 2010; Webber et al., 2014:14). Hence, it is imperative to advocate for the empowerment of individuals and families including the transformation of service delivery (Gray, 2010:79). Families seek help from social workers to cope with challenges of caregiving for their relatives with mental illness (Lee et al., 2006:546; Crowe & Lyness, 2014:186). Therefore, social workers should provide services that are responsive to the needs of MHCUs and caregivers across the continuum of care (Sherman & Carothers, 2005:115; Corrigan & McCracken, 2005:32; Khumalo et al., 2012:423). Such services may include psychosocial support in the form of material aid, social grants, skills development and rehabilitation programmes (Proctor, 2004:196; Kyzar et al., 2016:1). The role of social work is, therefore, to promote accessibility and quality of mental health care to help MHCUs achieve their functional capacity.

6.3.2.1 Subtheme 2.1: Psychosocial support to MHCUs and their families

In South Africa, social workers provide services to MHCUs and their families at both hospital and community levels. Psychosocial support is one of the key services that social workers provide to reduce the severity of psychiatric symptoms by improving caregiving skills, social and family functioning, and promote recovery (Rapp et al., 2014:606). Social workers apply psychosocial approach focusing on the contexts in which MHCUs and families live (Lerner cited by Greenfield, 2011:532; Masoga & Shokane, 2018:6) (cf. Chapter Two, Item 2.2.6.3). The approach views every family member as affected by the effects of mental illness and therefore the entire family becomes the target of intervention (Bland & Foster, 2012:517; Gambrill, 2012:481). Supportive family intervention in the form of psychotherapy and advocacy is one of the therapeutic strategies used by social workers to help families and their relatives with mental illness to cope with the impact of mental illness (McFarlane, 2011:57; McFarlane, 2016:461) and to enhance personal, family and social functioning (Ward et al., 2011:4).

Social workers should advocate for policies that help individuals, families and communities to access mental health services (Faust, 2008:293; Shankar et al., 2009:29; Ahmed-Mohamed, 2011:11). Advocacy ensures that social workers provide social support to MHCUs to address the psychosocial effects of mental illness and to cope with caregiving responsibilities (Foldemo, Gullberg, Ek & Bogren, 2005:137; Chereni, 2017:508). Their use of the strength perspective enables them to recognise skills, insights, hopes and aspirations of caregivers in their provision of services (Rani, 2015:445) (cf. Chapter Three, Item 3.5.1). Participants reported to have used assessment skills to understand needs and provide services to families and their relatives with mental illness.

> *We have a basket of services that we are rendering to MHCUs and caregivers. Counselling is key, particularly trauma counselling based on the nature of behaviour displayed by MHCUs in the past and considering that they have to go back to live with the family members they have offended which may make their acceptance difficult. We also give support services to MHCUs and caregivers to cope.* (Female, 33 years, HB)

> *The first is support and counselling – we offer counselling to the MHCU or the family. We offer psychoeducation to the MHCU about their medication and substance use.* (Female, 46 years, HB)

> *In fact, psychosocial support is required. The first thing is to offer counselling for the family. Most of the time the family may no longer understand the MHCU who has become a burden. The MHCU, on the other hand, would be complaining that they were not receiving proper care from the family and felt overwhelmed. It becomes necessary to bring them together to understand the need for them to work together. This requires counselling, focusing on supporting the family so that they do not become overwhelmed. There are those who think the MHCU is not sick but just being difficult because there is a time when a MHCU functions well and a time when they do not.* (Female, 43 years, HB)

The findings are consistent with the case management process for social work practice applying counselling as a technique of intervention (Rapp & Goscha, 2004:320; Kanter, 2016:341). The four counselling paradigms are the organic-medical, psychological, systemic-relational and social constructivism (Cottone, 2007:192). The first three paradigms focus on the illness and its impact on the family functioning (Becvar & Becvar, 2009:275; Sicras-Mainar et al., 2014:1), while social constructivism focuses on the socio-cultural context of the illness and its impact on the family functioning (Kumar, Srivastava, Kumar & Kiran, 2015:157). Although social workers may apply all paradigms, social constructivist counselling as a contextual approach seems more appropriate when working with families (Cottone, 2007:192; Ahmed-Mohamed, 2011:9) within their PIE context.

The findings emphasise the impact of mental illness on the interpersonal and family functioning. Social workers apply the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Harkness, 2011:224) and the social constructivist intervention to recognise the social aspects of mental illness (Ratts et al., 2016:29). Counselling allows the social worker to work with both the MHCU and the family to help them understand the diagnosis, its effect on the family functioning, the importance of adherence to medication and family support (Gavois, Paulsson & Fridlund, 2006:102; Makgoba, 2017:2). In addition to counselling, the participants have also identified psychoeducation as part of the basket of the services provided to MHCUs and their families.

> *We first offer them education* [psychoeducation] *on mental health care. We give them a full explanation of what mental illness does to a person. We also give them counselling for emotional healing and acknowledge their contribution in caring for the MHCU as it is not easy to discover what a MHCU can become – they may kill you or do something to hurt one unintentionally. They may hit your head with a rock and say "I was killing a snake." We also offer counselling because most of them* (MHCUs) *experience emotional pain.*

A study by McFarlane (2016:462) explains the effectiveness of psychoeducation in promoting the caregivers' abilities. Psychoeducation and psychosocial support programmes form part of the family intervention programmes offered to MHCUs and family members (Chien, 2008:29; Economou, 2015:259). Participants confirm providing psychoeducation to MHCUs and their families to promote recovery and family functioning (McFarlane, 2016:462). Even though there is no evidence of success for MHCUs and their families, the experiences of the participants suggest that psychoeducation is effective in improving family relations and functioning (Economou, 2015:259) by involving the MHCU, caregiver and family members in an ongoing treatment and rehabilitation (McFarlane, 2016:460). Some of the participants reported that they had provided significant amounts of services as part of the continuum of care.

> *We provide care and support through counselling for MHCUs and their families depending on the situation. We admit MHCUs, rehabilitate and discharge them.*

> *We also provide aftercare services after the MHCU had been discharged from hospital. Subsequently, we visit the families to assess if patients were still on treatment, relationships in families and how they were coping after the hospitalisation of the MHCUs. (Male, 40 years, HB)*
>
> *We offer several services. In the first place, there are families which lack information and knowledge. They may be traumatised – living with a person, who was once normal and afflicted by mental illness. This has an impact on the functioning of the family. So, we provide support services through counselling. Most of these families are poor and, therefore, may not afford to provide material support to MHCUs. They use their financial means to seek help for the MHCU. Where they lack in terms of material supply, we provide food parcels. …We also provide psychosocial support for MHCUs to understand their illness (its nature) and to enable self-management. The family is also helped to ensure that they assist the MHCU to take medication as prescribed.* (Female, 30 years, HB)
>
> *We also provide emotional support to help them (caregivers) cope with caregiving challenges. We offer mainly family support services to preserve families, especially that most of the time the MHCU would have been caused damage before they were admitted into hospital. At times the family would reject the MHCU and we would try to rebuild relationships so that the family became functional again.* (Male, 42 years, CB)

The findings are consistent with those from a study conducted in Tanzania which found that MHCUs and their families needed psychosocial support to improve their quality of life (Iseselo et al., 2016:2). The provision of psychosocial support is predicated on the understanding that families experience constraints due to lack of income, lack of social support, family dysfunction, stigma and discrimination, and MHCU’s disruptive behaviour (Quah, 2014:596; Iseselo et al., 2016:1).

Social workers provide family support to strengthen the caregiving functions of the family and their relative with mental illness (Singer, Biegel & Ethridge, 2009:98; Crowe & Brinkley, 2015:286). Family support as a psychosocial intervention include individual and family therapy to restructure family relations, the provision of material support and facilitation of access to social services (Mavundla et al., 2009:363; Shor & Shalev, 2014:69; Wong, 2014:242). The intervention is based on the social model approaches which recognise diversity and uniqueness of people within their social and cultural contexts (Cottone, 2007:198; Neal & Neal, 2013:723). The findings show that social workers interact with individuals and families within their environment to understand their needs and to work together in developing appropriate interventions (Gambrill, 2012:482).

Linked to psychoeducation is awareness raising which participants identified as part of the services they provide to MHCUs and their families.

> *When families visit the hospital during awareness campaigns, we inform them about our open-door-policy to the provision of services. The policy stipulates that they are free to communicate telephonically or visit offices for assistance. Our use of Bathopele* [person-centredness] *Principles ensure access to services. …Most of the time families would come and we would have discussions with them. There is an event committee which is responsible for awareness raising programmes in the communities (outside the hospital) with the main focus on schools because we have realised that the high rate of admissions is caused by substance abuse especially dagga*. (Male, 26 years, HB)

> *Dagga leads to the development of psychosis. Occupational therapists encourage MHCUs to do gardening at home as many families have access to water. They advise them to buy seeds from the local shops and teach them how to plant them*. (Male, 33 years, HB)

Awareness raising is a preventative intervention in families and communities (Kakuma et al., 2010:117; Weine, 2011:411). It is a community-based activity linked to the developmental approach applied in social work to empower individuals and families in dealing with their challenges (cf. Chapter Three, Item 3.2.4). Studies in South Africa have revealed high levels of stigmatising attitudes towards MHCUs and their families (Kakuma et al., 2010:117; Zelst, van Nierop, van Dam et al., 2015:2). Stigmatisation has an impact on interpersonal relationships, family and social functioning (Gonzalez-Torres, Oraa, Aristegui et al., 2007:14; Audu et al., 2011:55). Hence, public stigma requires awareness raising of the public to fight it.

The focus of awareness raising programmes is about enhancing social network support for families; knowledge and caregiving responsibilities; communication within the family; linking the family with mental health services and community support network (Weine, 2011:411). The findings are consistent with Sithole's (2017:302) appeal to social workers to make community development part of their methods of practice because of its role in awareness raising programmes. Previously, community development approaches had focused on community pathology without challenging structural inequalities (McCabe & Davis, 2012:506). Social workers use developmental approaches to focus on the social environment through the involvement of families in addressing mental health problems (Cottone, 2007:193; Weine, 2011:410; McCann, 2016:2). Families become empowered to perform their caregiving responsibilities.

6.3.2.2 Subtheme 2.2: Use of case management in the provision of services to MHCUs and their families

According to the Mental Health Policy Framework and Strategic Plan 2013-2020 (n.d:21) social workers facilitate the integration of MHCUs and families, and the provision of social support network. The provision of mental health services is a shared responsibility that requires a multidisciplinary approach to ensure effective provision of mental health services through the referral process. Social workers use case management to facilitate access to services offered by community-based social workers, home-based care and other mental health services (Frankel & Gelman, 2012:163). Case management enables social workers in both hospital and community settings to "provide the link between patients, their families and communities to facilitate better discharge arrangements and community care" (Avirum, 2002:620) (cf. Chapter two, Item 2.3.5). The services provided in these settings form a continuum of care. For example, MHCUs who received professional assistance in hospitals will continue receiving services from social workers based in communities. Equally, MHCUs may be referred to hospitals by community-based social workers, thus promoting communication among professionals and institutions for effective delivery of mental health services.

Participants reported to have linked MHCUs and their families to support networks:

> *When a person is discharged in the presence of their relatives, we emphasize the importance of ensuring that when they submit a referral at the local clinic, they must make attempts to have contact with area/community-based community social workers to help them address problems that we could not address at the hospital. We may phone the social worker, informing them that the MHCU and relatives would consult them as and when they require assistance. This is how we can work with them* (community-based social workers). (Male, 26 years, HB)

> *Sometimes, if the families are from far-flung areas, we refer them to community-based social workers before discharging the MHCU and they would take over the process of assisting them. We also communicate with community-based social workers telephonically to monitor if the MHCUs are coping. Sometimes we refer them to the home-based carers who would take care of the MHCU to enable the family members to go to work.* (Female, 40 years, HB)

> *There are home-based carers in the community. If a family member responsible for caring a MHCU should go to work, part of my role as a social worker is to refer such a family to home-based carers. Nowadays the home-based carers are everywhere. Where there are no home-based carers, we have found an alternative. We try to find another family member who will be willing to assist the family.* (Female, 46 years, CB)

> *Our home-based carers can to look after the MHCUs. We also refer the MHCUs to our community projects in the rehabilitation centres. We also involve area social workers by informing them, for example that in a certain village there is an MHCU who is always at home and smokes dagga. The community-based social workers can include the MHCUs in their community projects to alleviate the burden of care by the family members who may be forced to leave employment to care for the MHCU*. (Male, 33 years, HB)

The findings highlight the significance of coordination of services between the hospital team and the community-based social workers. Coordination of services, which involves communication with other service providers, is undertaken through case management which social workers apply in their work environment (Rapp & Goscha, 2004:320; Kanter, 2016:341). Case management enhances the provision of services through assessments, interventions, referrals and monitoring across the continuum of care (Rapp et al., 2014:605). The services offered in a hospital setting are linked through referral to other services in the community for further treatment and care.

Furthermore, the findings recognise the provision of services as a multidisciplinary and intersectoral focus which should be coordinated to ensure the continuum of care is maintained. Therefore, case management ensures a transition from the hospital-based treatment which focuses on the illness through medication, psychotherapy and vocational rehabilitation, to community-based mental health services that include medical treatment, psychosocial services, family intervention and social network support services.

Moreover, the findings show the role of community-based social workers in integrating MHCUs with their families through family intervention. The integration involves collaboration with other community-based service providers to provide mental health services. The services offered include monitoring the MHCUs' treatment compliance and linking them and their families with community resources which include clinics, home-based care services and other amenities (Saunders & Marchik, 2007:74; Sullivan, Kondrat & Floyd, 2015:349). Community-based social workers provide a shift from custodial care, to a more collaborative recovery approach focusing on empowerment of service users (Barbato, Agnctti, D'Avanzo et al., 2007:775; Kramers-Olen, 2014:499). The community-based rehabilitation centres provide interventions to improve the occupational, social, educational, behavioural, cognitive and family functioning of MHCUs. Rehabilitation programmes provide a transition from the medical focus of treatment to the social orientation which involves the ordinary public providing socially developed resources of managing mental illness (Graham et al., 2013:326).

Unfortunately, there are minimal or no amenities in rural areas. Lack of resources may lead MHCUs to drift into substance abuse and relapse (Seloilwe, 2006:267; Sariah, Outwater & Malima, 2014:175). The new policy framework on mental health acknowledges inadequate rehabilitation placements which may have contributed to the tragic neglect of MHCUs (Kramers-Olen, 2014:506; Makgoba, 2017:1). The problem is further exacerbated by the high unemployment rate which makes it difficult if not impossible for MHCUs to access the open labour market (Hall & Sambu, 2018:138). Therefore, community-based social workers have a responsibility to facilitate access to social services.

Beyond poverty alleviation, the MHCUs should be kept constructively busy to improve their well-being. The function of community-based social work is the integration of MHCUs by involving them in family activities, cultural and religious rituals to reduce stigma and discrimination and promote social functioning and recovery (Kramers-Olen, 2014:501). Among the key roles of community-based social workers is the mobilisation of communities as partners in promoting mental health care by providing a context that supports effective prevention, caregiving, treatment and advocacy

(Campbell & Burgess, 2012:381 & 387). The MHCUs and their families are members of their communities and together share common values and support networks (Goodsell, Colling, Brown & England, 2011:278). Hence, deinstitutionalisation relies on the services of community-based social workers (du Plessis et al., 2004:4; Payne, 2014:257) to promote mental well-being and caregiving (McCabe & Davis, 2012:506). Moreover, in South Africa, community practices were found to transcend informal forms of helping between family members and neighbours (Patel et al., 2012:13).

6.3.2.3 Subtheme 2.3: Facilitation of the provision of social assistance to MHCUs and their families

The effects of mental illness on MHCUs and their families may require the provision of social assistance in terms of Social Assistance Act (Act No. 13 of 2004) (Lee et al., 2006:546; Hall & Sambu, 2018:137). The social programmes provided in terms of the White Paper for Social Welfare (1997) and the Social Assistance Act (Act No. 13 of 2004) include cash transfers and social relief in the form of food parcels to supplement the family's limited resources. Social work practice incorporates social assistance within its basket of social support services to mitigate the effects of mental illness (James, 2012:7). All the participants reported to have provided social assistance to MHCUs and their families.

> *The MHCU receive a social grant which equals that of the old age pension* [R1600] *which supplement the family income. The little social grant they receive is just too little.* (Male, 26years, HB)
>
> *I ensure that I share information regarding disability grants as I have realised that most families are not aware of it. However, it is only the medical doctor who determines if a person qualifies for a social grant. It is the doctor who knows about mental illness, the nature of the illness affecting the person, the diagnosis and whether the MHCU deserves a disability grant.* (Female, 46 years, CB)
>
> *To receive a social grant, the MHCUs must go through an assessment process at SASSA for approval. To ensure proper management, there are those who receive temporary approval of a 12-months period with a review. The review register must show that the person is part of a support group. Those who do not receive a social grant would not receive food and/or clothes from their families. Some MHCUs do not want their mothers to have control of their social grant. The MHCU is asked to identify the person to assist them with the management of the grant. The person would be asked to draw a list of things the MHCU requires on the day of payment of the grant. The family would*

> *confirm if the MHCU needed e.g., a pair of shoes and toiletry and they would receive pocket money as well. Bank accounts are opened for the MHCUs to safe money for the future. Some families marry wives for male MHCUs. Social workers monitor the MHCUs' monthly savings to ensure proper management.* (Male, 33 years, HB)

The accounts of social workers confirm their holistic role in the provision of social assistance to individuals with mental illness. They reveal the importance of applying the PIE. The PIE assessment enables social workers to determine the extent of need and required resources to address such a need. The findings are consistent with a study on social support by Davis and Brekke (2013:40) in the US which confirms the benefits of social support. Consistent with the findings, is a study in Taiwan by Huang and Ku (2011:734) which revealed the effectiveness of social assistance programmes targeting low-income families. Social workers have observed that the social grants are not only used for the needs of MHCUs, but for the benefit of other members of the family. This suggests that the social grant earned by the MHCU may be the only income or a supplement of the family income.

The provision of social assistance in the form of social grants is not only limited to the MHCUs but include their caregivers who receive grant-in-aid for their caregiving responsibilities:

> *There is also social assistance for those family members who may not be employed as they are caring for the MHCU 24 hours. It is called grant-in-aid based on the understanding that the caregiver is offering a 24-hour care. An assessment process is undertaken in which the doctor completes forms to confirm that the MHCU requires care. The grant-in-aid received by the family is recognition of the care the caregiver provides.* (Female, 33 years, HB)

Family intervention forms part of the holistic approach to the provision of mental health service to improve the wellbeing of MHCUs. It involves social work assessment of the needs and ability of the family to provide for its members while caring for the MHCUs. Family caregivers need information and support about mental illness to enhance their capacity for caregiving. The finding confirms that social work assessment enabled a social worker to understand the role of caregivers and the challenges they experience. For example, the finding established that caregivers provided a 24-hour service which made it difficult to have their own needs and those of other members of the household met. Consistent with the findings, the Social Assistance Act (Act No. 13 of 2004) provides social assistance to caregivers in the form of a grant-in-aid (Hall & Sambu, 2018:137). Therefore, social workers facilitate access to social assistance by educating caregivers. However, some caregivers indicated that social workers failed to provide social work services to families of the MHCUs (cf. Chapter Five, Item 5.3.2.3 Subtheme 2.3).

6.3.2.4 Subtheme 2.4: Lack of cooperation between the hospital and community-based social workers

The practice of social work is guided by legislative and regulatory frameworks for cooperation and coordination among practitioners (Maas, Shokane, Fronterotta et al., 2018:194). Social work uses different methods (casework, group work, community development, social development, research, and management) within diverse contexts (cultural diversity, poverty, unemployment, crime, and illness) to provide effective social work services that promote human rights and social justice (Gray, 2010:82). However, cooperation among practitioners, which is a vehicle to successful partnership with caregivers (Mamaleka, 2018:221), seems to be inadequate between hospital- and community-based social workers.

> *Honestly speaking, we lack support from our own colleagues* [community-based social workers]. *This is why we have too much work of aftercare services where, after discharging the MHCU, we have to visit their families regularly. After communicating with the family about the importance of the MHCU taking medication properly, not mixing it with muthi* [traditional medicine], *we go back to the families to assess their level of understanding of what was discussed and to discuss other important issues. (Female, 33 years, HB)*

> *We used to refer them* [MHCUs] *to local social workers to receive aftercare services, unfortunately, some relapsed within two weeks of discharge from the hospital. That's why I say we lack support. I understand because they normally work in remote areas and they lack transport, hence it is difficult for them to reach families as required. The MHCUs in the meantime relapse and return to the hospital. This is the reason we visit families ourselves. It is better to take the community-based social worker along to show them the MHCU's family so that the day when the family visit the clinic, they should recognise them and offer help. However, the services by community-based social workers are not effective.* (Female, 43 years, HB)

> *We personally visit all these families, but it is not always easy considering distances. Sometimes we refer them specifically to community-based social workers However, we have not been getting support from them. We rely on visiting families ourselves; it is challenging taking into consideration the vastness of Limpopo Province.* (Male, 40 years, HB)

The participants' experiences were consistent with those reported in Australia indicating the tension between the generic and specialist roles in the delivery of mental health services (Lloyd, King & McKenna, 2004:119). However, the perceived lack of cooperation may suggest conflicting priorities. This lack of collaboration persists despite existing policies that seek to promote collaboration across sectors, organisations and professional boundaries (Scott, 2005:132; Mental Health Policy Framework and Strategic Plan 2013-2020: n.d). This impacts negatively on the provision of social work services (Roncaglia, 2016:15). Therefore, the adoption of a social model in practice is important as it encourages consideration of a PIE to promote collaboration of relationships among practitioners. A social model of intervention ensures comprehensive delivery of social work services linking mental health to broader social issues and recovery (Lloyd et al., 2004:119; Shankara, Martin & McDonald, 2009:28; Beresford et al., 2010:5).

Not every community-based social worker has experience in the provision of mental health services (Olkers, 2008:35; Van Breda & Addinal, 2020). Most community-based social workers provide generic social work services focusing on developmental programmes for poverty alleviation (Lombard et al., 2012:178). However, their generic approach does not suggest they may not encounter mental health problems among their caseloads. Although developmental approaches claim allegiance to the ecological systems framework informing social work practice (Ahmed-Mohamed, 2011:9), the dominance of the medical model has rendered its practice ineffective (Payne, 2014:186). Its quest to empower and harness strengths and capacities of individuals, families and communities to address their conditions and improve their quality of lives (Gray, 2010:77) has not been effective. Nevertheless, social workers work with individuals, families and communities in order to address their personal and social problems concerning mental illness. Community-based social workers are entrenched in communities to address the social context of mental illness

(Romakkaniemi & Kilpeläinen, 2015:440), and should provide PIE interventions. The rural communities are well placed to benefit from their services. Therefore, cooperation between the hospital and community-based social workers is a necessary ingredient of the social model to provide a holistic approach to mental health services (Shlonsky, Noonan, Littell & Montgomery, 2011:362).

The White Paper on Social Welfare (DSD, 1997) describes the provision of mental health services as the responsibility of psychiatric hospitals, specialist mental health societies and community service organisations, with social workers forming part of the mental health care practitioners. However, hospital-based participants expressed dissatisfaction with the attitude expressed by the community-based social workers to MHCUs and their families.

> *It is a serious challenge, because community-based social workers who have never worked within the hospital setting do not want to work with the MHCUs. They still think the person is sick and there is nothing that could be done to help them.* (Female, 43 years, HB)
>
> *The challenge that we have identified is that community-based social workers do not understand mental health, and that is a key challenge. As a result, families cannot benefit from their services. They are not well- informed. The remote areas that we cannot easily access become a challenge. Maybe that is one area that needs to be addressed.* (Female, 33 years, HB)
>
> *The families complain that the area social workers are not as informed about mental health compared to those in the hospital. The families reported that the community-based social workers just refer them back to hospital. This leaves the family feeling that help will only be found in the hospital. Most of the time, the families are not happy with the services they receive from the area social workers attributing it to little knowledge on mental health. Others insist that hospital-based social workers should render services to MHCUs and their families as they have better knowledge of the case from the beginning. The challenge was the difficulty of finding family members when we visited homes. We have decided that the MHCUs come with their family members when visiting the hospital.* (Male, 33 years, HB)

The hospital-based social workers and some families seem to perceive community-based social workers as lacking skills and competencies to provide mental health services (Lloyd et al., 2004:119). Moreover, spectrum approach of the DSM-5 gives recognition to the environmental and social factors that may predispose, precipitate and perpetuate mental illness as fundamental to social work practice (Castillo & Guo, 2016:220). However, the reality of the situation is that community-based social workers offer generic services which could explain their inability, either perceived or real, to provide satisfactory mental health services (Nathan & Webber, 2010:17).

Moreover, community-based social workers struggle with the provision of mental health services due to lack of clarity regarding the practice of mental health (Nathan & Webber, 2010:16). They have been found to have inadequate training, support and resources to provide mental health services (Sawyer et al., 2016:130). Individuals, families and communities are thus deprived of services that social workers should be providing. This suggests that the provision of social work services relating to mental health is inadequate in communities. Hence, family caregivers seeking social work intervention in hospitals. Nevertheless, social workers should be guided by the PIE approach to work with families to address the effects of mental illness on MHCUs, their families and communities.

Poor collaboration between the hospital and community-based social workers may have an adverse effect on partnership between the mental health practitioners and families of the MHCUs. Hence, Kotzè, van Delft and Roos (2010:83) recommended the strengthening of collaboration and cooperation between the hospital-based and community-based social work services which has not happened thus far. However, it is anticipated that suggested guidelines for social work practice (cf. Chapter Seven) will provide impetus to this important initiative.

6.3.3 Theme 3: Social workers' views of partnership with families of MHCUs

The provision of mental health care requires a comprehensive approach involving multiple role-players working together in partnership to meet the complex needs of individuals with mental health problems. Consistent with the ecological systems approach, the multiple role-players work as partners in sharing information and expertise (Chien, 2008:29; Hansson et al., 2010:2).

Partnership encourages social workers to embrace a social model that values the role of families and their experiences and to practice beyond the constraints of the medical model (Bland & Foster, 2012:517). The adoption of the ecological systems approach helps to recognise the strengths, hopes, dreams and aspirations of caregivers as essential to working in partnership with families (Kirsh & Tate, 2006:1055; Thompson, 2013:220). The recognition of caregivers' strengths enhances their coping abilities, strengthen partnership, and promote recovery of the MHCUs (Bryan, 2009:507; Wallcraft, Amering, Freidin et al., 2011:230; Kleintjes, Lund & Swartz, 2012:2274). Hence all participants emphasized the importance of partnership with families.

> *It is important for us social workers to work with families of MHCUs to provide support to the MHCU. In partnership, the MHCU will know that the social worker will be notified when they display deviant behaviour. When in hospital, and behaving inappropriately, they will know that the hospital and community professionals are working together, and obviously their family will soon learn about their ill-discipline. It is important to work in partnership to support and to try to make the MHCUs feel accepted by professionals including their families.* (Female, 46 years, CB)

> *Partnership can work. My understanding is that when we work in partnership, we will be able to educate one another on how best to enhance this relationship between the institution and the family and the importance of caring for the MHCUs to recover. There are those families who think that they are not responsible for the care of the MHCU. They always think it is the responsibility of the hospital - they even refer to them as "your people". So, if we are in partnership, we will make them realise that they are at the core of caring and they need to lead the team in helping MHCUs to reunite with families and be reintegrated into the community.* (Female, 43 years, HB)

The findings are consistent with studies describing the concept of partnership in the promotion of the recovery of MHCUs and the strengthening of the mental health service delivery system (Davis, Brigell, Christiansen, Snyder et al., 2011:317; Petch, Cook & Miller, 2013:624; Bunger, Doogan & Cao, 2014:514). The UK government has adopted partnership as a policy that requires social workers to work with families by giving them support to enhance their caregiving abilities (Duggan et al., 2002:7; Gandi & Wai, 2010:323). This is consistent with the developmental approach which incorporates partnership in social work intervention to empower families and to improve their social functioning.

The findings show that partnership is a social model construct that promotes social interaction and support network (Perry & Pescosolido, 2015:116). It fits in well with the ecological systems approach connecting all levels of the system to function as an interdependent network. Families and social workers collaborate as interdependent systems in the provision of mental health services. Both the social workers and caregivers should work together as support systems to share information regarding the mental condition, family circumstances, diagnosis, treatment compliance, and support services for recovery. Their partnership may instil a sense of hope in the MHCU who may be motivated to comply with the requirement for treatment and recovery. The MHCU may also start showing changes in behaviour to signal the involvement in the treatment process to set them on the road to recovery.

Social workers regard caregivers as the primary resource in understanding the illness context that guides the provision of social work services (Simpson & House, 2003:89; Grover et al., 2015:5). Therefore, in partnership both social workers and families may learn from each other and work together to understand the behaviour and needs of the MHCU. To strengthen partnerships, social workers should educate families and MHCUs about the positive role they play in the provision of mental health services.

> *Partnership is very important because the MHCU is part of the family. It is important that there be partnership between families and service providers because when the person is admitted into the institution, they must still go back to the family. The family is the link between the service providers and the patient. If we* [social workers] *educate the family on mental illness and how to manage the patient will be easy to care for the MHCU with confidence.* (Female, 30 years, HB)
>
> *Families are helpful in the provision of services to MHCUs because they are the ones who spend most of the time caring for them. The MHCUs only come to us at the hospital when they are sick or had a relapse and thereafter, they must go back to their families. The policy deinstitutionalisation requires that the patients should live permanently with their families. It is important that we support families, show them their role, share their problems and try as much as we can to assist them to ensure that the MHCUs stay longer at home.* (Male, 26 years, HB)

The involvement of the family in the provision of mental health services is important (Pillai & Parsatharathy, 2014:71). The findings suggest that social workers need families for successful intervention. Families perform roles that support the efforts of practitioners to improve individual, family and social functioning for both the MHCU and family members. This means families are the eyes and ears of social workers as they provide information about the MHCU, the illness, compliance, self-care, and family functioning. This is consistent with the strengths-based perspective that implores service providers to recognise and capitalise on the strengths of service users. Social workers apply solution-focused techniques involving psychoeducation to facilitate the involvement of family members (McFarlane, 2016:460) to create a collaborative environment that supports and enhances social interactions for the family (Giron et al., 2010:73; Petersen, Bhana, Fairall et al., 2019:2). Psychoeducation promotes the social functioning and family wellbeing rather than focusing on pathology (Kramers-Olen, 2014:501; McFarlane, 2016:460). The social worker can understand the socio-cultural context of mental illness from the family perspective (McCann, 2016:5) and how the family value system influences their caregiving responsibilities (Bojuwoye, 2013:84).

Furthermore, the findings reveal the important role that deinstitutionalisation played in relation to family integration. Deinstitutionalisation policy strengthened the understanding of MHCUs as belonging to their families and the obligation that families have as caregivers (Du Plessis et al., 2004:4; Swartz, 2004:81; Githaiga, 2016:2). The deinstitutionalisation process is linked to reintegration of MHCUs with their families to promote meaningful interpersonal relationships and recovery (Wong, Matejkowski & Lee, 2009:51; McCabe & Davis, 2012:506). Moreover, families need support services to perform their caregiving responsibilities (Du Plessis et al., 2004:4; Payne, 2014:257). Although deinstitutionalisation requires active participation of both social workers and families, however, families are left without adequate professional support. Participation by both social workers and families has the potential to promote partnership.

Partnership is generally benefiting the mental health system (Simpson & House, 2003:89; Stanton & Skipworth, 2005:155; Muhlbauer, 2008:100; Petch, Cook & Miller, 2013:625) in which families provide the continuum of care as mental health practitioners for as long as the illness afflicting MHCUs persists. Their support provides a social function of the treatment process (Petrowski & Stein, 2016:2873) thus contributing to the reduction in the rate of relapses, re-institutionalisation, and increased compliance with treatment by the MHCU. The family participation in the process of discharge makes MHCUs feel accepted and ready for family reunification and community integration. Below are illustrations of some of the benefits shared by the participants.

> *The benefit will be that the MHCU may rarely experience relapses - this is the first benefit. The second benefit – if the MHCU has left the hospital, the family will monitor the use of medication. The other benefit is that when the MHCU is*

> *in hospital and become stable, the family will not refuse when asked to take them home. They will accept them back at home.* (Female, 46 years, CB)

> *They* [families] *play a significant role. What we expect from them is looking after these patients following their discharge and even when they are still in hospital. The information they provide is used for diagnostic purposes to facilitate the rehabilitation process. Sometimes during the admission of MHCUs you hear something else, but when you visit their homes you hear something* different [from family members]. *That is where we are able to corroborate the information, get to the bottom of the matter, and provide therapy. So, we use it (information) for diagnostic purposes. We do share with them* (family) *information mainly in trying to provide insight relating to mental illness – how they should relate with the MHCU, how they should treat him, how they should interact with them at family level.* (Male, 40 years, HB)

> *The benefit is that the MHCU is not institutionalized. The MHCU would at least be living within a community setting and able to adjust their life. So, as professionals* [social workers] *we rely on the families to ensure the patient complies with treatment requirements and is well-behaved in the community. Other benefits of working with families involve our* [social workers] *goal as the reunification of families with MHCUs so that they stay at home for a longer time. It is also because others* (MHCUs) *have families, they come to the hospital having left children at home. So, they must go back home to bring-up their children. It is important to discuss with families the assistance required for the care of MHCUs.* (Male, 26 years, HB)

The acknowledgement of the role of families as support systems provides a justification for partnership in the provision of mental health services to MHCUs (Boydell & Rugkasa, 2007:217; Perry & Pescosolido, 2015:116). Families provide 24 hours of caregiving (Lefley cited by Jewell, Downing & McFarlane, 2009:868; Grover et al., 2015:5) while mental health practitioners spend a few moments with them (MHCUs), then hand them over to families. They are always there to notice if their relative is not well and to share the information with social workers during assessment to determine intervention (Ahmed et al., 2018:108). Social workers work with families to prepare for discharge and integration of the MHCUs with the family and community to promote recovery (Bryan, 2009:507; Gandi & Wai, 2010:323). Furthermore, they are of the view that partnership between the family and the mental health practitioners should be enhanced for the provision of mental health services to the MHCUs.

> *We should be there for the family, especially when they need us most, we should avail ourselves to assist the family where possible. I think this is where*

> *the family will have faith in us knowing that we can assist them.* (Male, 42 years, CB)
>
> *Partnership is about cooperation for the family to understand what professionals expect and for the professionals to conversely understand what the family expects from them. Most of the time, families can hardly understand what the professionals expect from them given the cultural background of our communities, the country - we are in Africa and therefore we are more traditional than westernized. The services we are rendering, unfortunately are too western even if they work. But with proper counselling for the family, and good ethical standards on the part of the professionals to respect families – it will lead to a very good partnership.* (Female, 33 years, HB).
>
> *There is a need for policies that can adequately guide the provision of mental health services to MHCUs. There is also a need for continuous training or briefing for both service providers and families. There must also be imbizos [gatherings] for people caring for MHCUs to provide inputs in the development of policies so that, as families, state what assistance they would require and how things should be managed. Most of the time mental health is not something that most service providers take seriously. Policies and training programmes to assist in the provision of services are limited. In the end, the MHCUs and their families find themselves on their own. Even if the services are there, they are very limited. Maybe this research will be a turning point or a starting point so that as service providers we can now provide services to the users as expected.* (Female, 30 years, HB)

Families and social workers need each other as partners in the provision of mental health services to enhance recovery of the MHCU from mental illness and promote family and community functioning (Bryan, 2009:507; Thornton & Lucas, 2011:24). Social workers have the responsibility to facilitate a conducive context that allows partnership to be enhanced through the provision of services (Boydell & Rugkasa, 2007:219; Ahmed-Mohamed, 2011:11; Shor & Shalev, 2014:68), for example, social workers can facilitate access to services regarding social grants and advocating for rights of families and the MHCUs. Community development projects are some of the activities that social workers use to involve families in social integration, social networking and protection from stigma and discrimination (McCabe & Davis, 2012:506), and therefore, enhancing partnership and the recovery of MHCUs from mental illness. Furthermore, social support network, trust and shared norms and values will be strengthened (Dhillon, 2009:687; Upvall & Leffers, 2018:228) through partnership. Subsequently, families will in turn develop strengths, become resilient, believe in the expertise of the social worker and begin to embrace partnership (Gavois et al., 2006:102; Boydell & Rugkasa, 2007:219; Kyzar et al., 2016:1).

Sithole (2017:302) has however noted challenges facing DSD social workers who must choose between social work practice and community development despite the latter being a component of social work practice. As the findings show, lack of support is a stressor that may exacerbate a burden of caregiving for families (Streid, Harding, Agupio et al., 2014:317). The provision of services requires a holistic approach to address personal, family and community needs. All methods of social work intervening at individual, community and social levels are required to target family interactions and larger social systems (Becvar & Becvar, 2009:281; Fuller, Hermeston, Passey et al., 2012:1). Families may, subsequently, feel an obligation (Du Plessis et al., 2004:4; Swartz, 2004:81; Semrau et al., 2016:1) to participate in these programmes to enhance their caregiving capabilities and partnership.

6.3.4 Theme 4: Social workers' opinions on key role players of mental health care team to work with families of the MHCUs

Mental illness is a complex condition that requires the mobilisation of every available resource to bring about change in the lives of the MHCUs and their families. Multidisciplinary teams bring complementary rich knowledge and expertise from different disciplines to provide comprehensive service delivery within the mental health system (Roncaglia, 2016:15). Social workers are part of a multidisciplinary team which includes psychiatrists, clinical psychologists, psychiatric nurses and occupational therapists working in collaboration to ensure a comprehensive provision of mental health services. Their collaboration suggests that mental health care requires a collective approach from different disciplines. Hence, the participants have extended the team beyond the traditional mental health multidisciplinary team.

> *My understanding is that the family is central to our work as social workers. We prioritize them, then the practitioners, and we should not exclude the traditional healers – maybe I can just give an example – somebody was saying, "Groothoek (hospital) - maybe it was before I was born - had a traditional healer who was attached to the hospital. When a patient is admitted, we would call the traditional healer to make it easy for those who believe have been bewitched, and they [hospital authorities] were satisfied that the patient was receiving care. The hospital authorities acknowledge that our medication is just temporary. We should include the traditional and faith healers - because it is what the person*

> *believes - for a person to be healed". So, if we are a team which includes the believe systems of the patient, I think we can be able to reach our goal. The family must be number one on the system - we are just a support system because, without them, we cannot reach our goal.* (Female, 43 years, HB)
>
> *The first* [role players] *must be MHCUs, their families, communities, traditional healers, faith healers, social workers, doctors, nurses, occupational therapists and psychologists. Everyone has a role to play and an understanding of services they are providing to people with mental illness. The patients will be able to manage themselves by ensuring that they comply with treatment and how to behave when they experience problems. The families have a role of assisting the MHCUs and to give information to service providers to enable them to offer assistance. The professionals have a role of providing information and support the patients and to give treatment.* (Female, 30 years, HB)
>
> *The community as a whole must also be part of the team because when the MHCU leaves the hospital they are going to live with them, it is important that the community becomes part of the team. The police must also be part of the team – everybody is an important player. We also have a multidisciplinary team within the hospital which includes nurses, occupational therapists, doctors, physiotherapist as an important part of the team.* (Female, 40 years, HB)

These storylines seem to suggest that the involvement of families (Semrau et al., 2016:1; Bartholomew, 2016:106), traditional and faith healers (Campbell-Hall et al., 2010:619) in mental health care is gaining support amongst social workers. Their inclusion suggests recognition of the role of families and traditional and faith healers in the provision of mental health services. Like the mental health care practitioners, the traditional and faith healers conduct assessments and determine the nature of the problem and treatment which are reflective of the cultural and religious conviction of families (Mpono, 2007:3; Grover et al., 2014:119). The traditional healers throw bones, beat drums, dance and sing to establish and explain the nature of problems afflicting the person (Bojuwoye & Sodi, 2010:289), while faith healers use prayer and spiritual rituals (Shields, Chauhan, Bakre et al., 2016:371). Like families, the role of indigenous healing practitioners represents the social aspect of mental illness.

The inclusion of indigenous healing practitioners is consistent with the social model approach which requires practitioners to take into consideration the influence that social-cultural norms and values of families have on the provision of mental health services (McCann, 2016:5). Like social workers, their inclusion brings the social dimension of mental illness to the provision of mental health services (Ahmed-

Mohamed, 2011:6; Evans, Huxley, Baker et al., 2012:24). Social workers bring the social dimension in a multidisciplinary setting.

A multidisciplinary team is fundamental to the effective provision of mental health services. Mental health literature identifies professionals involved in the provision of mental health services as psychiatrists who diagnose and prescribe medication, a psychologist who offers psychotherapy services, the occupational therapist who offers social skills training, the psychiatric nurse who implements and monitor treatment programmes, the social worker who conducts individual and family interventions (Swartz, 2004:80; Cottone, 2007:192; Mcneil et al., 2013:291). Consequently, the multidisciplinary team members share information derived from their respective diagnostic systems while promoting social inclusion of the MHCUs (Evans et al., 2012:24).

> *Obviously, the MDT [multi-disciplinary team] professionals within the hospital that includes social workers, medical officers, psychiatrists, physiotherapists are part of us; dietitians to guard against weight problems – obesity; psychologists work along-side psychiatrists, although you always have running battles regarding diagnosis, but that is good because without them you don't get the correct diagnosis. I forgot to enlist the nurses who are playing a key role especially when it comes to observation cases. Occupational therapists are also part of us. The traditional and faith healers, as I indicated the conflict, are dealing with 'who', when we are dealing with 'what' causes mental illness. Unfortunately, all the information goes to one party who is the client in this case. The fact that somebody is receiving conflicting information can be dangerous.* (Female, 33 years, HB)

> *Team members such as occupational therapists would assess a particular MHCU for me and would come with their own findings to determine the diagnosis. We also ask the psychologist and psychiatric nurse in the hospital for assessment reports. We then meet as a team to look at the reports about the family and MHCU. Families tend to give different stories – when they are with the social worker, comments like the following are often made: "we no longer want this person"; when they are with an occupational therapist: "No, it is just that we did not understand what mental illness does to a MHCU – no, we accept them"; but in my office they have already stated that they no longer want them; "we are done with them". So, as a Hospital, the multidisciplinary team participates in family conferences with family and MHCU when they are stable. The family conferences are not conducted when the MHCU is still psychotic. We have family conferences with our MHCUs, we also have a support group which meets every month to enable us to manage them (MHCUs). The home-*

> *based carers would also assist us by bringing to the hospital those living alone and have no family members. Others would be living with elderly parents and not able to come to the support group by themselves.* (Male, 33 years, HB)

Multidisciplinary team members work together to share skills, knowledge and experience (Scott, 2005:132; Kane & Luz, 2011:437) in the development of diagnostic assessment for the treatment of MHCUs (Dziegielewski, 2015:25). The findings show that various team members perform diagnostic assessments to determine the nature of the mental condition afflicting the MHCU (Bojuwoye & Sodi, 2010:289; Shields, Chauhan, Bakre et al., 2016:371). The mental health care practitioners use the Diagnostic and Statistical Manual of Mental Disorders-V (DSM-5) to guide diagnostic assessment and treatment (Dadlani et al., 2012:175; DSM-5, 2013:748; Dziegielewski, 2015:184). They also work in collaboration with community home-based care workers who are always available to provide much needed services to vulnerable members of the community (Swartz & Colvin, 2015:139). Such collaboration provides a foundation for the development of partnership practice.

> *Social workers and community home-based carers always inform the family about the social grant. Community home-based carers may refer the family to the social worker, and the social workers would assist the MHCU with the processes that must be followed.* (Female, 46 years, CB)

The finding reveals that professionals alone are not able to provide comprehensive and cost-effective mental health services (Thabethe, 2011:789), and therefore, need collaboration with community home-based care workers. Community home-based care workers are embedded within the community. They are seen as performing a “strategic role in ‘bridging the gap’ between the health system and the community” (Swartz & Colvin, 2015:139). They serve as the ‘eyes and ears’ of professionals who may be overburdened with caseloads and unable to reach distressed families on time. As members of the community, they may conduct themselves in ways that are culturally acceptable to both MHCUs and family members and caregivers, thus mitigating the effects of stigma and social isolation. As a link between caregivers and professionals, they have the potential for collaboration and partnership, and facilitate integration of MHCUs in the community. Therefore, the role of social workers in building partnership as a social orientation that recognises the social norms and values of partners will be enhanced (Tew, 2011:12; Evans et al., 2012:25) to ensure effective provision of mental health services.

> *My understanding is that there is a need to close that gap. As practitioners we need to meet, educate one another, so that we can ensure that, if the [families] come from far, even when we refer, they would be in good hands, receiving the same services as they receive from our institution. …Fortunately, we have started [initiated] something together with Occupational therapy [OT] team; after seeing a MHCU in hospital, we conduct home visits as a team. … We prefer to involve the whole family because our focus is on the entire family. …We encourage teamwork with the family while supporting one another.* (Female, 43 years, HB)
>
> *I can phone the social worker working among communities to inform them about a patient who is due for discharge, or when conducting home visits or when the patient has been discharged, I would inform the social worker about the patient that is in hospital, that they are about to be discharged or they are already home and I would be on my way to visit them. I would discuss any challenges relating to the patient to ensure that they (social worker) continue offering services.* (Male, 26 years, HB)

The inadequacies in the provision of mental health services suggests a need for an alternative approach to ensuring effective provision of services (Roncaglia, 2016:15). The current inadequacies reveal the inability in the mobilisation and utilisation of resources. Partnership seems to emerge as an approach that can bring together different role-players to ensure effective provision of services. The fact that the majority of Black South Africans utilize both traditional and western systems of treatment indicate the importance of collaboration and partnership (Burns & Tomita, 2015:867). This suggests that both systems of treatment share the same population which can be effectively served through a partnership that recognises family members as part of the treatment process (Bryan, 2009:507; McCloughen, Gillies & O'Brien, 2011:47).

Partnership allows partners to share information regarding diagnosis and discuss the services required for the treatment of a MHCU. The information is further shared with community-based practitioners in preparation for the discharge of the MHCU from hospital. This is done through case conferences and meetings, and visits to families to interact with family members to enhance partnership. Regular communication among practitioners promotes partnership. The community-based social workers use the information to work with families during intervention to build on the partnership process that started when the MHCU was receiving hospital treatment.

Although studies support collaboration among practitioners (Kane & Luz, 2011:437; Shields et al., 2016:368) the current mental health system questions the effectiveness of indigenous practices in mental health (Campbell-Hall et al., 2010:611), hence tensions arise in a multidisciplinary team (Scott, 2005:136; McNeil et al., 2013:293).

> *I am including everybody in the hospital - starting from a nurse, occupational therapist, physiotherapist, doctors, everybody. The traditional healers, on the other hand need to sometimes understand that if the hospital [medical team] says this, they must have some limitations. With regard to traditional and faith healers, I have problems with faith healers. In church you don't question anything. When asked to do things in a particular way, you wouldn't question that; you would just have to do as instructed. On the other hand, it damages the MHCU.* (Female, 46 years, CB)

The enactment of the Traditional Health Practitioners Act (Act No. 22 of 2007) promotes indigenous knowledge systems of treatment as recognition of the need for collaboration with traditional treatment systems (Sorsdahl et al., 2010:593; Louw & Duvenhage, 2017:72) (cf. Chapter Three, Items 3.2.5 & 3.4). Studies have established that the traditional system of treatment is the treatment of choice among some Black South Africans (Mpono, 2007:16; Campbell-Hall et al., 2010:611). The traditional system of treatment is common in rural areas, accessible and acceptable for the treatment of mental illness (Sorsdahl et al., 2010:591). Even though MHCUs who have been admitted in mental hospitals receive psychotropic drugs, they still consult traditional or faith healers prior and/or following hospitalisation (Bartholomew, 2016:61). However, supporters of the medical approach caution about the risk of using culturally derived methods of intervention (Pharr et al., 2014:1). Nevertheless, for these communities, traditional healthcare is an integral part of their culture which is consistent with the social model of mental health that gives recognition to family beliefs, attitudes, customs and established practices reflecting their worldview (Mpono, 2007:16; Nwoye, 2015:310).

Although the medical framework of mental health practice still excludes the social explanation of mental illness, social workers render services to families and communities who believe in the use of traditional medicine (Mzimkulu & Simbayi, 2006:417; Campbell-Hall et al., 2010:611). Therefore, they need the understanding of community practice within the social model approaches to recognise and collaborate with those who provide services to the people within their environment (Payne, 2014:209). The involvement of traditional healers in a hospital setting would contribute to the indigenisation of mental health care for the benefit of families and MHCUs (Ramgoon et al., 2011:90). Hence, social workers are required to collaborate with traditional and faith healers when providing mental health services.

Although social workers may be critical of traditional healing, they need to understand that they also serve communities with knowledge and believe systems informing their choices of treatment that include traditional healing practices (Bojuwoye & Sodi, 2010:283). This suggests that social workers should be familiar with the treatment offered which may be in the form of muti [traditional medicine], performing ceremonies with drums and dance to appease the ancestors, slaughtering animals and engaging in all-night prayer services (Mpono, 2007:37; Laher, 2014:193). Hence the need for social workers to show cultural competence that recognises diverse values and beliefs to meet the MHCUs' and families' social and cultural needs (Pouchly, 2012:65). Cultural competence exposes social workers to the knowledge of traditional perspectives on mental health (Bojuwoye & Sodi, 2010:286; Campbell-Hall et al., 2010:614). A culturally competent practitioner uses the PIE approach to gain understanding of the socio-cultural needs of individuals, families and communities. Therefore, such a practitioner may work in partnership with families for effective provision of mental health services to bring about the recovery of MHCUs.

6.4. Conclusion

The views of social workers regarding the MHCUs families' understanding of mental illness and its treatment are outlined. Furthermore, the involvement of the multidisciplinary team including indigenous healing practitioners in mental health care is presented. Although partnership between families and multidisciplinary teams is identified as fundamental to the provision of mental health services, its application has not been realised.

Although social workers recognise the role of families and indigenous healing practitioners, as partners in the provision of mental health services, they still view them as having limited understanding of mental illness and the needs of MHCUs. However, their explanation of partnership reflects the dominance of the medical model in mental health care. Therefore, the chapter shows the relevance of the social model which promotes partnership in the provision of mental health care. The ecological systems approach, together with its related approaches which include family systems theory, PIE, strengths-based perspective and indigenous approaches guided the interpretation of the findings.

CHAPTER SEVEN

PRACTICE GUIDELINES FOR SOCIAL WORKERS TO DEVELOP AND ENHANCE PARTNERSHIP IN THE PROVISION OF MENTAL HEALTH SERVICES

7.1 Introduction

Social work is developmental in nature and seeks to promote human rights and social justice. It may also transform mental health service delivery through the provision of effective and sustainable services to MHCUs and their families. Unfortunately, social workers have been criticised by service users for failing to provide adequate required services. Similarly, hospital-based social workers complain about their counterparts' (based in communities) failure to provide adequate mental health services (cf. Chapter Six). It is for this reason that practice guidelines are developed to set forth standards for the implementation of partnership practice.

Guidelines provide a guide describing common standards, methods and systems to determine a plan of action (Kredo et al., 2016:123) to meet a need (WHO, 2012:7). The purpose of these guidelines is to enable social workers to advocate for a partnership practice to enhance the provision of mental health services. They are presented as a step-by-step process of building partnership practice that outlines the roles and functions of partners in mental health care.

7.2 Partnership process

Partnership is a process committed to engaging all participants through collaboration. It brings together organisations with different perspectives, cultures, and values to find an equitable approach to address challenges (Stibbe & Prescott, 2016:3). The nature of the challenges being addressed through partnership practice determines the process for the development of the guidelines. Therefore, development of partnership reveals a process as depicted in three models of partnership in Table 7.1 below.

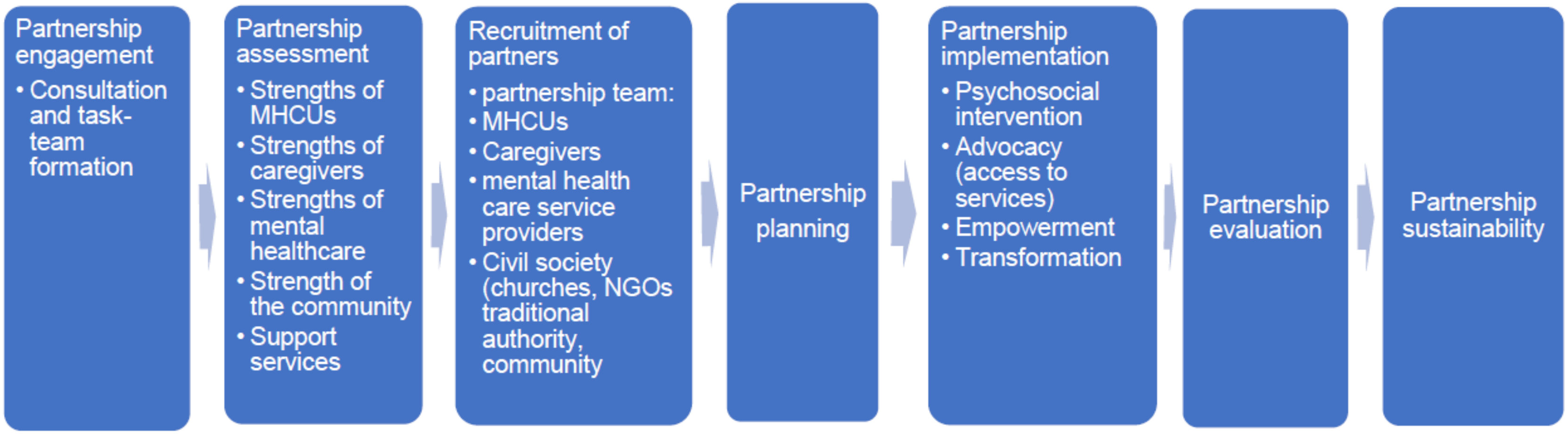
Table 7.1 Partnership processes

School-family-community partnership process model (Bryan & Henry, 2012)	Life-cycle process model (Reid, Hayes & Stibbe, 2014)	Strategic partnership process (Gole, 2018)	Tasks
▪ Preparing to partner ▪ Assessing needs and strengths	▪ Scoping	▪ Strategic assessment	▪ Context and needs analysis ▪ Map existing initiatives ▪ Identify key interested parties ▪ Identify potential resources ▪ Raise awareness
▪ Coming together ▪ Creating shared vision and plan	▪ Building	▪ Partnership planning ▪ Partner engagement	▪ Engage stakeholders and build commitment ▪ Develop vision and objectives ▪ Identify host institution ▪ Create governance and management structure ▪ Secure resources l
▪ Taking action	▪ Implementing	▪ Partnership execution ▪ Partnership governance	▪ Establish communication and operation structures ▪ Build capacity of implementers ▪ Identify priority projects ▪ Put in place M&E processes ▪ Awareness raising

	Consolidating		Consolidate core staff skills Capture and implement learning Develop long-term business model Sustain stakeholder commitment Move to local ownership and resourcing
Evaluating and celebrating progress			Determine how you will evaluate each partnership Measure and evaluate the results of each partnership implemented Celebrate and share accomplishments with partners
		Termination considerations	Objectives have been achieved

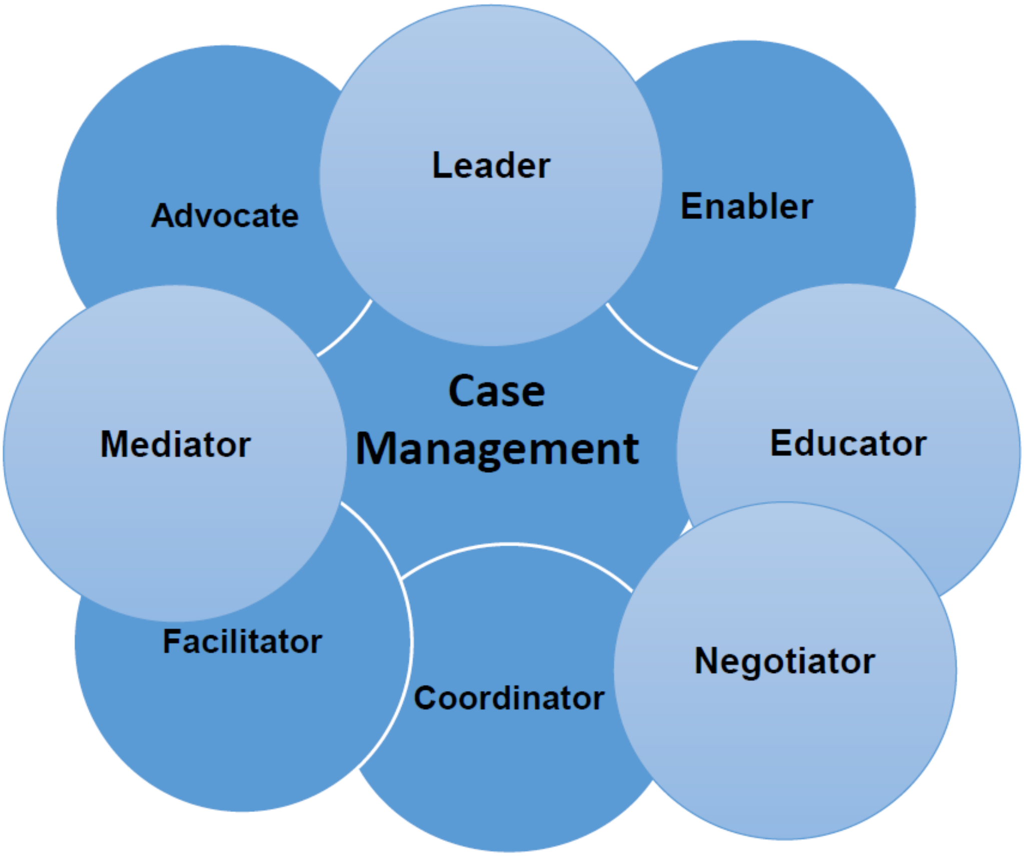
The three models above are complementary and have guided the process for the current guidelines namely, partnership engagement; partnership assessment; recruitment of partners; partnership planning; partnership implementation; partnership evaluation and partnership sustainability. Figure 7.1 below is a schematic illustration of the partnership process.

Figure 7.1 Partnership Process



The schematic presentation above illustrates comprehensive components of a partnership process to guide partnership practice. The process requires a well-structured partnership to balance and maximise contributions of partners. Case management plays a key role in determining the roles and functions in partnership practice (Baxter et al., 2017:366) as depicted in Figure 7.2 below.

Figure 7.2 Case management roles in partnership practice



Partnership implies shared roles. The role of leadership is essential for initiating the process of partnership (Haworth, Miller & Schaub, 2018:6). Having identified the need for partnership, a social worker may assume the role of a leader to initiate the partnership process. The leadership roles involve engagement, consultation and assessment which are discussed below:

7.2.1 Partnership engagement

During this phase of the partnership process, the social worker becomes a catalyst who initiates the partnership process by bringing people together (National Resource Centre, 2010:14). The main function of engagement is consultation with key stakeholders (Kramer et al., 2012:540) for the purpose of bringing potential partners together in order to develop partnership practice (Gole, 2018:6).

7.2.1.1 Consultation

The first task of the social worker is consultation with management to obtain support for establishing a task-team (Acharya, Maru, Schwarz et al., 2017:2). In a mental health setting, management represents different professional groups offering mental health services. An explicit need for partnership will be expressed to management including a request to allow identified professionals to become part of a task-team for the coordination and development of partnership (WHO, 2012:13; Gole, 2018:12). The purpose of a task-team is to broaden consultation to MHCUs, caregivers, mental health service providers and civil society.

In this case, the task-team may comprise mental health care practitioners (a psychiatrist, a nurse, a psychologist and a social worker). The social worker is responsible for convening an initial task-team meeting to outline the rationale for the formation of a task-team (WHO, 2012:10).

7.2.2 Partnership assessment

An assessment of how to make partnership effective to improve service delivery should be undertaken by the task team. The process should include the examination of resources related to the; identification of potential partners’ abilities regarding their skills and competencies. Furthermore, the suitability of the environment politically, socially, economically, culturally and religiously needs to be determined since it has a bearing on the effectiveness and sustenance of partnership. The type of resources that need to be identified include community home-based care, NGOs, CBOs, respite care, community clinics, social work services, schools for children of MHCUs, employment opportunities for stabilised MHCUs, access to social grants, churches, local municipality, housing, tribal leadership and traditional and faith healers. The strength of all partners is the cornerstone of partnership practice. Therefore, assessment will facilitate an understanding of the strength of the MHCUs, their caregivers, mental health care providers and civil society as outlined below:

7.2.2.1 Strengths of MHCUs

The medical model, which influences the practice of mental health care, maintains that the MHCUs are incapable of making correct decisions about their lives (Rogers & Pilgrim, 2010:244), thus strengthening societal discrimination and negative attitudes towards the MHCUs. However, the social model regards the MHCUs as having the ability for involvement in improving their recovery from mental illness (Chamberlin, 2005:10; Rogers & Pilgrim, 2010:180). Nevertheless, not all MHCUs have the ability for self-care and social functioning. Therefore, only those who are mentally stabilised and have the ability for self-care and perhaps limited social functioning will be expected to:

- make decisions concerning the use of hospital treatment and indigenous healing;
- adhere to prescribed medication to avoid relapse;
- avoid the use of dagga and alcohol, often taken together with medication;
- avoid defaulting treatment and risk a relapse;
- participate in self-care activities (bathing, preparing a meal for self or family), family responsibilities (cleaning the surroundings), and leisure activities involving games (*morabaraba*[17], football, taking a walk, skipping rope challenge, watching movies); and
- use disability grants responsibly by contributing towards groceries, transport expenses for treatment reviews, and personal needs (clothes, etc).

7.2.2.2 Strengths of caregivers

The strengths of caregivers reflect their resilience in the midst of caregiving challenges (Van Breda, 2018:2). Caregivers provide fulltime care to MHCUs to ensure their stability and recovery from mental illness. The caregiving strengths show the ability to:

- assist MHCUs to apply for disability grants;

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[17] Morababara is an indigenous two-player game played in most African countries. It is known by many names, including mlabalaba, mmela, muravava, and umlabalaba and is played on a board or ground, and is associated with enhancing problem-solving skills of an individual (Deprtment of Sports & Recreation, 2018:37).

- provide housing, food, and financial support to MHCUs;
- monitor MHCUs' adherence to treatment to avoid relapse;
- ensure the admission of MHCUs when relapse happens;
- perform additional responsibilities including the care of their own children; other family members and those of MHCUs;
- advocate on behalf of the MHCUs for access to services including schools for children, housing, disability grants and community-based support services to ensure their integration in communities; and
- participate in community programmes for access to support services.

7.2.2.3 Strengths of the community

The community is a terrain full of resources needed to improve the living conditions of MHCUs, caregivers and families. It serves as a context for the development of a network of stakeholders sharing resources and competencies to build a more comprehensive partnership (Guidelines on stakeholder engagement, n.d:3). Stakeholders involved in partnership may include government, business, non-governmental organisations, and civil society organisations (Stibbe & Prescott, 2016:3). The strength of the community reflects the roles that stakeholders play. MHCUs, caregivers and their families require support services from stakeholders to enhance their quality of life. Social workers also need support from stakeholders to enhance partnership practice. The task of the partnership team is to conduct a community profile to establish the scope of resources that stakeholders provide as support networks for MHCUs, caregivers and their families. The community has the ability to:

- create a conducive environment for people to access resources. Social workers play an essential role of assessment of support services related to mental health care, social work, social assistance and respite;
- mobilise resources to support individuals and families in need, promote shared norms and avoid discrimination of MHCUs and caregivers; and
- promote a multi-sectoral approach to improve the quality of support and increase the effectiveness and efficiency of service delivery.

The strengths and specific contribution including limitations of these stakeholders are described as illustrated in Table 7.2 below (adapted from Acharya et al., 2017:3).

Table 7.2: Service providers contributing to partnership practice

Partner type	Services	Contribution	Potential limitations
Public institutions - DSD, DoH, DoJ&CD, SAPS	▪ Mental health care ▪ Social work services ▪ Provide statutory services to families and assist with admission of state patients to hospitals ▪ Provide social assistance ▪ Restrain violent MHCUs	▪ Guarantor of health as a right for all citizens ▪ Scale-up and sustain promising programmes ▪ Develop or modify existing mental health policy	▪ May avoid taking risks with new interventions needed to innovate in healthcare delivery. ▪ May lack resources needed for high quality services (e.g. social workers, police, transport)
NGOs - SAFMH	▪ Mental health care ▪ Community home-based care	▪ Invest in sustainable programmes and take risks with new interventions ▪ Integration of clinical and community-based mental health services into general healthcare services	▪ May lack local contextual and cultural perspectives of the specific intervention site ▪ May not have the general healthcare delivery infrastructure

		▪ Specialized focus on cross-cultural adaptation of psychiatric concepts, research scales, and protocols ▪ Training of health workers ▪ Advocacy for mental healthcare services	
Mental health care users and caregivers	▪ Stabilised MHCUs, caregivers, families	▪ Provide feedback to mental health care providers and guidance for mental healthcare services ▪ Advocate for quality services and human rights protection	▪ May have limited engagement due to societal stigma ▪ May not have access to specialized, clinical knowledge ▪ May lack agency to challenge such established institutions
Indigenous healing practitioners	Traditional and faith healers	▪ Provide contextual and culturally-relevant framework for interventions ▪ Have local presence to provide ongoing treatment of mental illness	▪ May not have access to specialized, clinical knowledge
Academia	▪ Mental health ▪ Social work	▪ Research infrastructure for implementation science, impact evaluation, and structured curriculum development	▪ May not have healthcare delivery systems to test interventions in community settings

		▪ Training and mentorship ▪ Support for principal investigators ▪ Cross-disciplinary collaborations ▪ Contextual expertise in healthcare delivery	▪ May not have local expertise in community settings ▪ Lack of funding for research projects
Private sector	▪ Business ▪ Media	▪ Provide financial and material support and innovation (network connectivity including Wi-Fi) ▪ Awareness raising about the causes and treatment of mental illness; stigma and discrimination associated with mental illness	▪ May not have local expertise in community settings ▪ May maintain stigma against mental illness
Civil society	▪ Retired professionals ▪ Churches ▪ *Letšema* support groups ▪ Tribal authority	▪ Provide contextual and culturally-relevant framework for interventions ▪ Mobilise community support services (*stokvels*, *letšema* and support groups) for MHCUs, caregivers and families ▪ Promote integration of MHCUs in the community	▪ May have superstition about mental illness ▪ May maintain stigma against mental illness

It is advisable for the adhoc task team to compile a report on the assessment of services, contribution and limitations of potential partners. The report should be presented and discussed with management for approval. This will enable the task-team to initiate the recruitment process of partnership members, planning and implementation of partnership.

7.2.3 Recruitment of partners

Screening and selection of potential partners which is part of recruitment takes place in order to identify partners for the implementation of partnership. A list of partners generated by the task team will enable the beginning of a conversation about issues related to mental illness, how it should be addressed, and the need for partnership practice. Negotiation with potential partner organisations should facilitate the identification of appropriate persons guided by interest, skills and resources as potential partnership members. Recruitment requires the task-team to understand that partners are not a homogeneous group. Therefore, conflicting interests may change opinions and attitudes of members during the course of the implementation process, and may also be difficult to influence. Some of the partners to consider include MHCUs, mental health care practitioners, (a doctor, a nurse, a social worker), caregivers (representing caregivers in the area), representatives of traditional healers, faith healers, community-home carers, retired professionals, traditional leaders, churches, business and local government.

Each potential partner organisation will be informed about the intention to include them as members of a partnership team. The initial meeting of identified partners, should serve as an opportunity for potential members to raise issues and concerns, ask questions, make suggestions about partnership formation, and derive possible solutions. The meeting will enable the task-team to gain more information on partners; identify potential barriers to participation and find ways to mitigate possible challenges; explore mandates of potential partners; be open to suggestions and address concerns to avoid misunderstanding; and identify potential partners for partnership planning and implementation processes.

7.2.4 Partnership planning

Planning is the third phase of a partnership process and a primary function that precedes all other functions in the implementation of programmes. It provides a roadmap to indicate what should be done, when and by whom (Maleka, 2014:15). Partnership practice requires a truly participatory planning process that contributes to improving the mental health system to address challenges experienced by MCUs and their caregivers.

At this stage, the partnership team has been identified and selected to participate in the planning process. The initial task of the team is to have a brainstorming session to develop a shared understanding of issues. The social worker conducts the brainstorming session to enable the team to understand the concerns of the MHCUs and their caregivers, and social workers to guide partnership planning. The concerns established through the current study are provided in Table 7.3 below.

Table 7.3 Concerns of MHCUs, caregivers and social workers regarding the provision of mental health services

MHCUs	Caregivers	Social workers
Lack of understanding of mental illness due to lack of information from mental health care practitioners	Lack of understanding of mental illness due to lack of information from mental health care practitioners and traditional healers	Community-based social workers have limited understanding of mental illness and its treatment
	MHCUs relapse due to non-adherence to medication and the use of dagga	Relapse due to non-adherence to medication and the use of dagga.
Aggression towards family members due to delusions and a desire to feed the habit with dagga	MHCUs' aggression towards family and community members	Aggression towards family and community members

Lack of support from the mental health care practitioners - e.g. home visits are done	▪ Lack of support from the mental health care practitioners – the doctor, nurses and social worker lack of empathy to understand their circumstances when they asked for intervention. Some social workers who promised to conduct home visits failed to do so. Some made appointments which they never honoured. ▪ Lack of police assistance to restrain violent MHCUs	▪ Lack of cooperation and collaboration between the mental health care practitioners and social workers. ▪ Lack of cooperation and collaboration between hospital-based and community-based social workers
Challenges with access to social grants	Lack of information on grant-in-aid and foster care grants to care for the children of MHCUs	Social workers do not share information on grant-in-aid and foster care grants to care for the children of MHCUs

7.2.4.1 Action plan

The partnership team develops an action plan to guide the implementation process. The role of the team is to set objectives, decide on a partnership structure, implement partnership, and evaluate the effectiveness of the implementation of partnership. The objectives should ensure partnership that is built on shared understanding; and SMART [specific, measurable, achievable, relevant and time-bound] (Patzak & Rattay, 2012:63). The objectives will guide the partnership team on what to do, with whom, when, where and how partnership should unfold. SMART objectives are:

- **Specific** to promote partnership between caregivers and mental health care practitioners to enhance the provision of mental health services for the wellbeing of MHCUs and their families.

- **Measurable** in that the circumstances of MHCUs, their caregivers and social workers have to improve as a result of partnership practice in the provision of mental health services.
- **Achievable** to ensure that appropriate skills and support services are mobilised from mental health service providers and civil society for the provision of comprehensive services.
- **Relevant** in that mental health services are part of social services. MHCUs and families will access mental health services through partnership practice.
- **Time-bound** involves the setting of deadlines to achieve the objectives. Partnership practice is long-term. However, intervention should involve short-, medium-, and long-term activities for MHCUs to recover and to function as family and community members; enable caregivers to develop resilience and social workers to acquire the relevant knowledge and skills and offer psychosocial support. Time-bound activities may be planned as follows:
    - **Short-term** activities must include assessment, consultation with stakeholders, creation of a partnership team, development and implementation plan.
    - **Mid-term** activities should involve engagement of service providers, identification of MHCUs and caregivers as beneficiaries of partnership practice.
    - **Long-term** activities must ensure the enhancement and sustainability of partnership practice and access to support services by the MHCUs and caregivers. The involvement of community-based social workers in offering mental health services should be promoted. This will facilitate the recovery of MHCUs, their integration in the community, and improvement of their social functioning.

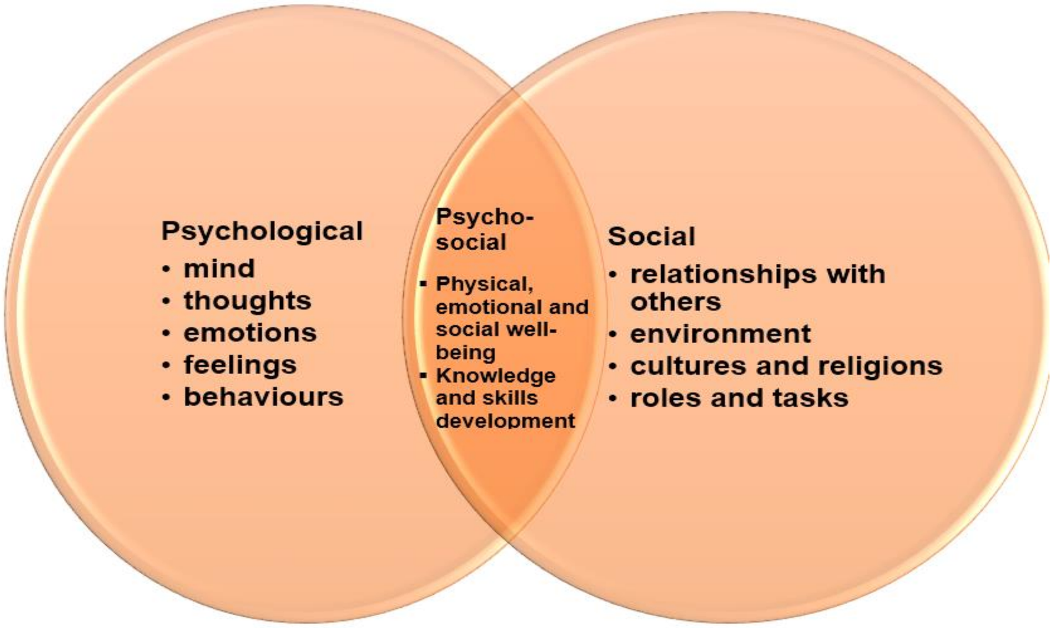
7.2.5 Partnership implementation

This phase entails the active involvement of all partners to ensure the success of partnership practice. It reflects a psychosocial orientation that promotes a well-integrated and cross-sectoral approach involving families, private sector and civil society. Effective partnership implementation requires psychosocial intervention through advocacy, empowerment and transformation to promote the wellbeing of

MHCUs, caregivers and their families. Adoption of partnership practice will enable various service practitioners to advocate and promote the rights of MHCUs and their families to access a range of services that would empower them through knowledge and transformation of mental health system. The family of the MHCU needs to be acknowledged, recognised and involved as a key partner in the delivery of mental health services.

Psychosocial intervention incorporates the ecological, PIE and strengths models that emphasise an interaction between the individual's psychological and social experiences (De Jong, 2011:70; Parikh, 2015:242). Therefore, an interaction of factors is responsible for the psychosocial wellbeing of individuals hence the biological, emotional, spiritual, cultural, social and material aspects of experiences cannot necessarily be separated from one another. Figure 7.3 below illustrates an integration of the psychological and social factors leading to the psychosocial wellbeing.

Figure 7.3: Psychosocial factors



Adapted from ARC resource pack study material Foundation Module 7 Psychosocial Support (2009:10).

Psychosocial intervention suggests a multidisciplinary approach to treatment within the mental health system. Each discipline has a view about the causes and interventions for mental health problems. Mental health care practitioners provide psychosocial services to individuals and families guided by a PIE intervention. Families play a significant role of caregiving and should be considered an important stakeholder for the success of partnership practice. Each partner contributes to partnership in the form of ideas, suggestions, services, and resources. The role of the partnership team is to coordinate the implementation of a sustainable partnership practice through advocacy, empowerment and transformation.

Partnership practice advocates for social justice and the empowerment of MHCUs, caregivers and families to bring about positive transformation in mental health service delivery. The outcomes of effective advocacy should enable service users to access and receive services that would enhance their wellbeing as illustrated in Table 7.4 and 7.5 below.

Table 7.4: Services to address the needs of MHCUs

Needs of MHCUs	Service providers	Psychosocial intervention
1. Access to mental care services Promote prevention, curative, rehabilitative services and continuing care in hospitals, homes and communities	**Social work intervention** should demonstrate understanding of the impact of mental Illness on the individual through: ▪ **Assessment** to establish the needs of MHCUs, level of functioning, adherence to treatment, interpersonal relationships. ▪ **Family intervention** since families may experience stigma or discrimination for having a MHCU ▪ **Facilitate referral** for further intervention	▪ Interviews with the MHCU ▪ Share information regarding mental illness, alcohol and drug abuse (their effects on mental health), social work and mental health services ▪ Provide family intervention to address concerns of the family regarding the MHCUs and other needs; seek their inputs and involvement to address identified needs ▪ Share information on services provided by the police to help transport aggressive MHCUs to hospital for admission ▪ Referral on needs basis to a medical doctor, psychologist, social worker, indigenous or community-based workers and the police
	Psychiatric intervention plays a major role in the management of schizophrenia (Mahaye et al., 2012:608)	▪ **Psychiatric assessment** determines the severity of the symptoms to decide on a diagnosis, prescribe medication, discharge MHCUs, recommend disability grants and monitor recovery

		▪ Relapsed MHCUs will need medication to stabilise symptoms to facilitate caregiving and provide psychosocial services
	Nursing care involves the provision and monitoring of medication	▪ Nursing care is offered in both hospitals (during admission) and community settings (through community health care and home visits following discharge) to monitor non-adherence to treatment, determine possibility of a relapse, and recommend readmission ▪ Provide information on the diagnosis and treatment offered
	Psychotherapy complements biological treatments (Lysaker et al., 2010:76; Baandrup, Rasmussen, Klokker, et al., 2016:237)	▪ Assessment conducted to determine the psychological effects of the illness ▪ Provide information on the diagnosis and treatment offered ▪ Offer psychotherapy through individual, group and cognitive-behavioural therapy to develop individuals' self-concept, improve their coping, recovery and quality of life ▪ Refer MHCUs and caregivers to other service providers for further intervention
	Indigenous healing conducted by traditional and faith healers to provide alternative treatment	▪ Cleansing of the MHCU and the family of evil spirits may be through washing, steaming, induced vomiting, and exorcizing of evil spirits through singing, dancing and praying

2. Access to child maintenance	**Collaboration of services** ▪ Social work intervention ▪ Maintenance court ▪ Police (trace defaulting parent to appear in court)	▪ Facilitate MHCUs' access to child maintenance for children to receive support from the other parent ▪ Enforcement of maintenance by defaulting parents
3. Access to basic education	**Collaboration of services** ▪ DBE ▪ Business ▪ Non-governmental organisations (NGOs)Transport and taxi associations	▪ Ensure that the children of MHCUs benefit from school fee exemption at all levels of education ▪ Business and NGOs be mobilised to support children with school uniform and transport
4. Access to social assistance	**Collaboration of services** ▪ Social work intervention ▪ SASSA	▪ Provide information regarding access and the use of disability grant paid to a MHCU (e.g. food, transport and treatment)
5. Access to housing and basic services	**Collaboration of services:** ▪ Department of Human Settlements ▪ Local government ▪ Business ▪ Tribal authority	▪ Social workers to advocate for MHCUs' families to access housing ▪ Department of Human Settlements to provide housing subsidies to eligible MHCUs Local government (municipalities) to provide free housing and free water to families of MHCUs (Reconstruction and Development Programme [RDP] and the Local Government Municipal System Act [Act No. 32 of 2000])

		▪ Encourage business to finance the building or refurbishing of MHCUs' dilapidated homes ▪ Encourage tribal authority to raise funds and tap available skills in communities to refurbish MHCUs' dilapidated homes

Table 7.5 Services for caregivers

Needs of caregivers	**Service Providers**	**Psychosocial intervention**
1. Access to information to enhance caregiving capacity	**Collaboration of services** ▪ Education on mental illness and treatment ▪ Psychotherapy ▪ Social work intervention ▪ Indigenous healing	▪ Ensure understanding of the diagnosis, treatment and its effects; supervision of MHCUs after discharge regarding adherence to treatment and review thereof at stipulated timeframes ▪ Offer community-based mental health services ▪ Offer social work services ▪ Offer indigenous healing to mental illness ▪ Clarify the involvement of family members in identifying challenges and monitoring effects of rituals and traditional treatment

2. Access to social assistance to enhance quality of life	**Collaboration of services** ▪ Social work intervention ▪ SASSA	▪ Provide information on access to social grants and other forms of social assistance. Those include: • Child support grant paid to primary caregivers of children of MHCUs Foster child grant paid to a court-appointed foster parent caring for children in need of care and protection. The caregiver of the MHCU may be appointed as a foster parent of her children • Grant-in-aid is paid to the primary caregiver of a MHCU • Social relief of distress is a temporary financial assistance for persons in urgent need for instance. Food parcels are also offered as social relief. The assistance should be offered while MHCUs and caregivers are waiting for approval of grants
3. Psychosocial support to enhance their quality of life	**Collaboration of services** ▪ Social work intervention ▪ Nursing care ▪ Indigenous healing practitioners	▪ Provide psychoeducation to enhance caregiving capacity ▪ Share information on dagga and alcohol addiction and rehabilitation services for MHCUs ▪ Inform caregivers on respite services ▪ Facilitate the formation of caregivers’ support committees or forum

		▪ Mobilise support for families to enhance knowledge and caregiving responsibilities ▪ Improve family interaction ▪ Strengthen referral system to ensure that MHCUs and caregivers receive a broad range of services
4. Community support to raise awareness and promote social cohesion	**Collaboration of services** ▪ Mental health care providers ▪ Retired professionals ▪ Tribal authority ▪ Business ▪ Churches ▪ Local government ▪ Media	▪ Initiate the development of support networks for caregivers ▪ Convene community meetings (*imbizos*) to educate the community about mental illness, stigma and discrimination of MHCUs and their families, adverse effects of alcohol and dagga on mental health, involvement of some MHCUs and caregivers in community activities ▪ Use platforms (*imbizos,* community meetings, media, schools and churches) to campaign against the selling of drugs in communities ▪ Encourage and involve the community in the development and enhancement of support services or networks for the MHCUs and their families

Mental health professionals advocate for the rights of MHCUs and caregivers as part of the empowerment process. Empowerment as a function of partnership promotes human rights and social justice. The desired outcome of empowerment is the recovery of the MHCUs, resilience of caregivers and family members, and the ability to make informed decisions and take charge of their lives. Empowered MHCUs will develop the ability for self-care which involves adherence to medication, refraining from the use of substances (e.g. dagga and alcohol), appropriate use of finances and maintain good interpersonal relationships. On the other hand, caregivers will be able to participate in support networks to enhance their caregiving capacity. Therefore, both MHCUs and caregivers will be able to develop self-advocacy, self-efficacy, self-determination, knowledge and competence.

Since capacity building facilitates empowerment of all partners involved in the provision of mental health services, the partnership team should be responsible for organising such training. Key focus areas should include the social model; mental illness (and its causes); development of proactive programmes to promote abstinence from substance abuse; adherence to treatment; caregiving and family functioning, roles and responsibilities of mental health care practitioners; collaboration between mental health care practitioners, indigenous healing practitioners and families of MHCUs in the provision of mental health services.

Partnership practice strives to transform mental health system which implies doing things differently (Gass, 2011:1). It also provides an impetus to achieve effective transformation to bring about positive change in attitudes and systems of governance that embrace multidisciplinary, collaborative, cooperative, intersectoral and complementary approaches to service delivery (Nadeau, Jaimes, Rousseau, et al., 2012:92). This suggest a shift from the biomedical model to the social model of mental health to promote partnership practice.

7.2.6 Evaluation of the implementation of partnership

Evaluation is essential for measuring success. Even though partnership is not a once-off activity, the team should ensure that evaluation (included in the implementation plan) takes place over a stipulated time-frame to provide feedback on the effectiveness of the services provided to the MHCUs, caregivers and their families. The outcomes of the evaluation will assist the team to examine successes and challenges encountered during implementation and to develop new and fresh ideas to improve partnership practice.

7.2.7 Sustaining partnership

Sustainability is one of the stages of partnership development. It is used by the public and private institutions to sustain businesses and programmes. The United Nations 2030 Agenda underscores partnership as a means to achieve 17 UN Sustainable Development Goals (SDGs) by pulling resources together (Banerjee et al., 2020:2). Equally, the focus of public-private partnership is on sustainable socio-economic development (Nikoliuk, 2018:15). This suggests that successful implementation of programmes requires sustainable partnership. However, sustainability is dependent on participation of partners and resources (Documet, McDonough & Van Nostrand, 2018:395). Lack of sustainability may discourage further partner participation in partnership programmes (Bryan & Henry, 2012:417). Therefore, this study invokes partnership practice as an indicator for the successful implementation of partnership resulting in the empowerment and promotion of social justice, and improved provision of services.

Partnership sustainability is essential in poor communities to maintain social support networks in which community members share ways to address issues of concern relating to the provision of mental health services. It is a call for the transformation of policies and systems that limit the capacity of people to develop (Ngang & Kamga, 2017:46). Therefore, sustainability requires partnership team to maintain regular assessment, monitoring and evaluation to enhance the implementation of partnership (Martens & Carvalho, 2016:1087). The implementation plan should be continuously revisited to reassess needs and strengths in order to determine whether to maintain what is working, improve what is not working, or provide more resources (Bryan & Henry, 2012:417). The authors further identify the provision of continuous capacity building and mentoring to maintain the required knowledge, skills and resources to sustain participation in partnership activities. Therefore, sustained partnership encourages continuous participation in partnership programmes and sustained access to the much-needed support services.

7.3 Conclusion

Social work practice guidelines were developed to provide guidance on the establishment and enhancement of partnership practice in mental health care. Such a practice strives to promote social justice and the wellbeing of the MHCUs and their families. The guidelines were informed by the experiences and suggestions of the MHCUs, caregivers and social workers regarding the provision of an effective, comprehensive and sustainable mental health services. Even though the guidelines are not conclusive, an attempt has been made to demonstrate the importance of advocacy and empowerment of MHCUs, families and communities when implementing partnership practice to transform the mental health system.

CHAPTER EIGHT

MAJOR FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

8.1 Introduction

The presentation is based on the major findings, conclusions and recommendations demonstrating how the research process; overarching research questions, goals and objectives of the study were attained. The conclusions based on the research process and research findings centred on ten themes are presented. The next section focuses on recommendations related to education, practice, policy and suggestions for future research.

8.2 Major findings of the study

Major findings drawn from the experiences of MHCUs, their caregivers and social workers discussed in Chapter Five and Six are presented as follow.

8.2.1 Major findings from MHCUs and their caregivers

This section describes major findings drawn from the experiences of mental health care users (MHCUs) and caregivers. Six major findings derived from the findings are discussed below.

8.2.1.1 Theme 1: Description of mental illness by the MHCUs and their caregivers

The findings show that MHCUs and caregivers shared common descriptions of mental illness which they describe as behaviour deemed not normal. However, the accounts show differences in the descriptions of behaviour which suggest differences in their level of awareness. The MHCUs' descriptions seem to support the view that people who suffer from mental illness lack awareness due to the severity of the symptoms. Caregivers' descriptions filled the gaps in the memories of MHCUs to confirm their awareness of mental illness.

The MHCUs and their caregivers relied on their cultural belief systems to explain their understanding of the causes of mental illness. Some caregivers confirmed the use of dagga as having contributed to the onset and course of mental illness, thus refuting the supernatural argument held by MHCUs. The caregivers' understanding of the role of dagga in mental illness shows that support for supernatural factors was not universal. Therefore, they did not support the behaviour of MHCUs which they perceived as contributing to the development of mental illness.

8.2.1.2 Theme 2: Experiences of services provided by mental health professionals

The MHCUs received multidisciplinary mental health services from admission to discharge and aftercare. Practitioners involved in the provision of mental health services include psychiatrists, psychiatric nurses, psychologists, occupational therapists, social workers, and traditional and religious practitioners. The mental health care practitioners failed to share information with both MHCUs and their caregivers regarding the illness. Moreover, both the MHCUs and caregivers were not able to differentiate between medical practitioners and psychiatrists whom they refer to as doctors. Nevertheless, doctors communicated the diagnosis as mental illness and also prescribed medication.

Nursing care was provided to MCHUs in hospitals, clinics, and communities. Rural communities benefit more from services offered by the primary health care nurses who, due to lack of general practitioners, function as mini doctors responsible for diagnosing, treating common illnesses, and monitor compliance with medication. However, not all caregivers were satisfied with the services provided by some nurses who used MHCUs to commit transgressions on their behalf.

Social work services were inaccessible to most MHCUs and their caregivers. The findings show that social workers for some reason failed to offer required services which should be accessible to MHCUs, caregivers and their families. Some MHCUs and caregivers received social work services in hospitals and communities. Limited outreach to families of MHCUs by the mental health professionals also compromised effective service delivery.

The indigenous healing practitioners formed part of the mental health care providers. The MHCUs consulted indigenous healing practitioners with the help of their family caregivers to establish the nature of the problems they are experiencing. However, not all MHCUs and their caregivers were satisfied with the diagnosis and treatment administered by indigenous healing practitioners. Caregivers, in particular, felt helpless and dissatisfied as they were excluded from participation during the diagnosis process to understand the type of illness, causal factors and the treatment.

8.2.1.3 Theme 3: Family caregivers as support systems in the provision of care to their relatives with a mental illness

The finding shows that families are traditionally the main providers of caregiving for their members with mental illness. Family caregivers have become the primary source of support for the day-to-day needs of MHCUs. Most families have made caregiving a collective responsibility through which members, namely mothers, siblings, and a cousin, were designated caregiver roles. Support is also provided by other members of the family or extended family in the absence of the designated member. Nevertheless, caregivers perform their responsibilities despite inadequate support from their social environment as a result of poor service delivery.

8.2.1.4 Theme 4: Caregiving challenges experienced by caregivers

The finding shows that caregivers experience challenges resulting from the effects of mental illness afflicting MHCUs. Mental conditions such as schizophrenia, are long lasting with no known prevention or cure thus contributing to stress experienced by both MHCUs and their caregivers. Although antipsychotic medication is available, it can only reduce the severity of psychotic symptoms without completely returning the MHCU to the initial normal functioning. The effects of mental illness are systemic in that they not only affect the MHCU, but the family. Such effects include non-compliance with treatment and substance abuse resulting in relapse, violent behaviour, a burden of caregiving and lack of support from mental health care practitioners.

The family members experience violence by MHCUs. The violence involves threats, often culminating in physical assaults, and destruction of property. Furthermore, MHCUs’ violent behaviour is not limited to family members but extends to members of the public who may be neighbours, friends and acquaintances. As a result, caregivers shoulder the responsibility for the violence committed by MHCUs.

Furthermore, caregivers endure the burden exacerbated by the scarcity of services, especially for families in rural communities who must travel long distances to receive professional support. Some family members, are forced to leave their employment to take care of the MHCU, thus placing a strain on the financial and the general wellbeing of the family. Moreover, caregivers contend with stigma and social isolation for being associated with MHCUs. To mitigate the burden, resilience enables caregivers to continue to provide care despite caregiving challenges, inadequate knowledge, experience and resources.

8.2.1.5 Theme 5: MHCUs' and caregivers' perceptions of the community regarding mental illness

The findings show that the community has both negative and positive roles in the wellbeing of the MHCU and the family. MHCUs are not only members of their own families, but are part of communities within which they live, sharing common norms, values, identity and a social environment. Community members' understanding of the negative effects of mental illness on both the family and the individuals with mental illness motivate them to offer support. Social institutions have offered social services such as food, clothes, shelter and counselling to individuals and their families, and assisting MHCUs to participate in community activities.

However, the findings show that the community can be a source of stigma negatively affecting the MHCU's self-image, and creating a barrier to receive support. They show that the community is complicit in stigmatizing and discriminating MHCUs and their families. Community members seem to hold attitudes that are prejudicial to the mentally ill and their families, thus perpetuating rejection, social isolation and their withdrawal from participation in public activities. Nevertheless, the community can facilitate a conducive environment for the provision of services to families.

8.2.1.6 Theme 6: MHCUs' and caregivers' expectations of mental health service providers

The finding shows that the MHCUs and caregivers need support services from mental health service providers to overcome the effects of mental illness their functioning. The effects of mental illness encourage MHCUs and caregivers to expect support from the mental health care practitioners to rescue them from stressful life circumstances. MHCUs and caregivers expect doctors, nurses, social workers and indigenous healing practitioners to listen to their concerns and to share information about diagnosis and treatment; MHCUs and caregivers should receive disability grant and grant-in-aid respectively; police should protect family members from violent MHCUs;

institutionalisation of MHCUs should relieve caregivers from the burden of caregiving; social workers should visit families to establish how they are coping with mental illness, and to assist them to access services. Although both MHCUs and their caregivers did not use the term partnership, their expectation is for mental health care providers to work with families.

8.2.2 Major findings from social workers

This section describes major findings drawn from the experiences of social workers in the provision of mental health services. Four major findings derived from the findings are discussed below.

8.2.2.1 Theme 1: Social workers' experiences in working with families of MHCUs

Social workers perceive families of MHCUs as having average understanding of mental illness and their role regarding the provision of mental health services. However, social workers acknowledge that families experience a myriad caregiving challenges which involve MHCUs' defaulting on medication; trapped in substance abuse; suffering from psychotic symptoms; and displaying violent and disruptive behaviour. Most caregivers perform their caregiving responsibilities with minimal or no support from other family members. Caregivers are overwhelmed by the traumatic experiences of caring as they contend with disruptive behaviours of the MHCUs on an ongoing basis; they are usually on their own, faced with an overwhelming burden of caregiving including rejection within the family and the community, stigma, discrimination and socioeconomic factors, and minimal support from professionals.

Furthermore, families are resilient in that they mobilise resources in the form of support from relatives, communities, the police, mental health practitioners and indigenous healing practitioners. Their belief systems based on cultural and religious practices, guide their understanding of mental illness and its treatment. Most of them prefer indigenous healing (traditional and faith healing) as the treatment of choice for mental illness, especially in rural communities where the services of mental health care practitioners are scarce. Family caregivers may either alternate or use both indigenous healing and hospital treatment.

8.2.2.2 Theme 2: Services provided by the social workers to MHCUs

Different types of interventions are applied in responding to the needs of MHCUs and caregivers across the continuum of care. Social workers interact with individuals and families within their environment to understand their needs and to work together in developing appropriate interventions. Psychosocial support which involves case management for coordination of services, counselling, psychoeducation, advocacy and awareness campaigns is a technique used to reduce the severity of psychiatric symptoms, promote recovery and caregiving skills. In this way, advocacy for social justice and access to services to improve personal, family and social functioning is initiated.

The referral system was used among the multidisciplinary team members within the hospital, community-based social workers and community home-based carers. Social workers used referrals to facilitate access to the following services: hospital care services, community-based social workers, home-based care and other mental health services. Furthermore, social support services are received through assessments, interventions, referrals, coordination and monitoring.

Social work practice incorporates social assistance within its basket of social support services to mitigate the effects of mental illness. For instance, social workers collaborate with doctors and SASSA to facilitate access to social assistance in the form of cash transfers (social grants) and social relief (food parcels) to MHCUs and their families to supplement the family's limited resources.

Cooperation among practitioners, in the form of partnership was not evident between hospital and community-based social workers. Additionally, not every community-based social worker had experience in the provision of mental health services. Most of them provided generic social work services focusing on poverty alleviation programmes. This exposed conflicting priorities and competencies in providing mental health services as well as inadequate training, support and resources to provide mental health services. This has contributed to individuals, families and communities being deprived of services that social workers should be providing. Hence, family caregivers preferred hospital-based social work intervention than community-based social work.

8.2.2.3 Theme 3: Social workers' views of partnership with families of MHCUs

Social workers support partnership between the family and the mental health practitioners to enhance the provision of mental health services to MHCUs. The provision of mental health care requires a comprehensive approach involving multiple role-players working together in partnership to meet complex needs. Social workers regard caregivers as the primary resource in understanding the context of the illness that guides the provision of social work services. There is an acknowledgement that families perform roles that support the efforts of practitioners to improve the wellbeing of MHCUs. Although there was no partnership with families in providing mental health care, the need for their involvement as partners was acknowledged.

8.2.2.4 Theme 4: Social workers' opinions on who should form part of the mental health care team to work with families of the MHCUs

Social workers are of the view that partnership team should include mental health care practitioners (psychiatrists, clinical psychologists, psychiatric nurses, social workers and occupational therapists); police; priests; indigenous healing practitioners (traditional and faith healers); the private sector and civil society (retired professionals across the board). It is based on the understanding that mental illness is a complex condition that requires the mobilisation of every available resource to bring about change in the lives of the MHCUs and their families. Multidisciplinary teams bring complementary rich knowledge and expertise from different disciplines to provide comprehensive service delivery within the mental health system. However, the finding shows that the current multidisciplinary team is limited to psychiatrists, clinical psychologists, psychiatric nurses, occupational therapists and social workers. The finding further shows that the provision of mental health care is not limited to the traditional multidisciplinary team, but extends to traditional and faith healers. Notably, social workers have acknowledged the role of traditional and faith healing practitioners in mental health. Families and community home-based carers are viewed as an integral part of the provision of mental health services sharing skills, knowledge and experience in the development of diagnostic assessment for the treatment of MHCUs, and the building of partnership. Therefore, their role ensures an effective comprehensive mental health care from different disciplines beyond the current traditional mental health multidisciplinary team.

The next section presents conclusions based on the research findings.

8.3 Conclusions based on the research process

The conclusions based on the outcomes of the qualitative research process and the ethical considerations are provided below.

8.3.1 Research questions

The following two broad research questions guided the study.

- What are the participants' experiences of the family as a partner in the provision of mental health services?

The MHCUs', caregivers' and social workers' accounts revealed that partnership was not experienced. Among the MHCUs, only two were unable to express their views due to the effects of mental illness on their cognitive functioning. Eight MHCUs and seven caregivers expressed the desire to work with mental health care practitioners. Their desire was motivated by the need to access support services. Similarly, nine social workers expressed the need for partnership between families and mental health care practitioners. For example, one of the social workers stated that "*It is important for us social workers to work with families of MHCUs to provide support to the MHCU. In partnership, the MHCU will know that the social worker will be notified when they display deviant behaviour".* Their support for partnership was based on their acknowledgement that families were already involved in the provision of care to MHCUs with limited support from service providers.

- What are the participants' experiences of mental health care providers as partners in the provision of mental health services?

The MHCUs and caregivers displayed unfamiliarity with partnership as a concept in their engagement with social workers. Their concern was that mental health care practitioners were not sharing information regarding diagnosis, treatment and social grants (disability grant and grant-in-aid). However, social workers expressed the view that caregivers lacked an understanding of mental illness and the role of social workers in mental health care. Moreover, they also acknowledged their role in the provision of mental health services and lack of understanding of mental health care, support and resources. Nevertheless, social workers expressed the desire to work with families as partners in the provision of effective and comprehensive mental health services.

8.3.2 Research goals and objectives

- Goal 1: To develop an in-depth understanding of the family as a partner in the provision of mental health services.

This goal was realised. Semi-structured interviews were used to generate contextually rich data to gain an in-depth understanding of the participants' experiences (cf. Chapter Five & Six). Although the narratives of the MHCUs and caregivers describe their understanding of the role of the caregivers as providing care to MHCUs, they made no reference to partnership. For example, one MHCU stated that "*The mental health care practitioners must check with my mother if I am taking medication and whether I attend review sessions"*. Social workers, on the other hand, explained the need for partnership with families. For example, one of the social workers stated that "*Partnership is very important because the MHCU is part of the family. It is important that there be partnership between families and service providers…".* Therefore, partnership practice could promote the recovery of MHCUs and family resilience. As a result, a transformed mental health service delivery system is required.

- Goal 2: To proffer guidelines for social work practice to promote and enhance partnership between the family and mental health care providers.

Guidelines were developed to promote and enhance partnership between the family and the multidisciplinary team in the provision of mental health services. Chapter Seven contains guidelines that show how partnership should be formed and strengthened among all service providers, family, mental health care practitioners, indigenous practitioners, community-based organisations, NGOs and private sector.

The research objectives of the study were achieved as follows:

(i) To explore and describe the advantages of partnership between the families of the MHCUs and the mental health care providers in the provision of mental health services.

This objective was partly met in relation to the MHCHs and caregivers. Semi-structured interviews conducted in the MHCUs and caregiver's indigenous language (Sepedi) facilitated the exploration of the participants' experiences (cf. Chapter Five & Six). However, although the MHCUs and caregivers did not mention the term partnership, they however expressed the importance of working with mental health care practitioners to enhance access to mental health services. The advantages of partnership were described by social workers as involving: deinstitutionalisation; monitoring adherence to treatment and reduction of relapses; improved recovery; integration of families in communities; and support and enhancement of family functioning.

(ii) To describe partnership in the provision of mental health care from the perspective of MHCUs, caregivers and social workers:

The objective was partly met. Although the MHCUs and caregivers expressed the need to collaborate with mental health care practitioners to improve access to services, there was no mention of partnership. The social workers, on the other hand, expressed the importance of working in partnership with families to improve the provision of mental health services and quality of life for MHCUs and their caregivers. For example, one of the social workers stated that "*Partnership can work. My understanding is that when we work in partnership, we will be able to educate one another on how best to enhance this relationship between the institution and the family and the importance of caring for the MHCUs to recover"; another stated that "Partnership is about cooperation for the family to understand what professionals expect and for the professionals to conversely understand what the family expects from them"* (cf. Chapter Six).

(iii) To draw conclusions and make recommendations about partnership between the family and mental health care providers in the provision of mental health services.

The objective was met as major findings, conclusions and recommendations illustrating how the research process, research questions, goals and objectives of the study were attained (cf. Chapter Eight). Furthermore, practice guidelines were developed as recommended to enhance partnership practice in the provision of services (cf. Chapter Seven).

8.3.3 Research approach

The qualitative research approach was chosen to afford the participants an opportunity to share their lived experiences relating to mental illness, caregiving, and the provision of mental health services. This enhanced interaction between the researcher and the participants. Reflexivity was used to mitigate contamination of the participants' narratives during semi-structured interviews including the interpretation and presentation of the findings.

8.3.4. Research designs

The study applied an exploratory, descriptive and contextual research designs to determine how MHCUs, caregivers and social workers make sense of, and interpret, experiences of mental illness. A pilot test of the interview guides was conducted with two participants from each group (MHCUs, two caregivers and social workers). The use of open-ended questions generated relevant information on their experiences.

The exploratory design facilitated the identification of the participants' subjective meaning and understanding of mental illness and its impact on the personal, family and social functioning. It also assisted in establishing the need for partnership with mental health care practitioners in service delivery. On the other hand, the descriptive design provided an opportunity for the participants to describe their experiences. Most important is that participants shared their lived experiences within their social, religious, personal, economic and cultural context.

8.3.5. Ethical considerations

The human rights and social justice approach was adopted to guide the ethical conduct of the researcher. The ethical considerations observed are informed consent, confidentiality and anonymity, protection of participants from harm and management of information. All the participants consented to take part in the study. They were also provided with information regarding available services for those who may need them. However, none of the participants expressed a need for the services. The interactions between the researcher and the participants were based on respect, privacy and non-judgemental attitude.

8.4. Conclusions based on the research findings

Conclusions derived from the findings presented in terms of chapters five and six are discussed below.

8.4.1 Conclusions based on research findings on mental health care users (MHCUs) and caregivers

Conclusions drawn from the findings (cf. Chapter Five) of MHCUs and caregivers are presented below in terms of the themes.

8.4.1.1 Theme 1: Conclusions on the descriptions of mental illness by the MHCUs and caregivers

The accounts of MHCUs and caregivers demonstrate their ability to describe mental illness. The descriptions show the MHCUs' and caregivers' understanding of the causes, seasonal occurrence of mental illness, and the need to seek intervention. Although some MHCUs were able to describe onset on their illness, this could not be corroborated by their caregivers. Instead, some MHCUs denied having mental illness. However, the denial could be due to the fear of the illness itself, and rejection. Therefore, the conclusion drawn from the finding is that the ability of MHCUs and their caregivers to describe mental illness makes them important partners in the provision of mental health services.

8.4.1.2 Theme 2: Conclusions on experiences of services provided by the mental health professionals

The MHCUs and caregivers expressed dissatisfaction with the services provided by some mental health professionals. Their dissatisfaction emanates from the practitioners' failure to share information regarding the nature of the illness, its treatment and support services. Moreover, poor services in the communities has forced caregivers to seek help from hospital-based instead of community-based social workers.

The conclusion is that families need support services to enhance self-care of MHCUs and capacity for caregiving. However, mental health professionals' failure to provide support denies caregivers the knowledge and understanding of the MHCUs’ condition. Therefore, the rights of MHCUs and caregivers are violated as they are denied access to services to improve their quality of life.

8.4.1.3 Theme 3: Conclusions on family caregivers as support systems in the provision of care to their relative with mental illness

The accounts of MHCUs and caregivers show that families are responsible for caregiving. The family is responsible for the distribution of responsibilities that include assigning a caregiver for the MHCU. Caregivers perform their caregiving responsibilities of supervising and monitoring medication compliance to prevent relapses and improve personal, family and social functioning of the MHCUs. Additionally, support is not only sought within the immediate family, but extended to families, community members and service providers. The support received contributes to the recovery of the MHCU from mental illness, and promotes the wellbeing of the family.

The conclusion is that families are involved in the provision of care to their relative with mental illness.

8.4.1.4 Theme 4: Conclusions on caregiving challenges experienced by caregivers

The accounts of MHCUs and caregivers show that the effects of mental illness do not only affect the ill member, but extend to other family members (Chapter Two, Item 2.2.5). The challenges that caregivers experience include the MHCU’s unpredictable and disruptive behaviour which may be difficult to manage. Caregivers feel unappreciated by MHCUs who treat them with hostility. The challenges are further aggravated by the scarcity of resources and poor professional support.

The conclusion drawn from the findings is that caregivers experience a burden of caregiving which leave them feeling overwhelmed, distressed and despondent. Therefore, the challenges they experience support the need for partnership in the provision of mental health services. Partnership will enable families to access the expertise of social workers and other service providers relating to psychosocial services such as family intervention, social support network, advocacy and empowerment to promote recovery.

8.4.1.5 Theme 5: Conclusions on MHCUs' and caregiver's perceptions of the community regarding mental illness

The accounts show that the MHCUs and caregivers form part of their communities. As members of the community, they abide by the norms and values guiding their conduct. Moreover, their descriptions of mental illness reflect a shared understanding with fellow community members. Hence, some families have received support from the community.

The conclusion is that MHCUs and caregivers are not only members of their own families, but are part of communities. Extended families, friends, neighbours and community structures connect them to communities. However, the accounts reveal that communities can be both supportive and be the source of suffering to MHCUs and their families. Communities may contribute to the stigmatisation of mental illness, thus resulting in the victimisation and social isolation of MHCUs and their families. Nevertheless, most support services are based in communities for access by families.

8.4.1.6 Theme 6: Conclusions on MHCUs' and caregivers' expectations of mental health service providers

The MHCUs and caregivers expect the mental health care practitioners to provide services to improve their quality of life. Additionally, the mental health service providers should be accessible, listening, sharing information and supportive to MHCUs and caregivers. Moreover, support to improve caregiving and recovery for the MHCUs are the desired outcomes.

8.4.2 Conclusions on research findings on the experiences of social workers

Social workers provide mental health services to MHCUs, their families and caregivers. The conclusions reached on their experiences drawn from the findings (cf. Chapter Six), and are presented below.

8.4.2.1 Theme 1: Conclusions on the social workers' experiences in working with families of MHCUs

Social workers regard families of MHCUs as lacking an understanding of the services they provide in a mental health setting. However, the findings reflecting poor provision of services by social workers may explain the reason for the lack of understanding. Moreover, caregivers have the decision-making ability to determine the type of treatment for their relatives with mentally illness despite inadequate knowledge, experience and resources. Both hospital treatment and traditional or religious methods of healing may be used concurrently.

8.4.2.2 Theme 2: Conclusions on services provided by social workers to MHCUs

Social workers apply different intervention strategies to respond to the needs of MHCUs and caregivers. Their accounts show the provision of services has mainly been the responsibility of hospital-based social workers. Lack of cooperation between hospital-based and community-based social workers may contribute to poor provision of social work services. For example, the hospital-based social workers had to conduct family visits to monitor how MHCUs and their caregivers are coping with the effects of mental illness.

Social work services are clearly regarded as holistic and developmental to provide psychosocial intervention; mobilise family and community support; promote empowerment through advocacy; coordinate and monitor treatment compliance; and awareness raising to diminish stigma and discrimination. However, inadequate resources and support by management particularly in rural areas, makes it difficult for social workers to provide required services to MHCUs and their families.

8.4.2.3 Theme 3: Conclusions on social workers’ views on partnerships with families of MHCUs

The accounts show that there is no partnership between the family and the mental health practitioners. Notably, social workers have articulated the important role families play in the provision of care to MHCUs, as support for partnership practice. Moreover, they view partnership as vital to enhancing the provision of mental health services to the MHCUs.

The conclusion is that families have the ability to care for MHCUs, and that partnership with mental health care providers will promote access to services, the integration of MHCUs in the community, and recovery form mental illness.

8.4.2.4 Theme 4: Conclusions on social workers' opinions on who should form part of the mental health care team to work with families of the MHCUs

Social workers support the view that service providers involved in the provision of mental services should form part of the partnership team (cf. Item, 8.2.2.4). Moreover, families provide caregiving which contributes to the reduction in the rate of relapse, re-institutionalization, and increased compliance with treatment by the MHCU. Therefore, families should form part of the partnership team to provide mental health services.

The major findings and conclusions above informed the recommendations presented below.

8.5 Recommendations

They are based on the findings of the study to improve the provision of mental health services through partnership between families of MHCUs and mental health care practitioners. The recommendations focus on social work practice, policy, social work education and future research.

8.5.1 Recommendations for social work practice

Social work is a practice-based profession that promotes social change and development, social cohesion and empowerment. Considering ineffective partnership practice in the service delivery system, DSD in collaboration with SACSSP, DoH and relevant NGOs, social work should recognise and encourage partnership with families of MHCUs to promote:

- social change and development, social cohesion, and the empowerment and liberation of people;
- principles of social justice, human rights, collective responsibility, the values of *ubuntu*, cultural competence and respect for diversities;
- engagement with MHCUs, families, caregivers and community to address life challenges and enhance wellbeing; and
- social workers' initiatives to develop networks for caregivers.

Cognisant of the role of indigenous practitioners in mental health care, DSD in collaboration with SACSSP, DoH, and relevant NGOs should promote partnership with caregivers in order to improve the provision of mental health services.

Director-General of DSD should consider the adoption of suggested social work practice guidelines (cf. Chapter Seven) to promote partnership with families in the provision of mental health services.

8.5.2 Recommendations for policy

- Considering the role that caregivers play in the care of MHCUs, DSD in collaboration with DoH should initiate the review of the Mental Health Care Act (Act No. 17 of 2002) to incorporate partnership as articulated in the mission of the Mental Health Policy Framework and Strategic Plan 2013-2020. Subsequently, the Act will serve as a policy requirement in the provision of mental health care in order to give recognition to the role of families in the care of their relatives with mental illness.
- Regarding recognition of the role of social workers at the level of governance (management), which is not evident despite their critical role in the integration of MHCUs within their families and communities; DSD in collaboration with DoH SACSSP, ASASWEI, SAFMH and NGOs involved in the provision of mental health services should review the recruitment policies. This step will ensure the appointment of social workers in management positions who will positively influence policy and decision-making.
- Seeing that the grant-in-aid is not sufficient to take care of the needs of caregivers, DSD should review the Social Assistance Act (Act No. 13 of 2004) to align it with the National Minimum Wage Act (Act No. 9 of 2018) which promulgated a minimum wage of R20.00 per day. Caregiving is a 24 hour and seven (7) days responsibility. This means caregivers work three (3) times more hours than the required 8 hours.
- In an effort to improve communication between MHCUs, caregivers and service providers, DSD in collaboration with DoH should promote the use of technology such as telephones, video calls, use of mobile devices (skype, mobile phones,

tablets) and social media (WhatsApp and Facebook) by social workers offering aftercare services and support to MHCUs and their families.

- Concerning stigma and social isolation experienced by MHCUs and caregivers, social workers should facilitate participation of MHCUs and caregivers in various forums, such as, community *makgotla* (indabas), seminars, symposiums, workshops, and conferences represented by religious denominations, mental health care practitioners, and civic and traditional leaders to promote mental health policies that respond to the needs of MHCUs and their families.
- Relating to shortage of community-based social work services to MHCUs and their families, DSD should provide adequate infrastructure (offices, laptops/computers/tablets, internet, and transport) and employment of community-based social workers to provide mental health services.

8.5.3 Recommendations for social work education

Mental health problems have become endemic in communities and social workers are always called upon to intervene despite inadequate training in mental health. The provision of mental health services is heavily reliant on trained practitioners. However, the research findings reveal that social workers have not acquired sufficient knowledge and skills relating to the provision of mental health services to MHCUs, families and communities. Therefore, the following recommendations are made based on the findings:

- The SACSSP should lead in developing specialisation in mental health in collaboration with DSD, DoH, universities, non-governmental mental health organisations and practitioners.
- The universities should develop a compulsory mental health curriculum at bachelor of social work (BSW) level to incorporate modules in disciplines such as psychology and sociology with emphasis on systems theory to help students integrate social influences on mental health. Systems theory places emphasis on the application of knowledge and understanding of human behaviour and social systems to promote social relationships, partnership, communication,

support networks and social wellbeing, and appreciate the role of MHCUs, families and communities as partners in the provision of mental health services.

- Professional bodies such as the SACSSP, ASASWEI, South African Nursing Council (SANC) and Health Professions Council of South Africa (HPCSA) can work with education and training institutions to support the inclusion of partnership in the curricula.
- In order to assist practitioners to keep abreast of new developments brought about by the need for partnership practice, DSD in collaboration with SACSSP and university should design a CPD training on mental health and partnership practice to develop competencies in working with MHCUs, families and community support networks (indigenous practitioners, community organisations) for comprehensive provision of mental health services.
- The Director-General of DSD should initiate discussions with institutions of higher learning and the SACSSP on the establishment of a directorate responsible for mental health in the department during the 2021/22 financial year. Additionally, the Director-General will facilitate the appropriation of budget for infrastructure, recruitment of social workers and the development of mental health policies and programmes.

8.5.4 Recommendations for further and future research

The study has highlighted a number of researchable aspects that could be pursued further by social workers and other practitioners using the social model to promote partnership approach in providing mental health services. Based on the research findings and conclusions, it is recommended that:

- A qualitative research should be undertaken to determine the contribution made by indigenous knowledge systems in the promotion of partnership in mental health services.
- A longitudinal study be undertaken to explore and describe partnership between family caregivers and mental health care practitioners in rural areas to ensure transformation of mental health service delivery.

8.6 Conclusion

Major findings, general conclusions and recommendations based on the outcome of the research study are offered. The conclusions reveal that participants' experiences on mental health and partnership varied significantly. However, the recommendations stressed the importance of partnership that should be promoted through social work practice. Additionally, policies should be reviewed to accommodate families as partners in the provision of services. Moreover, social work training should incorporate mental health curriculum based on the social model to promote social justice and the values of *ubuntu*. Furthermore, the guidelines should be adopted to promote partnership practice. Finally, future research should promote partnership practice in various settings.

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ADDENDA

Addendum A: Confirmation of approval by Unisa Ethics Committee

UNISA university of south africa

MASHIANE S MR
7 PICCOLO COMPLEX
12TH AVENUE
GEZINA
0084

STUDENT NUMBER : 3248-731-2
ENQUIRIES : POSTGRADUATE QUALIFICATIONS
TELEPHONE NO : (012) 441-5702
FAX : (012) 429-4150

2013-08-05

Dear Student

I have pleasure in informing you that your research proposal has been approved and that you may register online for the research component of the degree for the 2014 academic year. Registration for 2014 commence on 26 November and closes on 15 March 2014.

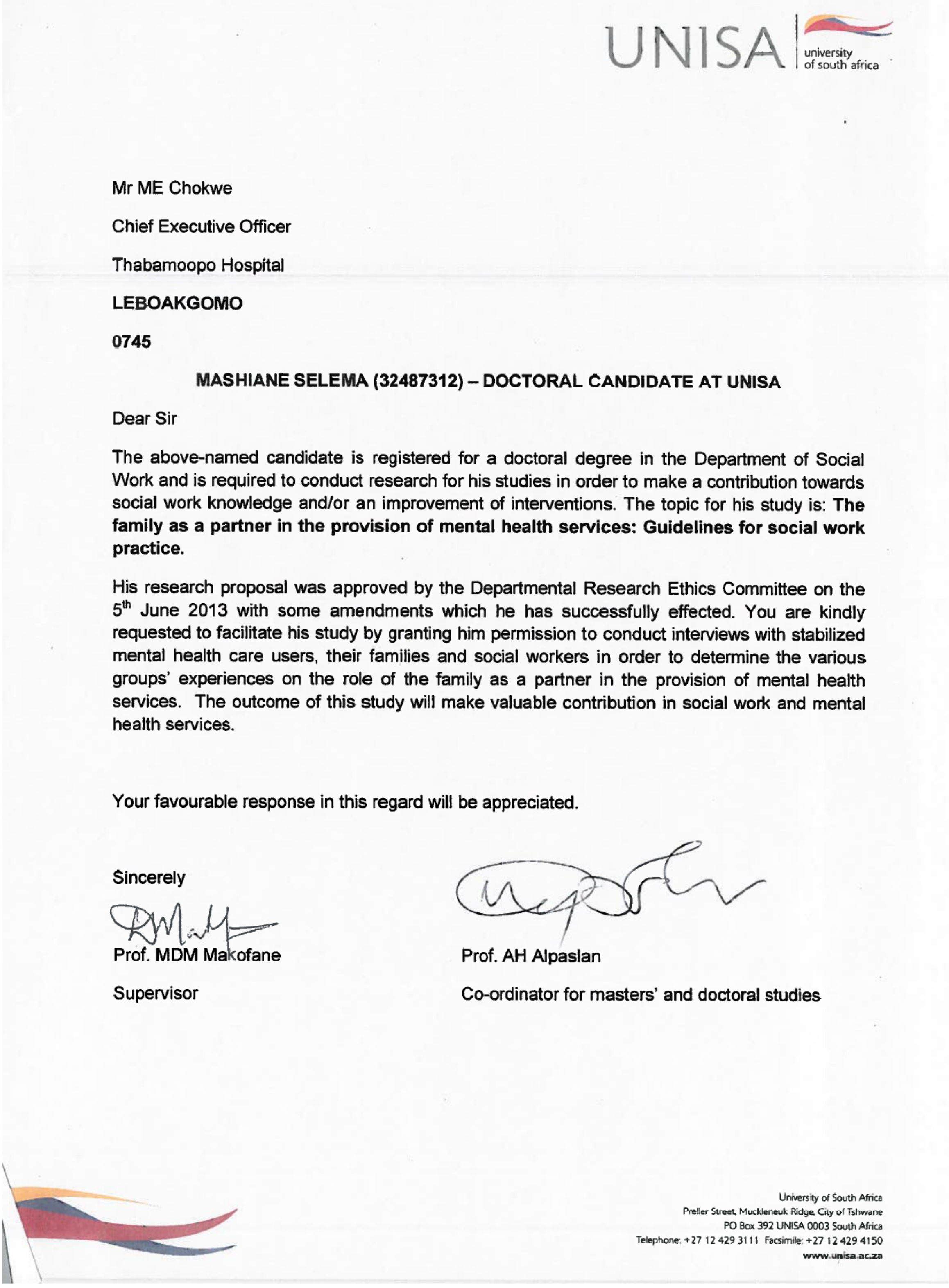
You may continue with your studies for the rest of this academic year. Your supervisor is Prof M D M Makofane

Yours faithfully

for Registrar

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

Addendum B: Request for permission-Thabamoopo Hospital



UNISA
university
of south africa

Mr ME Chokwe

Chief Executive Officer

Thabamoopo Hospital

LEBOAKGOMO

0745

MASHIANE SELEMA (32487312) – DOCTORAL CANDIDATE AT UNISA

Dear Sir

The above-named candidate is registered for a doctoral degree in the Department of Social Work and is required to conduct research for his studies in order to make a contribution towards social work knowledge and/or an improvement of interventions. The topic for his study is: **The family as a partner in the provision of mental health services: Guidelines for social work practice.**

His research proposal was approved by the Departmental Research Ethics Committee on the 5th June 2013 with some amendments which he has successfully effected. You are kindly requested to facilitate his study by granting him permission to conduct interviews with stabilized mental health care users, their families and social workers in order to determine the various groups' experiences on the role of the family as a partner in the provision of mental health services. The outcome of this study will make valuable contribution in social work and mental health services.

Your favourable response in this regard will be appreciated.

Sincerely

Prof. MDM Makofane

Supervisor

Prof. AH Alpaslan

Co-ordinator for masters' and doctoral studies

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

Addendum C: Request for permission- Dept. of Health

7 Piccolo Flats
12th Avenue
GEZINA
0084
26 August 2013

The Head of Department
Department of Health
Private Bag X9302
POLOKWANE
0700

The Head of Department

RE: PERMISSION TO CONDUCT RESEARCH IN AREAS THAT ARE SERVICED UNDER THABAMOOPO HOSPITAL

I am a part-time doctoral student in the Department of Social Work at the University of South Africa (UNISA). As a fulfilment of the requirements I am required to undertake a research study. The purpose of this letter, therefore, is to request permission to conduct a research study within the jurisdiction of your institution.

My research study focuses on the topic: **Family as a partner in the provision of mental health services: guidelines for social work practice.**

The goal of the study is to develop an in-depth understanding of the partnership between families of MHCUs with mental health practitioners in the provision of mental health services. The study intends to explore and describe the partnership between families of MHCUs with mental health practitioners in the provision of mental health services. The ultimate goal is to develop practice guidelines for social work practitioners to promote these goals.

The study will be conducted with families whose mentally ill members receive mental health services the jurisdiction of your institution. It will be appreciated if permission is granted on the following:

1. A list of discharged mental health care users (MHCUs) who still receive mental health services from the hospital.

2. The MHCUs must live within the jurisdiction of the hospital, namely communities receiving services from the hospital.
3. Interviewing of MHCUs identified in terms of criterion 1 above.
4. Interviewing of families of MHCUs identified in terms of criterion 1 above.
5. Interviewing of social workers offering mental health services to the MHCUs and their families.

The participants must be within communities receiving services from the hospital. Consent will be sought with families before the start of the research. A face-to-face interview will be conducted with these families as well as social workers during the research process.

Attached please find documents that will provide an understanding on the proposed research process:

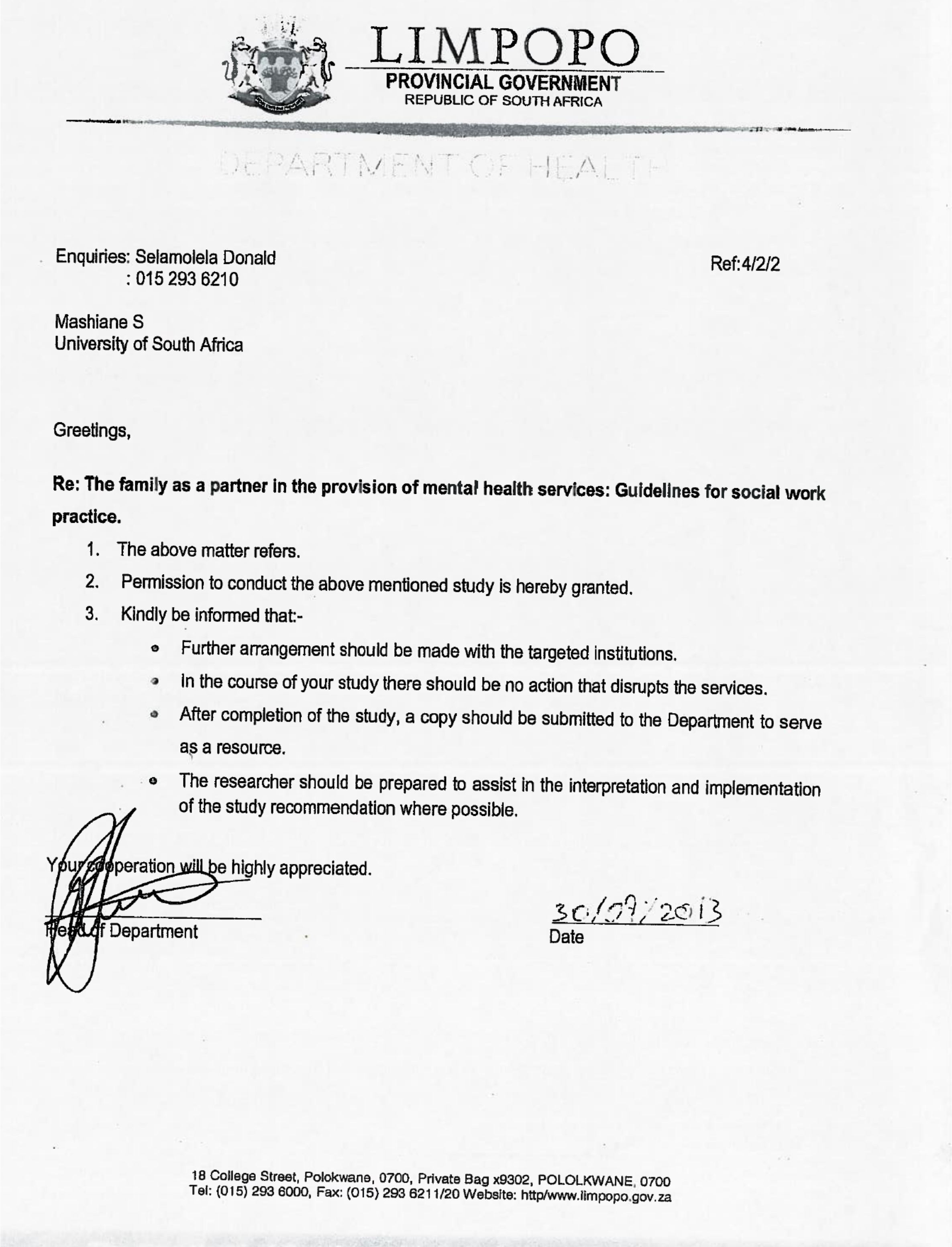
- A preamble to an information and informed consent document for the families and the mental health care users who will be participating in the research study.
- A preamble to an information and informed consent document for the social workers who will be participating in the research study.

A written response at your earliest convenience will be appreciated.

Yours Faithfully

Selema Mashiane
Phone: (012) 312 7371
Cell: 073 234 5675
e-mail: selemam@dsd.gov.za

Addendum D: Permission to conduct research



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Selamolela Donald
: 015 293 6210

Ref:4/2/2

Mashiane S
University of South Africa

Greetings,

Re: The family as a partner in the provision of mental health services: Guidelines for social work practice.

1. The above matter refers.
2. Permission to conduct the above mentioned study is hereby granted.
3. Kindly be informed that:-
    - Further arrangement should be made with the targeted institutions.
    - In the course of your study there should be no action that disrupts the services.
    - After completion of the study, a copy should be submitted to the Department to serve as a resource.
    - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.

Your cooperation will be highly appreciated.

Head of Department

30/09/2013
Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: http/www.limpopo.gov.za

Addendum E: Informed consent - MHCUs and caregivers

A PREAMBLE TO AN INFORMATION AND INFORMED CONSENT DOCUMENT FOR A FAMILY MEMEBR OF A MENTAL HEALTH CARE USER

Dear Participant

I, Selema Mashiane, the undersigned, am a social worker in service of the National Department of Social Development, Pretoria, and also a part-time doctorate student in the Department of Social Work at the University of South Africa. In fulfilment of requirements for the BA/master's/doctoral degree, I have to undertake a research project and have consequently decided to focus on the following research topic: **Family as a partner in the provision of mental health services: guidelines for social work practice.**

In view of the fact that you are well-informed about the topic, I hereby approach you with the request to participate in the study. For you to decide whether or not to participate in this research project, I am going to give you information that will help you to understand the study (i.e. what the aims of the study are and why there is a need for this particular study). Furthermore, you will be informed about what your involvement in this study will entail (i.e. what you will be asked/or what you will be requested to do during the study, the risks and benefits involved by participating in this research project, and your rights as a participant in this study).

This research project originated as a result of the need to develop an in-depth understanding of the partnership between families of MHCUs with mental health practitioners in the provision of mental health services. The study intends to explore and describe the partnership between families of MHCUs with mental health practitioners in the provision of mental health services. The ultimate goal is to develop practice guidelines for social work practitioners to promote these goals.

Should you agree to participate, you would be requested to participate in a face-to-face interview(s) that will be conducted at your home at a mutually agreed time for one hour per interview. During the interview(s)[18] the following questions will be directed to you:

1. The following questions will be used as a guide to direct the interview process with the MHCU:
   - Tell me your understanding of your mental condition?
   - What do you understand to be the cause of this condition?
   - What type of medical treatment are you receiving and from where?
   - How do you feel about having a mental health problem?
   - What are your duties and responsibilities as a MHCU?
   - What type of support do you receive from members of your family?
   - What are challenges that you face as a MHCU (For example food, medication, care, by family members).
   - How do you cope with the above challenges being a MHCU?
   - How do you view your role in the family as a MHCU?
   - How would you like to be helped in fulfilling your role in the family?
   - What kind of help or support do you receive and from where?
   - What type of services do you receive from social workers? If not, what support would you like the social workers to provide you with?
   - What services do you receive from other professionals such as psychiatrists, psychiatric nurse, doctor, occupational therapist? If not, what services would you like to be provided with?
   - What type of support do you receive from outside the family (e.g. church, community, SASSA in the form of social grants)? If not, what support would you like to be provided with?
2. The following questions will be used as a guide to direct the interview in order to elicit more in-depth information from the family members of the MHCU:
   - Share with me your understanding of the illness of the MHCU.
   - What do you understand to be the cause of this condition?
   - In your opinion, who of the family members is of assistance to the MHCU and how?

---

[18] Any other expectations required from participants need to be clearly spelled out, for example: filling in questionnaires, completing schedules focusing on biographical information, reading through the verbatim transcriptions compiled from the interviews conducted with them, follow-up interviews, etc.]

- What type of services do social workers provide to the MHCU? If not, what services would you like the social workers to provide to the MHCU?
- What role does your family play as a partner of the mental health team? What role do you think your family should play as a partner of the mental health team?
- What type of services are provided by other professionals such as psychiatrists, psychiatric nurse, doctor, occupational therapist MHCU? If not, what services would you like the MHCU provided with?

With your permission, the interview(s) will be audio-taped. The recorded interviews will be transcribed word-for-word. Your responses to the interview (both the taped and transcribed versions) will be kept strictly confidential. The audiotape(s)/videotape(s) will be coded to disguise any identifying information. The tapes will be stored in a locked drawer at 7 Picollo Flats, 12th Avenue, Gezina, Pretoria and only I will have access to them. The transcripts (without any identifying information) will be made available to my research supervisor(s)/promoter(s), a translator (if they need to be translated into English), and an independent coder[19] with the sole purpose of assisting and guiding me with this research undertaking. My research supervisor(s)/promoter(s), the translator and the independent coder will each sign an undertaking to treat the information shared by you in a confidential manner.

The audiotapes and the transcripts of the interviews will be destroyed upon the completion of the study. Identifying information will be deleted or disguised in any subsequent publication and/or presentation of the research findings.

Please note that participation in the research is completely voluntary. You are not obliged to take part in the research. Your decision to participate, or not to participate, will not affect you in any way now or in the future and you will incur no penalty and/or loss to which you may otherwise be entitled. Should you agree to participate and sign the information and informed consent document herewith, as proof of your willingness to participate, please note that you are not signing your rights away.

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[19] The independent coder is someone who is well versed and experienced in analysing information collected by means of interviews and is appointed to analyse the transcripts of the interviews independently of the researcher to ensure that the researcher will report the participants' accounts of what has been researched.

If you agree to take part, you have the right to change your mind at any time during the study. You are free to withdraw this consent and discontinue participation without any loss of benefits. However, if you do withdraw from the study, you would be requested to grant me an opportunity to engage in informal discussion with you so that the research partnership that was established can be terminated in an orderly manner.

As the researcher, I also have the right to dismiss you from the study without regard to your consent if you fail to follow the instructions or if the information you have to divulge is emotionally sensitive and upsets you to such an extent that it hinders you from functioning physically and emotionally in a proper manner. Furthermore, if participating in the study at any time jeopardises your safety in any way, you will be dismissed.

Should I conclude that the information you have shared left you feeling emotionally upset, or perturbed, I am obliged to refer you to a counsellor for debriefing or counselling (should you agree).

You have the right to ask questions concerning the study at any time. Should you have any questions or concerns about the study, contact this number 073 234 5675.

Please note that this study has been approved by the Research and Ethics Committee[20] of the Department of Social Work at Unisa. Without the approval of this committee, the study cannot be conducted. Should you have any questions and queries not sufficiently addressed by me as the researcher, you are more than welcome to contact the Chairperson of the Research and Ethics Committee of the Department of Social Work at Unisa. His contact details are as follows: Prof AH (Nicky) Alpaslan, telephone number: 012 429 6739, or email alpasah@unisa.ac.za.

---

[20] This is a group of independent experts whose responsibility it is to help ensure that the rights and welfare of participants in research are protected and the study is carried out in an ethical manner.

If, after you have consulted the researcher and the Research and Ethics Committee in the Department of Social Work at Unisa, their answers have not satisfied you, you might direct your question/concerns/queries to the Chairperson, Human Ethics Committee[21], College of Human Science, PO Box 392, Unisa, 0003.

Based upon all the information provided to you above, and being aware of your rights, you are asked to give your written consent should you want to participate in this research study by signing and dating the information and consent form provided herewith and initialling each section to indicate that you understand and agree to the conditions.
Thank you for your participation.

Kind regards

____
Signature of researcher
Contact details: 073 234 5675
(Email) selemam@dsd.gov.za

---

[21] This is a group of independent experts whose responsibility it is to help ensure that the rights and welfare of participants in research are protected and the study is carried out in an ethical manner.

INFORMATION AND INFORMED CONSENT DOCUMENT

TITLE OF THE RESEARCH PROJECT: Family as a partner in the provision of mental health services: guidelines for social work practice.

REFERENCE NUMBER: ______________________________________

PRINCIPAL INVESTIGATOR/RESEARCHER: Mr. Selema Mashiane

ADDRESSCONTACT: 7 Picollo Flats, 12th, Gezina, 0084
TELEPHONENUMBER: 073 234 5675

DECLARATION BY OR ON BEHALF OF THE PARTICIPANT: I, THE UNDERSIGNED, ______________________________ (name), [ID No: ________________________] the participant or in my capacity as ___________________________ of the participant [ID No ______________________________] of _____________________ ____ ____(address) **A. HEREBY CONFIRM AS FOLLOWS:** 1. I was invited to participate in the above research project which is being undertaken by Selema Mashiane of the Department of Social Work in the School of Social Science and Humanities at the University of South Africa, Pretoria, South Africa.	Initial
2. The following aspects have been explained to me and the mental health care user. Aim: The researcher is studying the family as partner in the provision of mental health services to their family members with mental problems. The information will be used to develop practice guidelines for social work practitioners.	Initial
2.1 I understand that the interview will be face-to face and will be taking place at home for the duration of an hour. Family members as well as the mental health care user will be participating in the interviews. Interview(s) will be audio-taped and the recorded interviews will be transcribed word-for-word. The responses to the interview (both the taped and transcribed versions) will be kept strictly confidential. The audiotape(s)/videotape(s) will be coded to disguise any identifying information. Participation is voluntary I deserve the right to discontinue.	Initial
2.2 Risks:	Initial

I am obliged to refer you to a counsellor for debriefing or counselling should the information I divulge leave me feeling emotionally upset, or perturbed.	
Possible benefits: As a result of my participation in this study the care I provide to the mentally ill member will enhance partnership with mental health practitioners, social workers in particular, in the provision of mental health services.	Initial
Confidentiality: My identity and that of mental health care user will not be revealed in any discussion, description or scientific publications by the researchers.	Initial
Access to findings: Any new information/benefit that develops during the course of the study will be shared with me.	Initial
Voluntary participation/refusal/discontinuation: My participation is voluntary. My decision whether or not to participate will in no way affect me now or in the future.	Initial
3. The information above was explained to me……………………….. by Selema Mashiane in English/Tswana/Pedi. I am in command of this language was given the opportunity to ask questions and all these questions were answered satisfactorily.	Initial
4. No pressure was exerted on me to consent to participate and I understand that I may withdraw at any stage from the study without any penalty.	Initial
5. Participation in this study will not result in any additional cost on me and the mental health care user.	Initial
B. I HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE PROJECT. Signed/confirmed at ______________ on ________________2012 __________________________________ _________________ Signature or right thumbprint of participant Signature of witness	

CONSENT FORM REQUESTING PERMISSION TO PUBLISH PHOTOGRAPHS, AUDIOTAPES AND/OR VIDEOTAPES OR VERBATIM TRANSCRIPTS OF AUDIOTAPE/VIDEOTAPE RECORDINGS[22]

As part of this project, I have made a photographic, audio and/or video recording of you. I would like you to indicate (with ticks in the appropriate blocks next to each statement below) what uses of these records you are willing to consent to. This is completely up to you. I will use the records only in ways that you agree to. In any of these records, names will not be identified.	Place a tick [✓] next to the use of the record you consent to
1. The records can be studied by the research team and photographs/quotations from the transcripts made of the recordings can be used in the research report.	
2. The records (i.e. photographs/quotations from the transcripts made of the recordings) can be used for scientific publications and/or meetings.	
3. The written transcripts and/or records can be used by other researchers.	
4. The records (i.e. photographs/quotations from the transcripts made of the recordings) can be shown/used in public presentations to non-scientific groups.	
5. The records can be used on television or radio.	
___________________ Signature of participant	______ Date

STATEMENTS AND DECLARATIONS

STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S) I, Selema Mashiane, declare that • I have explained the information given in this document to____ (name of participant) and/or his/her representative ______________________________ (name of representative); • he/she was encouraged and given ample time to ask me any questions; • this conversation was conducted in English/tswana/ Sepedi and no translator was used.	

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[22] Adopted and adapted from Silverman, D. 2001. *Interpreting qualitative data. Methods for analysing talk, text and interaction.* London: Sage.Publications

Signed at ____________________ on ________________20___
(place) (date)

_____________________________________ __________________
Signature of investigator/representative Signature of witness

IMPORTANT MESSAGE TO PARTICIPANT	
Dear Participant Thank you for your participation in this study. Should at any time during the study • an emergency arises as a result of the research, or • you require any further information with regard to the study, or kindly contact Selema Mashiane at 073 234 5675.	

MHCU **CONSENT FORM**

I, _______________________________________, understand that my parents/guardian have given permission for me to participate in a study concerning ____ ____ under the direction of ____ (name of the researcher(s)).

My involvement in this project is voluntary, and I have been told that I may withdraw from participation in this study at any time without penalty and loss of benefit to myself.

____
Signature

Addendum F-Informed consent - Social workers

A PREAMBLE TO AN INFORMATION AND INFORMED CONSENT DOCUMENT FOR SOCIAL WORKERS

Dear Participant

I, Selema Mashiane, the undersigned, am a social worker in the service of the National Department of Social Development, Pretoria, and also a part-time doctorate student in the Department of Social Work at the University of South Africa. In fulfilment of requirements for the doctoral degree, I have to undertake a research project and have consequently decided to focus on the following research topic**: Family as a partner in the provision of mental health services: guidelines for social work practice.**

In view of the fact that you are well-informed about the topic, I hereby approach you with the request to participate in the study. For you to decide whether or not to participate in this research project, I am going to give you information that will help you to understand the study (i.e. what the aims of the study are and why there is a need for this particular study). Furthermore, you will be informed about what your involvement in this study will entail (i.e. what you will be asked/or what you will be requested to do during the study, the risks and benefits involved by participating in this research project, and your rights as a participant in this study).

This research project originated as a result of the need to develop an in-depth understanding of the partnership between families of MHCUs with mental health practitioners in the provision of mental health services. The study intends to explore and describe the partnership between families of MHCUs with mental health practitioners in the provision of mental health services. The ultimate goal is to develop practice guidelines for social work practitioners to promote these goals.

Should you agree to participate, you would be requested to participate in a face-to-face interview(s) that will be conducted at your work at a mutually agreed time for one hour per interview. During the interview(s)[23] the following questions will be directed to you:

- Tell me about your experience in working with families of MHCU?
- What would you say are the services your organization provides to MHCUs? (For example, do you provide material aid, psychosocial support, social grants, skills development and rehabilitation programmes)?
- What is your view of a working partnership with families of MHCU for the provision of mental health services to the MHCUs?
- In your opinion what are the benefits of working in partnership with families of MHCU for the provision of mental health services to the MHCUs?
- How do you think the partnership between the family and the mental health practitioner should be enhanced for the provision of mental health services to the MHCUs?
- Who, in your opinion should form part of the mental health team to work with families of the MHCUs?

With your permission, the interview(s) will be audio-taped. The recorded interviews will be transcribed word-for-word. Your responses to the interview (both the taped and transcribed versions) will be kept strictly confidential. The audiotape(s)/videotape(s) will be coded to disguise any identifying information. The tapes will be stored in a locked drawer at 7 Piccolo Flats, 12th Avenue, Gezina, Pretoria and only I will have access to them. The transcripts (without any identifying information) will be made available to my research supervisor(s)/promoter(s), a translator (if they need to be translated into English), and an independent coder[24] with the sole purpose of assisting and guiding me with this research undertaking. My research supervisor(s)/promoter(s), the translator and the independent coder will each sign an

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[23] Any other expectations required from participants need to be clearly spelled out, for example: filling in questionnaires, completing schedules focusing on biographical information, reading through the verbatim transcriptions compiled from the interviews conducted with them, follow-up interviews, etc.]

[24] The independent coder is someone who is well versed and experienced in analysing information collected by means of interviews and is appointed to analyse the transcripts of the interviews independently of the researcher to ensure that the researcher will report the participants' accounts of what has been researched.

undertaking to treat the information shared by you in a confidential manner. The audiotapes and the transcripts of the interviews will be destroyed upon the completion of the study. Identifying information will be deleted or disguised in any subsequent publication and/or presentation of the research findings.

Please note that participation in the research is completely voluntary. You are not obliged to take part in the research. Your decision to participate, or not to participate, will not affect you in any way now or in the future and you will incur no penalty and/or loss to which you may otherwise be entitled. Should you agree to participate and sign the information and informed consent document herewith, as proof of your willingness to participate, please note that you are not signing your rights away.
If you agree to take part, you have the right to change your mind at any time during the study. You are free to withdraw this consent and discontinue participation without any loss of benefits. However, if you do withdraw from the study, you would be requested to grant me an opportunity to engage in informal discussion with you so that the research partnership that was established can be terminated in an orderly manner.

As the researcher, I also have the right to dismiss you from the study without regard to your consent if you fail to follow the instructions or if the information you have to divulge is emotionally sensitive and upsets you to such an extent that it hinders you from functioning physically and emotionally in a proper manner. Furthermore, if participating in the study at any time jeopardises your safety in any way, you will be dismissed.

Should I conclude that the information you have shared left you feeling emotionally upset, or perturbed, I am obliged to refer you to a counsellor for debriefing or counselling (should you agree). You have the right to ask questions concerning the study at any time. Should you have any questions or concerns about the study, contact this number: 073 234 5675.

Please note that this study has been approved by the Research and Ethics Committee[25] of the Department of Social Work at Unisa. Without the approval of this committee, the study cannot be conducted. Should you have any questions and queries not sufficiently addressed by me as the researcher, you are more than welcome to contact the Chairperson of the Research and Ethics Committee of the Department of Social Work at Unisa. His contact details are as follows: Prof AH (Nicky) Alpaslan, telephone number: 012 429 6739, or email alpasah@unisa.ac.za.

If, after you have consulted the researcher and the Research and Ethics Committee in the Department of Social Work at Unisa, their answers have not satisfied you, you might direct your question/concerns/queries to the Chairperson, Human Ethics Committee[26], College of Human Science, PO Box 392, Unisa, 0003.

Based upon all the information provided to you above, and being aware of your rights, you are asked to give your written consent should you want to participate in this research study by signing and dating the information and consent form provided herewith and initialling each section to indicate that you understand and agree to the conditions.

Thank you for your participation.

Kind regards

____

Signature of researcher

Contact details: 073 234 5675
(Email) selemam@dsd.gov.za

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[25] This is a group of independent experts whose responsibility it is to help ensure that the rights and welfare of participants in research are protected and the study is carried out in an ethical manner.

[26] This is a group of independent experts whose responsibility it is to help ensure that the rights and welfare of participants in research are protected and the study is carried out in an ethical manne

INFORMATION AND INFORMED CONSENT DOCUMENT[27]

TITLE OF THE RESEARCH PROJECT: Family as a partner in the provision of mental health services: guidelines for social work practice.

REFERENCE NUMBER: ____

PRINCIPAL INVESTIGATOR/RESEARCHER: Mr. Selema Mashiane

ADDRESSCONTACT: 7 Piccolo Flats, 12th Avenue, Gezina, 0084
TELEPHONENUMBER: 073 234 5675

DECLARATION BY OR ON BEHALF OF THE PARTICIPANT: I, THE UNDERSIGNED, ______________________________ (name), [ID No: _______________________] the participant or in my capacity as ___________________________ of the participant [ID No _____________________________] of ____________________ ____ ____(address) **A. HEREBY CONFIRM AS FOLLOWS:** 1. I was invited to participate in the above research project which is being undertaken by Selema Mashiane of the Department of Social Work in the School of Social Science and Humanities at the University of South Africa, Pretoria, South Africa.	Initial
6. The following aspects have been explained to me. Aim: The researcher is studying the family as partner in the provision of mental health services to their family members with mental problems. The information will be used to develop practice guidelines for social work practitioners.	Initial
2.3 I understand that the interview will be face-to-face and will be taking place at work for the duration of an hour. Interviews will be audio-taped and the recorded interviews will be transcribed word-for-word. The responses to the interview (both the taped and transcribed versions) will be kept strictly confidential. The audiotape(s)/videotape(s) will be coded to disguise any	Initial

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[27] A copy of the completed information and informed consent document must be handed to the participant or their representative.

identifying information. Participation is voluntary I reserve the right to discontinue.	
2.4 Risks: I am obliged to refer you to a counsellor for debriefing or counselling should the information I divulge leave me feeling emotionally upset, or perturbed.	Initial
Possible benefits: As a result of my participation in this study I'll recognise and enhance families as partners in the provision of mental health services to their members.	Initial
Confidentiality: My identity will not be revealed in any discussion, description or scientific publications by the researchers.	Initial
Access to findings: Any new information/benefit that develops during the course of the study will be shared with me.	Initial
Voluntary participation/refusal/discontinuation: My participation is voluntary. My decision whether or not to participate will in no way affect me now or in the future.	Initial
7. The information above was explained to me……………………….. by Selema Mashiane in English and I am in command of this language. I was given the opportunity to ask questions and all these questions were answered satisfactorily.	Initial
8. No pressure was exerted on me to consent to participate and I understand that I may withdraw at any stage from the study without any penalty.	Initial
9. Participation in this study will not result in any additional cost for me.	Initial
B. I HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE PROJECT. Signed/confirmed at _______________ on _________________2012 ____________________________________ __________________ Signature or right thumbprint of participant Signature of witness	

CONSENT FORM REQUESTING PERMISSION TO PUBLISH PHOTOGRAPHS, AUDIOTAPES AND/OR VIDEOTAPES OR VERBATIM TRANSCRIPTS OF AUDIOTAPE/VIDEOTAPE RECORDINGS[28]

As part of this project, I have made a photographic, audio and/or video recording of you. I would like you to indicate (with ticks in the appropriate blocks next to each statement below) what uses of these records are you willing to consent to. This is completely up to you. I will use the records only in ways that you agree to. In any of these records, names will not be identified.	Place a tick [✓] next to the use of the record you consent to
6. The records can be studied by the research team and photographs/quotations from the transcripts made of the recordings can be used in the research report.	
7. The records (i.e. photographs/quotations from the transcripts made of the recordings) can be used for scientific publications and/or meetings.	
8. The written transcripts and/or records can be used by other researchers.	
9. The records (i.e. photographs/quotations from the transcripts made of the recordings) can be shown/used in public presentations to non-scientific groups.	
10. The records can be used on television or radio.	
____________ Signature of participant	_________ Date

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[28] Adopted and adapted from Silverman, D. 2001. *Interpreting qualitative data. Methods for analysing talk, text and interaction.* London: Sage.Publications

STATEMENTS AND DECLARATIONS

STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S)

I, Selema Mashiane, declare that

- I have explained the information given in this document to____ (name of participant) and/or his/her representative ______________________________ (name of representative);
- he/she was encouraged and given ample time to ask me any questions;
- this conversation was conducted in English and no translator was used.

Signed at ____________________ on ________________20___
(place) (date)

____________________________________ _________________
Signature of investigator/representative Signature of witness

IMPORTANT MESSAGE TO PARTICIPANT

Dear Participant
Thank you for your participation in this study. Should at any time during the study

- an emergency arise as a result of the research, or
- you require any further information with regard to the study, or

Kindly contact Selema Mashiane at 073 234 5675.

Addendum G: Interview Guide

1. **Mental Health Care Users (MHCUs):** The following questions will be used as a guide to direct the interview process with the MHCU:

    - Tell me your understanding of your mental condition?
    - What do you understand to be the cause of this condition?
    - What type of medical treatment are you receiving and from where?
    - How do you feel about having a mental health problem?
    - What are your duties and responsibilities as a MHCU?
    - What type of support do you receive from members of your family?
    - What are challenges that you face as a MHCU (For example food, medication, care, by family members).
    - How do you cope with the above challenges being a MHCU?
    - How do you view your role in the family as a MHCU?
    - How would you like to be helped in fulfilling your role in the family?
    - What kind of help or support do you receive and from where?
    - What type of services do you receive from social workers? If not, what support would you like the social workers to provide you with?
    - What services do you receive from other professionals such as psychiatrists, psychiatric nurse, doctor, occupational therapist? If not, what services would you like to be provided with?
    - What type of support do you receive from outside the family (e.g. church, community, SASSA in the form of social grants)? If not, what support would you like to be provided with?

2. **Caregivers:** The following questions will be used as a guide to direct the interview in order to elicit more in-depth information from the caregivers of the MHCU:
    - Share with me your understanding of the illness of the MHCU.
    - What do you understand to be the cause of this condition?
    - In your opinion, who of the family members is of assistance to the MHCU and how?
    - What type of services do social workers provide to the MHCU? If not, what services would you like the social workers to provide to the MHCU?

- What role does your family play as a partner of the mental health team? What role do you think your family should play as a partner of the mental health team?
- What type of services are provided by other professionals such as psychiatrists, psychiatric nurse, doctor, occupational therapist MHCU? If not, what services would you like the MHCU provided with?

3. **Social Workers:** The following questions will be used as a guide to direct the interview in order to elicit more in-depth information from the social workers providing mental health services.

- Tell me about your experience in working with families of MHCU?
- What would you say are the services your organization provides to MHCUs? (For example, do you provide material aid, psychosocial support, social grants, skills development and rehabilitation programmes)?
- What is your view of a working partnership with families of MHCU for the provision of mental health services to the MHCUs?
- In your opinion what are the benefits of working in partnership with families of MHCU for the provision of mental health services to the MHCUs?
- How do you think the partnership between the family and the mental health practitioner should be enhanced for the provision of mental health services to the MHCUs?
- Who, in your opinion should form part of the mental health team to work with families of the MHCUs?

Addendum H: Interview Guide-Sepedi translation

1. The following questions will be used as a guide to direct the interview process with the MHCUs:

Translation: Dipotšišo tše di latelago di tla šomišwa bjalo ka ditlhahla tshepetšo ya dipoledišano le Badirišakalafi-ya-Monagano:

- Tell me your understanding of your mental condition?

Translation: A ke o hlalose o kwešišo ya seemo sa kelello ya gago?

- What may be the causes of your mental problems?

Translation: Na e ka ba eng tšeo di go hloletšego mathata a monagano?

- What kind of medical treatment do you receive at the moment?

Translation: Na gabjale o hwetša kalafo ya mohutamang?

- Where do you go for treatment?

Translation: Na o alafšwa kae?

- Who offer you treatment (nurses, doctors)?

Translation: Ke bomang bao ba gofago kalafi?

- How do you feel about your mental health problems?

Translation: Na o ikwa bjang ka ga mathata a gago a monagano?

- What are your duties and responsibilities as a MHCU?

Translation: Bjalo ka Modirišakalafi-ya-Monagano na mediro le maikarabelo a gagoke afe?

- What kind of support do you get from your family members?

Translation: Na o hwetša thušo ya mohutamang go tšwa malokong a lapeng leno?

- As an MHCU, do you have challenges with getting food, medication, from family members)?

Translation: Bjalo ka Modirišakalafi-ya-Monagano na o na le mathata a go whetša dijo, dihlare go tšwa go maloko a lapa?

- How do you cope with the challenges of being an MHCU?

Translation: Na o kgona bjang go katana le dikgwetlho tša go ba Modirišakalafi-ya-Monagano?

- As an MHCU how is your relationship with other family members?

Translation: Bjalo ka mo Modirišakalafi-ya-Monagano na tswalano ya gago le maloko a mangwe ka lapeng ke ya mohuta mang?

- What kind of support would you like to be afforded in order to fulfil your roles in the family?

Translation: Na o nyaka thekgo ya mohuta mang gore o boele sekeng bjalo ka leloko le le feletšego la lapa?

- What type of services do you receive from social workers?

Translation: Na o whetša ditirelo tša mohutamang go tšwa go badirelaleago?

- What support would you like to be provided with by the social workers?

Translation: Ke thekgo ya mohutamang yeo o ka ratago go e hwetša go tšwa go badirelaleago?

- What services do you receive from other professionals such as psychiatrists, psychiatric nurse, doctor, occupational therapist?

Translation: Na o hwetša ditirelo tše dingwe tša kalafo bjalo ka kalafo ya monagano, phekolo ya malwetši a hlogo, tšhidillokalafi ya ditho tša mmele?

- If not, would you like to receive such services?

Translation: Ge go se bjalo na o ka rata go hwetša ditirelo tše bjalo?

- What type of support do you receive besides that of your family (e.g. church, community, SASSA, social grant, etc)?

Translation: Ke thekgo ya mohutamang yeo o e hwetšago ntle le ya ka lapeng leno (mohl. Kereke, setšhaba, SASSA, mphiwafela, bj,bj)?

- If not, what support would you like to be provided with?

Translation: Ge go se bjalo na o ka rata go fiwa thekgo ya mohuta mang?

2. The following questions will be used as a guide to direct the interviews in order to elicit more in-depth information from family members of the MHCUs:
Dipotšišo tše di latelago di tla dirišwa bjalo ka mešupatsela ya dipoledišano lebakeng la go goka tshedimošo ye e tseneletšego go tšwa malokong a boModirišakalafi-ya-Monagano:

- Could you share with me your understanding of the illness of MHCUs?

Translation: Na o ka ntlhalosetša ka fao o kwešišago molwetši wa Modirišakalafi-ya-Monagano?

- What do you understand to be the cause of this condition?
- Na o kwešiša seo se hlotšego bolwetši bjo?
- In your opinion, who of the family members is of greater assistance to the MHCU and how?

Translation: Go ya ka tsebo ya gago, Ke mang go maloko a lapa yoo a hlokomelago moMHCU kudu, gona ka tselamang?

- What type of services do social workers provide to your MHCU?

Translation: Ke ditirelo tša mohuta mang tšeo badirelaleago ba di neago Modirišakalafi-ya-Monagano wa gago?

- If not, what services would you like the social workers to provide to the MHCU?

Translation: Ge go se bjalo, na o ka rata gore badirelaleago ba thuše Modirišakalafi-ya-Monagano wa gago ka ditirelo tša mohutamang?

- What role do you think your family should play as partners of the mental health team?

Translation: Na o nagana gore lapaleno, bjalo ka bakgathatema sehlopheng sa tša kalafo, le ka thuša ka tselamang?

- What types of services are provided by other professionals such as psychiatrists, psychiatric nurse, doctor, occupational therapist MHCU? If not, what services would you like the MHCU provided with?

Translation: Na ditirelo dife tše dingwe tša kalafo ya monagano tšeo di fiwago molwetsi wa lena?

Addendum I: Newspaper articles on mental illness

Article 1: THAMSANQA JANTJIE: THE NELSON MANDELA MEMORIAL SIGN INTERPRETER

News 24, dated 11/05/2014

Johannesburg - The Gauteng health department won’t launch an investigation into circumstances surrounding the pass that was granted to controversial sign-language interpreter Thamsanqa Jantjie.

Jantjie – who is being treated for schizophrenia at Sterkfontein Hospital, a state psychiatric facility on Gauteng’s West Rand – was recently granted a pass to attend a family event. But it turned out he used the time to film an advert for an Israeli company, Livelens.

Now questions are being asked about whether Jantjie broke the rules by requesting a pass, claiming that he had to attend a family event when he knew he wanted time to shoot an advert.

Department spokesperson Simon Zwane said Jantjie had done nothing wrong because he had a pass “and returned on the agreed time and date”.

He explained that all patients who are hospitalised for a long period because of the nature of their illness and treatment are granted time to go and be with family.

In the 1.19-minute advert, Jantjie, who shot to infamy in December when he signed gibberish during former president Nelson Mandela’s memorial service in Joburg, says: “I am Thamsanqa Jantjie from Nelson Mandela’s funeral.

“Believe me, I am a real professional sign-language interpreter. I am really sorry for what happened. Now I want to make it up to the whole world.”

He goes on to tell the viewers about Livelens, a new social streaming app, and explains how people can use it to share live video with their friends.

It is not clear how much Jantjie was paid by Livelens.

City Press visited his wife at their home in Braamfischerville, Soweto, on Friday.

Siziwe Jantjie refused to talk about how her husband landed the deal and how much he was paid.

However, London newspaper The Telegraph reported this week that Livelens marketing manager Sefi Shaked told NBC News that he asked a Zulu-speaking journalist to tell hospital staff that Jantjie needed to be released for one day for a family event.

The paper quoted Shaked as saying: “We saw him with our own eyes, he’s a normal guy. Now he can have the closure and earn some money from it. It’s morally right.

“We helped him get on the right track. At the end of the day, a schizophrenic guy got paid and did a nice campaign. We see it as sort of a sad story with a happy ending.”

- City Press

Article 2: 'FAKE' INTERPRETER SAYS HE IS SCHIZOPHRENIC

12 December 2013, 11:15

Cape Town – The sign language interpreter accused of using fake hand signals at former president **Nelson Mandela**’s memorial says he suffered a schizophrenic episode.

Thamsanqa Jantjies told the **Cape Times** that he was unsure whether it was the magnitude of what he was doing or the happiness he felt throughout the day that might have triggered the attack while on stage.

At a certain point during the proceedings Jantjies, who uses medication for schizophrenia, lost concentration, started hearing voices and began hallucinating.

He later apologised for his actions saying he was ‘alone in a dangerous situation’ and that there was nothing he could do.

International media have zoned in on the incident which saw US president Barack Obama’s speech interpreted by a ‘fake’.

Fox News highlighted security concerns quoting White House Principal Press secretary who said that he was not aware of any security concerns near Obama.

Article 3: MENTAL ILLNESS SIGN LANGUAGE, SCHIZOPHRENIA AND THE STIGMA OF MENTAL ILLNESS

Article by Simon Shear, eNCA

Thursday 12 December 2013 - 4:07pm

US president Barack Obama walks to the podium as sign language interpreter Thamsanqa Jantjie looks on at the Nelson Mandela memorial on Tuesday, 10 December 2013. Jantjie is accused of using incorrect signs. He's also admitted to being schizophrenic. Photo: Werner Beukes / SAPA

JOHANNESBURG - Thamsanqa Jantjie, the sign language interpreter who stood mere feet away from international dignitaries, including US President Barack Obama, at Nelson Mandela's memorial service has told reporters he had visions of angels during the event and has apparently acted violently in the past. He has also been diagnosed as having schizophrenia.

News of Jantjie's mental illness was seen by many as an obvious security lapse – even before news of his violent history was revealed.

"The fake sign language guy at Mandela's Memorial now says he's been having treatment for schizophrenia. How did he get to stand with Obama?" CNN host Piers Morgan tweeted.

Many others expressed similar sentiments, asking how a schizophrenic person could pass local and US Secret Service security vetting.

Is this an appropriate way to understand mental illness in general and schizophrenia in particular?

- **A state of fear**

According to psychiatrist Jan Chabalala, the perception that schizophrenics are dangerous rests on a lack of knowledge. In fact, said Chabalala, people suffering from schizophrenic hallucinations are more likely to be fearful than dangerous. Chabalala pointed out that the way we perceive mental illness can obscure the way we look at individuals.

"When people know that you have a diagnosis of mental illness, everything you do, every time you get too excited, people attribute it to your mental illness."

The public finds it difficult to separate mental illness from the person, Chabalala said, and "the mental illness becomes you".

Chairman of the Schizophrenia and Bipolar Disorder Alliance Ronnie Creasy pointed out that with the appropriate treatment, many schizophrenics are able to live fully functional lives, holding jobs and not posing any kind of danger. He added, however, that some people can become frustrated by their symptoms and become violent.

Is that not sufficient reason to keep people with schizophrenia, if not locked away, under close scrutiny? Only if we ignore the leap of logic that moves from recognising that frustration and marginalisation can lead to violence to wishing further to marginalise and frustrate people with mental illness. As psychiatrist Solomon Rataemane points out, a diagnosis of a mental illness does not mean you cannot work or fulfill any other life roles -- but in many cases, people with mental illness need our support.

- **Social inclusion**

Why does violence manifest in some instances and not others? That is too complex a question for a simple answer, but we can look at some factors.

Psychiatrists generally agree that schizophrenia is a biological phenomenon, but as anthropologist Tanya Luhrmann has pointed out, research indicates that people diagnosed as schizophrenic tend to have significantly different rates of recovery from country to country. In particular, patients have better outcomes in African and India than in Western countries.

Luhrmann cites the theory of social defeat, a state that sees an individual losing a clash with another individual. Luhrmann’s research chronicles the lives of a number of poor, social marginal women in Chicago.

Their daily experience consists of "constant vigilance against always-simmering violence", of being coerced and talked down to, of being moral harangued like disobedient schoolchildren.

Luhrmann does not claim that the "constant grind of humiliation, repudiation, and rejection that these women experience" causes schizophrenia. Rather, she asks us to consider the multifarious causes of behaviour, at both a social and individual, and the origins of violence and anti-social acts.

- **Stigma**

The harmful effect of stigma in the fight against HIV/Aids has been extensively documented.

The shame from social norms that lead HIV positive people to feel they have behaved irresponsibly or even immorally can aggravate epidemic in a number of ways, such as preventing people from being tested or seeking treatment, and hiding their status when they do learn they have been infected by the virus.

The effects of stigma on mental illness are complex for a number of reasons, including the fact that mental illness is no one single thing. From the misguided idea that depression is all in the sufferer’s head and they should ‘walk it off’ or ‘man up’ to the unsupported worry that schizophrenics pose a especial threat of violence, these social anxieties are not simply analytically deficient, they exacerbate the problems they seek to avoid. Despite lurid headlines about schizophrenic mass murderers, people with schizophrenia are more likely to be shunned by society than harm it.

As Dr Chabalala said, "I’ve been a psychiatrist for 20 years, and I haven’t been attacked. The reason is, I treat patients as human beings."

Does this mean that a person with a history of violence, who has allegedly made false claims about his work, should have been cleared to work at an event of such magnitude? Almost certainly not. But by those criteria, it is not clear how many of us would have passed, regardless of the state of our mental health.

Talking about the proper way to understand the sign language debacle, Deputy Minister for Women, Children and Persons with Disability Hendrietta Bogopane-Zulu said that, rather than being an embarrassment, the incident should remind us all that Mandela stood for equality for all people, including the physically disabled.

We should respect Mandela’s legacy, and ensure that the hearing-impaired South Africans realise "their liberation, their freedom, have their language recognised as an official language," Bogopane-Zulu said.

Equally, rather than recoiling in horror, we should remember Mandela’s legacy and remember that the mentally ill deserve to be supported and welcomed into society, not shunned and feared. And that by doing so we enrich our culture, and defeat many of the sources of that which we so fear.

Addendum J: Maps-Location of Thabamoopo Hospital

Figure. 3.1 Limpopo district and local municipalities

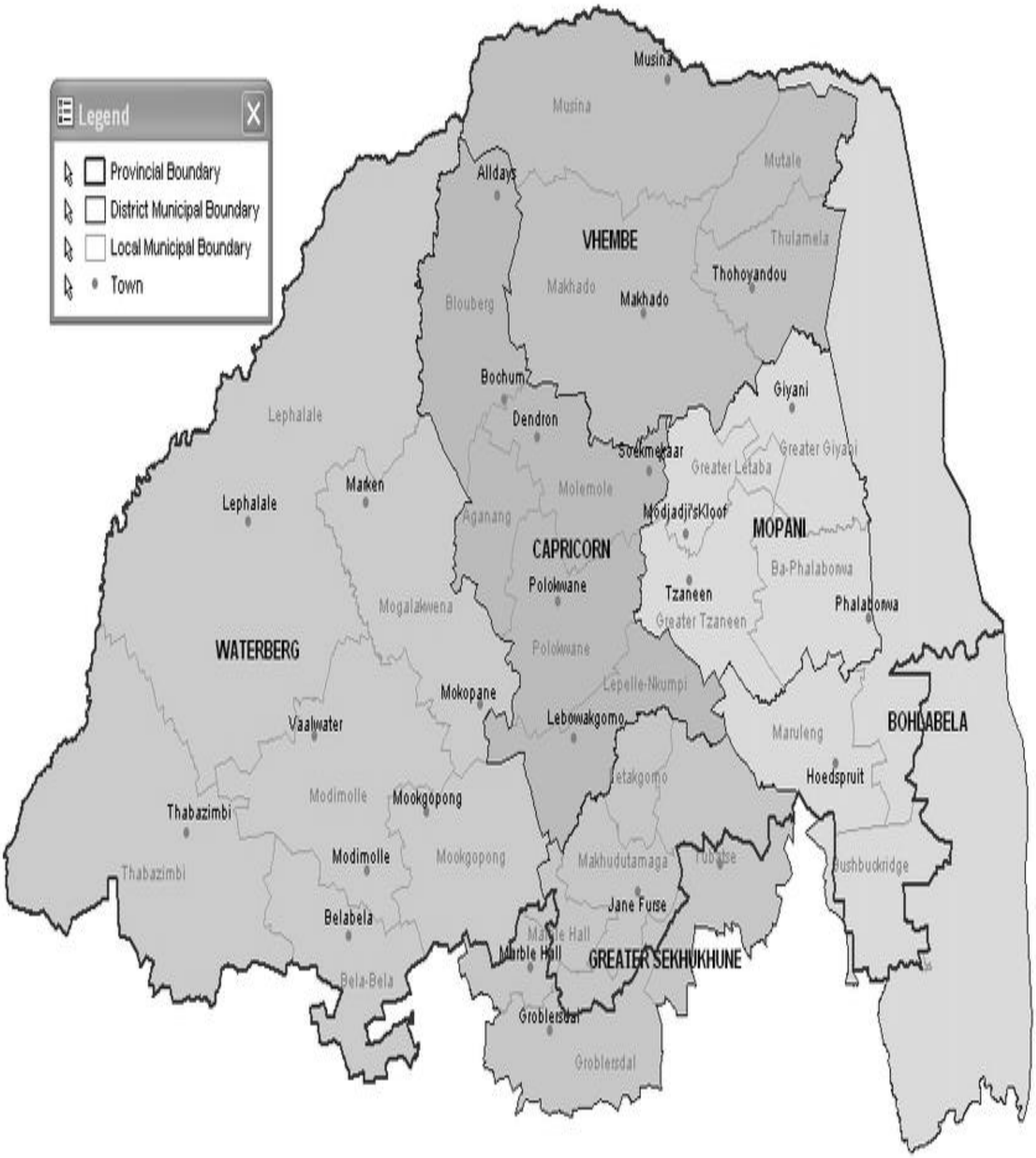

Figure. 3.2 Lepelle-Nkumpi municipality