

A community-based programme to improve the well-being of people with mental illness and their families in a rural setting

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DECLARATION

I, Thabisa Coleen Matsea, hereby declare that the thesis entitled “*A community-based programme to improve the well-being of people with mental illness and their families in a rural setting*” is my own original work and that I have not, previously, in its entirety or in part submitted it at any university for a qualification.

Signature:.....

Date:.....

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This study would not have been possible without the might of the Lord Almighty for giving me strength to continue with this project.

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ABSTRACT

A community-based programme to improve the well-being of people with mental illness and their families in a rural setting

Keywords: Community-based programme, mental health, mental illness, rural setting, well-being, families

Mental illness is a universal challenge. People with mental illness and their families often experience several challenges related to dealing with mental illness. Community-based programmes appear to be an effective approach that can facilitate reintegration of the patient into the community, empower people with mental illness and reduce the burden of care in families. The overall aim of this study was to develop a framework for a community-based programme for people with mental illness and their families in rural settings. The specific research questions were:

- How do health care professionals perceive the mental health services they render to people with mental illness and their families in rural settings?
- How do people with mental illness and their families in rural settings cope with mental illness?
- What role do different stakeholders in rural settings currently play with regard to mental illness?
- What can be done to guide social workers to develop and implement community-based programmes to improve the well-being of PWMI and their families in rural settings?

The thesis consists of the following five sections:

- Section A: Orientation and methodological overview
- Section B: The journal articles
- Section C: Conclusions and recommendations
- Section D: Annexures
- Section E: Consolidated reference list

The primary results of the research are presented in the form of four articles intended for scientific journals. These are contained in **Section B**. Each article focuses on a specific goal and the research methodology which was utilised, in order to achieve the overall goal of the development of a community-based programme for people with mental illness

and their families in a rural setting. The results and the nature of the results achieved with each article are covered briefly below.

Article 1: The first article covers the results of a survey that was intended to assess the mental health services that are rendered by health care professionals in a rural setting. The assessment was based on the comprehensiveness, accessibility, service coverage, continuity of care, quality, person-centeredness, care coordination as well as accountability and effectiveness of the service, which are the eight attributes of good mental health service delivery. Data were sourced through a self-administered questionnaire with health care professionals from four health establishments that render mental health services to people of Mashashane. The health care professionals comprised doctors, nurses, occupational therapists, psychologists and social workers. Quantitative and qualitative data analyses were adopted. The results suggested that, of the eight attributes, only comprehensiveness was positively perceived. The study revealed that lack of resources is the major obstacle to the delivery of mental health services, while lack of training is also a contributing factor to the provision of ineffective mental health service. These results depict the inadequacy of mental health services, hence their inability to improve the well-being of people with mental illness and their families. The results contributed to the development of a framework that would guide social workers to develop and implement community-based programmes in a rural setting.

Article 2 focuses on the results of an investigation of the coping strategies adopted by people with mental illness and their families living in the selected rural setting. The data was collected through semi-structured interviews with 20 participants (10 people with mental illness and 10 family members considered primary caregivers) who met a predetermined set of criteria. The results show that participants' understanding of mental illness is based on their belief systems, values and perceptions about the cause of mental illness. Culture seemed to influence perceived causes of illness. Mental illness has a social, emotional and financial impact on all participants, whereas only people with mental illness reported experiencing any physical health impact caused by the side effects of the treatment. The study revealed that participants received inadequate support from both formal and informal systems. As a result, they rely on one another to cope with challenges posed by mental illness. Participants were found to have adopted

both adaptive and maladaptive strategies in order to cope. A community-based programme was recommended as a strategy that could improve participants' well-being.

The views of stakeholders of their role as a support system of people with mental illness and their families are covered in **Article 3**. The data was generated via the use of focus group discussions with various stakeholders. These stakeholders were traditional leaders, traditional health practitioners, church members, police officers and home-based care groups. A total of seven focus group discussions were conducted with a minimum of five and a maximum of eight participants respectively. The study revealed that stakeholders based their understanding of mental illness on how other people should react towards people with mental illness, the cause of mental illness and the unusual behaviour displayed by people with mental illness. Witchcraft seemed to be the predominant perceived cause of mental illness. Stakeholders acknowledged the availability of both formal and informal systems but viewed them as ineffective in terms of providing support to people with mental illness and their families. Fear and lack of skills on how to cope with people with mental illness were found to be the main factors that prevent stakeholders from providing adequate support. Collaboration was identified as a suitable mechanism for improved mental health service delivery, provided a third party intervenes to facilitate the process. These findings and those of Articles 1 and 2 contributed to the formulation of recommended guidelines for stakeholders and health care professionals to provide support to people with mental illness and their families.

Article 4 focused on the development of a community-based framework. The results obtained via the empirical studies (see articles 1 to 3), combined with a literature study, were used to develop a framework for a community-based programme for people with mental illness and their families. A six-module educational programme was developed as an intervention aimed at people with mental illness and their families. Secondly, guidelines to improve support for people with mental illness and their families were formulated as an intervention aimed at health care professionals and stakeholders. These interventions were validated to assess content suitability and usefulness for the context. The results indicated the appropriateness and usefulness of the framework in the rural context. A seven-step framework that can be used by social workers to develop and implement community-based programmes in rural settings, was proposed. This framework outlines important aspects for consideration during the development and implementation processes.

OPSOMMING

'n Gemeenskapsgebaseerde program om die welstand van mense met geestesongesteldheid en hul gesinne in 'n landelike omgewing te verbeter

Sleutelwoorde: Gemeenskapsgebaseerde program, geestesgesondheid, geestesongesteldheid, landelike omgewing, welstand, gesinne

Geestesongesteldheid is 'n universele uitdaging. Mense met geestesongesteldheid en hul gesinne ervaar dikwels etlike uitdagings wat verband hou met die hantering van geestesongesteldheid. Gemeenskapsgebaseerde programme blyk 'n effektiewe benadering te wees wat die herintegrasie van die pasiënt in die gemeenskap kan fasiliteer, mense met geestesongesteldheid bemagtig en die las van sorg in gesinne kan verminder. Die oorhoofse doel van hierdie studie was om 'n raamwerk vir 'n gemeenskapsgebaseerde program vir mense met geestesongesteldheid en hul gesinne in landelike omgewings te ontwikkel. Die spesifieke navorsingsvrae was:

- Hoe beskou gesondheidswerkers die geestesgesondheidsdienste wat hulle aan mense met geestesongesteldheid en hul gesinne in landelike omgewings lewer?
- Hoe bied mense met geestesongesteldheid en hul gesinne in landelike omgewings geestesongesteldheid die hoof?
- Watter rol speel verskillende belanghebbendes in landelike omgewings tans met betrekking tot geestesongesteldheid?
- Wat kan gedoen word om maatskaplike werkers te lei om gemeenskapsgebaseerde programme te ontwikkel en te implementeer om die welstand van PWM en hul gesinne in landelike omgewings te verbeter?

Die proefskrif bestaan uit die volgende vyf afdelings:

- Afdeling A: Oriëntering en metodologiese oorsig
- Afdeling B: Die tydskrifartikels
- Afdeling C: Gevolgtrekkings en aanbevelings
- Afdeling D: Bylaes
- Afdeling E: Gekonsolideerde verwysingslys

Die primêre resultate van die navorsing word aangebied in die vorm van vier artikels bedoel vir wetenskaplike tydskrifte. Hierdie artikels is vervat in Afdeling B. Elke artikel fokus op 'n spesifieke doelwit en die navorsingsmetodologie wat gebruik is om die algehele doelwit te bereik, naamlik die ontwikkeling van 'n gemeenskapsgebaseerde program vir mense met geestesongesteldheid en hul gesinne in 'n landelike omgewing. Die aard van en resultate wat met elke artikel behaal is, word hieronder kortliks bespreek.

Artikel 1: Die eerste artikel bevat die resultate van 'n opname wat beoog om die geestesgesondheidsdienste wat deur gezondheidswerkers in 'n landelike omgewing gelewer word, te assesseer. Die assessering is gebaseer op die agt eienskappe van goeie geestesgesondheidsdienslewering, naamlik volledigheid, toeganklikheid, diensdekking, kontinuïteit van sorg, gehalte, persoon-gesentreerdheid, sorgkoördinasie, sowel as aanspreeklikheid en effektiwiteit. Data is verkry deur middel van 'n selfgeadministreerde vraelys gerig aan gezondheidswerkers van vier gezondheidsinstellings wat geestesgesondheidsdienste aan mense van Mashashane lewer. Die gezondheidswerkers bestaan uit dokters, verpleegkundiges, arbeidsterapeute, sielkundiges en maatskaplike werkers. Kwantitatiewe en kwalitatiewe data-analises is onderneem. Die resultate dui aan dat van die agt eienskappe slegs volledigheid positief waargeneem word. Die studie het voorts aan die lig gebring dat gebrek aan hulpbronne die grootste struikelblok is vir die lewering van geestesgesondheidsdienste, met gebrek aan opleiding ook as 'n bydraende faktor tot die verskaffing van ondoeltreffende geestesgesondheidsdienste. Hierdie resultate toon die ontoereikendheid van geestesgesondheidsdienste, met ander woorde hul onvermoë om die welstand van mense met geestesongesteldheid en hul gesinne te verbeter. Die resultate het bygedra tot die ontwikkeling van 'n raamwerk wat maatskaplike werkers sal lei om gemeenskapsgebaseerde programme in 'n landelike omgewing te ontwikkel en te implementeer.

Artikel 2 fokus op die resultate van 'n ondersoek na die hanteringstrategieë van mense met geestesongesteldheid en hul gesinne wat in die geselekteerde landelike omgewing woon. Die data is ingesamel deur middel van semi-gestruktureerde onderhoude met 20 deelnemers (10 mense met geestesongesteldheid en 10 familieledes as primêre versorgers) wat aan 'n voorafbepaalde stel kriteria voldoen het. Die resultate toon dat die deelnemers se begrip van geestesongesteldheid gebaseer is op hul geloofstelsels, waardes en persepsies oor die oorsaak van geestesongesteldheid. Kultuur beïnvloed

waarnemings van die oorsake van siekte. Geestesongesteldheid het 'n sosiale, emosionele en finansiële impak op alle deelnemers, terwyl slegs mense met geestesongesteldheid die fisieke gesondheidsimpak ondervind het wat veroorsaak word deur die newe-effekte van die behandeling. Die studie het aan die lig gebring dat deelnemers onvoldoende ondersteuning ontvang van beide formele en informele ondersteuningsisteme en dat hulle op mekaar staatmaak om die uitdagings van geestesongesteldheid te hanteer. Die studie het verder getoon dat sowel adaptiewe as wanadaptiewe strategieë aangeneem word om die situasie die hoof te bied. 'n Gemeenskapsgebaseerde program is aanbeveel as 'n strategie wat die deelnemers se welstand kan verbeter.

Die mening van belanghebbendes met betrekking tot hul rol as 'n ondersteuningsstelsel van persone met geestesongesteldheid en hul gesinne word in artikel 3 behandel. Die data is gegenereer deur middel van fokusgroepbesprekings met verskeie belanghebbendes. Hierdie belanghebbendes was tradisionele leiers, tradisionele gesondheidspraktisyns, kerklede, polisiebeamptes en tuisgebaseerde sorggroepe. Altesaam sewe fokusgroepbesprekings is gevoer met 'n minimum van vyf en 'n maksimum van agt deelnemers onderskeidelik. Die studie het getoon dat belanghebbendes hul begrip van geestesongesteldheid gegrond het op hoe ander mense moet reageer teenoor mense met geestesongesteldheid, die oorsaak van geestesongesteldheid en die ongewone gedrag wat mense met geestesongesteldheid toon. Heksery was 'n oorheersende waargenome oorsaak van geestesongesteldheid. Belanghebbendes erken die beskikbaarheid van beide formele en informele stelsels, maar beskou die stelsels as ondoeltreffend vir die ondersteuning van mense met geestesongesteldheid en hul gesinne. Vrees en gebrek aan vaardighede oor hoe om mense met geestesongesteldheid te hanteer, is bevind as die oorheersende faktore wat verhoed dat belanghebbendes voldoende ondersteuning bied. Samewerking is geïdentifiseer as 'n geskikte meganisme vir verbeterde geestesgesondheidsdienslewering, mits 'n derde party tussenbeide tree om die proses te fasiliteer. Hierdie resultate het bygedra tot die formulering van aanbevole riglyne vir belanghebbendes en gesondheidswerkers om ondersteuning te bied aan mense met geestesongesteldheid en hul gesinne.

Artikel 4 fokus op die ontwikkeling van 'n gemeenskapsgebaseerde raamwerk. Die resultate wat verkry is deur die genoemde drie empiriese studies is gekombineer met 'n

literatuurstudie. Dit is gebruik om 'n raamwerk vir 'n gemeenskapsgebaseerde program vir mense met geestesongesteldheid en hul gesinne te ontwikkel. 'n Opvoedkundige program van ses modules is as 'n intervensie ontwikkel wat gemik is op mense met geestesongesteldheid en hul gesinne. Tweedens is riglyne vir die verbetering van ondersteuning aan mense met geestesongesteldheid en hul gesinne geformuleer as 'n intervensie wat gemik is op gesondheidswerkers en belanghebbendes. Hierdie intervensies is gevalideer om inhoudsgetrouheid en bruikbaarheid vir die konteks te evalueer. Die resultate het die toepaslikheid en nut van die raamwerk in die landelike konteks aangedui. 'n Sewestap-raamwerk wat deur maatskaplike werkers gebruik kan word om gemeenskapsgebaseerde programme in landelike omgewings te ontwikkel en te implementeer, is voorgestel. Hierdie raamwerk beskryf belangrike aspekte vir oorweging tydens die ontwikkelings- en implementeringsprosesse.

FOREWORD

The article format was chosen in accordance with regulation A12.2.2 of the yearbook 2016 North-West University for the PhD (SW) degree. Each article will comply with requirements specified in a particular accredited journal in social work and health-related issues.

The thesis incorporates the following articles formatted according to the guidelines of these accredited journals:

- 1 Assessing mental health services in a rural setting: service providers' perspective - *International Journal of Mental Health. (Submitted).*
- 2 Coping with the disease: experiences of families and people with mental illness in a rural setting – *Journal of Family Studies.*
- 3 Stakeholders' views regarding their role as support system for people with mental illness and their families in rural South Africa – *Community Mental Health Journal. (Submitted).*
- 4 A framework for a community-based program for people with mental illness and their families in a rural setting – *Southern African Journal of Social Work and Social Development.*

In order to make each article a functional unit, each will be provided with its own bibliography. For convenience sake, a combined bibliography for the whole thesis will be provided at the end.

Note should be taken of the fact that, in order to make each article a functional unit, some data will have to be repeated in each article. Attempts have been made to keep such repetitions to a minimum.

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SECTION A:

ORIENTATION AND METHODOLOGICAL OVERVIEW



1 INTRODUCTION

The presence of mental illness is challenging for people in rural areas as the essential services for the condition are often inadequate. This results in the persistence of the illness and the poor well-being of both people with mental illness (PWMI) and their families. It is therefore important to work towards developing/ introducing programmes that will enhance the general well-being of all those affected. This study focused on the development of a framework for a community-based programme that is aimed at improving the well-being of PWMI and their families. As a social worker, the researcher took into cognisance factors such as the environment that have influence on individuals and their families' well-being.

This section begins with outlining the orientation and problem statement. Secondly, the main aim and objectives of the study, the theoretical framework on which the study is drawn as well as the methodological aspects are discussed. The section also highlights ethical aspects that were considered, limitations of the study and provides definitions of key concepts informing this research.

2 ORIENTATION AND PROBLEM STATEMENT

Mental illness is a universal problem, despite this, mental health services are still poor. Mental health and mental disorders have been ignored, neglected and still remain a low priority in most parts of the world (Sowers & Rowe, 2007; WHO, 2001). According to Prince, Patel, Saxena, Maj, Maseko, Phillips and Rahman (2007), 14% of the global burden of the disease has been attributed to neuropsychiatric disorders, mostly due to the chronically disabling nature of depression and other common mental disorders such as alcohol use and substance-use disorders, as well as psychoses. Mayosi, Flisher, Lalloo, Sitas, Tollman, and Bradshaw (2009) and Prince, et al. (2007) assert that mental illness is related both to communicable diseases and other related health risks. Mental illness increases the risk of other diseases which in turn aggravates mental illness further and contributes to unintentional and intentional injuries and significant cause of long-term disability, dependency and high mortality.

The WHO (2001) Mental Health Report estimates that about 450 million people suffer from mental or neurological disorders. The report is also estimated that about one person in every four will be affected by mental disorder at some stage of life. Bird, Omar, Daku,

Lund, Nsereko, Mwanza and the MHaPP Research Programme Consortium (2011) and Prince, et al. (2007) note that despite this high prevalence, prioritizing mental health remains poor in most low-income countries, especially in Africa. This can be proved by the inadequate mental health policy and minimal budget allocated, resulting in under-resourced mental health services.

During the apartheid era, the South African society was characterized by racial segregation and violation of human rights. According to Petersen, Bhana, Campbell-Hall, Mjadu, Lund, Kleintjies, Hosegood, Flisher and the Mental Health and Poverty Research Programme Consortium (2009) the focus of mental health services under the apartheid government was on institutional care and psychopharmacological treatment of people with psychiatric disorders. This involved removal of patients from their familiar surroundings to psychiatric institutions which were generally urban-based, resulting in disintegration in relationships as families and friends could not visit them.

Post-apartheid marked a new era in the lives of South African citizens including PWMI. This era is characterised by increased accessibility, improved inclusion and people's participation in decisions that affect their lives. The country made great strides in improving mental health policies and legislations; for instance, the White Paper for the Transformation of Health Services in South Africa 1997 was developed to improve the national health care system. This document focuses on the restructuring of health care, putting more emphasis on universal primary health care (PHC) aimed at increasing access to community-based health services (Petersen, 2002). The legislative framework was also improved resulting in the introduction of a new Mental Health Care Act 17 of 2002. Mental health policies and legislation made provision for free health care to selected members of the population, the development of health districts and the building of many primary health care clinics (Petersen & Lund, 2011).

The development of these documents raised hopes for improvement of mental health care but their implementation has proved challenging. A study to investigate progress made, reported that the need for adequate mental health care is still existing (Lund, Kleintjies, Kakuma, Flisher and the MHaPP Programme Consortium, 2010). This study attributed this challenge to unequal distribution of resources towards mental health care, lack of standardisation of the training of PHC staff in mental health and a lack of inter-sectoral collaboration with other related departments and stakeholders.

According to Sowers and Rowe (2007), care and reintegration in the community of people with mental disorders are major barriers in most countries. Although an integrated PHC system is essential, Petersen, Lund, Bhana, Flisher & MHaPP (2012) argue that the system in South Africa is already overburdened as a result of the HIV/AIDS prevalence that has shifted PHC focus, contributing to the non-prioritization of mental health, especially in rural areas. Lourenco (2012) asserts that accessing health services is a major problem for rural people around the world. This is happening despite the fact that the majority of people, especially in developing countries, live in rural areas. Studies show that health services in rural areas are under-serviced (Petersen, et al., 2012) with most countries facing the challenge of non-existent infrastructure and lack of transportation (Gustafson, Preston & Hudson, 2009; Harris, Goudge, Ataguba, McIntyre, Nxumalo & Jikwana, 2011) as well as serious staff shortages (Marais & Petersen, 2015).

Various authors, including Botha, Koen, Oosthuizen, Joska and Hering (2008), and Mayosi, et al. (2009) are of the opinion that integration of mental health services into PHC has had substantial impact on PWMI and their families. Most PWMI are released into the care of their families, as a result families are forced to reorganise their household routines and adjust in all aspects of life. This has had detrimental effects not only on the families' finances but their whole lives as well. According to Mavundla, Toth and Mphelane (2009), the majority of PWMI receive disability grants but this does not alleviate the financial pressure on their families as they are sometimes forced to travel long distances to seek clinical resources and specialised treatment that are not available in rural areas.

Economic factors are not the only challenges associated with mental illness. PWMI also have to deal with social challenges. Stigma and discrimination are major social problems that are experienced by PWMI (Ben-Zeev, Young, & Corrigan, 2010). Corrigan and Shapiro (2010) state that public stigma robs PWMI of rightful opportunities related to work and other important life goals. Myths and misinformation exacerbate, encourage and promote stigma and discrimination. PWMI are often mistreated by their own families, friends as well as the community. They often are not taken seriously and deprived of the opportunity to participate in societal activities and even make decisions that will affect their lives. The loss of family support, limited access to opportunities and important services worsen the effect of mental illness resulting in the revolving-door phenomenon

(Kakuma, Kleintjies, Lund, Drew, Green, Flisher & MHaPP Programme Consortium, 2010; Botha, et al., 2008).

Management of mental illness requires a combination of clinical interventions to address its complex nature. Weine (2011) states that much of the mental health care offered professionally only focuses on individuals and excludes their families and communities. This calls for a different type of intervention that will address the shortcomings of the current mental healthcare services and address challenges faced by PWMI and their families. The focus of this restructured intervention should not only be on the medical part of illness but should include empowering PWMI and enhancing their well-being.

Keyes (2006), Westerhof and Keyes (2009) as well as Moore, Bates, Brierley-Bowers, Taaffe and Clymer (2012) regard 'well-being' subjectively. Subjective well-being is seen as fundamental to quality of life. In an attempt to explain subjective well-being, two concepts have been introduced, namely 'hedonic well-being' and 'eudaimonic well-being'. Hedonic well-being focuses on pleasant feelings over unpleasant ones; this concept is also called 'emotional well-being'. Eudaimonic well-being involves psychological and social well-being. Psychological well-being involves striving to become a better person whereas social well-being focuses on the social functioning of an individual striving to be a better fellow member of the community. In the context of this study, emotional, psychological and social well-being are seen as interdependent, therefore an individual cannot function well in the absence of either of these components. Given that PWMI and their families face various challenges, improving all aspects of their well-being is therefore essential.

Evidence shows that community-based interventions can be effective in dealing with mental health challenges. According to Guttmacher, Kelly, and Ruiz-Janecko (2010) community-based interventions move beyond a focus on changing the behaviour of individuals to acknowledging the importance of interpersonal or group behaviour, institutional climate, community resources and policy effects. The involvement, therefore, of families, communities and various stakeholders contribute to the success of such intervention. Miller (2012) puts emphasis on the importance of involvement of families in the intervention process as they also experience challenges associated with the illness. Acknowledging the role of the family in the treatment of mental illness helps in determining the most appropriate intervention strategy and services to empower families to enable them to manage the challenges associated with mental illness.

From a social work point of view, any community-based activity is seen as a direct service delivery strategy implemented in the context of the local community. The scope of practice is narrowed down to working *in* and *with* the community in order to benefit the participating community members directly and, in a lesser or more indirect way, other non-participating residents. This type of service represents the processes that have traditionally been associated with community organisation and development practice. It, for example, encompasses grassroots level organisation, empowerment-centred interventions, citizen participation and a local (indigenous) leadership with emphasis on local self-help, self-sufficiency and teamwork (Weyers, 2011).

This study was motivated by the researcher's experience as a practising social worker in a health setting. She was often confronted by families who wanted social workers to motivate that the family member with mental illness be confined in a psychiatric institution, permanently. In some cases, families would refuse to fetch patients after their discharge; this resulted in the patients staying longer than necessary in hospital. It was also realised that discharged patients whose families had rejected them and made a special request for them not to be discharged, were often readmitted within a short period of time or they roamed the streets posing a danger not only to themselves but other people as well. This raised a concern about the availability and effectiveness of community-based programmes to help both PWMI and their families deal with challenges of mental illness.

The study was also motivated by the fact that, although several mental health studies have been conducted in the country, few have focused on a study of this nature. There is also a dearth of mental health and illness-related research pertaining to the Limpopo Province. This study will fill this gap. Its findings may also be of value to other rural communities in the country that experience similar difficulties. Finally, the intended framework, which will be the core 'product' of this research, may help to introduce or improve community-based programmes. This type of programme may reduce the revolving-door phenomenon, open up opportunities for PWMI and relieve the burden of their families.

Nicholas, Rautenbach and Maistry (2010), DuBois and Miley (2010) as well as Zastrow (2010) regard social work as an empowering profession due to social workers' ability to help people to regain their dignity, self-worth and encourage self-reliance. Using various methods of intervention, social workers work with different people in all spheres of life.

They are known for playing different roles such as empowerer, advocate, facilitator, educator or mediator that are targeted at the broader aspect of health (DuBois & Miley 2010). According to Horner (2012) social workers play a significant role in health promotion and disease prevention, and in this role they work collaboratively with clients, professionals and other stakeholders. It is within this context that there is a need to develop a framework that will guide social workers to develop and implement a community-based programme to improve the well-being of PWMI and their families.

The following research questions gave direction to the undertakings of this study:

- How do health care professionals perceive the mental health services they render to people with mental illness and their families in rural settings?
- How do people with mental illness and their families in rural settings cope with mental illness?
- What role do different stakeholders currently play with regard to mental illness in rural settings?
- What can be done to guide social workers to develop and implement community-based programmes to improve the well-being of PWMI and their families in rural settings?

3 AIM AND OBJECTIVES OF THE STUDY

The primary aim of this study to:

- to develop a framework for a community-based programme to improve the well-being of people with mental illness and their families in a rural setting.

In order to achieve this aim, the following objectives were pursued:

- to establish how health care professionals assess mental health services that they render in rural setting.
- to establish how people with mental illness and their families currently cope with mental illness,
- to explore the current and potential roles of the different stakeholders as support system of people affected by mental illness, in a rural setting,
- to develop the framework to guide social workers on the development and implementation of a community-based programme in a rural setting and

- to evaluate the appropriateness and relevance of the framework for a community-based programme in improving the well-being of people with mental illness and their families, in rural setting.

4 CENTRAL THEORETICAL STATEMENT

The study is based on the assumption that community-based programme can improve the well-being of people with mental illness and their families. The framework can assist social workers to develop and implement a sustainable community-based programme that will improve the well-being of PWMI and their families.

5 THEORETICAL FRAMEWORK

The ecological perspective and resilience theory were used to give direction to the study and to form the basis of the intended programme framework.

5.1 Ecological perspective

The ecological perspective focuses on the goodness of fit between people within their environment. Its main emphasis is on addressing the relationships, interactions and interdependence between individuals and their environment. This perspective seeks to understand how different factors interact to contribute to any problem and then come up with solutions that will not focus only on the individual but the entire society (Ambrosino, Heffernan, Shuttlesworth & Ambrosino, 2008). This framework is augmented by the systems theory which explains the interactions between the physical environment individuals, families, communities and the society and highlights how these subsystems affect each other within the bigger system (DuBois & Miley, 2010).

5.2 Resilience theory

Resilience theory is well suited for the understanding of the people's ability to make changes on certain aspects of their lives in order to fit the current situation (Troy & Mauss, 2011). To conceptualize the experience of PWMI and their families, resilience theory is valuable in explaining the adaptability of these people under stressful circumstances. This theory highlights the importance of the ability to adapt to life's challenges that result in disruption in social functioning (Walsh, 2012). An individual is understood within the context of the environment as it is believed to provide the necessary resources that help

in nurturing and reinforcing resilience (McLaren & Hawe, 2005; Wright, Masten & Narayan, 2013). Family forms part of the social environment that plays a crucial role in creating the nurturing environment that supports adaptation and enhances resilience. In addition, this theory focuses on strengthening key interactional processes that enable families to adapt to disruptive challenges they face (Walsh, 2012).

6 METHODS OF INVESTIGATION

The study made use of both qualitative and quantitative paradigms. Phase 1 considers different theoretical approaches and perspectives in order to understand the problem completely. This strengthened the study and increased the chances of getting better results (Creswell, 2014; Delport & Fouché, 2011). The researcher used a quantitative survey with a sample selected from different primary health care centres, mobile clinics and two hospitals that render mental health services in rural communities. The survey was used to assess mental health services based on eight attributes of good health services. This section explains the various methods of investigation undertaken to answer the research questions.

6.1 Literature review

A literature review is one of the most important components of research. According to Bless, Higson-Smith and Kagee (2006) as well as Fouché and Delport (2011), a literature review helps to strengthen the theoretical framework of the research hence helps the researcher to identify information relevant to the study and what other researchers have done with regard to the topic to be researched. For the purpose of this study, several publications were consulted. These included different books and professional journals. Databases included EBSCOhost, ProQuest, SA Publications and Google Scholar. The following topics were included in the literature search:

- Mental health in rural communities,
- The coping experience of individuals and their families with mental illness,
- The impact of mental illness and
- Developing a community-based intervention programme.

6.2 Empirical investigation

The empirical investigation includes information on the research design, the research context, population and sample, recruitment and criteria for selection as well as various methods of data collection and analysis. Also included in this section are aspects regarding development and evaluation of a community-based programme.

6.2.1 The research context

The study was conducted at Mashashane, a rural setting situated about 37 km outside Polokwane in the Capricorn District and 30 km outside Mokopane in the Waterberg District of Limpopo Province, in the northern region of South Africa. Until recently, this area was one of the traditional authorities under Aganang Municipality, one of the five municipalities under the Capricorn District. The Municipal Demarcation Board, however, approved a re-determination of certain municipal boundaries resulting in the amalgamation of Aganang with Polokwane Municipality (MDB Circular 5/2015). Mashashane is not different from other rural areas of South Africa as it is administered by a tribal authority. It is a cluster region comprising of 22 villages, each with its traditional leader who account to the chief. The most widely spoken language in this area is Sepedi which is spoken by the baPedi, the largest ethnic group in Limpopo Province. Other widely spoken languages include Ndebele and Xitsonga.

Although, provincial government has embarked on improving the provincial road network by upgrading existing gravel road between Mashashane and Mokopane to a sealed surfaced all-weather road, most parts of Mashashane have unpaved roads. Similar to other rural areas, there is lack of resources and inadequate services (Petersen et al., 2012) and no economic opportunities, as a result unemployment rate is high (Ardington, Bärnighausen, Case & Menendes, 2013). The majority of people of working age migrate to neighbouring towns and provinces. This project targeted villages that are within a 10 kilometre radius from the Chief's Kraal. Health services are provided in the local clinic although some villages receive health services from mobile clinics that visit fortnightly. These clinics do not render specialised health services, therefore people who need this kind of service are referred to hospitals in Polokwane or Mokopane. Social work services are rendered by social workers based in the local clinic. Mashashane also has a fully

functional police station. There are a number of schools and various church denominations in the area.

6.2.2 Research design

Babbie and Mouton (2012) refer to a research design as a plan that clearly outlines how one intends to conduct a research. In this study, grounded theory and case study designs were used to understand the experiences and coping strategies of PWMI and their families (Fouché & Schurink, 2011). The purpose for using grounded theory is to develop a theory based on the data gathered and analysed. Grounded theory eased data collection through the researcher's social interaction with the participants, observations and semi-structured interviews (Nieuwenhuis, 2007).

The study was explorative in nature because of its aim to venture into an unfamiliar aspect in mental health (Marlow, 2005). There had been very little done with regards to designing of community-based programmes framework in the country. The study was also descriptive in nature as it provided information that was vital for the development of a programme framework (Marlow, 2005; Ivankova, Creswell & Clark, 2007).

The research was conducted in three phases. The first phase focused on a needs assessment; the identification and understanding of these needs led to the second phase which is the development of a framework for a community-based programme and an evaluation of the programme framework constituted the third phase. The process of this study is summarised in Table 1 below:

Table 1: Outline of the research method

PHASE 1: THE SITUATION-ANALYSIS	
PHASES	RESEARCH DESIGN & PROCEDURE
<p>Phase 1a: The nature and state of mental health services in rural areas Purpose: To assess the nature and state of mental health services in general and especially those pertaining to rural areas. Respondents: Multidisciplinary health care professionals. The targeted professionals included nurses, doctors, occupational therapists and social workers in two hospitals and PHC centres within the study area. Data collection method(s): Questionnaire (survey) Data analysis method(s): Utilisation of statistical analysis procedure (e.g. SPSS) with assistance of a statistician.</p>	<p>Type of research: Quantitative design Sampling: Purposive Basic research procedure: 1. Contacted management of the two targeted hospitals (Aganang and Polokwane) and the provincial PHC Directorate to obtain permission to conduct the survey. 2. Contacted potential respondents via the hospital management and obtained informed consent for survey. 3. Distributed and collected questionnaires. 4. Completed statistical analysis.</p>
<p>Phase 1b: The circumstances and needs of PWMI and their families</p>	<p>Type of research: Qualitative design Sampling:</p>

<p>Purpose: To ascertain how families and family members with mental illness in a rural area currently cope with mental illness.</p> <p>Participants: PWMI and their family members.</p> <p>Data collection method(s): Face to face semi-structured interviews.</p> <p>Data analysis method(s): Categorised data in codes and analysed.</p>	<ol style="list-style-type: none"> 1. Purposive sampling of PWMI and their families in the study are. <p>Basic research procedure:</p> <ol style="list-style-type: none"> 1. Contacted nurses at local clinics to obtain information about potential participants that meet the requirements. 2. Contacted potential participants and obtained informed consent for interviews. 3. Conducted interviews separately with PWMI then their families and captured data by means of audio recordings. 4. Transcribed and analysed the interviews.
<p>Phase 1c: The views of stakeholders regarding their role as a support system</p> <p>Purpose: To ascertain</p> <ol style="list-style-type: none"> (a) how stakeholders perceive their role as a support system for PWMI and their families, (b) the availability of resources in the community and (c) mechanism that could be put in place in order to improve services to PWMI and their families. <p>Participants: Traditional leaders, church members, traditional health practitioners (THPs) – (traditional healers and faith-based healers), police officers from South African Police Services (SAPS) and home-based caregivers (HBC).</p> <p>Data collection method(s): Focus groups</p> <p>Data analysis method(s): Categorised data in codes and themes.</p>	<p>Type of research: Qualitative design</p> <p>Sampling:</p> <ol style="list-style-type: none"> 1. Purposive sampling of stakeholders in the selected communities. <p>Basic research procedure:</p> <ol style="list-style-type: none"> 1. Personally contacted stakeholders and invited them to focus group sessions. 2. Obtained informed consent. 3. Conducted separate focus groups discussions with different types of stakeholders. 4. Captured data by means of audio recordings. 5. Transcribed and analysed the interviews.
<p>PHASE 2: DESIGN A CONCEPT COMMUNITY-BASED PROGRAMME FRAMEWORK</p> <p>Note: The nature, contents and design of the programme were determined by the findings produced by Phase 1</p>	
<p>PHASES</p> <p>Purpose: To design a structured intervention programme framework that would</p> <ol style="list-style-type: none"> (a) empower PWMI and their families to cope more effectively with mental related issues in a rural setting, as well as (b) guide the health care professionals and other stakeholders to play a more supportive role in this regard 	<p>RESEARCH DESIGN & PROCEDURE</p> <p>Type of research: Intervention design and development (D&D)</p> <p>Basic research procedure:</p> <ol style="list-style-type: none"> 1. Utilised data obtained from especially the multidisciplinary health care professionals (see Phase 1a) and the stakeholders (see Phase 1c) to design a programme framework for improved service delivery to PWMI and their families (See annexure 25) 2. Utilised data obtained from PWMI and their families (see Phase 1b), as well as all other resources to design a community-based programme. (See annexure 24)
<p>PHASE 3: EVALUATING THE PROGRAMME FRAMEWORK</p> <p>Note: The nature of the evaluation of the framework was primarily determined by the findings produced by phases 1 and 2</p>	
<p>PHASES</p> <p>Purpose: To assess the appropriateness AND usefulness of the programme framework</p>	<p>RESEARCH DESIGN & PROCEDURE</p> <p>Type of research: Intervention design and development (D&D)</p> <p>Basic research procedure:</p> <p>It involved utilising some of the professionals and stakeholders mobilised during phase 1 in completing questionnaires with open-ended questions in order to assess the appropriateness and usefulness of the programme framework.</p>

6.2.3 Phase1: Situation analysis

The purpose of this phase was to conduct a situation analysis that would help in the development of a community-based programme. Situation analysis provides an opportunity to prioritize pressing issues, analyse the contributing factors and determine intervention as well as the beneficiaries of such intervention (Couillard, Garon & Riznic, 2009; Afifi, Makhoul, Hajj & Nakash, 2011). For the purpose of this study various perspectives were captured from three standpoints. Articles 1 to 3 address these perspectives.

6.2.3.1 Population and sample

Population refers to objects or people that have common characteristics and upon whom the research focuses. It is from this population that the sample was drawn (Bless et al. 2006). The researcher selected various sampling methods for the three groups of participants, namely, (1) multi-disciplinary health care professionals, (2) the PWMI and their families, and (3) the stakeholders.

6.2.3.1.1 Multi-disciplinary health care professionals

The target population for this section of the study consisted of multi-disciplinary health care professionals from Mashashane local clinics and two district hospitals that serve this area. Although purposive sampling is non-probability sample and is often used in qualitative study, it was used in this study because the group studied would add meaningful data based on their knowledge and experience of mental illness (Babbie & Mouton, 2012; Strydom & Delport, 2011; Vogt, Gardner & Haeffele, 2012). The health care professionals included doctors, nurses, occupational therapists, psychologists and social workers. The selected sample was regarded as representative of the larger population (Bless, et al., 2006). Due to the population size of nurses in hospital and the importance of getting information required by the study, the researcher limited participation to professional nurses who work in general male and female wards, casualty as well as outpatient departments. These nurses were believed to have direct contact with PWMI and their families.

The estimated population of health care professionals was 156 and he targeted sample was 66. A total of 60 questionnaires were delivered. The majority of nurses showed little willingness to participate because each clinic and relevant units in hospitals have a dedicated mental health nurses who also participated in the study. After several attempts

to contact respondents, only 35 of 60 returned completed questionnaires. The return rate therefore was 58%, which is satisfactory for analysis and reporting (Babbie & Mouton, 2012).

6.2.3.1.2 The people with mental illness and their families

The target population for this section of the study consisted of PWMI and their families residing at various villages of Mashashane that are located within 10 km radius from the tribal authority. The sample was purposively drawn from this population based on the assumption that PWMI and family members have the necessary knowledge and experience of mental illness to add meaningful data to the study (Bless, et al., 2006).

6.2.3.1.3 The stakeholders

The crucial role that stakeholders play in mental health and related issues is widely documented. WHO (2013) emphasises the need to involve several stakeholders including families, as well as religious leaders, faith healers, traditional healers, school teachers, police officers and local non-governmental organizations (NGOs) in the care of PWMI. For the purpose of this study and based on their availability in the research area, traditional leaders, traditional healers, churches, police officers and home-based care groups as part of NGOs were identified as crucial in providing support and care to PWMI and their families within the rural communities. Although their specific role in mental health is not clear, the South African legislation recognizes traditional leaders as custodians of African culture that are significant in health, welfare and safety and security in the communities (Ross, 2010; Knoetze, 2014).

Several studies consider traditional health practitioners (THPs) such traditional and faith healers as important in the treatment of mental illness. They argue that PWMI and their families consult THPs before consulting mental health services. This is influenced by THPs accessibility in rural areas (Ndetei, Khasakhala, Kingori, Going & Raja, 2008; Sorsdahl, Stein, Grimsrud, Seedat, Flisher, Williams & Myer, 2009; Atindanbila & Thompson, 2011). Similarly, according to Magezi (2012) and Faull (2012), the church plays a crucial role in promoting health, enhancing general well-being and promoting social functioning of individual members of the community by shaping and influencing people's behaviour and reaction towards various aspects of life.

Police officers are known for their role in law enforcement. They are believed to be in constant contact with PWMI (Hoch, Hartford, Heslop & Stitt 2009; Anderson, Fuhrer,

Schmitz & Malla, 2013) as they are often the first people to be called when a person with mental illness displays any unusual behavior (Livingston, Desmarais, Verdun-Jones, Parent, Michalak & Brink 2014; Livingston, Desmarais, Greaves, Parent, Verdun-Jones & Brink, 2014). Home-based care groups (HBC) play a significant role in providing social, emotional as well as material support to sick people including those with mental illness and their families. They provide care to the sick in the comfort of their home (Ama & Seloilwe, 2011).

All stakeholders were purposively selected because it gave the researcher freedom to make selection decisions based on her knowledge of the population, the elements that contain most characteristics and the purpose of the study (Strydom & Delpont, 2011; Bless, et al., 2006).

6.2.3.2 Recruitment and criteria for selection

To enable the researcher to get the relevant sample, the participants were recruited using the following selection criteria:

6.2.3.2.1 Health care professionals

Health care professionals in the hospital include nurses, doctors, social workers as well as occupational therapists. These professionals were approached as a group in their work stations during their lunch break. The potential respondents who were not on duty but found to be relevant for the study were contacted individually through their mobile phones. The researcher and research assistant distributed questionnaires and explained its contents to those who showed interest to participate. The criteria for selection were as follows:

- Take part in the multi-disciplinary team meetings and provide input in the intervention regarding PWMI.
- Involved in either admission or discharge of PWMI.

Health care professionals in the local clinics were professional nurses including those who specialise in mental health as well as social workers.

6.2.3.2.2 People with mental illness and family members

The initial plan was to recruit potential participants during their routine check-up at the clinic with nurses as gatekeepers to authenticate the process. However, due to the

government initiative to increase accessibility of primary health care, many villages at Mashashane receive health care services from the mobile clinics. Mobile clinics visit each village fortnightly. After eight consecutive visits to the mobile clinic sites, seven potential participants were recruited. The researcher consulted with nurses and this resulted in the researcher's referral to home-based care groups who assisted with a list of other eligible participants.

HBC are volunteers from the villages who operate under the Department of Health by assisting sick people within their villages. These groups, therefore work closely with nurses. The home-based care givers provided a list of other potential participants who were then recruited from their homes. The caregiving family members were also recruited from their homes because they do not accompany the ill individuals to the clinic site as it is within the community. The recruited participants had to meet the following criteria:

- ***People with mental illness***

- Age: 18 – 60 years.
- Formally diagnosed with mental illness and had previously been hospitalised due to mental illness.
- Had not relapsed for the past six months. This means that the person had been adhering to treatment and had not been hospitalised due to mental illness for the past six months.
- Only people who were able to hold and maintain normal conversation were regarded as stable. This was determined during recruitment process.

- ***Family members***

- Has been staying with a person with mental illness for a minimum period of six months in the same household.
- The member is involved in the day-to-day caring of PWMI as a primary carer.

6.2.3.2.3 Stakeholders

The researcher sought permission to the conduct the research from the authorities of each stakeholder group. To recruit the individual members of each group, the researcher requested to meet with the members who are actively involved with PWMI so as to explain the purpose of the project and request them to participate. Stakeholders included

traditional health practitioners, traditional leaders, the church, police officers as well as HBC and they were selected on the basis of their interaction with PWMI.

6.2.3.3 Methods of data collection

This study adopted both the qualitative and quantitative methods of data collection as discussed in the following section:

6.2.3.3.1 Questionnaires

This study adopted a quantitative methods of data collection through the use of self-administered questionnaires. Self-administering the questionnaires minimized bias errors that could be a result of interviewer's characteristics and the inconsistencies in interviewing skills. Furthermore, an interviewer's absence affords greater anonymity for the respondent and also increases the reliability of responses (Phellas, Bloch & Seale, 2011). The questionnaires were designed in a manner that would enable the respondents to complete it with ease (Phellas, et al., 2011; Babbie & Mouton, 2012).

A questionnaire was developed for gathering data from health care professionals and its development was based on the literature reviewed. Besides the demographical and organizational setting information, the questionnaires consisted of questions that sought to understand the mental health service rendered with regards to its comprehensiveness, accessibility, coverage, continuity, quality, person-centeredness, coordination and accountability and effectiveness (See Annexure 17). The questionnaires consisted of both closed and open-ended questions. Closed-ended questions were not only used for their easy transference of data for processing but to gather data that did not necessarily need narration, while open-ended questions elicited respondents' opinion about what was asked (Babbie & Mouton, 2012; Vogt, et al., 2012).

6.2.3.3.2 Face to face semi-structured interviews

Interviewing is the most common method of data collection in qualitative research. The researcher used semi-structured interviews with the aim of understanding participants' experiences and the meaning they attached to mental illness as well as strategies adopted with the condition (Greeff, 2011; Babbie & Mouton, 2012). PWMI were interviewed separately from the family members who are their caregivers. All the interviews were conducted in the participants' homes. A guide was designed to facilitate the interviewing process. This guide contained questions that sought to understand the

participants' insight about mental illness, experiences within the community, the support they get from various systems within the community and the manner in which they solicit support (See Annexures 14 and 15).

6.2.3.3.3 Focus groups

The focus groups was conducted with various stakeholders in the rural setting. The researcher explored the stakeholders' understanding of mental illness, their views with regard to the role they play as support system of PWMI as well as their view on working with other stakeholders in order to improve mental health services in a rural setting. The focus group discussions with church members, traditional health practitioners and traditional leaders' interviews were in the tribal office as that location was considered neutral and easily accessible. The discussions with police officers were conducted in the police station and HBC meetings were in the clinic. Focus groups gave stakeholders an opportunity to get together and create meaning out of an issue at hand (Greeff, 2011; Babbie & Mouton, 2012).

A focus group consisted of a minimum of five to a maximum of eight participants as this enabled everyone to participate. The reason for working with the small number of participants was that there was a limited number of some stakeholders such as members of SAPS. Due to the diverse nature of these stakeholders and to increase the level of participation, the researcher conducted focus group with each group. A focus group protocol was developed to facilitate participation and consistency (See Annexure 16). The information gathered was regarded as adequate when participants repeatedly gave the same information, therefore indicating a level of saturation.

6.2.3.4 Procedures

Several procedures have to be considered when undertaking a study of this nature. The study took place in the community; therefore the researcher had to negotiate entry into this community. Following are the procedures which were followed:

- The researcher requested permission from the provincial Department of Health in Limpopo, in order to conduct the study with the health care professionals to get information on PWMI. (See Annexure 3)
- Permission was also sought from and granted by the Chieftaincy of Mashashane region as well as the Provincial Department of South African Police Services. (See Annexures 2 and 6)

- Written consent forms were obtained from the participants. (See Annexures 7 – 13)
- The researcher made arrangement with the local social worker to assist with counselling of the respondents should the need arise.

6.2.3.5 Methods of data analysis

This section presents quantitative and qualitative analysis as methods of data analysis that were adopted in this study.

6.2.3.5.1 Quantitative data analysis

The survey data were analysed according to quantitative methods. Data in quantitative method is analysed based on the type of question or hypotheses and it uses appropriate statistical test to address the data collected (Creswell & Clark, 2007). Prior to the analysis of the quantitative data, responses were coded by hand according to the levels of measurement. Data capturing was managed by the Microsoft Excel 2013, and then transferred into SPSS (Statistical Package for Social Sciences). Analysis was undertaken with the SPSS (22.0). This allowed for univariate and bivariate analysis. Univariate analysis refers to the investigation of a single variable for purposes of description while bivariate analysis is the simultaneous analysis of two variables in order to test a relationship (Babbie, 2010).

In order to describe and assess mental health services in the Mashashane area, frequency tables were generated (univariate analysis). Frequency distributions describe the number of times the different attributes of a variable are observed in a sample. This allows for the comparison of different variables. As to the bivariate analysis, statistical tests of significance were conducted on the services rendered, accessibility of service, service coverage, continuity of care and quality of service in order to explore independent variables for example profession of respondents and health care centres differences. A Chi-square (χ^2) test was used to calculate significant differences in the perceptions of the mental services rendered in the study area among the different professionals and health centres providing the services (Babbie, 2010). A 95% level of significance which is most commonly used in social research was adopted (Fielding & Gilbert, 2006).

6.2.3.5.2 Qualitative data analysis

Babbie (2010) as well as Creswell and Clark (2007) advise researchers to categorize and code data, and assign labels to each unit because data collection, in qualitative

method comprises of texts. Data from interviews were transcribed into text units and thereafter transcripts were read through several times in order to make sense of the data as a whole. Data were categorized according to the topics discussed during interviews. Category formation is an important part of qualitative data analysis during which the researcher describes the data in great detail and develops themes through a system of classification.

6.2.3.6 Validity, reliability and trustworthiness

Babbie and Mouton (2012) as well as Shenton (2004) point out the difficulty of addressing the concepts of validity and reliability in a naturalistic work. There are however strategies that each researcher can employ in order to ensure the validity, reliability and trustworthiness of a study.

6.2.3.6.1 Validity

Validity focuses on whether the measuring tool measures what it is intended to measure. Neuman (2006) and Drost (2011) assert that validity focuses on truthfulness and authenticity. The researcher conducted a pilot study to test the feasibility of the questionnaire; this included the methodology, administration procedure and the questionnaire items so as to check for any ambiguities and inaccuracies (Blaxter, Hughes & Tight, 2006; Strydom & Delpont, 2011). The pilot study was conducted with five health care professionals consisting of a doctor, two professional nurses and two social workers who were excluded in the actual study.

6.2.3.6.2 Reliability

Reliability involves the consistency of the results that a measuring instrument produces when used somewhere else (Neuman, 2006; Babbie & Mouton, 2012). Literature suggests test-retest, split-half, use of established measures and reliability of research workers as methods to ensure reliability (Babbie & Mouton, 2012). The use of self-administered questionnaires in this research reduced any researcher's biases and inconsistencies, thereby increasing the reliability of responses (Phellas, et al., 2011). Conducting a pilot study helped to identify double-barrelled and ambiguous questions as aspects that could have had a negative impact on the data's reliability. In addition, consistency of responses obtained from the pilot study with those of the main study was another way in which reliability was confirmed.

Another method to ensure reliability included the use of Cronbach's alpha. Rotation, preliminary interpretation and naming of factors (subscales) were done, then followed the calculating of Cronbach's alpha as well as the overall scale. Cronbach's alpha quantifies the degree of internal consistency (reliability), that is, the extent to which a set of items measures a single unidimensional latent construct or dimension of a construct (Tavakol & Dennick, 2011). Cronbach's alpha indicates the extent of coherence or homogeneity of the scale or each subscale (Tavakol & Dennick, 2011).

6.2.3.6.3 Trustworthiness

Trustworthiness is an important aspect of qualitative research. In an attempt to establish trustworthiness, the researcher employed several methods as recommended in Guba's approach (Shenton, 2004). These include ensuring credibility, transferability, dependability and confirmability of the data.

- Credibility

Literature emphasises the importance of prolonged engagement to allow the researcher an opportunity to get a better understanding of the culture of the context and to build a relationship of trust with all the relevant people (Shenton, 2004; Babbie & Mouton, 2012). Credibility in research focuses on the congruency of research findings by taking into cognisance the context in which data were collected and to create differences between the researcher's interpretations and those of the participants (Shenton, 2004; Babbie & Mouton, 2012). In this study, the researcher focused on understanding the experiences of PWMI and their families through the use of interviews as data gathering method. To ensure authenticity, during data gathering, the researcher asked open-ended and probing questions to encourage participants to give their own views about their experiences.

Credibility was established through triangulation that involved semi-structured interviews and focus group discussions as methods for data collection (Shenton, 2004; Schurink, Fouché & De Vos, 2011). Several other processes included the purposeful sampling of the study participants, application of appropriate data gathering methods and research instruments, verbatim transcriptions and peer debriefing (Shenton, 2004; Loh, 2012).

- **Transferability**

Transferability refers to the extent to which findings of the study can be applied to another setting (Shenton, 2004; Loh, 2012). The literature suggest techniques that can be used to establish transferability. Firstly, transferability can be established through thick description of the research context to allow the readers to determine the extent in which they can transfer presented results and conclusions to other similar contexts. An emphasis is also put on providing thick description of the phenomenon under investigation for the readers to gain a better understanding that will enable them to make comparisons with similar phenomenon (Shenton, 2004; Babbie & Mouton, 2012). Secondly, the purposive selection of participants maximized the chances of obtaining specific information (Babbie & Mouton, 2012).

- **Dependability**

Dependability can be established if similar results are obtained on the work repeated in the same context, with the same methods and the same participants (Shenon, 2004). Detailed data collection and analysis methods followed are given to allow other researchers to follow the similar steps therefore ensuring dependability.

- **Confirmability**

According to Shenton (2004) and Schurink, et al. (2011), confirmability focuses on the researcher's objectivity. It is argued that the researcher should ensure that findings are the results of the ideas and experiences of participants rather than those of the researcher. The researcher kept records such as transcripts, field notes and interview schedule to provide details of the exact data provided by the participants (See Annexures 18 -21).

6.2.3.7 Ethical aspects

People with mental illness are considered vulnerable due to their mental or emotional health problems and cognitive impairment. It was therefore important to consider ethical aspects as suggested by Keogh and Daly (2009), Strydom (2011) and as it is clearly stipulated in section 71 of National Health Act 61 of 2003, regulations relating to human subjects as well as Ethics in Health Research of 2004. This research enforced these by ensuring:

Informed consent – Following the explanation about the aims, processes to be followed and voluntary nature of the study, participants gave written consent as a sign that they understood the conditions of the study and were participating out of their own accord.

Confidentiality and anonymity - In order to maintain confidentiality, pseudonyms were used in the data collected. Given that confidentiality is difficult to maintain in a focus group, participants were requested not to share any information with people outside of the group. Pseudonyms were used in any recorded data. The data will be kept in the hard drive that requires a password. This will be kept for a period of five years after which it will be destroyed.

Deception of participants - Honesty is important when dealing with human research participants, especially vulnerable groups. To prevent compromising the quality of the study and creating expectations, participants were informed that no incentives would be given.

Competency of the researcher - Conducting research with vulnerable groups requires researchers to be competent and qualified to undertake a scientific research. The researcher holds a Bachelors and Master's degree in Social Work and has eight years practice experience as a social worker, four of which were in a health setting. To ensure the smooth progress of the project, the researcher had constant contact and reflective discussions with her research supervisors, both of whom are competent researchers.

Additionally, Institutional ethical permission was granted. (See Annexure 1)

6.2.4 Phase 2: Design a concept community-based programme framework

The purpose of this phase was to develop a community-based programme framework that will be used by social workers to improve the well-being of PWMI and their families in a rural setting (De Vos & Strydom, 2011). This development was guided by the results of a situation analysis conducted in Phase 1 of this study. Situation analysis outlined the challenges experienced by PWMI and their families. It also afforded an opportunity for the researcher to identify the contributing factors. This knowledge underpinned the development of a six module educational programme delivered in a social group work format and guidelines for stakeholders and health care professionals to provide support to PWMI as well as their families.

The main purpose of the social group work educational programme was to empower by providing information to improve knowledge and minimise the myths about mental illness. The programme also focused on enhancing understanding about self-care as well as reduce worry about the future. Other modules included empowering the attendees with the development and reinforcement of problem-solving and communication skills, the ability to generate appropriate strategies to cope with any problematic life situations as well as to improve the ability to create and maintain relationships with social contacts (See annexure 24). PWMI and their families who were part of Phase 1 participated in the pilot testing of this programme.

The developed guidelines have four key areas with recommended elements that should be implemented in order to achieve the intended goals. These key areas include giving information about available support, the establishment of a task team and related responsibilities, training and involvement of PWMI and their families in the relevant processes (See annexure 25).

6.2.5 Phase 3: Evaluating the programme framework

Programme evaluation is important to determine its effectiveness and impact to the specific target group (Babbie & Mouton, 2012). Given the challenges that exist in rural areas including social context, inadequate public transportation systems and infrastructural related challenges including vast geographical, it is important to evaluate a programme framework to determine its suitability for the context spaces (Strauss, Boyas & Murphy-Erby, 2012). Kilbourne, Neumann, Pincus, Bauer and Ronald (2007) as well as Wight, Wimbush, Jepson and Doi (2015) point out that community inputs are required to assess appropriateness, feasibility and usefulness of the intervention. According to Rodríguez-Campos (2012), stakeholder engagement in the process of evaluation increases the sense of ownership, which then increases the likelihood of support, action on the results and recommendations of the evaluation.

This programme framework was validated by various experts including health care professionals and external stakeholders. Although it was initially intended that the process of validation would be done through interviews with relevant participants, commitments of targeted groups prevented them from availing themselves. As a result, a self-administered questionnaire with open-ended questions (See Annexures 22 and 23) was designed. These questionnaires were delivered to the contact person who

distributed them to the potential participants. These participants were already in possession of the proposed intervention documents (See Annexures 24 and 25) as these were delivered in preparation for the interviews. Due to low levels of literacy some stakeholders including traditional leaders, THPs as well as PWMI and their families could not participate validating the proposed interventions. Article 4 outlines the details of the process followed.

7 LIMITATIONS AND DEMARCATION OF THE STUDY

Limitations are the problems encountered that can negatively interfere with the progress and results of a study. Fouché and Delpont (2011) state that limitations can even be found in a carefully planned study and further suggest that steps have to be taken to avoid them.

- The study was primarily limited by the fact that it was practically impossible to cover all rural communities in South Africa by an in-depth research of this nature. The alternative was to select one district of a province as a 'case study'. The results achieved by studying this district could then, with the necessary adaptations, be made applicable to other rural communities in the province and further afield.
- The study was, as far as the empirical research is concerned, limited to the six sub-villages that are found within a 10 kilometre radius from the Chiefs' Kraal area of Mashashane area in the Limpopo. This choice holds a number of advantages. Firstly, mental health service found in this district can be viewed as similar to that of other rural areas in the Limpopo Province and other provinces since health care is dependent mainly on Primary Health Care. Secondly, the researcher's familiarity with the area gave her access to organisations and people that 'outsiders' would find difficult to accomplish.
- The researcher's status might influence the responses of the participants, especially 'ordinary' community members. To prevent this, the aims of the study were clearly stipulated and emphasis put on the importance of truthful responses and informing participants that their involvement would be voluntary.
- The study was limited to participants who met a set criteria. This might have had a contributing factor to the small sample size.
- The unavailability of stakeholders and poor literacy of some participants had an impact on conducting the evaluation process of the programme framework.

8 DEFINITION OF CONCEPTS

- **Community-based programme**

Community-based programme is an intervention designed and implemented in partnership with PWMI and their families within their locality; with the aim of improving their well-being (Janardhana & Naidu, 2011).

- **Mental health**

Mental health is a fundamental aspect of health, a basis for well-being and a resource for effective functioning of an individual, families, as well as a community to contribute to human, social and economic capital (Jenkins, Baingana, Ahmad, McDaid, & Atun, 2011). WHO (2003:7) defines mental health as “a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community”.

- **Mental illness**

According to Gustafson, et al. (2009) as well as Janardhana and Naidu (2011) the term ‘mental illness’ stands for different types of health conditions that are associated with distress and characterised by impaired psychological functioning, alterations in thinking, mood or behaviour.

- **Rural setting**

Rural setting is regarded as a sparsely populated, area characterized by high travel costs, due to health care facilities with limited scope, limited access to specialized health care services, shortage of health care providers and lack of other essential services (Hart, Larson & Lishner, 2005; Lourenco, 2012).

- **Well-being**

Well-being is viewed as a difficult concept to define but various, authors including Keyes (2006), Ereaut and Whiting (2008) as well as Dodge, Daly, Huyton and Sanders (2012), agree that well-being includes the presence of positive emotions, absence of negative emotions and satisfaction with life that leads to fulfilment and positive functioning.

Furthermore, well-being is a state that allows people to realize their dreams, satisfy their needs and to cope with the environment as well as the challenges in it.

Within the context of this study, ‘well-being’ refers to an individual’s ability to maintain emotional, psychological, physical and social stability that result in the fulfilment and meeting of needs.

9 CHOICE AND STRUCTURE OF RESEARCH FORMAT

This section outlines the way this thesis is structured to address the problem statement. The thesis consists of five sections:

Section A: Orientation and methodological overview

This section outlines the problem statement and the motivation for the study. It gives an overview of the past and recent statistics of mental illness and also outlines the challenges associated with this illness. The methodical processes followed are also discussed.

Section B: The journal articles

Section B comprises of four research articles. The articles are produced according to different accredited journals ‘guidelines (See Annexure 23). Table 1.2 provides an outline of the articles and journals.

Table 2: Outline of Articles and intended journals

TITLE OF ARTICLE	INTENDED JOURNAL
<ul style="list-style-type: none"> Article 1: Assessing mental health services in a rural setting: service providers’ perspective 	International Journal of Mental Health
<ul style="list-style-type: none"> Article 2: Coping with the disease: experiences of families and people with mental illness in a rural setting 	International Journal of Family Studies
<ul style="list-style-type: none"> Article 3: Stakeholders’ views regarding their role as support system for people with mental illness and their families in rural South Africa 	Community Mental Health Journal

<ul style="list-style-type: none"> Article 4: A framework for a community-based program for people with mental illness and their families in a rural setting 	Southern African Journal of Social Work and Social Development
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Each journal's guidelines for authors are contained in the annexures.

Section C: Conclusions and recommendations

This section summarizes the whole study from its aims to the findings. It also highlights the conclusions and recommendations made.

Section D: Annexures

This section contains annexures such as letter from ethics committee, letters of permission, research instruments, consent forms and journal guidelines for authors.

Section E: Consolidated reference list

This section has a list of all references used in this thesis.

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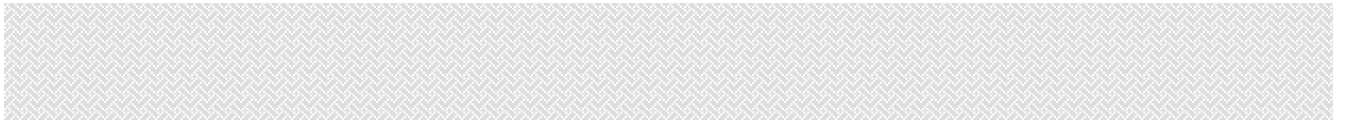
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SECTION B: THE JOURNAL ARTICLES



ARTICLE 1

ASSESSING MENTAL HEALTH SERVICES IN A RURAL SETTING: SERVICE PROVIDERS' PERSPECTIVE

ABSTRACT

Addressing the inadequate and poor provision of mental health services in rural areas is a world-wide challenge. Most people with mental illness in these areas do not have access to mental health services. Using eight attributes of good mental health service as criteria, the purpose of this study was to assess mental health services at Mashashane, a rural area in the Limpopo Province, South Africa. A survey was conducted with a purposively selected sample of health care professionals from four health establishments serving Mashashane. Data was collected using a questionnaire with closed and open-ended questions. Quantitative and qualitative data analysis were used. The results show that out of eight attributes assessed only comprehensiveness was positively perceived. This is an indication of the inadequacy of mental health services, hence their inability to improve the well-being of people with mental illness and their families. Lack of resources was identified as the major hindrance to the delivery of appropriate mental health services. The findings highlighted aspects that contributed to the development of a framework for a community-based programme to improve the well-being of people with mental illness and their families in a rural setting.

Keywords mental health services, rural setting, service providers, attributes, South Africa

1 INTRODUCTION

Research on mental health shows that mental health services are characterised by inadequacies despite the high prevalence of mental illness [1]. Studies assert that lack of funding and budget allocations are indications of the little priority given to mental health services [2-3]. Although there is no significant difference in the prevalence of mental illness between rural and urban areas, the state of rural mental health services is appalling [4].

Mental health services play a crucial role in improving the well-being of people with mental illness (PWMI) and their families [5]. To achieve this, mental health services require an integration of basic elements of mental health care systems delivered at

various levels. Within the South African context, mental health services are delivered at primary, secondary and tertiary care levels [6]. Primary care level is the most important because it is the patients' first contact with the formal health care system. Primary care increases accessibility of health services including mental health, by being positioned within the community. Besides health services, such as, maternal and child care, health promotion as well as treatment of various conditions, this level diagnoses, prevents and treats mental disorders [6-7]. This level, however, is not well capacitated to deal with all health conditions due to multiple challenges such as extensive workload and inferior infrastructure, inadequate human resources which include lack of specialists [1, 8-10]. Close links therefore, with the secondary care level is necessary.

Secondary care level provides specialized services for conditions that cannot be managed at primary care level [6]. Another important aspect of this level is the admission of people with mental challenges to general wards, either voluntarily or involuntary for a 72 hour observation. The results of this observation determine whether to release or admit the ill individual into a psychiatric institution which falls under tertiary care level [11-12]. Tertiary care level provides more specialised and advanced mental health services that include long term admission of people with chronic and unusual mental disorders that cannot be dealt with at primary and secondary care levels [6, 13]. At all these levels, social work plays a crucial role by providing preventative, psychosocial and rehabilitative services to ensure the improved well-being of PWMI and their families. To improve the well-being of PWMI and their families, social workers work collaboratively with other health care professionals [14].

Within the South African context there has been extensive research on mental health service delivery and health care professionals' perceptions about their role in mental health service [3, 11,15], but few such studies were conducted in the Limpopo Province. One study conducted in this province focused on community members' perspective of the quality of primary health care services in a rural area [16] while the present study aimed at capturing perspectives from three parties, namely, health care professionals, people with mental illness and their families, and various community stakeholders, such as, traditional health practitioners, traditional leaders, church members, police officers as well as home-based caregivers. The results of this broader study will inform a proposed community-based programme framework. This section of the study reports on the findings of the assessment of mental health services based on health care

professionals' perspectives as service providers. This assessment was based on eight attributes of good mental health service delivery as set out by the WHO [17-18] to benchmark the current services in the selected rural setting in South Africa. These attributes are comprehensiveness, accessibility, service coverage, continuity of care, quality, person-centeredness, coordination as well as accountability and effectiveness.

2 METHODS

2.1 Research design

This was a quantitative study in the form of survey conducted at two hospitals, a clinic and a mobile clinic which are four health establishments serving the area of Mashashane. Due to geographical proximity of the targeted health establishments and the perceived large number of participants, a survey methodology was used to collect data from a number of health care professionals from these establishments.

2.2 Study sample

The sample of the study was drawn from purposively selected health care professionals from the four health establishments. Although purposive sampling is non-probability sample and is often used in qualitative study, it can be used in quantitative studies because the group studied was relevant in giving information required by the current study [19]. The health care professionals included 11 nurses, 5 doctors, 6 occupational therapists, 2 psychologists and 11 social workers. The criteria for selection were based on their involvement in either the admission or discharge of PWMI and their participation in the multi-disciplinary team meetings regarding PWMI. Except for the professional nurses, the sample of other health care professionals was representative of the population in the four health establishments.

Due to the population size of nurses in the hospital and the importance of getting exact information required by the study, participation was limited to professional nurses who work in male and female wards, casualty as well as outpatient departments. These nurses were believed to have direct contact with PWMI and their families. Health care professionals in the local clinics consisted of professional nurses including those who specialize in mental health and social workers. A total of 60 questionnaires were

delivered but only 35 completed ones were returned. The return rate was 58%, which was satisfactory for analysis and reporting [20].

2.3 Measures

The respondents anonymously completed a self-administered questionnaire assessing mental health services. Demographic details provided included gender, language, qualifications as well as experience as a health care professional. Besides the demographical and organizational setting information, the questionnaires consisted of questions that sought to understand mental health service rendered in terms of its comprehensiveness, accessibility, coverage, continuity, quality, person-centeredness, coordination and accountability and effectiveness as the eight attributes of good mental health service [17-18]. The questionnaire consisted of both closed and open-ended questions. To ensure validity, a pilot study was conducted with five health care professionals - a doctor, two professional nurses and two social workers who did not participate in the main study.

2.4 Data analysis

The quantitative data analysis was done with the assistance of a statistician. Data was analysed based on the type of question or hypotheses and the analysis used appropriate statistical tests to address the data collected [21]. Prior to the analysis of the quantitative data, responses were coded by hand according to the levels of measurement. Data analysis was undertaken using the Statistical Package for Social Sciences (SPSS 22.0); this allowed for univariate and bivariate analysis. Univariate analysis was used to describe responses by individual health care professionals, while the bivariate analysis is the simultaneous analysis of two variables in order to test a relationship.

Qualitative responses were transcribed into text documents and manual analysis of the transcribed data was conducted to identify differences and similarities. Transcribed data was subjected to content analysis.

3 ETHICAL CONSIDERATION

The Human Research Ethics Committee of the North-West University granted permission for the researcher to conduct this study. Permission obtained from the Provincial Department of Health gave the researcher access to different health care

centres. Written consent was obtained from all respondents. Questionnaires were completed anonymously to protect the privacy of the respondents.

4 RESULTS

The results are presented under demographical information, organizational setting and the attributes of good mental health service.

4.1 Demographical information

The demographic characteristics and organizational setting of the participants in the study is displayed in Table 1.1.

Table 1.1: Description of demographic characteristics and organizational setting

Dimensions	Sample
Gender:	
Male	n=5 (14%)
Female	n= 30 (86%)
Language:	
English	n=2 (6%)
Sepedi,	n=19 (52%)
Tsonga	n=2 (6%)
Venda	n=4 (12%)
Sotho	n=6 (18%)
Zulu	n=2 (6%)
Occupation	
Medical doctor	n=5 (12%)
Psychologist	n=2 (6%)
Social worker	n=11 (32%)
Occupational therapist	n=6 (18%)
Nurse	n=11 (32%)
Qualification	
Higher certificate	n=6 (18%)
Diploma	n=6 (18%)
Bachelor's degree	n=22 (61%)
Postgraduate qualification	n=1 (3%)
Other	0
Work experience (number of years/ months in current occupation)	
0-6 months	n=2(6%)
6-12 months	0
1-2 years	n=5(15%)

3-5 years	n=13(38%)
6 years+	n=15(41%)
Number of years at current work place	
0-6 months	n=2(6%)
6-12 months	0
1-2 years	n=5(15%)
3-5 years	n=13(38%)
6 years+	n=15(41%)
Organizational setting	
Level of care	
Primary care level	n=9(25%)
Secondary care level	n=25(72%)
Tertiary care	n=1(3%)
Type of health establishment	
Hospital	n=25 (71%)
Clinic	n=7 (20%)
Mobile clinic	n=3 (9%)
Other:	0
Location	
Urban	n=4 (12%)
Rural	n=31(88%)

The baseline demographic information suggests that the majority of the respondents (86%) were females from diverse ethnic backgrounds. The majority of the respondents (52%) spoke Sepedi, which is the language that is predominantly spoken at Mashashane. This shows that language is not a major concern as Sepedi is the predominantly spoken language at Mashashane. The sample was dominated by nurses and social workers (each contributing 32%), with only 12% being medical doctors, 18% occupational therapists and 2% of psychologists. All the respondents had a post-matric qualification. Most respondents (41%) had more than six years work experience as health care professionals in their current setting. These results suggest that there is significant difference in the distribution of certain professions. In addition, these health care professionals are duly qualified and have reasonable experience.

With regards to organizational setting, the majority of the respondents (71%) work in hospitals, followed by clinics (20%) and then mobile clinics (9%). 88% of the respondents described their work environments as predominantly rural. Overall, there is an unequal distribution of health care professionals between the secondary and primary care levels.

4.2 Attributes of good mental health service

The responses of the health care professionals are presented according to the eight attributes used as criteria for assessment.

4.2.1 Comprehensiveness of service

A comprehensive service would be an integrated service [7, 22] that provides a range of services from preventive to rehabilitative [22-23], meet human needs holistically, collaborate inter-sectorally, and have a multidisciplinary team (MDT) of health care professionals. This team should conduct health promotion activities through assertive outreach and promote patient advocacy and practical support [24]. The respondents were asked to indicate the service they predominantly render and show aspects of comprehensiveness that they offer, such as, the frequency in addressing matters beyond client's concern, collaboration with and referral to other health care professionals. Figure 1.1 illustrates the services that are predominantly rendered by participating health care professionals.

FIGURE 1.1: SERVICES PREDOMINANTLY RENDERED

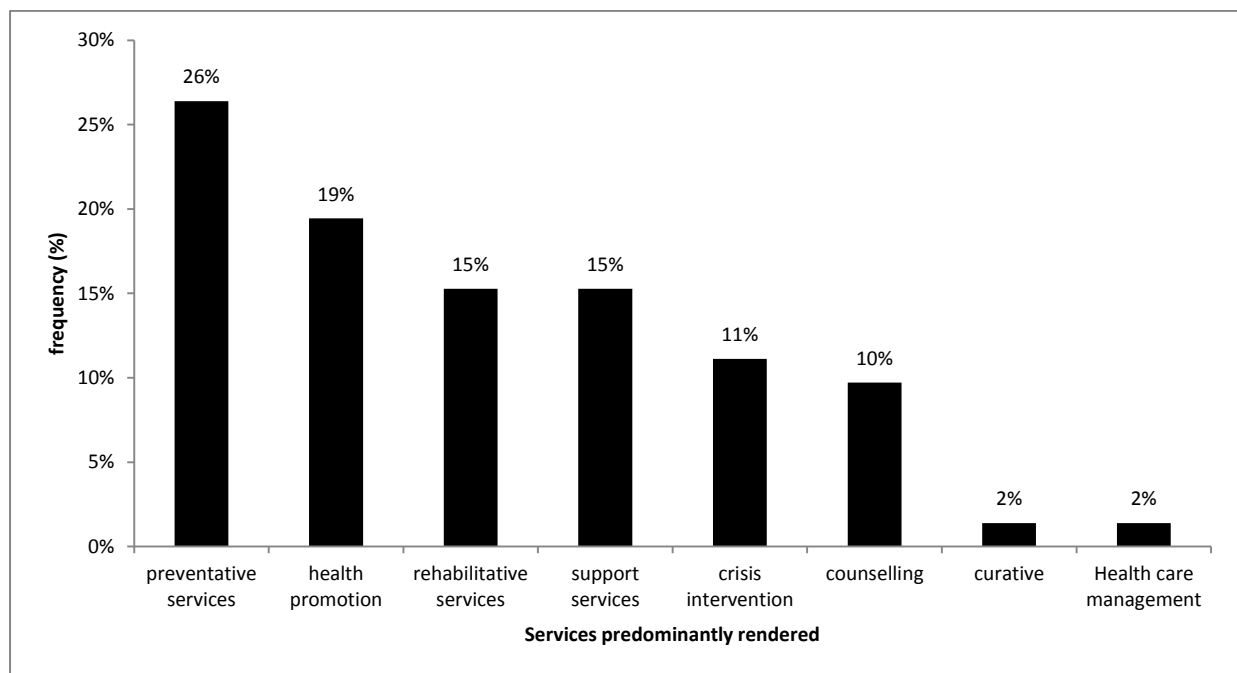
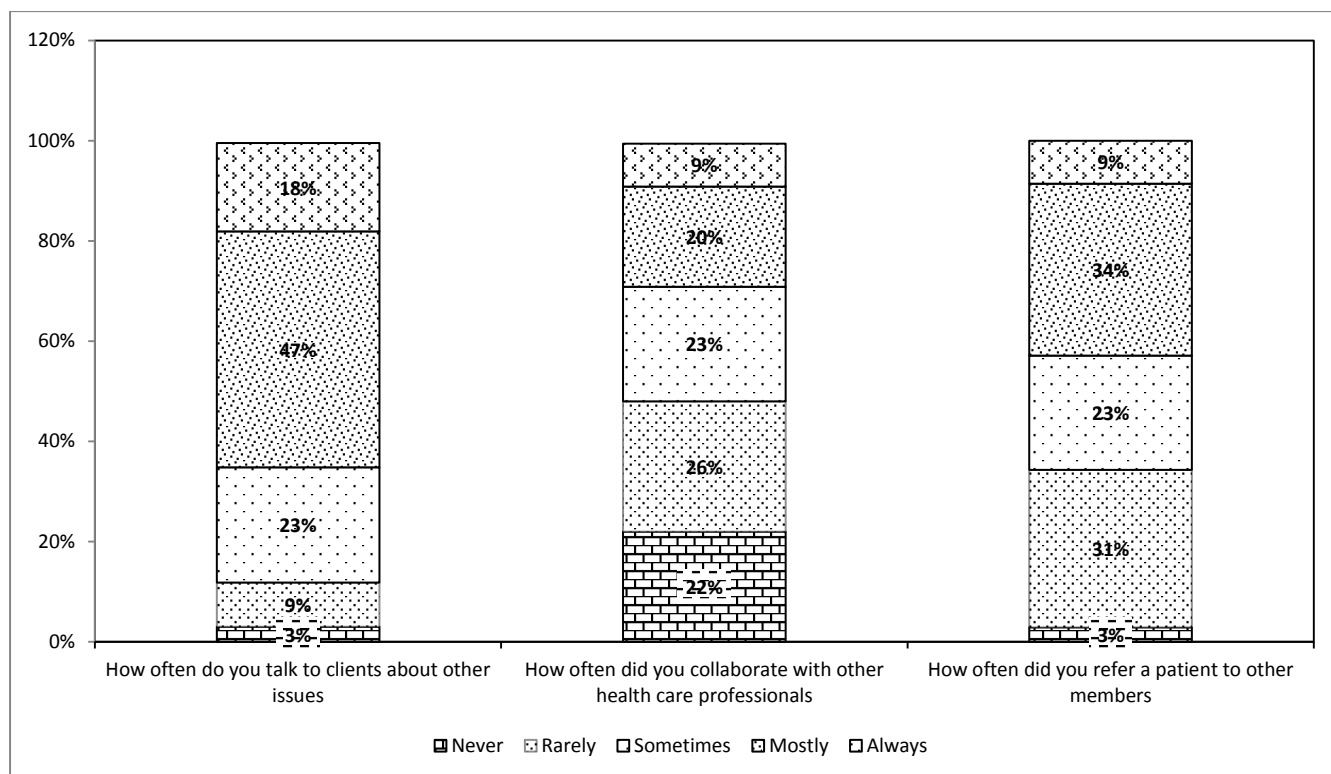


Figure 2.1 shows that 26% of the respondents render preventative services followed by 19% health promotion, 15% rehabilitative and support services, 11% crisis intervention while 10% reported rendering counselling. Only 2% render curative and health

management services therefore, preventative services were predominantly rendered by the respondents. Figure 2 illustrates the aspects of comprehensiveness.

FIGURE 1.2: ASPECTS OF COMPREHENSIVENESS



According to Figure 2, 65% (if responses *always* and *mostly* are combined) of the respondents reported that they talk to their clients about other issues or concerns besides what clients consulted for. In terms of collaboration 71% (if responses *sometimes* is added to responses *never* and *rarely*) of the respondents do not or rarely collaborate while only over 20% reported collaborating with other professionals to develop care-plans for PWMI. Almost half, 43% (combining *always* and *mostly*), of the respondents indicated that they refer clients to members of MDT.

The qualitative findings indicated that the respondents viewed the availability of a MDT as a strength. They reported that MDT renders holistic treatment to PWMI, hence, was viewed as a support system for one another. Social workers stated that they constantly do awareness campaigns and render preventative service. With regards to weaknesses, the respondents reported weak ties in MDT as those in the clinics do not attend to mental illness cases. It was also reported that, due to lack of knowledge about MDT members' roles, services such as occupational therapy are underutilized. This is reflected by the low referral rate from other MDT members. Lack of resources, especially staff shortage was reported as a major hindrance to comprehensiveness. These findings suggest that

although the availability of MDT was viewed as a strength, it was also considered a weakness due to the limited collaboration among different health care professionals. Despite the negative perception of MDT operations, it is clear that the mental health service provided at Mashashane is fairly comprehensive.

4.2.2 Accessibility of service

Accessibility of service encompasses availability of services and necessary resources to facilitate mental health service delivery and the removing of barriers that can hamper service access [25-27]. Table 1.2 summarizes the results of how the respondents rated the accessibility of services in Mashashane.

Table 1.2: Accessibility of service

Items	Yes	No			
Do you render a 24 hour service?	14 (40%)	21 (60%)			
	Never	Rarely	Sometimes	Mostly	Always
If the answer is "no", in the past three months, how often did you make arrangements for rural people with mental illness and their families to access your services during a crisis situation after hours?	5 (22%)	7 (30%)	5 (22%)	5 (22%)	1 (4%)
In the past three months, how often did your rural clients have to wait for more than an hour to consult with you?	6 (17%)	10 (29%)	6 (17%)	11 (31%)	1 (3%)
In the past three months, how often did you give rural clients information about how to prevent further problems with mental illness?	1 (3%)	11 (31%)	8 (23%)	10 (29%)	5 (14%)
In the past three months, how often did you experience language barriers when assisting a rural person who needed your service?	13 (37%)	13 (37%)	8 (23%)	1 (3%)	0 (0%)

The results show that the majority of the respondents (60%) do not render 24 hour service. A closer analysis of the data indicates that 40% of those who render 24 hour services are doctors and nurses. Although the majority do not render 24 hour service, only 22% *mostly* and 4% *always* make arrangements for clients to access these services in times of crisis. In terms of waiting period, the results indicate that almost half of the clients have to wait for more than an hour to be served while the other half gets assistance within a reasonable time. Most respondents give information on prevention of mental illness to their clients, while about a third do not. The results show that although 37% of those who *never* or *rarely* experience language barriers when interacting with

their clients, 23% of respondents *sometimes* and 3% *mostly* do experience language barrier.

From the qualitative findings, the respondents identified several strengths with the service. Clinic-based professionals regarded geographical location and the mobile clinics' visits to the various communities as an advantage for patients. Nurses and doctors regarded the visit of psychiatrists from tertiary institutions as a strength of their service as it increases accessibility. They also reported that operating 24 hours a day increased accessibility. Hospital-based professionals viewed 72 hour observation as a strong indication of accessibility. Other respondents such as social workers and occupational therapists viewed conducting outreach service as their strength. All the respondents reported availability of emergency services (EMS) and police officers, whose assistance includes bringing PWMI to the health establishments as increasing their accessibility.

With regards to weaknesses, doctors and nurses reported that lack of facilities resulted in invasion of clients' privacy. Inadequate facilities also prevent them from rendering rehabilitative service (due to the 72 hour observation rule). For occupational therapist, psychologists and social workers not rendering 24 hour service was a weakness. The geographical location of hospitals restricts their accessibility. Weaknesses associated with external doctors included infrequency of their visits, unreliable and poor communication in terms the doctors not informing health establishments about their visit as well as their refusal to attend to emergency referrals. As a result, newly-diagnosed patients do not get help quickly enough. Occupational therapists reported that lack of knowledge about their service makes them inaccessible.

These results show that a limited amount of service is rendered. Giving information and there being no language barriers were positively perceived however, lack of facilities, limited specialized services and underutilization of other services reflect inaccessibility of mental health services.

4.2.3 Service coverage

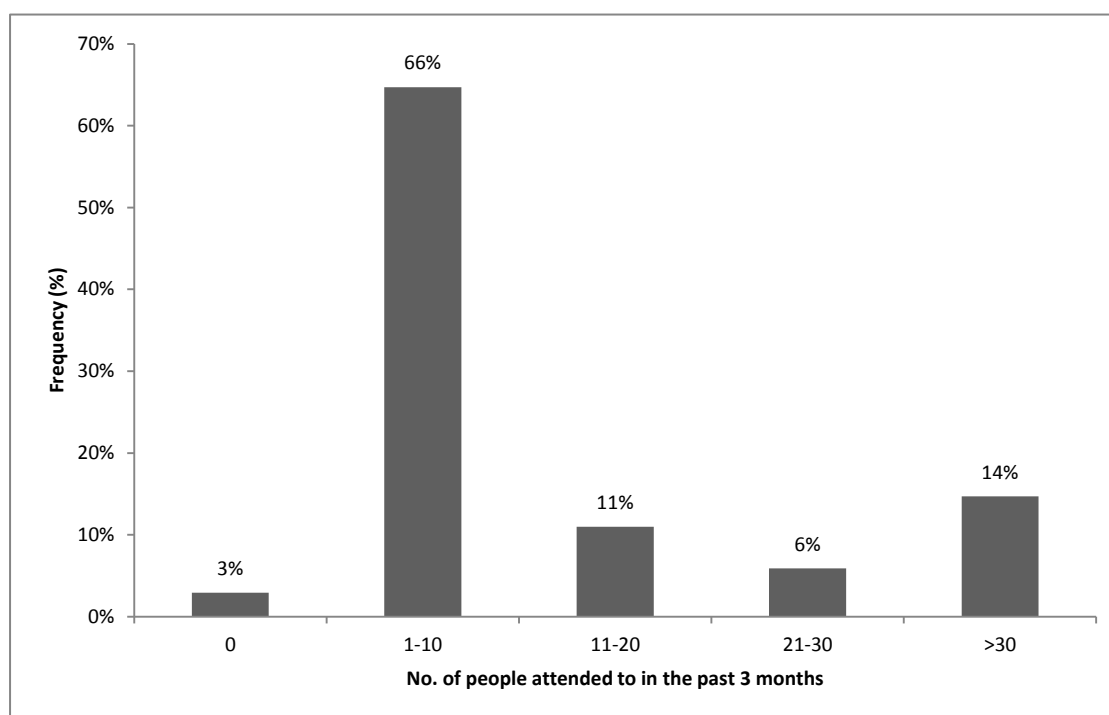
Service coverage involves conducting outreach and ensuring that a proportion of target groups benefit from the services without any barriers, such as costs [24, 28]. Table 3 summarizes on the responses of service coverage within a specified period.

Table 1.3: Aspects of service coverage

Items	Never	Rarely	Sometimes	Mostly	Always
In the past three months, how often did you conduct outreach services specifically for people with mental illness?	16 (46%)	5 (14%)	5 (14%)	3 (9%)	6 (17%)
In the past three months, how often did you assist people with mental illness from areas that do not fall under your jurisdiction?	16 (46%)	8 (23%)	6 (17%)	5 (14%)	0 (0%)

Most respondents (46%) indicated that they do not conduct outreach programmes. In terms of serving PWMI outside their jurisdiction, 46% reported *never* while only 14% *mostly* serve them. As illustrated in Figure 1.3, the respondents were requested to indicate the number of PWMI attended to in the preceding three months.

FIGURE 1.3: NUMBER OF PEOPLE ATTENDED TO



Of the total sample, the majority (66%) of the respondents attended to between 1 – 10 PWMI in a three month period, while only 14% attended to more than 30. Few mental illness cases are dealt with on monthly basis.

In the qualitative findings, social workers and occupational therapists viewed conducting outreach services, in the form of clinics and home visits, as their strength. Other strengths included working with home-based care groups and booking appointments for PWMI. With regards to weaknesses, the respondents viewed discontinued ward sessions by visiting psychiatrists and lack of resources such as transport to conduct

home-visits as factors that contributed to the reduced number of mental illness cases they attended to. The doctors indicated that the required 72-hour observation period restricted their intervention as they only stabilized these people and discharged them before they were totally stable. This also affected the intervention by other MDT members because patients are released before they can attend to them. These findings indicate that there is poor mental health service coverage.

4.2.4 Continuity of care

Continuity of care involves building a trusting relationship with clients over a long period of time, sharing and receiving client information through referral practices [29-31]. As presented in Table 1.4, the respondents were asked to rate aspects of continuity of care in the preceding three months.

Table 1.4: Aspects of continuity of care

Items	Never	Rarely	Sometimes	Mostly	Always
In the past three months, how often did you attend to the same person with mental illness?	5 (14%)	8 (23%)	14 (40%)	5 (14%)	3 (9%)
In the past three months, were there times when a client refused to be attended to by one of your colleagues and requested to only be attended by you?	21 (60%)	9 (26%)	4 (11%)	0 (0%)	1 (3%)
In the past three months, how often did you provide service to a client referred to you by other health care professionals without any background information?	14 (40%)	8 (23%)	7 (20%)	6 (17%)	0 (0%)
In the past three months, how often did you follow-up on rural people with mental illness who had missed their appointments?	14 (40%)	7 (20%)	9 (26%)	2 (6%)	3 (8%)
In the past three months, how often did you follow-up on referrals to ensure that rural people with mental illness received proper service?	9 (26%)	10 (29%)	5 (14%)	6 (17%)	5 (14%)

The results indicate that most respondents do not attend to the same person within a specified period. The majority (60%) of the respondents indicated that they had *never* experienced situations where a client refused to be attended to by any other health care professional other than the one who served him/her on previous occasion. Most respondents (40%) *never* attended to a referred client without information, prior notice or a referral letter while only 8% mostly do. The results show that most respondents do not follow-up on clients who missed appointments and those they referred.

Although the quantitative findings were dominated by negative responses, in the qualitative findings most professionals indicated that they gave necessary information to PWMI. The occupational therapists and social workers indicated that they conducted home visits as a way to maintain the relationship and to get to know the clients holistically. With regards to weaknesses, most respondents identified poor communication that resulted in clients' referral without adequate information. They also admitted that they provide little or no support to both PWMI and their families. These findings therefore, indicate that there is poor continuity of care.

4.2.5 The quality of service

Table 1.5 presents the results of four elements of quality. Quality of services is measured by training, performance evaluation, technical support and benchmark as determinants that increase the chances to achieve the desired health outcomes [28, 32].

Table 1.5: Elements of quality of service

Items	Never	Rarely	Sometimes	Mostly	Always
In the past 12 months, how often did you attend training on mental illness and other mental health related issues?	15 (43%)	11 (31%)	6 (17%)	3 (9%)	0 (0%)
In the past 12 months, how often was your performance evaluated?	10 (29%)	4 (11%)	8 (23%)	11 (31%)	2 (6%)
In the past six months, how often did you receive technical support or supervision with regard to the service delivered to people with mental illness and their families?	14 (40%)	11 (31%)	6 (17%)	3 (9%)	1 (3%)
In the past 12 months, how often did you benchmark yourself according to other institutions delivering a similar service?	19 (54%)	10 (29%)	4 (11%)	2 (6%)	0 (0%)

Of the total sample, 43% *never* attended training on mental illness and mental health related issues in the past twelve months while only 9% *mostly* attended. Most health care professionals' performance have been evaluated. In terms of technical support, 40% of the respondents *never* received any technical support or supervision. The majority (54%) indicated that they have *never* benchmarked with other institutions delivering a similar service.

Results from the qualitative findings show that doctors and nurses identified the availability of evidence-based medication as a strength. All the respondents viewed multidisciplinary intervention as a strength. Hospital-based nurses reported that the

weekly visits by psychiatrists in the outpatient department enhanced the quality of their service. In terms of weaknesses, most respondents identified lack of knowledge about mental illness and mental health related issues, lack of relevant resources, lack of supervision and lack of in-service training as well as lack of monitoring and evaluation. Nurses reported that only nurses specializing in psychiatry receive training. They also identified lack of follow-up as a contributing factor to non-compliance and relapse of PWMI. The negative aspects of quality of service outweighed the positive aspects. It can be concluded that the respondents perceived the quality of service rendered as generally poor.

4.2.6 Person-centeredness of the service

Person-centeredness involves participation of PWMI and their families in decision-making regarding service design and treatment choices [33, 34]. Table 1.6 summarizes the results.

Table 1.6: Assessing person-centeredness of service

Items	Never	Rarely	Sometimes	Mostly	Always
In the past six months, how often did you involve rural people with mental illness and/or their families in decision-making with regards to their treatment choices?	5 (14%)	10 (29%)	6 (17%)	10 (29%)	4 (11%)
In the past six months, how often did you involve rural people with mental illness and/or their families when making plans to change some aspects of your service?	6 (17%)	11 (31%)	7 (20%)	8 (23%)	3 (9%)

The results show that there is no significant difference between the respondents that do not and those that involve PWMI and their families in decision-making regarding treatment choices. In terms of involvement when making plans to change aspects of the service, 78% (if responses *never*, *rarely* and *sometimes* are combined) of respondents indicated that they do not involve their clients. The qualitative findings suggest that some respondents involve their clients in decisions regarding their treatment or when planning to change some aspects of their service although the quantitative data showed little involvement of PWMI and their families. This could mean that some health care professionals value the input of their patients as important in improving their well-being.

With regards to weaknesses, the respondents reported that giving patients an opportunity to decide on what they want delays progress and that is why they end up deciding for them. They also indicated that lack of clients' knowledge about what

treatment is good for them influences the respondents' decision to make choices for clients. Other respondents reported failure on their side to treat PWMI as any other human being. There is contradiction between the quantitative and qualitative findings with regards to involvement of clients in decision-making process. It can however be concluded that involving patients in decision-making is not common, therefore there is poor person-centeredness in the services.

4.2.7 Coordination of care

Care coordination involves collaboration between health care professionals and relevant stakeholders with the aim of providing better mental health service for people with mental illness and their families (24, 35). Table 1.7 summarizes the results on aspects of coordination, such as, involving external stakeholders in mental health services, referring clients to these stakeholders and community programs.

Table 1.7: Assessing coordination of service

Items	Never	Rarely	Sometimes	Mostly	Always
In the past six months, how often did you encourage your rural clients to attend programs in the community that could help them cope with mental illness?	11 (31%)	8 (23%)	9 (26%)	3 (9%)	4 (11%)
In the past six months, how often did you engage voluntary groups in the community to provide support to rural people with mental illness and their families?	10 (29%)	11 (31%)	10 (29%)	4 (11%)	0 (0%)
In the past six months, how often did you establish networks with other mental health stakeholders such as traditional health practitioners, traditional leaders, home-based care groups, church members, as well as police officers, in order to improve referrals, strengthen linkages and expand resources for rural clients?	12 (34%)	7 (20%)	11 (31%)	4 (11%)	1 (3%)
In the past six months, how often did you refer rural clients to or receive referrals from the above stakeholders?	8 (23%)	6 (17%)	14 (40%)	6 (17%)	1 (3%)

According to Table 1.7, 31% of the respondents *never* encourage their rural clients to attend programs in the community while only 11% *always* do. Most respondents, 60% (if *never* and *rarely* are combined) indicated that they do not engage with voluntary groups in the community or establish networks with external stakeholders. The results also show that most respondents do not refer to or receive referrals from external stakeholders.

On identified strengths, the respondents reported involving mostly home-based care groups (HBC) as partners in their services. Reasons for not engaging external stakeholders included the stakeholders' inability to uphold confidentiality principle, lack of relevant resources and unacceptable treatment practices especially those of traditional healers. These findings suggest poor coordination of care resulting from limited interaction between health care professionals and external stakeholders.

4.2.8 Accountability and effectiveness

This attribute focuses on the management of mental health services by making sure standards are upheld and that the organization's goals and objectives are achieved in the preceding 12 months. As presented in Table 1.8, the respondents were requested to indicate the level at which they agree with a number of statements regarding aspects of accountability and effectiveness.

Table 1.8: Aspects of accountability and effectiveness

Items	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agrees
The service you render is audited, in order to identify the opportunities and priorities for improving rural care.	4 (11%)	8 (23%)	7 (21%)	12 (34%)	4 (11%)
Management allocates resources relevant to the delivery of service to rural people with mental illness.	8 (23%)	15 (43%)	6 (17%)	6 (17%)	0 (0%)
Management places priority on the training needs regarding services to rural people with mental illness and/ or their families.	10 (29%)	13 (37%)	5 (14%)	6 (17%)	1 (3%)
Management places a priority on hiring and retaining skilled staff to deliver mental health service to the rural areas.	5 (14%)	13 (37%)	3 (9%)	12 (34%)	2 (6%)
Communication channels are used to engage staff members on a regular basis to discuss changes regarding service delivery in rural areas.	6 (17%)	12 (34%)	4 (12%)	13 (37%)	0 (0%)
There are clear standards, procedures and protocols that guide mental health service delivery in rural areas.	7 (20%)	7 (20%)	7 (20%)	13 (37%)	1 (3%)

The results show variations on auditing of services with most (34%) *agreeing* on auditing of their service. In terms of resource allocation, 23% *strongly disagreed*, 43% *disagreed*, 17% *neither agreed nor disagreed* and only 17% *agreed*. Most respondents indicated that management neither allocates resources relevant to mental health service delivery,

nor places priority on training needs as well as hiring and retaining skilled staff. Of the total sample, 17% *strongly disagreed*, 34% *disagreed*, 12% neither *agreed* nor *disagreed* and 37% *mostly agreed* about the use of communication channels to engage staff members. There was no significant difference between those who *disagree* or *agree* about the availability of clear standards, protocols and procedures.

On identified strengths, nursing staff reported monthly audits of their service. Some respondents reported that standards are followed. The weaknesses identified in this regard outweighed the strengths as all the respondents reported poor allocation of resources, no focus on training needs, poor monitoring and evaluation. Most respondents reported that mental health services are not well established and are poorly managed. Other respondents identified poor procedures for dealing with complaints. They indicated that they are not consulted on decisions that may affect their service provision neither do they get any support from management. These results indicate poor management of mental health service and this can have detrimental effects on accountability and effectiveness of the services rendered.

5 DISCUSSION

The purpose of the study was to assess mental health services in rural setting based on the perceptions of health care professionals as service providers. This assessment focused on comprehensiveness, accessibility, service coverage, continuity of care, quality, person-centeredness, coordination, accountability and effectiveness as attributes of good mental health service. Overall, the findings suggest that mental health services in rural settings are inadequate.

Comprehensiveness of service

The health care professionals had positive perceptions of comprehensiveness. The findings suggest that a variety of services are rendered. This is important because for a service to be declared as comprehensive, preventative, rehabilitative as well as support services should be rendered. This is a crucial finding as it shows that rural mental health services are on par with mental health services from other areas in rendering of a variety of services [9, 18, 22-23, 25, 30]. It was revealed that most health care professionals talk to their clients about issues that are beyond what they have consulted for. This is an indication of the health care professionals' genuine concern about the general well-being

of their clients. Furthermore, this can result in building trust and improved relationship. In line with previous studies [24, 30], the findings suggest the availability of MDT. However, their availability is not beneficial to the PWMI and their families as well as other professionals because it was revealed that the team does not attend to mental illness cases in clinics. This demonstrates disintegration of mental health MDT and the lack of a holistic approach in dealing with mental illness and improving clients' general well-being [36]. The findings suggest weak ties between members of MDT as is reflected by the poor referral practices and lack of knowledge about other MDT members' roles, resulting in underutilization. This may be attributed to the significant difference in the distribution of health care professionals between the clinics and the hospitals [30]. This study argues that various health care professionals can only be considered as MDT when they work jointly to meet the complex needs of PWMI and their families.

Accessibility of service

The majority of the respondents (60%) do not render 24 hour service. A closer analysis of data shows 40% of the respondents who render 24 hour services are nurses and medical doctors. Despite the unavailability of 24 hour services, the findings suggest that there are no other arrangements for clients to access these services during crisis situations after hours. This can be attributed to the fact that health care professionals, such as, psychologists and occupational therapists are considered 'scarce skills' and hence they do not render 24-hour service [9]. Another explanation could be that more value is placed on medical needs [36, 37] rather than on the psychosocial needs of PWMI [38]

The study found that clinics are more accessible than hospitals in terms of geographical location. This compliments the South African governments' commitment to integrate mental health services with PHC in order to increase accessibility [7]. Whilst, the accessibility of PHC is commendable, the current study revealed inadequate services and unavailability of a full complement of health care professionals as well as mental health facilities as characteristics of PHC [39]. As a result, clients are often required to go to hospitals for more specialized mental health services. A consultation in hospitals does not guarantee that clients will receive specialized services as it was revealed that hospitals rely on visiting psychiatrists who are viewed as unreliable because of their infrequent visits. The uncertainties about getting required services and the travel costs

associated with the geographical location of the hospital might discourage people from consulting and result in underutilization of mental health services [2, 40]. About 40% of the respondents reported that their clients wait for more than an hour to consult. This concern is not unfounded as previous studies [40] identified long queues and waiting period as barriers to access to service.

It was reported that most respondents give their rural clients information about how to prevent further problems with mental illness. This findings is inconsistent with previous studies [37, 41] that found that clients lack important information they need to deal with mental health challenges. The findings suggest that most respondents do not experience language barriers when dealing with rural clients. This is in line with the demographic data of the current study that indicate that the majority of the respondents speak the language that is predominantly spoken at Mashashane. This, however, raises a question of how mental health system plans to prevent occurrences of language barriers to accommodate growing changes of health care professionals and client population [42].

Service coverage

The current study found that most respondents do not conduct outreach services. This is attributed to lack of resources such as transport [39]. It was revealed that most respondents do not assist PWMI from areas outside their jurisdiction. While 66% of the respondents reported attending to less than 10 PWMI in three months, only 14% reported attending to more than 30. Additionally, the discontinued psychiatric ward sessions contributes to low numbers of PWMI attended to as it denies other health care professionals an opportunity to attend to PWMI while they are still admitted. This can be an indication of underutilization of mental health services or little priority placed on mental illness cases.

Continuity of care

The findings on continuity of care show weak relationship between clients and health care professionals. It was reported that the respondents do not attend to the same client over a period of time. This is consistent with previous studies on continuity of care. A study to identify barriers that influence continuity of care by health and social care professionals identified inadequate staffing levels, high caseloads and administrative

duties that could limit time spent with patients as barriers for relational, personal, and longitudinal continuity [43].

The majority of the respondents (60%) reported that there was never a time when a client refused to be attended to by other colleagues. This coincides with the notion that changes in patient and population demographics have an impact on relational continuity. In addition, increased movement of staff and patients as well as the growing size and nature of health care results in inconsistencies which make it difficult to build and maintain relationships [42]. The findings show that, on average, health care professionals do not provide service to a client referred by other health care professionals without background information. This implies that the health care professionals in this study acknowledge the impediments that can be caused by poor referrals [27]. On the other hand, this could imply that referring clients without background information is common practice among health care professionals. The current study found that the respondents do not follow-up on PWMI who have missed their appointments. Additionally, they do not follow-up on referrals to ensure that rural PWMI receive proper service. This can be attributed to lack of resources, shortage of staff and workload [39].

Quality of service

The health care professionals' perception of quality of service was generally negative. The findings suggest that most respondents do not receive mental health care training nor technical support despite service audits to identify professional developmental needs. As a result, the respondents identified lack of knowledge of mental illness and mental health related issues as weaknesses. It was reported that only nurses dedicated to psychiatry receive training. Given that nurses are the first points of contact for patients [44] and that rural areas often lack specialists [1, 39], prioritizing training for only nurses specializing in psychiatric management is a disadvantage as these nurses might not always be available. Lack of training has long-term consequences not only in terms of quality of services but increased mental health care expenditure caused by poor management of mental illness that results in its persistence. The absence of technical support can be attributed to the fact that there are few experts who can provide this support but they are overwhelmed by other responsibilities [9]. In this study, more than 50% of the respondents had not conducted a benchmark exercise in the past 12 months. This is incongruent with the notion that benchmarking is a strategy that helps health care

professionals to compare their clinical performances to those of their peers in order to improve their service [33].

Person-centeredness of the service

The findings show that PWMI and/ or their families are not involved in decision-making about treatment and changes regarding aspects of the services. This non-involvement denies these people an opportunity to exercise their constitutional right of choice and disregards the notion of self-determination. This could result in poor adherence as well as persistent psychotic symptoms [35]. The exclusion of PWMI and their families on decisions regarding treatment choices is an indication of the health care professionals' poor understanding of clients' needs.

Coordination of care

Contrary to a previous study [45] that found that community-based programme improves social functioning and lessens the risks of relapse, the current study revealed that health care professionals do not encourage their clients to attend programs in the community. This may be attributed to the fact that community-based programmes in rural areas either do not exist or are underdeveloped [11]. It was reported that health care professionals rarely engage voluntary groups in the community to provide support to rural PWMI and their families. This happens despite the availability of HBC, voluntary groups that are recognized as an extension of the Department of Health that provide relief to the health care system and support to sick people within their communities [46-47]. This raises the question of how government can maximize the use of these groups for the benefit of health care professionals as well the PWMI and their families.

The findings suggest that the respondents neither establish networks with other stakeholders nor refer clients to/ or receive referrals from other stakeholders. To justify their actions, the respondents reported that other stakeholders do not uphold the principle of confidentiality. In addition, the respondents do not approve stakeholders', especially traditional health practitioners' treatment practices. This finding is not unexpected, particularly in South Africa, as the diverse nature of culture and religions make it difficult to facilitate referrals to other stakeholders [48]. This disregards the current South African mental health policy which emphasize the importance of various stakeholders' involvement in mental health care.

Accountability and effectiveness.

The findings show a number of loopholes with regard to accountability and effectiveness of mental health services. It was reported that little priority is given to resource allocation, hiring and retaining of skilled staff. This is consistent with previous studies [9, 12, 39]. The respondents identified poorly-established and managed mental health services, poor monitoring and evaluation, poor procedures for dealing with complaints as well as poor support from management as some aspects related to accountability and effectiveness that have negative impact on mental health service delivery. This is in line with the notion that the persistence of bureaucratic approach to management strains the relationship between the authorities and staff members [49-50].

The study demonstrates the interdependence of the attributes in that lack of a certain aspect affect the existence of others. The inadequacies of mental health services indicate a need to explore evidence-based and innovative interventions that can be adopted to improve the well-being of PWMI and their families. Health care professionals should consider adopting cost-effective ways of rendering mental health services which brings the desired outcomes. This requires creativity and collaboration with external stakeholders who can bring needed expertise to improve mental health service delivery. The findings helped to highlight the important aspects that should be considered for a community-based programme framework.

6 LIMITATIONS

This study had several limitations. The sample was relatively small due to the very specific inclusion criteria. The low number of professional nurses participating in the study was of concern. The study only focused on mental health services for Mashashane area, therefore, although the study can be replicated in a similar context the findings do not represent all the rural areas in South Africa. The anonymous completion of the questionnaire did not provide an opportunity to probe individual views and some qualitative responses were inconsistent with the quantitative responses. The questionnaire was self-administered, hence some respondents in the same work station might have influenced each other's responses. Future research to assess the clients' perceptions of the attributes of good mental health services in rural settings is recommended.

7 CONCLUSION

In conclusion, the study highlights elements that impact on the effectiveness of mental health services. The majority of attributes were negatively perceived by health care professionals. Lack of resources and training of health care professionals remain a challenge. This, however, should not be seen as an obstacle but an opportunity for collaboration and care coordination with external stakeholders in order to improve mental health service delivery. It can then be concluded that, due to lack of training, health care professionals are not well equipped to deal with people suffering from mental illness. The findings of the study highlight important aspects that should be considered for a community-based programme framework.

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ARTICLE 2

COPING WITH THE DISEASE: THE EXPERIENCES OF FAMILIES AND PEOPLE WITH MENTAL ILLNESS IN A RURAL SETTING

ABSTRACT

Living with mental illness is challenging for both the people with mental illness and their families. This study examined the coping strategies adopted by people with mental illness and their families at Mashashane, in a rural setting in Limpopo Province in South Africa. Data was collected through semi-structured interviews conducted with purposively sampled people with mental illness and their families. The case study research design adopted in the study allowed for a context-specific study and the gaining of information about the people's experience of mental illness. Grounded theory was adopted to help with the development of a programme framework. Thematic analysis was used. Findings revealed that lack of understanding of mental illness was prevalent. Participants reported social, financial, emotional and physical health challenges posed by mental illness. Findings showed that participants adopt adaptive and mal-adaptive coping strategies. There is a need to educate people and create awareness about mental illness in order to help people cope better in future.

1 INTRODUCTION

Over the past decades, developing countries have introduced deinstitutionalization, a process that involves releasing people with mental illness (PWMI) from psychiatric institutions to receive care in their communities (Anderson, Fuhrer, Schmitz, & Malla, 2013). Following the democratization in 1994, South African government embarked on transformation of health services; these involved changes in mental health policies and legislation. That emphasis on the integration of mental health care with primary health care (PHC) to increase accessibility. The integration resulted in deinstitutionalization of people with mental illness. This meant that families have to take over the primary caregiving role without an understanding of the condition and the skills to deal with it, resulting in tremendous impact on both the family and the ill individual (Petersen, 2002; Lund, Kleintjies, Kakuma, Flisher, & MHaPP Programme Consortium, 2010).

Negative social aspects of mental illness such as stigma and discrimination have detrimental effects people's well-being (Botha, Koen, Oosthuizen, Joska, & Hering,

2008; Corrigan, & Shapiro, 2010). Studies show that PWMI and caregivers are often unable to participate in the labour markets making them susceptible to financial problems (Lund, Myer, Stein, Williams, & Flisher, 2013). Numerous challenges associated with mental illness increase the possibility of those affected to experience emotional and physical health problems (Jones 2004; Prince, Patel, Saxena, Maj, Maselko, Phillips, & Rahman, 2007). The spillover effect of mental illness is that, those caregiving family members undergo a lot of stress which in turn affect their personal health as well as their mental stability (Robinson, Rodgers, & Butterworth, 2008). As a result of experiencing numerous challenges, PWMI and their families may find it difficult to cope.

Globally, there is a copious amount of literature that focuses on how people cope with mental illness. Most prior studies examined how their families cope with caring for a person with mental illness (Knudson, & Coyle, 2002; Kartalova-O'Doherty, & Doherty, 2008; Maskill, Crowe, Luty, & Joyce, 2010) while others explored coping with stigma (Dalky, 2012, Karnieli-Miller, Perlick, Nelson, Mattias, Corrigan, & Roe, 2013). Although there have been a number of studies on mental illness within the South African context, they focused on parents or caregivers' experiences in a rural area (Mavundla, Toth, & Mphelane, 2009) and family resilience factors (Jonker, & Greef, 2009) in semi-rural areas. A study involving both the caregiver and a mental health service users was conducted in Cape Town, which is an urban area (Sibeko, Milligan, Temmingh, Lund, Stein, & Mall, 2016). The present study adopts a more nuanced approach by studying lived experiences and coping strategies of PWMI along with their families in the rural setting of Limpopo Province. This study forms part of a larger project which aims at developing a community-based programme to improve the well-being of PWMI and their families in a rural setting.

2 COPING WITH MENTAL ILLNESS

“Why do we need to cope?” Ebersohn and Eloff (2006) pose this question in an attempt to establish the importance of coping. They assume that people cope in order to be happy. Coping is defined as a sensible behavioural, cognitive, emotional and social processes adopted by an individual to reduce the effects triggered by demanding person-environment interactions that threaten to erode well-being of PWMI and their families (Ntoumanis, Edmunds, & Duda, 2009).

Central to coping is the assumption that the environment provides risks and stressors that challenge the process of achieving happiness (Ebersohn, & Eloff, 2006). Studies in coping suggest that stress, which is an element of mental illness, is a result of an interaction between the individual and the environment (Mitrousi, Travlos, Koukia, & Zyga, 2013). This coincides with the ecosystems perspective and resilience theory as both suggest that the problems that individuals encounter are a result of interactions with the physical and social environment. These theories are based on the notion that an imbalance within the system, destabilizes other subsystems (Zastrow, 2013; Wright, Masten, & Narayan, 2013).

Ecosystems perspective views coping patterns of individuals by focusing on optimizing different system levels namely, micro, mezzo and macro, in order to facilitate attainment of needs (Meyer, Moore, & Viljoen, 2008; Zastrow, 2013). A family is viewed as one of the crucial social systems that contribute to individuals' functioning, therefore mental illness does not impact on the ill individual only but the family as a whole. Resilience theory focuses on the family's ability to adapt to the presence of mental illness which had disrupted their functioning (Walsh, 2012; Wright, et al., 2013). Although the environment provides risks and stressors, it also provides the necessary resources that help in nurturing and reinforcing resilience (Wright, et al., 2013). In addition to environmental resources, people are believed to have innate qualities that can be manipulated to facilitate the coping and adaptation process (Ebersohn, & Eloff, 2006); these qualities influence the individuals' choice of strategies to adopt in order to cope.

2.1 Coping strategies

Studies on coping assert that there is no single, easy or correct way to cope with the demands and challenges of mental illness (Ntoumanis, et al., 2009). Each individual develops his/her ways of coping and adopts strategies that seem to work best (Knudson, & Coyle, 2002; Ntoumanis et al. 2009). Tenenbaum, Edmonds and Eccles (2008) and Ntoumanis, et al (2009) identified problem-focused and emotion-focused as significant coping strategies. Problem-focused strategy involves activities that are aimed at addressing disabling demands and other adversities of life. Emotion-focused strategy is the strategy that controls the unpleasant emotions that arise as a result of a demanding encounter.

Linked with these strategies are various coping styles which influence individual behaviours. Boschi, Adams, Bromet, Lavelle, Everett and Galambos (2000) identify *active behavioural*, *active cognitive* and *avoidance* as styles from which coping strategies emanate. The active behavioural style relates to external behaviours whereas the active cognitive style involves internal processes. Both styles are closely linked to the problem-focused strategy as both involve behaviours such as goal-setting, problem-solving, positive reassessment, support-seeking, and planning as well as priority management. On the other hand, the avoidance style is associated with an emotion-focused strategy. This includes behaviours such as avoidance and detachment, isolation and distancing as well as wishful thinking (Boschi, et al., 2000; Tenenbaum, et al., 2008; Ntoumanis, et al., 2009). The avoidance style is believed to result in disruptive behaviour such as substance abuse or getting involved in criminal activities (Boschi, et al., 2000).

Given that PWMI lack insight or knowledge about mental illness and treatment regimen, Saunders (2003) suggests that acquiring information to increase knowledge of mental illness, work as a coping strategy. Several studies assert that a range of coping strategies employed by affected people depend on attributes such as available resources as well as the clinical symptoms of the ill individual (Knudson, & Coyle, 2002), experience whether bad or good (Karnieli-Miller, et al., 2013), age, duration of the illness and place of residence of the ill individual (Kartalova-O'Doherty, & Doherty, 2008).

It is argued that coping strategies with their associated styles are adopted by most people experiencing life adversities such as mental illness. However, without the necessary resources in the form of support system, these may not be fully effective.

2.2 Support systems

The availability and accessibility of resources play a crucial role in facilitating coping with challenges. Resources are considered to be a form of support, which is regarded as an important aspect in coping with life adversities for the affected people (Knudson, & Coyle, 2002). Support for PWMI and their families takes many forms; formal and informal support are identified as two kinds of support. Formal support is the support provided by mental health services. Mental health services are regarded as a necessary resource that plays a crucial role in helping PWMI and their families to cope with the illness. For instance, due to complexity of mental illness, PWMI and their families need support,

medical care and information about the condition as well as advice on how to manage the symptoms (Schmidt, & Monaghan, 2012).

Informal support is the social and emotional support provided by friends, relatives and members of the community who may be experiencing the same challenges or have an interest in helping to improve the well-being through fostering self-esteem, positive emotion and reducing isolation by encouraging social integration. This includes participation in support or self-help groups (Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011; Schmidt, & Monaghan, 2012). Support or self-help groups are established based on the notion that interaction of people experiencing similar challenges have the potential to give individuals sense of empowerment, enhance coping skills and increase self-efficacy (Pistrang, Barker, & Humphreys, 2008; Schmidt, & Monaghan, 2012). Powell and Perron (2010) suggest that the empowering nature of these groups provides an opportunity to undertake new roles that help members restore their sense of purpose, provides motivation and encouragement to seek professional help and adhere to treatment.

In summary, literature shows that PWMI and their families use different strategies and styles to cope with mental illness. The adoption of any of these can be beneficial or result in more stressors to either the family or the ill individual.

3 METHODS

3.1 Research design

This study made use of qualitative paradigm as it afforded the researcher with an opportunity to explore and gain better understanding of the experiences of PWMI and their family members. It also allowed participants to express their views regarding their needs and coping strategies. The study was descriptive in nature as it provided information that is vital for the development of a programme framework. A case study design was used to understand the participants' experiences and meaning attached to mental illness and coping strategies of PWMI and their families (Fouché, & Schurink, 2011).

3.2 Study setting and sample

The target population for this study consisted of PWMI and their families residing at various villages of Mashashane, a rural setting situated in Aganang Municipality under Capricorn district which is among the five districts in Limpopo Province. Mashashane is a region formed by 22 villages. The sample was purposively drawn from this population based on the assumption that PWMI and family members have the necessary knowledge and experience of mental illness to add meaningful data to the study (Bless, Higson-Smith, & Kagee, 2006).

The sample was selected based on predetermined inclusion criteria. PWMI had to be between the ages 18 - 60 years, been formally diagnosed with mental illness and previously hospitalized due to mental illness. The participants should not have relapsed in the past six months. To ensure suitability for participation, mental capacity assessment was conducted during recruitment process and prior the interview. Family members were selected based on the fact that they have been staying with a person with mental illness for a minimum period of six months in the same household and were involved in the day to day care of this person. Recruitment of was done with the assistance of home-based care givers who provided a list of potential participants. All participants were also recruited from their homes.

3.3 Data collection

Data was gathered through semi-structured interviews. The semi-structured interviews were conducted with individual participants with the aim of understanding participant's lived experiences of mental illness. In addition, interviews allowed for comparative analysis of PWMI and their family members' experiences. An interview guide containing open-ended questions was developed based on literature reviewed. The use of open-ended questions during interviews allowed the participants to narrate their stories and express their experiences and feelings with regards to mental illness (Creswell, 2014).

This guide was validated by a pilot study that involved a participant with mental illness and a caregiving family member. These participants were excluded from the main study. All interviews were conducted in Sepedi. These interviews were recorded for analysis purposes. Participating in a study of this nature can be emotionally charging, therefore efforts were made to minimise this by setting a comfortable atmosphere. All participants

were interviewed in the comfort of their homes. PWMI were interviewed separately from their family members. Saturation was reached when no new information emerged.

3.4 Data analysis

A qualitative analytical approach using thematic analysis was adopted. The audio-taped interviews were transcribed verbatim in Sepedi and some in English. Transcripts were subjected to thematic analysis. These transcripts were read, reviewed and reread for specific patterns that emerged. Babbie (2010) as well as Creswell and Clark (2007) advise the researcher to categorize and code data, and assign labels to each unit because data collection in qualitative method comprise of text. This study applied the inductive process of research analysis in order to identify themes. Data was coded and categorised with the aim of uncovering themes.

4 ETHICAL CONSIDERATION

Human Research Ethics Committee of the North-West University granted permission to conduct this study. Participants gave written informed consent. To ensure anonymity pseudonyms were used for each participant. As stipulated in the consent form, participants were also informed that they would not be paid for participating in the study.

5 FINDINGS

The findings are presented according to the characteristics of the sample and themes that emerged from the data.

5.1 Characteristics of sample

Table 2.1 summarizes the participants' characteristics. The sample consisted of 10 PWMI and 10 caregiving family members. Eight participants with mental illness were males and two were females. Their ages ranged between 26 -54 years. The majority of participants had secondary education. Only one participant was married. All participants were diagnosed with mental illness before the age of 35 years. Participating family members were females between the ages of 21 to over 60 years. They mostly had primary education. Four participants were never married, four were married and two were widowed.

The majority of participants (9) from each group were recipients of some form of social assistance grants. Participants who do not receive any grants depended on other family members for financial support. Only two of the PWMI had worked before and after being diagnosed with mental illness but had to stop working due to constant relapse.

Five PWMI had dependent children while only two family members had dependants between the ages of 2 to 21 years. Participating family members consisted of six mothers, a sister, a wife/spouse, sister-in-law and an aunt.

Table 2.1: Participants' demographic characteristics.

INFORMATION	PWMI	FAMILY MEMBERS
GENDER:		
Male	08	
Female	02	10
AGE DISTRIBUTION:		
18 – 26 years		1
27 – 35 years	1	1
36 – 44 years	1	1
45 – 52 years	1	1
53 – 60	3	
60+ years	4	6
AGE DURING FIRST DIAGNOSIS:		
<18 – 26 years		
27 – 35 years		
36 – 44 years	7	
45 – 52 years	3	
53 - 60 years		
EDUCATION LEVEL:		
Never went to school		2
Primary education	2	3
Secondary education	6	5
Tertiary education		
Other	2 (ABET & post matric training)	

MARITAL STATUS:		
Never married		4
Married	9	4
Divorced	1	
Widowed		
Other		2
NUMBER OF DEPENDANTS:		
None		1
1 – 2	4	2
3 – 4	4	5
5 – 6	1	1
7 – 8	1	1
9 +		
AGE OF DEPENDANTS:		
0 – 1 year		
2 – 5 years	2	
6 – 10 years	3	1
11 – 15 years	3	1
16 – 20 years		
21 years +	2	8
RELATIONSHIP WITH PWMI/ CARER:		
Son-Mother	4	4
Mother-Daughter	2	2
Brother-sister	1	1
Nephew/Niece-aunt	1	1
Spouse-Spouse	1	1
Other (Sister/ brother-in-law, etc.)	1	1
SOURCES OF INCOME:		
Employed		
Social grants	9	9
Other (Spouse, other family members, etc.)	1	1

As the findings in Table 2.1 show, the majority of PWMI are men whereas caregivers are mainly women. These findings therefore suggest that women, especially the aged, play a significant role in caregiving.

5.2 Overview of themes

Six themes emerged from the data analysis: creating meaning of mental illness; experiences in the environment; making ends meet; experiencing emotional strain; experiencing physical challenges and coping with mental illness.

5.2.1 Creating meaning of mental illness

The participants were asked about the diagnosis and their understanding of mental illness. Their responses can be categorised in two is theme two subthemes: (a) giving 'it' a name and acknowledging importance of treatment (b) causes of mental illness;

(a) Giving 'it' a name and acknowledging importance of treatment

Five participants from PWMI group reported knowing their diagnosis. Two reported to have schizophrenia, the other two had substance induced mental illness while the last participant's mental illness was hereditary. One of these participant did not accept the diagnosis as he felt that it was based on the fact that he once used substance and the fact that he had mental illness long after had stopped using, was not considered. Although the participants knew the diagnosis, they lacked understanding about it, as reflected by one participants:

PWMI 4: "I understand that we should go for check-ups, take care by complying with treatment".

Five other participants did not know their diagnosis but they knew that they had mental illness because that is what they were told. The following extract illustrates the point:

PWMI 1: *"I only know that I have mental illness. They did not explain it to me"*.

Only two family members reported knowing the diagnosis. One reported it was substance induced whereas the other one said it was stress related. The majority of those who did not know the diagnosis reported that they were told that the individual has mental illness. They also reported that asking the health care professionals does not help as they are

often told that the individual has mental illness and that adherence to prescribed treatment is important.

FM 10: *“Can they tell you? I only know is that he has mental illness and that taking treatment is important; that is what we were told by the doctor”*.

All participants acknowledged and emphasised the importance of taking treatment. This was motivated by changes observed after taking treatment. One participant commented:

PWMI 7: *“Without treatment you cannot live well with other people, you cannot live well”*.

A family member reported:

FM 8: *“I could see things were beginning to go well and he began taking the tablets because he was seriously mentally ill; he had long hair, oh he was just somehow, but when we came he started taking tablets and became much better.”*

(b) Suspected causes of mental illness

One participant associated mental illness with ancestors while most participants believed that witchcraft was the cause of mental illness. The views about witchcraft varied from hearing sounds on the roof at night to losing an item that reappeared only to cause illness when the owner touched it. One participant stated:

PWMI 8: *“I don’t understand how this mental illness came about but I don’t think it’s because of substance. I lost books when I was at school and after finding them I just got somehow so I think somebody bewitched me”*.

The belief about witchcraft as the cause of mental illness influenced the help seeking behaviour as some participants reported consulting traditional healers.

FM 9: *“We do consult traditional healers from time to time because we know that he is bewitched”*.

These findings suggest that, in terms of understanding about mental illness, there was no difference between those who knew diagnosis and those who did not. The importance of adhering to treatment is emphasised irrespective of understanding or not understanding diagnosis. The findings also suggest that participants’ interpretation of what could be the cause illness is based on grounds that supernatural powers were involved.

5.2.2 Experiences in the environment

This theme consists of two subthemes about the experiences of both PWMI and their families within their environment: (a) Limited participation in social activities and (b) Strained family relations.

(a) Limited participation in social activities

While participants reported participating in social activities, they felt that the presence of mental illness limits their participation. For PWMI, participation is limited by the fear and uncertainties of when the illness can come. One participant explained:

PWMI 3: *"I am scared that the illness will come while I am with other people"*.

Some PWMI preferred to isolate themselves due to their past experiences of rejection. Although they acknowledge that things have improved and that they socialize with members of the community, they minimize their interaction for fearing that community member's attitude may change. An example given include:

PWMI 5: *"There is no problem now. Before, people would say things that were not nice but I don't see any problem now"*.

The majority of family members reported that they select activities to participate in accordance with priority and the role they should play in that particular activity. They stated that they cannot go away for longer periods due to fear that PWMI will not take treatment or can be abused. One participant commented:

FM 4: *"When I have attended a function or a funeral I go on Friday and come back on Saturday. Because I know I have a patient, I never take a week away. I cannot leave her for a long time"*.

(b) Strained family relations

Most participants reported having poor relationships with extended family members not living in their household. They mentioned that some of their relatives do not seem to care and they avoid them. One participant stated:

FM 6: *"I have siblings in this village but they do not visit us despite the efforts to reach out to them. I would be lying if I told you the reason for their behaviour. Even if my son is sick, they do not bother to find out how he is."*

These findings suggest that presence of mental illness impacts on social well-being of both groups. The limited participation of PWMI is closely related to past experiences and the fear caused by unpredicted psychotic episodes. The caring responsibilities, the nature of the activity and significance of the role to be played seemed to be major factors that influence participation in social activities. It appears that family members tend to be overprotective of PWMI as they do not want to leave them for longer periods.

5.2.3 Making ends meet

Except for two participants, other participants receive some form of social assistance grant, which was reported as not enough to sustain them. Participants, especially those with minor children, reported the inability to meet their growing children's needs as their concern.

PWMI 5: "My kids are growing so are their needs. One of them is in a tertiary institution. Even though his fees are paid for by a loan, he has other needs, so I cannot say he must wait because I am trying to budget."

Although most participants receive their treatment from the mobile clinics, they are required to visit the hospital every six months for review. They reported that they spend a lot of money on transport as the PWMI has to be accompanied to the hospital. Other participants revealed that they still seek assistance from traditional healers which requires a lot of money. One participant felt that it would be better if she was employed because she would be able to do other things for children. An example given include:

FM 7: "It is just that finances, isn't you know that a person is difficult more especially because I am not working. My understanding is that if I was working it would be better because I would buy mealie meal (food), pay societies and that would be it. You have to buy things (soap) and they must also go to school".

The financial difficulty was evident in both groups. These findings indicate that general cost of living is high especially for those with young children. It is evident that participants need money for both health and general needs. These findings also suggest that social assistance grants are not sufficient.

5.2.4 Emotional reactions

The emotional reactions that came out during the interviews were related to: (a) worry about the future and (b) feeling deserted.

(a) Worry about the future

While PWMI did not seem worried about the future, the family members worry included caring for the PWMI. These participants, especially those who live alone with PWMI reported experiencing enormous stress as they always think about who will take over caring responsibilities should they die. Some participants expressed their wish for PWMI to find life partners to take over the caring responsibility. One participant stated:

FM 1: *“Even now I pray for him. I pray that my sister’s child can do something and get himself a wife before I die”.*

These findings show the extent of worry about the future of PWMI. It is evident that caregiving family members acknowledge that death is inevitable, hence the need or wish for the PWMI to get married with the hope that the partner will care for him.

(b) Feeling deserted

Participants reported feeling deserted by either family or community members based on reported experiences. Although majority of PWMI did not experience this, one participant expressed feeling hurt and different from other people when he spoke about community members’ comments.

PWMI 7: *“The trees are flowering so he is ‘relapsing’. They say these things when I’m busy working in the garden or cleaning the yard. I don’t know whether they expect me to just sit because they will think I have fallen ill again. Comments like these hurt my feelings”.*

Participants in the family members group reported the lack of the extended family members’ interest on the well-being of the PWMI including that of the caregiving family members. It was reported that some family members do not bother themselves about the PWMI, even when told that he is not feeling well. One participant explained:

FM 2: *“I am here by marriage. I don’t know about mental illness, it’s the first time I come across this thing so I need their support. This guy has his siblings in the community but*

they don't care. Instead they threaten to take their mother, which means they are saying he is my problem".

The findings indicate that family members appeared to experience more emotional challenges than PWMI due to caregiving responsibility and low levels of support.

5.2.5 Experiencing physical challenges

Most PWMI reported experiencing physical health challenges due to severe treatment side effects. Other participants reported experiencing persistent headaches and other ailments. Participants reported that complaining to health care professionals does not help as they are often told that this is how the treatment is. One participant reported that he once stopped taking treatment because of side effects. It was only when he relapsed that the doctor listened to him and changed treatment. These side effects may last for few days or be continuous.

PWMI 10: *"After getting injection, I struggle for quite some time. I spend time sleeping, sometimes the whole week. Sometimes my tummy feels somehow and my like my intestines feel hot".*

Although none of the family members reported any physical health challenges that may be associated with the presence of mental illness, they were confirmed the effects the negative effect of treatment of PWMI.

FM 9: *"Treatment has negative effects on him. Sometimes it makes him appear as if he has stroke on the side.*

The findings indicate that PWMI are more susceptible to physical health challenges than the family members. It is evident that there is not much to be done to reduce these effects as they are treatment related.

5.2.6 Taking each day as it comes

People cope differently under different situations. Participants reported that they have been using various strategies in order to cope with the presence of mental illness. This theme has three subthemes: (a) acceptance and knowing the signs; (b) seeking and getting support; (c) ignoring negative comments and avoiding potential difficult situations.

(a) Acceptance and knowing the signs

Most participants reported accepting the illness as the most important coping mechanism for them. For family members, faith that includes believing that PWMI is a gift from God as well as the behavior displayed by the PWMI influence acceptance of mental illness. For PWMI, accepting that one has mental illness makes it easy to deal with other negative aspects associated with it. One participant commented:

PWMI 5: *"It's just that I have accepted my situation. That is what helps me to move forward."*

Acceptance seemed to be influenced by faith as captured in the following description by one participant:

FM 8: *"I mean if God gives what he has given, who will you give him to? He is your child"*.

Participants in the family members' group reported that living with PWMI for a long time helped them to know the signs of relapse. This helps them to cope because they seek assistance before the situation gets worse. The frequently noticed signs include: anxiety, anger, irritation, lose focus and doing same thing repeatedly. Example given included:

FM 4: *"I see her by being angry and then when you ask her something she shouts at you. When she says something is lost, then it's lost. You will find her looking for it, saying I lost my underwear and sometimes accuses us of stealing from her"*.

(b) Seeking and getting support

Participants identified both formal and informal systems as being available within the community. While few PWMI reported seeking and getting support from friends and other community members, the majority indicated that they rely on their immediate families for support. The following statement illustrates this:

PWMI 7: *"I only get support from my family"*.

The family members reported seeking and getting emotional support from family, friends, home-based care groups and church. Additionally family also provides material support when the need arises whereas the church provides spiritual support. One family member explained:

FM 10: *“Ah, ngwana ka (meaning my child). It may sound like I am marketing my church but believe me the support I get there is incomparable. You know, they sometimes visit and pray with us.”*

Although formal support systems were identified as available, most participants reported that they do not get support from most formal systems such as police officers and health care professionals. It was reported that formal systems either delay their response when called or they do not show up. One participant reported:

FM 2: *“I sometimes call the police and tell that he is refusing to take his treatment, but sometimes they come on their time. Other times they do not even come so I end up hiring a car, ask the young men in the neighborhood to help restrain him so that we can take him to hospital”.*

These findings show that PWMI rely on their immediate family for support whereas family members seek and get support from other sources like church, friends as well as home-based care group. However, it is evident that experiences with support systems, especially formal support systems was generally negative as it was reported that they do not provide the much needed support.

(c) Ignoring negative comments and avoiding potential difficult situations

PWMI reported experiencing comments from community members. They reported that they ignore people’s bad comments because they felt that responding to them will make things worse. Other participants reported that they just avoid situations where they suspect or feel they may experience problems. One participant said “

PWMI 5: *“I don’t go to places where you find many people who may say things I don’t like. For instance, I avoid going to weddings or parties because I know that some people get drunk and start saying nasty things”.*

Although family members reported not experiencing problems with PWMI’s behaviour and community members, they reported having problems with other members of the family. To cope with this, participants reported avoiding contact with these people. They, however, reported difficulty in doing this when living in the same household with the troublesome family member.

The findings suggest that both PWMI and the family members adopt various ways of coping with mental illness. On the other hand, the findings suggest that all participants find it easy to avoid difficult situations by keeping themselves busy and avoid interacting with people who may hurt their feelings.

6 DISCUSSION

Recent developments involving deaths of PWMI at Esidimeni in Gauteng Province, is a clear indication of the complexity of the challenge of living with mental illness and caring for PWMI at both the family and policy level. This shows the gravity of the situation in South Africa in as far as mental illness is concerned. The aim of this study was to investigate coping strategies adopted by PWMI and their families in a rural setting. The coping strategies adopted by PWMI and their families are crucial to the improvement of their well-being.

The findings show that PWMI and their families lack understanding of mental illness. However, they create meaning based on belief systems, values and perceptions of what causes mental illness. The perception about the cause of mental illness has culture relevance as witchcraft and ancestors were identified as some of the causes. The study reveals that cultural meaning attached to mental illness influences the decision to seek culture-oriented interventions, hence the reported consultation of traditional healers. This is in line with resilience theory's contention that belief systems help family members create meaning of the problematic situations by clarifying the nature and cause of the problem (Walsh 2012). Besides meaning creation, the study found that PWMI and their families put emphasis on the significance of treatment. Acknowledging the importance and positive aspects associated with treatment increases the likelihood of compliance despite severe side effects hence compliance to treatment demonstrates resilience.

While managing to define and understand mental illness in their own terms, illness-related outcomes vary in accordance to environmental and personal factors as important aspects of ecological perspective and resilience. These factors present opportunities and stumbling blocks that shape participants' coping abilities (Walsh 2012 & Wright, et al. 2013). The findings show that the presence of mental illness affects the participants' social well-being as it limits their participation in social activities. It is however important to note that PWMI's reasons for not participating vary from those of family members. For

PWMI, the past experiences of rejection and stigmatization has created fear, as result they resort to isolation. Isolation is therefore used as a defense mechanism to protect themselves from perceived negative reactions from community members. For family members, caring responsibilities limit their participation in most social activities especially those beyond the area of residence. The caregiving family members tend to be preoccupied with caring responsibilities and neglect their own well-being. This is in line with the ecological perspective's assumption that the environment influences peoples' behavior (Bronfenbrenner 2008).

Contrary to previous studies that associate mental illness with health problems amongst family members (Oosthuizen, Carey, & Emsley, 2008; Gamm Stone, & Pittman 2010), family members in this study did not report any health challenges associated with mental illness. However, most participants with mental illness reported experiencing physical health challenges that are associated with treatment side effects. The severity of these side effects are a threat to non-adherence to treatment.

Consistent with the view that seeking support is an element of resilience (Walsh 2012), the findings show that most participants seek support from other people to help them cope with mental illness. For instance PWMI rely mainly on immediate family members while caregiving family members rely on their faith, friends and community members. However, contrary to the resilience theory's view that strong social support increases resilience which in turn strengthens the ability to deal with challenges associated with mental illness (Vedder, Boekaerts & Seegers 2005), the findings show that there is little support received from both formal and informal systems. Families might be contributing to this low level of support as they isolate themselves from their regular social networks due to fear of blame and rejection (Watson, Kelly & Vidalon 2009).

Mental illness can be a source of stress. This can be understood in the context of caregiving family members' behavior and concerns about PWMI. According to Amaresha, and Venkatasubramanian (2012), the family members' constant and excessive worry about the PWMI's future is attributed to overprotectiveness which is identified as a predictor of emotional over involvement, one of the components of expressed emotions. Expressed emotion is a factor associated with caregiver's attitude towards PWMI and is regarded as a determinant of relapse (Butzlaff, & Hooley, 1998). This study revealed that family members were more susceptible to emotional challenges due to concerns about PWMI and the future. The observations show that family members get involved in smallest details of PMWI day to day activities and decision-making

process. This deprives the ill individual of an opportunity to be independent and increases functional impairment.

Although overprotectiveness appears to be a challenge, it is important to justify the family members' behavior within the context of the environment. The low level of support from various systems within the environment may influence the family members' overprotectiveness of PWMI. This is consistent with ecological perspective assumption that people's behavior may be an indication of the maladaptive transaction between the person and the environment (Bronfenbrenner 2008).

Financial challenges were found to be affecting both groups despite them being the recipients of social assistance. Although social grants provide relief, it appeared to be insufficient to meet the needs of the households. Lack of employment opportunities in rural areas diminishes the dream of becoming financially independent. Most people in rural areas migrate to urban areas in search of employment. This becomes difficult for caregiving family members because caregiving role is usually vested in only one person, although extended family members exist. Therefore, caring responsibilities and uncertainties about illness inhibits any attempts to seek employment outside the geographical area.

The findings indicate that most participants have accepted mental illness and can even identify some of the signs of relapse. This is in line with resilience theory's idea of positive outlook, an element that influences PWMI and their families' acceptance of mental illness as one of the circumstances beyond their control. Acceptance influences positive attitudes and behavior resulting in improved well-being (Walsh 2012).

The findings of this study show that there is a need to educate PWMI and their families as well as create awareness about mental illness in order to help them cope better in future. The programme should focus on education and demystifying myths about mental illness in order to create enabling social and physical environment. This research contributed to the development of the framework for a community-based programme for PWMI and their families in a rural setting.

7 LIMITATIONS OF THE STUDY

This study has several limitations that should be taken into consideration when interpreting the findings. The study was limited to a small number of participants. Due to

the vastness of the study area, the study was limited to the areas that are within 10 kilometre radius from the Chief's kraal. Inclusion of other areas might be helpful in increasing the numbers of participants. PWMI who lived alone were not included in this study. In addition people who were not taking treatment for their mental illness were also excluded. As the sample only included caregiving family members, the results cannot be representative of all family members. Information presented was based on the participants' memory and how they chose to respond to the questions asked. More research involving experiences and coping of family members who are caregivers of PWMI that refuse to take treatment is recommended.

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ARTICLE 3

STAKEHOLDERS' VIEWS REGARDING THEIR ROLE AS SUPPORT SYSTEM FOR PEOPLE WITH MENTAL ILLNESS AND THEIR FAMILIES IN RURAL SOUTH AFRICA

ABSTRACT

The diverse needs associated with mental illness warrant for the provision of mental health care by various sources. The South African government recognises the involvement of stakeholders as a potential means of narrowing the gaps in mental health service delivery. This study explored the views of the different stakeholders about their roles as support systems for people with mental illness and their families at Mashashane, a rural setting in Limpopo Province, South Africa. Focus group discussions were with various stakeholders, were audio-recorded, transcribed and coded. Stakeholders understanding of mental illness was based on reaction towards people with mental illness, causes of mental illness and the behaviour displayed by the ill individual. The identified formal and informal systems were seen as ineffective with regards to provision of support. Collaboration was recommended as a mechanism to improve mental health services. The findings contributed in the formulation of guidelines to improve support.

KEYWORDS: collaborations, mental illness, rural area, stakeholders, support system

1 INTRODUCTION

There has been a growing interest in stakeholder involvement in mental health and related issues. Within the context of this study, a stakeholder is an individual or a group of people in the community who, due to their expertise and experiences provide informal mental health care either individually or in collaboration with other providers (Griffiths et al. 2008). The fight against mental illness and promotion of mental health are regarded as everybody's business (Skeen et al. 2010).

Stakeholder involvement can be associated with the biopsychosocial approach which attributes mental illness causation to biological, psychological and social factors (Dogar 2007). Besides biopsychosocial factors, cultural, economic, political and environmental factors are additionally classified as determinants of mental illness (WHO 2013). Given the disparities in rural mental health services and the cultural beliefs that influence the acceptability and utilization of these service, the mental health needs of the majority are

not met (WHO 2013; Petersen and Lund (2011). As a result, there is a need for the involvement and collaboration of informal mental health care providers such as religious leaders, faith and traditional healers, school teachers, police officers and local non-governmental organizations (WHO 2013).

Several studies show that people with mental illness (PWMI) and their families do consult traditional health practitioners (THPs) such as traditional and faith healers for healing of mental illness. These practitioners use traditional and religious methods in their treatment practices (Mkhize and Uys 2004; Ndetei et al. 2008; Ndetei et al. 2013; Sorsdahl et al. 2009; Atindanbila and Thompson 2011; Nsereko et al. 2011). Home-based care groups (HBC) have also been recognized for their role in providing social, emotional and material support to sick people and their families (Mahilall 2009; Ama & Seloilwe 2011). According to Magezi (2012) and Faull (2012) the church plays a crucial role in promoting health, enhancing general well-being and promoting social functioning of individual members of the community.

The South African legislation recognizes traditional leaders as custodians of African culture that are significant in health, welfare, safety and security in the communities (Ross 2010; Knoetze 2014). A study conducted in Zimbabwe revealed that traditional leaders have a major role in making communities aware on how to deal with potential suicidal tendencies among individuals and how to carry out counseling on survivors (Munikwa et al. 2012). Since the implementation of deinstitutionalization, police officers are in constant contact with PWMI. They are usually the first people to be called when a person with mental illness displays violent behavior (Livingston et al. 2014; Livingston et al. 2014).

Although there is substantial evidence on stakeholders' pathways of care, treatment practices and management of PWMI (Sorsdahl et al. 2009; Magezi 2008a; Magadla and Kolwaphi 2013; Mamba and Ntuli 2014), their supportive role remains largely unexplored. Additionally, no studies have explored the role of traditional leaders within the context of mental illness. To date, no research has included traditional health practitioners, church members, police officers, home-based care groups and traditional leaders together in one study in the Limpopo Province. This research is part of a broader study which proposes a community-based programme framework based on findings of a situation analysis that captured perspectives from three standpoints. This paper reports on stakeholders' views regarding their role as support system for PWMI and their families

in a rural setting. The study's objectives were to understand mental illness, available systems in the community, stakeholders' roles as support system and mechanisms to improve mental health services delivery.

2 METHODS

2.1 Research design

This is a qualitative study. The qualitative approach was used to gain a better understanding of the stakeholders' perspective of their role as support system for PWMI and their families (Babbie and Mouton 2012). A case study design was adopted to allow the researcher to investigate the contemporary phenomenon where multiple sources of data were used to gather adequate evidence so as to fully understand the views of stakeholders (Yin 2003; Babbie and Mouton 2012; Creswell and Clark 2007).

2.2 Study sample

The study population from which a purposive sample of 41 stakeholders was selected, consisted of traditional health practitioners (THPs), traditional leaders (TL), church members (CM), home-based care groups (HBC) and police officers (PO) from Mashashane. The sample comprised 15 HBC, 11 CM, 6 THPs, 4 TL and 5 PO. The inclusion criteria was experience in working with PWMI and their families.

Each group of stakeholders was recruited differently. The researcher wrote letters to and also met with authorities from various churches, the tribal authority, traditional health practitioners and home-based care groups to request them to grant permission to some members to participate in the study. The researcher called the recommended people requesting them to participate in the study. As for THPs and police officers, the researcher met them as a group and explained the purpose of the study.

2.3 Data collection

The main data was sourced through focus group discussions (Babbie and Mouton 2012) based on an interview guide consisting of five main questions with sub-questions. Below are some of the questions that were asked: *What is your understanding of mental illness? How do you as a church member view your role in supporting PWMI and their families?* Focus group discussions created an opportunity for the researcher to identify the

differences and similarities between stakeholders regarding their role as support system for PWMI and their families. The discussions were conducted in Sepedi and English. All focus group discussions were recorded. A short survey to source a demographic profile of the participants preceded the focus group discussions.

2.4 Data analysis

Data was analysed according to qualitative methods. The researcher categorized and coded data and assigned labels to each unit because the data was in the form of text (Creswell and Clark 2007). Data from the discussions was transcribed into text units and thereafter transcripts were read through several times in order to make sense of the data as a whole. The researcher categorized data according to the topics discussed during interviews.

3 ETHICAL APPROVAL

The study was approved by the Ethics Committee of the North-West University, Potchefstroom with reference number NWU-00125-11-A1. Informed consent was obtained from all individual participants included in the study.

4 RESULTS

Findings are presented according to the objectives of this study. These are divided into: participants' characteristics; empirical findings which include understanding of mental illness; available system in the community; views on roles played by various stakeholders and views on mechanisms to improve mental health services.

4.1 Participants' characteristics

Forty one stakeholders participated in this study. The majority (76%) of participants were females. Most participants (n=31, 76%) were above 45 years of age. The majority of participating HBC, THPs, traditional leaders and police officers had more than 6 years working experience. Participating police officers included 4 constables and a lieutenant. Of the church members who participated, 5 were from an independent church while the other six members were from traditional churches. All participating THPs were diviners, while three traditional leaders were indunas and one councilor. Except for 2 THPs, the

majority of participants were literate with education level ranging from primary school to tertiary education.

4.2 Understanding of mental illness

Participants had various understanding of mental illness. The TLs, HBCs and THPs reported that dealing with PWMI requires patience. They reported that PWMI are unique, therefore it is important not to have pre-conceived ideas about them and that one remains calm when dealing with them as being harsh may result in aggression:

PWMI needs one to be patient. The important thing is that one should not be harsh and should avoid making him angry because he might become aggressive. (HBC9)

Most participants also based their understanding on what they believed to be the cause of mental illness. They indicated that mental illness was caused by excessive drug use, poverty and suffering, stress, hereditary and witchcraft. Witchcraft seemed to be dominating as the cause of mental illness. Except for THPs, participants held that in the African culture people can be bewitched for various reasons such as stealing, being intelligent or successful. One participant said:

I think mental illness is an umbrella term and it could be caused by a variety of factors. Some may arise from not being well before birth, others grow up normally but later in life they become mentally ill. In African culture we believe that one can be bewitched. (CM2)

Most participants regarded PWMI as otherwise fine but for some reason may behave in a manner that is regarded as abnormal. The most frequently reported abnormal behaviours were mood swings, aggression, poor hygiene and personal care, mumbling and random talking as well as walking naked in public. As reflected in one of the participants' comments, it was reported that PWMI tend to be behave in a socially unacceptable manner:

A person with mental illness does things that are not expected to be done by a normal person or sometimes touches things that are not supposed to be touched. For example, he may take a chicken or cat and kill it with bare hands. (HBC5)

These findings indicate that participants based their understanding of mental illness on expected reaction towards PWMI, the causes of mental illness and the behaviour that

PWMI display. It is indicated that, although the participants acknowledged that various factors can cause mental illness, their interpretation is mostly based on traditional beliefs.

4.3 Views on available systems in the community

Participants identified the family, community, police officers, clinic and home-based care group, health as well social services professionals as systems that provide support in the community. Although several support systems were identified, participants indicated that there is very little or no support given to PWMI. The family as the main support system was reported to be failing to give support:

I don't see any support for these people because in our communities PWMI are not valued. People are scared of PWMI, instead of supporting them they keep their distance. Even their families reject them. (HBC7)

Another participant observed:

It seems that the responsibility to support these people lies with the government. Even in the government the treatment or support is not enough. (PO5)

Participants reported that the families' lack of support might be caused by lack of knowledge or is done deliberately as families did not want a patient to recover for fear of losing the social grant as it is the only source of income for most people. Participants believed that lack of family support may lead to relapse, as a result the PWMI remain psychotic for a long time. One participant said:

Some people don't take us serious when we give them information about what can help because they do not care about the ill individual. I think maybe families think that this person may get healed resulting in discontinuation of disability grant because that is what they care for. (HBC6)

Although the available systems were reported as ineffective, most participants expressed that HBC is the only support system that provides support and effectively deals with PWMI and their families:

The support I see for these people is from HBC. HBC visit homes to check on the PWMI and whether they take their treatment as required. (PO4)

These findings indicate that both formal and informal support systems are available in the community. However, these support systems are not providing adequate support. The families seem ill-equipped to deal with PWMI. In addition, this lack of support may be influenced by the families' fear of losing social grant as their source of income. It is evident that HBC is the only effective support system.

4.4 Views about roles of stakeholders

All stakeholders acknowledged that that they have an important role to play as support systems. The THPs claimed they provide PWMI with remedies to help with their illness. THPs sometimes stay with the ill individual for long periods to ascertain that they are taking the recommended remedies. After releasing the patient they conduct home visits to monitor progress and to educate families about remedies. One participant said:

Our support to these people is to give them our remedies gradually from the day of arrival. I also involve the family throughout the process because they must continue giving people with mental illness treatment when they go home. Sometimes I conduct home visits to check if they administer treatment as instructed, in that way I prevent any relapse. (THP3)

Whilst some TL reported the inability to know about incidences regarding PWMI and provide support due vastness of their area jurisdictional area, some indicated that they play broker, mediation and advisory roles. One participant reported protecting PWMI from shopkeepers who take advantage by giving them credit:

Even if they do not need anything, I give advice. Sometimes PWMI misuse their grant. I advise the family to receive grant on behalf of the mentally ill to prevent misuse. Shopkeepers take advantage of these people, so I agree with them not to give PWMI any credit in the absence of a family member. (TL2)

Participating church members acknowledged that they are supposed to provide spiritual, emotional and material support, however, only a few members reported doing this. They reported that they conduct outreach programmes in various villages focusing not only on PWMI but every member of the community who needs support. Participants reported assisting by linking PWMI and their families with relevant resources. Some participants reported that their role as members of a church is to help PWMI and their families to

accept their situation. They also encourage affected people to join the church so that they can keep an eye on them and determine their spiritual growth. A participant said:

I think that regardless of who we are as we support them we cannot overlook the fact that we want them to grow spiritually. Therefore, we do not just give support and leave. We also need to give them direction and invite them to church to fellowship with us so that we can see if they are spiritually growing. (CM4)

HBC participants reported that they help prevent relapse by monitoring treatment administration, reminding PWMI and their families about follow-up appointments and encourage families to take care of PWMI. They reported that they also educate their clients about financial management, provide spiritual and material support. One participant said:

My role is to ensure that the family treats PWMI well; they keep him clean and give him food. It is important that I encourage them to take their treatment because if they fail to do so they relapse. I also tell them to save part of their grant. (HBC2)

Police officers reported that they are often called to attend to PWMI. They mentioned their main concern is the safety of the community, therefore, if they are called to the scene they assess the situation and intervene only if the PWMI is violent. One participant said:

When we are called to attend to a PWMI we go there because we think there maybe harm to the community as that is our main concern. But if the person is not violent or does not pose any threat we call the paramedics to handle the situation. (PO2)

Although participants have acknowledged different roles that they play or are supposed to play, they also admitted that they are not doing enough to support PWMI and their families. They stated fear and lack of skills to deal with PWMI as the contributing factors to their inability to provide support. One participant explained:

I cannot deal with them alone when they are still aggressive because of fear. I want to be honest with you, I work with PWMI but I am scared of them. (THP1)

Another participant reflected:

You see as for us police to deal with the mentally ill is a problem because we are not well trained about handling people with mental illness. We just go there physically so. Our aim of going there is to protect the community by removing this person. (PO5)

As reflected in one of the comments, fear can also be a motivating factor for stakeholders to play a supportive role to PWMI:

Because we are afraid of these people, sometimes we make it a point that they get necessary medication so that he/she can be healed. We do this not because we care but just to remove fear of being beaten up. (CM8)

The findings indicate that stakeholders do not provide adequate support to PWMI and their families despite knowing what roles they should play. It is evident that fear due to aggressive behavior believed to be displayed by PWMI prevents stakeholders from providing necessary support. Furthermore, stakeholders are not adequately equipped to deal with PWMI especially when they are psychotic.

4.5 Views on mechanisms to improve mental health services

All stakeholders suggested working in collaboration with health care professionals to conduct training, constant workshops and regular awareness campaigns to educate people about mental illness. The majority of stakeholders emphasized the need to form a coalition to improve working relationships and help them understand one another's roles. Stakeholders suggested forming committee that will be responsible for facilitating activities regarding PWMI and their families.

We need to conduct regular campaigns to educate or share information with the community and stakeholders about mental illness. (HBC4).

Stakeholders expressed the need for third-party intervention to facilitate the proposed collaborations. They suggested that relevant government departments should spearhead the necessary processes for collaborations. One participant said:

I think the departments that deal with wellness like Social Development or Health must take the first step. They must call a gathering in which a committee is established. (CM2).

From police officers' perspective, having a one-stop center would quicken the response to service users. They raised concern about the distance travelled by emergency

services to get to Mashashane during times of crisis. Participants reported that this results in delay and disintegration of service rendered to people with mental illness. One participant stated:

If it was possible, the EMS should be stationed closer to the police station. EMS comes from far, they come from one direction and we come from another direction. As a result, when we go somewhere to attend to a case we spend too much time waiting for them or them waiting for us. (PO 3)

Although some stakeholders reported that they already work well with other stakeholders, some did not seem keen to work with THPS. The business orientedness of THPs and the Christian belief systems were reported as the reasons for the unwillingness to work with THPs. One participant explained:

There's no teamwork; we don't have a good working relationship because traditional healers are after money. They should heal the individual and only ask for money afterwards. (THP 1)

As reflected in the following comment traditional healing was associated with darkness.

The bible says that darkness can never mix with the light. (CM 3)

On the other hand, THPs reported that their working relationship with some stakeholders is not as it should be. They stated negative attitudes and the conditions of their tools as the reasons other stakeholders do not want to work with them:

We do work together with other stakeholders but discrimination is still an issue because of people's negative attitudes towards traditional healing. We take our patients to clinics when the need arises but health care professionals don't want these people to consult us. (THP 1)

Another THP added:

They [health care professionals] won't allow us to work in the same environment with them because our things are dirty. (THP3)

These findings highlight the need for collaborations. However, negative attitudes and lack of understanding of other stakeholders' roles seem to be a barrier for the proposed

collaborations. It was evident that THPs experience some form of inferiority complex that prevents from attempting to work with other stakeholders.

5 DISCUSSION

The aim of this study was to explore the views of the different stakeholders about their current and potential roles as support system for PWMI and their families in a rural setting. This study contributes to the literature on roles of stakeholders in mental health.

Consistent with the previous studies, this study confirmed that participants based their understanding of mental illness on expected reactions towards PWMI, the behaviour they display and the causes of mental illness. Although several factors such as excessive drug use, poverty, stress and genetic disposition or heredity, witchcraft dominated as being the cause of mental illness. Contrary to what is expected of THPs as cultural experts to identify witchcraft as the cause of mental illness (Sorsdahl et al 2010), the present study revealed that THPs based their understanding of mental illness on the social approach where they emphasized on reaction towards people with mental illness. They focused on the importance of patience or remaining calm when dealing with PWMI as harsh reaction towards them results in aggression.

The findings confirmed that both formal and informal support systems were available in the community with the family classified as the main informal support system. Austin and Boyd (2010) as well as Schmidt and Monaghan (2012) have also regarded the family as an important support system that provides for the needs of PWMI. The present study has revealed that the family fails to provide the necessary support to PWMI. This can be attributable to the families' fear, lack of knowledge and lack of skills on how to handle PWMI. This is consistent with previous studies that reported lack of knowledge as having negative consequences in caregiving (Ganaseen et al. 2008; Mavundla et al. 2009). In addition, the study found that the family's lack of support is deliberate and influenced by the need to continue receiving social grant as it is often a source of income for most families. Furthermore, the findings also revealed the ineffectiveness of formal and other informal systems in providing support.

Similarly, the majority of stakeholders acknowledged certain roles that they play and should play as support system. THPs support was based on biomedical intervention as they provide remedies to heal people with mental illness. They also provide emotional support to affected families by conducting home visits to ascertain proper administering

of the medication they prescribe. This is consistent with the previous study that reported the intervention of traditional healers as inclusive of family when treating mental illness (Crawford and Lipsedge 2004). As Byaruhanga et al. (2008) reported that PWMI tend to adopt impulsive spending behaviors, the present findings reveal that TL protect PWMI from exploitation shopkeepers.

Although police officers are mandated by Mental Health Care Act (17 of 2002) to restrain PWMI and transport them to the nearest health establishment, other participants in the study reported that Police officers normally refuse to do expected. A possible explanation may be that there is fear of being found accountable should anything happen to the PWMI (Taljaard 2012). In addition, as confirmed by participating police officers, they are not well equipped to deal with PWMI. This is consistent with findings of a previous study (Magadla and Kolwapi 2013; Psarra et al. 2008) that reported that police office officers lack the necessary skills to deal with PWMI. This lack of skill may have an impact on how police officers interact with PWMI. As Watson et al. (2008) pointed out that, this lack of skill may result in police officers using force, unnecessary detention or fail to assist PWMI to receive relevant treatment.

The findings revealed that, although other participants reported that they were not providing the necessary support to PWMI and their families, they however, acknowledged the significant role HBC play as a support system. HBC groups have been widely recognized as playing a critical role on health related issues. They operate multi-dimensionally and provide support to sick people, irrespective of the kind of illness (Mamba and Ntuli 2014; Ama and Seloilwe 2010).

Consistent with the view that understanding or knowledge is important for the recognition, management and prevention of mental illness (Ganasen et al. 2008), that perceptions and common beliefs that regard PWMI as dangerous can result in rejection (Botha et al. 2006; Angermeyer and Dietrich 2006), the findings show that fear of PWMI has a serious bearing on how stakeholders render services to them. However, this fear or threats can be a motivating factor to ensure that the PWMI get medical attention and comply with treatment. This is mostly influenced not by the caring element but the determination to remove fear, threat or danger. Ultimately, it seems stakeholders are not adequately equipped to deal with PWMI during times of crisis.

Improving mental health services requires collaboration between various stakeholders with the government taking the lead in facilitating possibilities by introducing relevant coordinating policies (Danaher 2011). The findings indicate that the stakeholders reported that the existing collaborations are weak. Although they have expressed willingness to collaborate, they believe this can be possible if a third party intervenes to facilitate the process. In addition, despite this willingness, the findings showed that most participants were not keen to work with THPs. This might be attributed to lack of clarity about different stakeholders' responsibilities (Skeen et al. 2010). Another explanation can be related attitudes (Mokgobi 2014), belief systems and lack of knowledge about certain aspects of the prospective collaborators (Campbell-Hall et al. 2010). The stakeholders' unwillingness to collaborate with THPs may hamper the South African government's efforts to strengthen collaborations with various stakeholders in order to minimize the gap in mental health service delivery.

The findings that awareness campaigns about mental illness should be conducted to contribute to reducing the stigma of mental illness is consistent with the previous study (Greenwood et al. 2014). Stakeholders have little knowledge of the policies and legislation that put emphasis on their involvement in mental health and related issues. Interventions aimed at creating awareness and facilitating collaboration between all stakeholders will be beneficial as the training on management of mental illness is vital for all stakeholders.

6 LIMITATIONS

This study had limitations, some of which were beyond the researchers' control and occur generally in focus groups. Findings of this study were based on data gathered from stakeholders at Mashashane, a rural setting outside Polokwane in Limpopo Province. Recruitment was slightly difficult as participants had to be from a specific geographical area. As a result, there was relatively small sample of stakeholders such as police officers, traditional leaders and traditional health practitioners. Therefore, the findings from the study could not be generalized to all stakeholders in the country even those that are in the province. This was mainly because stakeholders may respond differently to the same phenomenon.

To prevent participants from influencing each other's responses during the discussion, the purpose of the focus group was explained without giving more details about the

research. In addition, participants were encouraged to relate their experiences with others. As a result, this allowed them to build on others' responses providing understanding of similarities and diversity within the group.

7 CONCLUSIONS

The study provided insight about the current roles of stakeholders as support system of PWMI and their families. Despite the emphasis of stakeholder involvement in South African mental health policy and legislation, the findings of the study show that stakeholders do not provide sufficient support. The study highlighted lack of skills and fear associated with perceptions regarding dangerousness of PWMI as barriers for stakeholder involvement. The study revealed the willingness of stakeholders to collaborate for improved mental health service delivery provided third party intervenes to facilitate collaborations. However, negative perceptions and poor knowledge about other stakeholders' roles may hamper the collaborative efforts.

Not every person can handle people with mental illness. Those who are not equipped to deal with PWMI need to be capacitated or trained before they can interact with these people. It is also recommended that future research should focus on the roles that traditional leaders play in the management of mental illness within the South African context.

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ARTICLE 4

A FRAMEWORK FOR A COMMUNITY-BASED PROGRAMME FOR PEOPLE WITH MENTAL ILLNESS AND THEIR FAMILIES IN A RURAL SETTING

Abstract

This paper provides a framework that social workers could use to develop community-based programmes for people with mental illness and their families in rural settings. It is based on an in-depth literature review, as well as a comprehensive empirical study into the factors that influence the functioning and well-being of people with mental illness and their families at Mashashane, a rural community in the Limpopo Province of South Africa. The proposed steps to be followed in service delivery have been verified with stakeholders, as has some of the interventions themselves. In order to contextualise the framework, the nature and some of the findings of the research on which it is based, will also be covered.

Key words: Framework, community-based programme, intervention, mental illness, rural setting

1 INTRODUCTION

The importance of community-based programmes in mental health related interventions is widely documented (Saxena, Sharan, Cumbreira and Saraceno, 2006:182; Lawrence and Kisely, 2010:64; Odenwald, Lingenfelder, Peschel, Haibe, Warsame, Omer, Stöckel, Maedl and Elbert, 2012:13). Yet there is little evidence-based information to provide guidance to professionals on how to develop and implement these interventions (Wight, Wimbush, Jepson and Doi, 2015:1). This applies especially to rural settings and even more so to South African circumstances. It was one of the core aims of the research on which this paper is based, to fill this major gap.

Within this context, a 'framework' is regarded as an essential, detailed tool that provides guidance about various processes to be followed when developing and implementing a community-based programme (Roduner, Schlappi, and Egli, 2008:10). It includes outlining the programme activities, resources and supports needed to attain the programme's outcomes (Afifi, Makhoul, Hajj and Nakash, 2011:509), as well as the level

at which a target group and other relevant stakeholders should be involved (Macpherson, 2011:3). It can also be used for planning, implementing, monitoring and as an evaluation tool (Afifi, *et al.*, 2011:514).

The framework contained in this paper is intended to guide social workers through the process of developing and implementing community-based programmes that would improve the well-being of people with mental illness (PWMI) and their families. Although the guideline's focus will be on rural settings, the principles involved would also apply to services in semi-urban and urban areas.

In order to contextualise the framework, a look will first be taken at the nature of and the need for community-based programmes in general, and in rural settings in particular. This will be followed by a brief overview of the research on which the framework is based, followed by a description of the framework itself.

2 THE NATURE OF AND NEED FOR COMMUNITY-BASED PROGRAMMES

A community-based programme can, within this context, be defined as a structured social work driven initiative that is conducted within a specific geographical area and that involves the active participation of PWMI, their families and other stakeholders in a process that aims to improve the well-being of the targeted PWMI and their families. It especially focuses on enhancing social functioning by reducing psychotic symptoms and risk of relapse among PWMI so as to provide relief from the burden of care on their families (Odenwald, *et al.*, 2012:13).

Central to a community-based programme is its intended empowering effect (Weyers 2011:9). According to Crowther (2013:2) and Wahlin (2017:172), empowerment involves a process that is aimed at the provision of opportunities for individuals to participate in decision making on factors affecting their lives and for groups and communities to work together to bring about change. Individual empowerment involves giving power through capacitation (Zastrow, 2010:52; Freudenberg, Pastor and Israel, 2011:126) resulting in improved resources, new knowledge, developed skills, and changed behaviours and attitudes (Crowther, 2013:2; Wahlin, 2017:172). Empowerment at group and community levels involves joint action by stakeholders as change agents who solve problems encountered by implementing proposed solutions (Cole, 2006:639). Social workers utilise various methods of intervention and play different roles in community-based

programmes; these include those of empowerer, advocate, facilitator and educator (DuBois and Miley, 2010:68; Zastrow, 2010:52).

Despite the importance placed on community-based programmes in the mental health field, their development in low and middle income countries in general and South Africa in particular remains limited (Saxena et al., 2006:183; Alem, Jacobsson and Hanlom, 2008:55; Petersen and Lund, 2011:752). This can be seen as a legacy of the institutional-based care paradigm that held sway until fairly recently (Saxena, et al., 2006:183; Petersen and Lund, 2011:754). This has resulted in the inadequate allocation of resources such as money, staff, facilities and other infrastructure, especially services in rural areas (Gustafson, Preston and Hudson, 2009:2; Harris, Goudge, Ataguba, McIntyre, Nxumalo, Jikwana and Chersich, 2011:118; Marais and Petersen, 2015:9). Another result is a lack of new, evidence-based programmes and guidelines (Wight, et al., 2015:1), as well as professionals who are now expected to implement these programmes, not yet having developed the required skills (Petersen and Lund, 2011:754; WHO and the Gulbenkian Global Mental Health Platform, 2014:31).

These deficiencies gave rise to this study aimed at the development of a framework for a community-based programme for people with mental illness and their families in a rural setting. The nature of this study will be briefly covered next.

3 GEOGRAPHICAL CONTEXT OF THE STUDY

The research setting was Mashashane, a rural settlement situated approximately 37 km outside Polokwane and 30 km outside Mokopane in the Limpopo Province in the northern region of South Africa. Mashashane is a cluster region comprising of 22 villages, each with its traditional leader who accounts to the chief. Until the year 2015, this area was one of the traditional authorities under Aganang Municipality, one of the five municipalities under the Capricorn District. This municipality had since been amalgamated with Polokwane Municipality to optimize its financial viability (Municipal Demarcation Board, 2015:8). The languages predominantly spoken at Mashashane are Sepedi followed by Ndebele and Xitsonga.

Mashashane is not very different from other rural areas in the country in terms of lack of resources and inadequate services. Although the provincial government has embarked on improving the provincial road network by upgrading existing gravel road between Ga-Mashashane and Mokopane to a sealed surfaced all weather road, roads within the

villages are gravel and in bad condition. Most residents depend on public transport such as buses and mini-bus taxis. The transport system in between villages is inadequate, as a result people walk long distances to access most services.

The research targeted 13 villages that are within 10 kilometre radius from the chief's kraal. Health services within the targeted area are provided in the local clinic that is situated in the same village as the chief's kraal. The clinic has professional nurses including a mental health nurse and junior level nurses, as well as social workers. There is neither a resident doctor nor other health care professionals such as occupational therapists, pharmacists, psychologists, physiotherapists, or dieticians. As part of the outreach programme, however, some of these health care professionals visit the clinic once a week. The clinic renders services to some of the targeted villages while others receive health services from mobile clinics that visit fortnightly. Mobile clinics are run by nurses and do not get visited by the doctors or other health care professionals, hence the referral of patients to the main clinic. For more specialised health services, people from Mashashane consult the hospitals that are situated in Polokwane and Mokopane.

The clinic also accommodates home-based caregivers (HBC). This is a group of volunteers who provide support to the sick people and link them to available resources within their communities. This group is registered with the Department of Health as a non-profit organization (NPO). During the mobile clinic visits, HBC assist the nurses at the site with administrative tasks such as arranging files according to the order of who has to consult first. Also accommodated in the clinic, is a youth initiative run by Lovelife, a non-governmental organization (NGO) that specializes in providing various youth programmes. Mashashane also has a fully functional police station. There are no ambulatory or emergency services (EMS) in the area. There are various early childhood centres, as well as primary and secondary schools in the area.

4 OVERVIEW OF THE RESEARCH ON WHICH THE FRAMEWORK IS BASED

The study consisted of an extensive literature review and an empirical component. The empirical investigation was conducted in three phases. Phase 1 focused on conducting a situation analysis by getting views on factors related to mental illness and mental health service delivery from three different standpoints. These standpoints were those of health care professionals, PWMI and their families, as well as various stakeholders. The results

of Phase 1 led to Phases 2 and 3. Phase 2 involved the design of a programme framework and Phase 3 focused on an evaluation of this framework.

4.1 Phase 1: Situation-analysis of Mashashane

The context targeted in the situation-analysis was Mashashane, a rural settlement in the Limpopo Province (see section 3 for details about this setting). Three groups were involved in the analysis included service providers, PWMI and their families as well as various other stakeholders.

The first group comprised of service providers. In this study, a survey to assess mental health service was conducted amongst 35 health care professionals, including doctors, nurses, occupational therapists, psychologists and social workers who each completed a self-administered questionnaire. The assessment was based on comprehensiveness, accessibility, coverage, continuity of care, quality, coordination, person-centeredness as well as accountability and effectiveness as the eight attributes of good health services (Haggerty, Burge, Lévesque, Gass, Pineault, Beaulieu and Santor, 2007:339; WHO, 2008:23). Results showed that only comprehensiveness was positively perceived. All other attributes were negatively perceived. This was primarily due to a lack of resources and skills, poor coordination of mental health services, and a lack of collaboration amongst health care professionals and relevant stakeholders. The results indicate that current mental health services are inadequate to improve the well-being of PWMI and their families.

The second target group were PWMI and their families who lived in Mashashane. Semi-structured interviews were conducted with 10 PWMI and 10 family members to ascertain how they currently cope with mental illness. The results suggested that PWMI and their families lack understanding of mental illness. Emotional reactions from both PWMI and their families were reported, although families experienced more reactions. Results also showed that PWMI experience physical challenges associated with their treatments' side effects. It was also revealed that PWMI and their families experience financial difficulties and that there was little support from both formal and informal systems within the community. Both PWMI and their families adopt adaptive and maladaptive coping strategies showing that there was a substantive need to educate PWMI and their families about mental illness in order to empower them to cope better with their circumstances.

The third group were community members who, due to the service they render to PWMI and their families, are recognized as important stakeholders in the mental health care system. Data collection involved focus group discussions with each group of stakeholders including traditional leaders, traditional health practitioners (THPs), church members, home-based care groups and police officers. Results showed that the majority of stakeholders provide inadequate support to PWMI and their families. Participants attributed this to fear of PWMI and a lack of skills to deal with PWMI. Results also showed little collaboration between stakeholders and health care professionals. It was evident that individual and community related factors contribute to the challenges experienced by PWMI and their families. It was, therefore, concluded that there is a need to improve provision of support to PWMI and their families. These results were used as indicators for the development of a community-based programme framework.

4.2 Phase 2: Design a concept community-based programme framework

A community-based programme was conceptualised and designed based on the results of the situation analysis and the factors that contributed to existing challenges highlighted. The situation analysis also indicated the required intervention at various levels (Wight *et al.*, 2015:4). As a result, two types of interventions, one targeting PWMI and their families and the other targeting the community and especially the relevant stakeholders, were proposed and proposed.

4.2.1 Interventions aimed at PWMI and their families

One of the primary results of the empirical research that informed the development of the framework, was the need amongst PWMI and their families for more education on mental illnesses and related matters. This finding correlates with the literature review that indicated that a similar need would probably also exist in most other equivalent rural communities. It was, consequently, decided to develop and pilot test such an educational programme in the Mashashane community.

A new, six module social group work educational programme was developed (see Annexure 24). It was especially intended to minimise the myths about mental illness and in so doing increase empowerment, improve knowledge about mental illness, enhance understanding about self-care and reduce worry about the future. The programme also focused on the development and reinforcement of problem-solving and communication

skills, the empowerment of attendees with the ability to generate appropriate strategies to cope with any problematic life situations and to improve their abilities to create and maintain relationships with social contacts. The programme's framework is summarised in Table 4.1.

Table 4.1: Contents of the educational programme aimed at PWMI and their families

Sessions	Programme Themes	Programme content and activities
Session 1	Group introduction and orientation	<ul style="list-style-type: none"> • Facilitate introduction • Establish rapport • Overview of the intervention structure • Set up of ground rules • Explore group expectations
Session 2	Gaining knowledge	<ul style="list-style-type: none"> • Presentation • Group discussions: <ul style="list-style-type: none"> ○ Information about mental illness, different types and signs ○ Managing mental illness – importance of adhering to treatment. ○ Sharing experiences • Evaluation
Session 3	Managing emotions	<ul style="list-style-type: none"> • Presentation • Discussions: <ul style="list-style-type: none"> ○ Identifying the triggers (stress, anger, excessive thinking). ○ Dealing with fear of stigmatization and rejection. ○ Learning to let go • Evaluation
Session 4	Making ends meet finances	<ul style="list-style-type: none"> • Discussions: <ul style="list-style-type: none"> ○ Managing finances ○ Learning to budget ○ Saving on important expenses • Evaluation
Session 5	Communication skills	<ul style="list-style-type: none"> • Learning how to handle difficult situations • Socializing – claiming your role in the community. • Soliciting support • Establishing support networks • Preparation for termination and evaluation
Session 6	Termination	<ul style="list-style-type: none"> • Review of the topics covered • Goal setting (short and long term goals). • Evaluation

The programme utilised educational social group work as it was deemed the most appropriate method to achieve the intended intervention's stated goals. Social group work is a goal-directed activity targeting individual members and a group as a whole with the aim of meeting their socio-emotional needs and accomplishing tasks (Toseland and

Rivas, 2012:11). This method is adopted based on the notion that groups have the capacity to foster change (Sands, 2003:6) and to enhance problem-solving skills through sharing experiences and ideas on how to tackle certain issues (Ross and Deverell, 2010:352).

4.2.2 Interventions aimed at health care professionals and stakeholders

The primary results that informed the development of this intervention were based on the survey of service providers and focus group discussions with stakeholders. The survey results revealed inadequacy of mental health services, lack of skills, lack of resources, poor coordination of mental health services and lack of collaboration amongst health care professionals and relevant stakeholders. In addition, stakeholders provide inadequate support to PWMI and their families; participants attributed this to fear and lack of skills to deal with them.

Little collaboration amongst stakeholders and health care professionals was also reported. The situation would probably be similar in other rural communities. This has resulted in the researcher developing guidelines (See Annexure 25) intended to assist health care professionals and relevant stakeholders to improve the provision of support to PWMI and their families, while facilitating collaboration. These guidelines have four key areas with recommended elements that should be put in place. These are

- Key area 1 focuses on giving information about available support. This would be done by assigning one of the team members to the targeted people and educating them about mental illness and related issues.
- Key area 2, is on the establishment of a task team and lines of communication, development of various measures, reaching agreements about role of each team member, as well as the extent of support each can provide when necessary.
- Key area 3 focuses on training on mental illness and related issues.
- Key area 4, recommendations are made and they include involving PWMI and their families in planning process, participation in support activities, identifying their roles and formulating processes for interaction.

The implementation of these guidelines requires active participation of health care professionals and stakeholders as equal partners. The social planning practice model of community work could be adopted in order to improve the provision of support and find solutions to other identified problems (Weyers, 2011:221). Social workers can create and

strengthen social support networks by reaching out to and facilitating the coalition of the available systems in order to build on community resources (Schenk, Nel and Louw, 2012:277). It is within these systems that social workers can mobilise an action committee that will facilitate decisions and agreements about the roles and responsibilities of each group of stakeholders (Weyers 2011:224; Proctor, Powell and McMillen, 2013:7).

4.3 Phase 3: Evaluating the interventions

Bhana and Govender (2010:67) point out that formative evaluation is a crucial activity that should be undertaken during the design of a programme in order to judge its appropriateness for a context. The targeted community's inputs are also required to assess the appropriateness, feasibility and usefulness of the intervention (Kilbourne, Neumann, Pincus, Bauer and Stall, 2007:6; Wight *et al.*, 2015:4).

A questionnaire consisting of 6 open-ended questions (See Annexure 22) was designed and distributed to 6 social workers who participated in Phase 1 of the study. This was used to assess the social group work educational programme in terms of: clarity of goals; clearness, conciseness and relevance of content; applicability of activities to the target group; potential to provide capacity for the social workers; possible constraints that can hinder implementation; and suggestions on aspects to be included in the programme. Following prior arrangements for distribution, the questionnaires were given to one of the social workers who delivered them to other social workers. These social workers were already in possession of the proposed educational programme document (See Annexure 24). Data was analysed using content analysis, which is usually performed by extracting themes from a textual data (Strydom and Delpont, 2011:384).

Results showed that the social workers found the goals of the programme to be clear and well-founded. Although they found the overall content to be relevant, they felt that session 2 was overloaded and therefore should be reduced to allow the participants an opportunity to better grasp the content. Based on this feedback, the number of types of mental disorders that should be discussed was reduced. It was also suggested that the number of sessions should be increased to give participants more time to adjust to the purpose of the group. The number of sessions can be adjusted based on the social worker's assessment of the needs of the target group. Social workers indicated that the programme has potential as topics to be discussed are relevant to the needs of PWMI

and their families. They all identified lack of resources as a potential constraint for implementation, while a few also identified time constraints and lack of skill to conduct group work as potential constraints.

A similar questionnaire (See Annexure 23) with open-ended questions was used to assess the intervention by health care professionals and stakeholders. These questionnaires were delivered to a contact person who distributed them to the potential participants. Participants were already in possession of the proposed guidelines (See Annexure 25) as they were distributed earlier. Unfortunately, some stakeholders could not participate in assessing the proposed intervention due to their low literacy levels. A total number of five health care professionals and three stakeholders validated the intervention. Results showed that participants thought the goals were well-founded and the contents of the interventions were feasible for the intended target groups. Participants identified lack of interest and commitment amongst health care professionals and stakeholders as possible barriers to the implementation of the guidelines.

5 THE PRINCIPLES FOLLOWED IN THE DESIGN OF THE PROGRAMME FRAMEWORK

A community-based programme usually encompasses a structured, mezzo level and structured plan of action that delineates the steps that a practitioner will follow to attain a predetermined result or outcome (Angeles, Dolovich, Kaczorowski and Thabane, 2014:101; Côté, Godin, Garcia, Gagnon and Rouleau, 2008:972; Weyers, 2011:88). This section focuses on the theoretical foundations that informed the development of the framework.

5.1 The theoretical foundation of the programme

One of the original choices that had to be made in the conceptualisation and designing of the programme, was which of the varied theories and approaches available to social work to use as its theoretical foundation. Based on available research results in the fields of programme development and mental health (McLaren and Hawe, 2005:8; Padesky and Mooney, 2012:289; Wright, Masten and Narayan, 2013:22), the choice fell on resilience theory and the ecological perspective. The reasons for this choice are based on the principles that these theories highlight the environment and its impact on people.

Resilience theory highlights the importance of the ability to adapt to life's challenges, which if not addressed, may result in disruption in social functioning (Walsh, 2012:399). In this theory, an individual is understood within the context of an environment that is believed to provide the necessary resources that help in nurturing and reinforcing resilience (McLaren and Hawe, 2005:8; Wright, *et al.*, 2013:22). The family is regarded as a functional unit that creates a nurturing environment to support adaptation and enhance resilience (Walsh, 2012:401). Resilience-based interventions are, therefore, aimed at promoting resilience and assisting families to discover strengths, identify protective factors and resources that they can use within the family and the environment (Padesky and Mooney, 2012:289). This is especially important in cases where family members have to take care of PWMI.

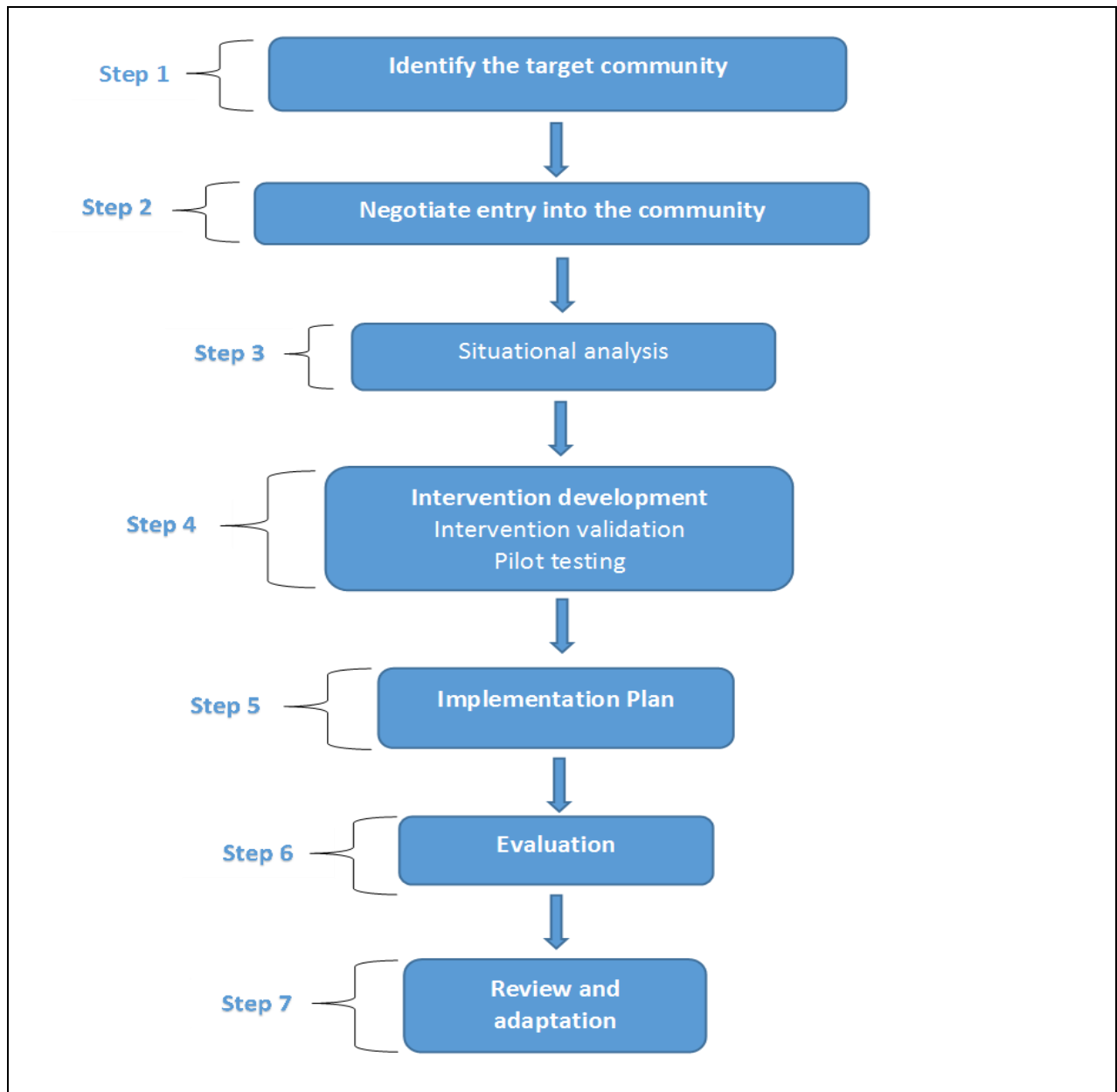
The programme was also informed by the ecological perspective, which puts emphasis on understanding an individual within the context of the immediate and larger environment. This perspective focuses on the balance that exists between human beings and their environment based on the notion that challenges experienced are a result of the person's interaction with the environment (Compton, Galaway and Cournoyer, 2005:23). Given that mental health and well-being are affected by the environment, the ecological perspective provides an essential framework that enables the design of community-based programmes that address the social context in which challenges occur (Merzel and D'Affliti, 2003:571). Evidence shows that interventions that extend beyond the individual level are most likely to succeed in bringing change (Merzel and D'Affliti, 2003:562; Parvanta, 2011:19).

5.2 The structuring of the programme framework

Due to the lack of clear guidelines for community-based programmes in the mental health field, the proposed broad framework emanated from common elements extracted from the frameworks and guidelines found in intervention research (De Vos and Strydom, 2011:476), logic models (Roduner, *et al.*, 2008:10; Afifi, *et al.*, 2011:509; Weyers, 2011:108-114), intervention development (Wight, *et al.* 2015:1) and community development (Weyers, 2011:153-4). The research theories especially, had to be adapted to meet the requirements of community-based programme in general and those aimed at PWMI and their families in particular. This was done by populating the framework with the lessons learnt from the research process and empirical data generated by it.

The resultant framework is contained in Figure 4.1. Step 1 focuses on the identification of the target community while step 2 deals with gaining entry into the community. In step 3, the focus is on situation analysis whose results lead to the intervention development in step 4. Step 5 focuses on implementation plan, whereas step 6 covers the evaluation of the outcomes of the intervention. In the final step 7, the intervention is reviewed, finalised and adapted.

Figure 4.1: A framework for a community-based programme



6 THE FRAMEWORK FOR A COMMUNITY-BASED PROGRAMME

The following framework contains the core scientific evidence on which it is based, as well as some practical recommendations and guidelines that a social worker can use and follow in the development and implementation of a custom-made programme for the rural community for which he or she is responsible. It is important to note that the framework could and should be adapted to meet local needs and circumstances.

6.1 Step 1: Identify the target community/ies

A target community is usually members of the group within a community or the whole community for which the community-based programme is intended. In terms of community-based intervention theory, a community can be seen as a setting, as a target for change, as a resource and or as an agent (McLeroy, Norton, Kegler, Burdine and Sumaya, 2003:529):

- In terms of a geographical area, the focus is on the rural area in which the intended programme will be implemented (McLeroy *et al.*, 2003:530).
- The specific target communities include both groups within the geographical area and so-called special interest communities outside of this area (Parvanta, 2011:26).
- The targeted groups within and outside of the geographic area can include stakeholders such as traditional leaders, THPs, church members, police officers as well as home-based care groups and health care professionals as they have influence on PWMI and their families due to services they render. These are people whose actions or lack of actions contribute to the existing problem (Parvanta, 2011:26).

The process of identifying the target community include identifying the problem to be addressed, determining the level of risk of developing a problem, the people most affected, and the possible benefits that could be obtained by participating in the programme (Monshouwer, Smit, Ruiter, Ormel, Verhulst, Vollebergh and Oldenhinkel, 2012:293; Contzen and Müller-Böker, 2014:1; Tyler and Hassen, 2015:48). The social worker can identify their specific target communities based on the existing caseloads, focusing on the commonly reported cases and the effect of the problems on individuals and the entire community.

The social worker should acknowledge that, although both formal and informal service providers are essential, their services can be inadequate. The extent of the service gaps in a specific rural area thus have to be assessed, hence the need to conduct a situation analysis. The social worker should be cognisant of negotiating entry into the community as one of the processes to be followed before conducting a situation analysis.

6.2 Step 2: Negotiating entry into the community

Negotiating entry into the community is the process of making contact and engaging with local authoritative structures with the aim of gaining access into the system (Wanat, 2008:194). Healy (2012:181) asserts that, within the social work context, negotiating entry involves meeting the community members with the aim of establishing a working relationship. The manner in which the social worker enters and makes contact in the community might have an impact on these relationships resulting in the success or failure of the intervention (Wanat, 2008:198; Johl and Renganathan, 2010:46; Healy, 2012:181). Given the rich South African cultural diversity, community entry requires the social worker to understand the dynamics of culture, and be sensitive and respectful to people of other cultures (Birkenmaier, Berg-Weger and Dewees, 2014:451).

This research conducted successfully in Mashashane could give an indication of one of the ways in which the required negotiation of entry could be undertaken in a rural community. In this case, the researcher first made contact with the community through random visits to various villages and informal conversations with various community members. Following this informal orientation, the researcher approached the Chieftaincy of Mashashane to negotiate entry and obtain approval to conduct the research. Making contact provided an opportunity to know the community and be known in the community as well as to obtain cooperation of potential participants (De Beer, 2012:157).

Negotiating entry had, however, proven to be a continuous process as the researcher has had to deal with gatekeepers at various levels within the community. According to Wanat (2008:201) and Reeves (2010:317), gatekeepers have a potential to help or hinder entry based on their perception about the significance of the proposed services in their community. Given that the study would include health care professionals and police officers, the researcher dealt with gatekeeping issues by seeking provincial level permissions from the Department of Health and the South African Police Services. Additionally, several other potential participants were consulted and the permission from

the Tribal Office proved effective as most structures would not agree to work with an outsider without this office's written permission. The written permission reduced chances of mistrust and enabled potential participants to assist the researcher towards identifying and solving existing problems related to mental illness (Reeves, 2010:321). This also facilitated the process of conducting the situation analysis.

The empirical study reaffirmed the importance of the gaining access to the identified community. It also became apparent that social workers interacting with PWMI and their families must take the following into consideration:

- Each community has formal and informal gatekeepers whose attitude towards any intended community-based programme can make access to the target community impossible.
- Cultural sensitivity is important in minimizing negative attitudes and maximizing trust.

6.3 Step 3: Situation analysis

The third step is based on the ecological perspectives' premise that the environment significantly influences the behaviour of individuals and that malfunctioning subsystems within the environment affect other systems (McLaren and Hawe, 2005:8). The situation analysis involves the process of collecting and analysing specific information about the target community and its context that is required for the formulation of a practical intervention plan (Singletary, 2004:3). The process includes identifying available resources in the form of formal and informal systems as well as their role in meeting the needs of the target group (Couillard, Garon and Riznic, 2009:37; Afifi *et al.*, 2011:511) and identifying barriers that may hinder any efforts to improve the group's quality of life (Singletary, 2004:4). The analysis also provides an opportunity to determine the levels of need and commitment to mental illness related issues (Kuipers, Kendall and Hancock 2001:25), as well as allows for exploration of possible intervention variations (Wight *et al.*, 2015:4).

Schenk *et al.* (2012:66) assert that understanding the community is built on the community members' views and motivations. Community members are regarded as experts who can give account of their needs and the potential factors that can facilitate or hinder the success of any intended intervention. In the case of the Mashashane research project, the members were divided into three groups namely service providers, PWMI and their families, and other stakeholders.

In the case of the service providers, the survey focusing on their views of the mental health services that they render. PWMI and their families were viewed as an important second group in that they experience various challenges as a result of living with mental illness. Semi-structured interviews were conducted to ascertain how this group copes with mental illness. The third group consisted of various stakeholders, who, as members of the target community are recognized as important support system due to their role as informal health care providers. Focus group discussions were conducted to get their views on the roles they play as support systems. The main focus when conducting the situation analysis was to determine the related risks and contributing factors to challenges experienced by PWMI and their families. It was also to identify available resources and their level of commitment to help PWMI and their families to cope with challenges. A situation analysis assists in determining the appropriate intervention to solve identified challenges.

As a point of departure, social workers should use reported cases regarding the PWMI and their families to identify the needs to be addressed. In addition, they should determine the level of commitment and collaboration regarding support for PWMI and their families through interaction with other professionals and stakeholders. The type of activities that are conducted in the community to address mental illness and related issues can also be used as a determinant of the targeted community's needs as well as service provision gaps.

Results of and experience gained during the Mashashane study reaffirmed the importance of conducting situation analysis. It became evident that the social worker must take into consideration the fact that the challenges experienced by PWMI and their families are also a result of various factors including individual and community factors.

6.4 Step 4: The development of an intervention

The development of an intervention is informed by the results of the situation analysis. These results influence decisions about the type and the components of the specific interventions (Singletary, 2004:3; Wight *et al.*, 2015:4). Based on the notion that interventions that extend beyond the individual level are effective in bringing about change (Merzel and D'Affliti, 2003:562; Parvanta, 2011:19), it is recommended that the intervention should focus on addressing identified issues on different levels within the community.

In the case of the Mashashane study, two interventions were proposed. One aimed at PWMI and their families and another at health care professionals and stakeholders. Following the results of the situational analysis that highlighted the need to educate PWMI and their families, a six module social group work educational programme was developed. Guidelines to improve support to PWMI and their families were also formulated as an intervention aimed at health care professionals and various stakeholders.

Results of and experience gained during the empirical study reaffirmed that effective changes are based on multiple level interventions. Therefore, the social worker must take into consideration that the development of the intervention should be based on the unique factors from their setting. These factors should guide the type of intervention and the level it is intended for. To ensure its suitability and relevance to the setting, the developed intervention should be validated.

6.5 Step 5: Implement the intervention

This step involves putting the planned intervention into action. Implementation is guided by the context in which it will take place (Kilbourne *et al.*, 2007:3; Damschroder, Aron, Keith, Kirsh, Alexander, and Lowery, 2009:3), hence the need for social workers to modify the framework to suit the unique characteristics of their setting. Kilbourne *et al.* (2007:3) and Damschroder *et al.* (2009:3) suggest that factors that can influence or hinder implementation should be taken into consideration. Planning is, therefore, crucial to prepare for unforeseen circumstances and ensure proper implementation.

Social workers should take into consideration that the implementation of any intervention may vary according to the available resources and skills, support from colleagues, management and stakeholders, as well as the attitudes of the target group.

6.6 Step 6: Intervention evaluation

Intervention evaluation is necessary to determine the impact of social interventions on specific target groups (Babbie and Mouton, 2012:335). Both qualitative and quantitative methods can be used. The social worker should consider evaluating the outcome and process of the programme through formative, process and summative evaluations. Formative evaluation will be conducted during the development and before

implementation of the intended intervention (Bhana and Govender, 2010:67; Babbie and Mouton, 2012:339) to assess its relevance to the context and to identify potential threats to the success of the community-based programme (Strauss, Boyas and Murphy-Erby, 2012:59).

Process evaluation should be conducted as an ongoing activity to detect problems and make relevant changes (Bhana and Govender, 2010:69; Lobo, Petrich and Burns, 2014:2). Summative evaluation is conducted on a programme that has been completed to determine its impact (Bhana and Govender, 2010:70). The effectiveness of the programme should, therefore, be determined based on the outcomes on which the programme was designed to impact. Given the high rate of functional illiteracy that exist amongst some groups in South Africa (Statistics South Africa, 2014:25), social workers should take cognisance of the probable low levels of literacy and consider using assisted evaluation sheets and informal group discussions when evaluating the programme.

6.7 Step 7: Review and adaptation

According to Naude and Weyers (2009:491), the review forms an important step in the process of determining and enhancing the relevance and suitability of an intervention. It involves re-evaluating the intervention and scrutinizing the results of the evaluation process in order to identify which possible changes should be made to future interventions. Social workers should conduct regular reviews of the intervention to assess suitability and to determine the mismatch between the intervention and the context as well as the target group (Chambers and Norton, 2016:126).

Adaptation is the process of making changes in the intervention to create a cultural and contextual fit between the intervention and the target group (Barrera, Castro, Strycker and Toobert, 2013:198; Marsiglia and Booth, 2015:424). Given that cultural competency is a social work ethical mandate (Marsiglia and Booth, 2015:428) and the cultural diversity in South Africa, social workers should consider making necessary cultural adaptations to interventions, especially those intended for rural populations, to increase the effectiveness of the interventions.

7 CONCLUSIONS AND RECOMMENDATIONS

The need for this research emanated from a general lack of data on the nature and implementation of community-based programmes that would alleviate challenges of

PWMI and their families in rural areas of South Africa. The proposed framework for a community-based programme was informed by the outcomes of an empirical research conducted in the Mashashane settlement and the context within which it functions. The research indicated, amongst others, the contributing factors to the problems that should be addressed and the parties that have vested interest in and are directly or indirectly affected by the identified issues. These results led to the development and testing of two separate interventions. It targeted individual PWMI and their families, and the health care providers and other stakeholders.

The proposed framework for the community-based programmes, for PWMI and their families, in rural settings should contribute to the filling of the considerable gap that exists in this regard in South African social work literature. It will, in addition, provide practitioners with practical guidelines on how to develop programmes that would address the needs in their unique practice settings.

The proposed framework should, however, only be seen as the first step in the development of more evidence based services. The two proposed interventions, should, in future, be subjected to more rigorous, scientific effect measurements. The framework itself should also be implemented on an experiential basis in other rural areas to verify its appropriateness for different settings. Only with such strategies could the social work fraternity in South Africa fulfil its responsibility to meet the needs of all people living with mental illnesses and their families.

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SECTION C:

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Section C:

Summary, conclusions and recommendations

1 INTRODUCTION

This section presents the summary of the research and examines the methodological, empirical and theoretical contributions of the study to literature on mental health. Responses to the research questions, conclusions and recommendations for future research are presented.

Literature suggests that that mental illness is a universal challenge that affects both developed and developing worlds (WHO 2001; Stein, Seedat, Herman, Moomal, Heeringa, Kessler, & Williams 2008). The recent incident in which about 100 people with mental illness (PWMI) died in Gauteng Province due to suspected negligence, is an indication of the challenging circumstances associated with management and care of mental illness. Given that this happened in urban areas which are known for being better resourced, it raises questions on how the situation might be in rural areas.

Community-based programmes have proved to be an effective strategy in enhancing the well-being, social functioning and quality of life of PWMI and their families even in resource limited areas (Saxena, Sharan, Cumbreira & Saraceno 2006; Bronowski, Sawicka & Charzynska 2011). This it is important to consider the development and implementation of similar programmes to overcome challenges associated with management and care of mental illness in South Africa. Studies show that, although the South African government had promised to introduce community-based programmes, they are currently not well developed due to the existence of hospital-based care that appears to be dominating and lack of skills among professionals expected to implement the programme (Petersen & Lund 2011; Ramlall, Chipps & Mars 2012). Wight, Wimbush, Jepson and Doi (2015) argue that there is little evidence-based information to provide guidance to professionals on how to develop and implement community-based programmes.

The current study is premised on the view that if community-based programmes can improve the well-being of PWMI and their families in other environments, a framework is needed to guide social workers on the development and implementation of such programmes in rural locations in South Africa.

2 RESEARCH METHODS AND DESIGN

This study adopted a mixed method approach in which a combination of qualitative and quantitative methods were used to consider the phenomenon at different levels in order to gain a better understanding of the research problem (Creswell 2014). Some elements of intervention research as outlined in De Vos and Strydom, (2011) were used to assist in the development of a framework for a community-based programme. This study was explorative and descriptive in nature.

Grounded theory was used to assist with the development of theory based on a thorough data gathering and analysis. A case study design was used to get a better understanding of the PWMI and their families' lived experiences and to expose the researcher to participants' context. Cases were selected to ensure the study focused on people currently experiencing mental illness and those engaged in providing support or service to PWMI and their families in rural settings. Criteria was set to avoid selecting people who will not add value to this research. The data were analysed according to qualitative and quantitative methods. The study adds to the body of knowledge because it researched aspects related to mental illness in rural areas rather than urban areas.

The review of the literature indicated the challenges posed by mental illness to both PWMI and their families. It also showed that community-based programmes are effective in improving social functioning of PWMI and their families in both developed and developing countries (Saxena, et al. 2006; Bronowski, et al. 2011). These programmes are underdeveloped in certain countries especially in South Africa, where this study was conducted (Petersen & Lund 2011; Ramlall, et al. 2012). The literature highlighted the importance of collaborations and stakeholders' involvement in mental health care (DoH 2012). In South Africa, where the government has made efforts for collaboration and even recognized stakeholders' involvement through policy and legislation, studies have indicated slow progress and poor implementation (Skeen, Kleintjies, Lund, Petersen, Bhana, Flisher & MHaPP 2010; Campbell-Hall, Petersen, Bhana, Mjadu, Hosegood, Flisher & MHaPP 2010).

Semi-structured interviews were used with the aim of understanding participants' experiences and the meaning they attached to mental illness as well as strategies adopted to cope with the condition (Greeff 2011; Babbie & Mouton 2012). Focus group discussions gave stakeholders an opportunity to get together and create meaning out of

an issue at hand (Greeff 2011; Babbie & Mouton 2012). The self-administered questionnaires (Annexure 17) with both closed and open-ended questions minimized bias errors that could have arisen from interviewer's characteristics and the inconsistencies in interviewing skills hence increasing the reliability of the responses (Phellas, Bloch & Seale 2011). Additionally, the interview schedules that were developed for both semi-structured interviews with PWMI and their families as well as the focus group discussions (Annexures 14 - 16) identified issues to be discussed with regards to coping with mental illness and the extent of support provided to PWMI and their families (Greeff 2011).

The quantitative data analysis were undertaken with SPSS (22.0) to allow for univariate and bivariate results (Babbie 2010). The qualitative data analysis involved transcribing recorded interviews and eventually coding of data which generated themes (Creswell & Clark 2007; Babbie 2010). For the interviews and focus group discussions case narratives were presented to provide a thick descriptions of PWMI and their families as well as stakeholders' views of the topics discussed (Babbie & Mouton 2012).

3 AIMS AND OBJECTIVES OF THE STUDY

The aim of this study was to develop a framework for a community-based programme for people with mental illness and their families in a rural setting. This assumption was that community-based programmes can improve the well-being of PWMI and their families in rural settings.

To achieve this aim, an extensive literature review focusing on mental health services in rural areas, the impact of mental illness, coping with mental illness and developing community-based programme framework was conducted. The literature review covered personal, social and the environment levels of the analysis. It also aided the delineation of the study and the development of tailor-made questionnaires and interview schedules for the different participating groups. The aim was also achieved through empirical investigations involving a situational analysis that captured the perspectives of health care professionals, PWMI and their families as well as various stakeholders within the community.

Based on both the literature review and empirical investigations, two-level interventions were developed. These were an educational social group work programme as an intervention aimed at PWMI and their families as well as guidelines for health care

professionals and stakeholders. Furthermore, from the results a framework for a community-based programme was developed.

4 REVISITING THE OUTLINE OF THE STUDY AND RESPONDING TO THE RESEARCH QUESTIONS

Chapter 1 gave a background on the prevalence of mental illness in the world. Although there is no significant difference in this prevalence between urban and rural areas, the discrepancies in terms of resource allocation make all the difference. This chapter also outlines various methods used to achieve the research aim. In the course of understanding factors associated with mental illness and attempting to develop a framework, this study sought to address a number of gaps in the literature and practice by answering the following research questions:

- 1) How do health care professionals perceive the mental health services they render to people with mental illness and their families in rural settings?
- 2) How do people with mental illness and their families in rural settings cope with mental illness?
- 3) What is the view of stakeholders with regards to the role they play as support system for PWMI and their families in rural settings?
- 4) What can be done to guide social workers to develop and implement community-based programmes to improve the well-being of PWMI and their families in rural settings?

These questions were based on the ecological perspective which states that people's behaviour is influenced by their interaction with their environment, therefore, they demand an exploration of how certain aspects of the environment affect or respond to the needs of PWMI and their families. The responses to these questions was categorised into three phases. Phase 1 attempted to respond to the first three research questions, which were addressed in Articles 1-3. The responses to these questions resulted in the formulation of the fourth question which was addressed in Phases 2 and 3, as outlined in Article 4.

4.1 Article 1: Assessing mental health services in a rural setting: service providers' perspective.

Article 1 focused on assessing mental health services as the first step in improving the well-being of PWMI and their families. This was a survey study aimed at establishing how health care professionals perceive the mental health services they render to PWMI and their families in a rural setting. The assessment of mental health services at Mashashane was based on the eight attributes of good mental health service delivery, namely, comprehensiveness, accessibility, service coverage, continuity of care, quality, person-centeredness, coordination as well as accountability and effectiveness (Haggerty, Burge, Lévesque, Gass, Pineault, Beaulieu, & Santor 2007; WHO 2008). Data was sourced through self-administered questionnaires completed by doctors, nurses, occupational therapists, psychologists and social workers from two hospitals and two clinics as health establishments that serve Mashashane.

Overall, the survey results showed that out of the eight assessed attributes, only comprehensiveness was positively perceived by health care professionals. The results showed that several services including preventative, health promotion, rehabilitative and support are rendered. In addition, health care professionals talked to their clients about other issues apart from those they consulted for. Although comprehensiveness was positively perceived, it should be noted there were certain aspects that were a cause for concern. The most important one was the reported availability of multi-disciplinary team (MDT), however, this team is not integrated in the primary health care (PHC) because the members of the team do not attend to mental illness cases in clinics. Secondly, the MDT members do not collaborate to develop care plans for PWMI, therefore, its availability is not beneficial to rural PWMI and their families. This implies that the needs of PWMI and their families are not addressed holistically.

Other attributes had positive elements identified, however these were outweighed by the negative elements. The results showed that although the majority of health care professionals do not render 24-hour service, they do not make arrangements for clients to access a particular service after hours and in times of crisis. These results also showed that clients wait for long periods to receive certain services. On a positive note, clinics were reported to be more accessible than hospitals in terms of geographic locations. The government's aim of increasing accessibility by integrating mental health services in PHC

has been achieved to some extent, although clinics do not have full complement of staff, namely, doctors, occupational therapists and psychologists. Clinics, therefore, rely on health care professionals from hospitals who visit clinics as part of their outreach. In addition, hospitals rely on infrequently-visiting psychiatrists from tertiary hospitals. The unavailability of certain services can have a negative impact on the help seeking behaviour of PWMI resulting in the persistence of mental illness. In addition, the clinics' reliance on hospitals put pressure on the hospitals' limited resources.

The results showed that there is poor continuity of care, as health care professionals neither attend to the same person over a long period of time nor do they follow-up on clients who missed appointments nor those they referred. The poor continuity of care denies the health care professionals the opportunity to build a trusting relationship that will enable them to gain better understanding of the needs of PWMI and their families.

With regards to the quality of service, most health care professionals indicated that they neither attend training nor receive any technical support or supervision. As a result, they lack knowledge about mental illness and mental health related issues. This may have negative impact on the well-being of PWMI and their families due to poor management caused by lack of knowledge of mental illness. The majority of health care professionals do not benchmark with other institutions delivering a similar service. This denies them the opportunity to be exposed to the latest evidence-based practices that can contribute positively to their professional development and practice.

In terms of person centeredness, most health care professionals do not involve PWMI and their families in decisions regarding treatment choices and when making plans to change some aspects of their service. These results imply that health care professionals do not recognize the meaningful contribution that can be made by PWMI and their families on mental health services. This also means that mental health services are not designed according to the needs of PWMI and their families which may result in underutilization of service, hence non-adherence to treatment.

The results showed poor coordination of care as health care professionals do not encourage rural clients to attend programmes in the community, engage with voluntary groups in the community or establish networks with external stakeholders. In addition, health care professionals do not refer or receive referrals from external stakeholders. This is an indication of an existing barrier that prevents collaboration between health care

professionals and other stakeholders despite the emphasis on the significance of collaborations in the literature.

With regards to accountability and effectiveness, most health care professionals indicated that their services are audited, however, this does not bring any change as management does not allocate resources relevant to mental health service delivery. In addition, training needs, hiring and retaining of skilled staff and the provision of support are not prioritized. There are communication channels to engage staff members, although health care professionals mentioned that they are not consulted on decisions that may affect their service provision. There are also poor procedures for dealing with complaints. This could result in poor mental health service delivery as health care professionals are overworked and demotivated. It may also result in poor relationship between health care professionals and management.

In conclusion, the study showed that there is little improvement in the delivery of mental health services despite the South African government's commitment through policy and legislation. These results reinforce the call for greater attention to be paid to forming and strengthening partnerships with other stakeholders in order to improve mental health service delivery in rural settings. The assessment of mental health services yielded important results that were used in the development of the community-based programme framework.

4.2 Article 2: Coping with the disease: the experiences of PWMI and their families in a rural setting.

Mental illness poses challenge for PWMI and their families. This study investigated coping strategies of both PWMI and their families. Data were collected through individual semi-structured interviews with PWMI and their families. The ecological perspective was used to gain an understanding of the interactional processes between the target group and the environment. The resilience theory highlighted the PWMI and their families' ability to deal with mental illness as a life adversity.

Both PWMI and their families mentioned that they have a poor understanding of mental illness irrespective of knowing or not knowing the diagnosis. In an attempt to create meaning out of the situation, results showed that participants based their understanding on commonly perceived causes of mental illness with witchcraft as a dominating cause.

The results also showed that participants acknowledged the importance of treatment and that treatment reduces the chances of relapse.

The results indicated that both formal and informal support systems are available but they, in general do not provide adequate support to PWMI and their families. This lack of support could be the reason caregiving family members are more susceptible to emotional reactions than the PWMI. These emotions exacerbate the feeling of obligation to care for PWMI resulting in caregivers' limited participation in social activities. PWMI isolate themselves due to past and current experiences with stigma. Additionally, PWMI experience physical challenges related to treatment side effects. The results also showed that both PWMI and their families experience financial challenges as the social assistance grant does not meet their needs. These aspects can influence non-adherence and underutilization of mental health services especially when PWMI are required to consult at a hospital and not at the nearest health-care centre.

Both PWMI and their families have adopted adaptive and maladaptive coping strategies. Adaptive coping strategy refers to accepting the presence of mental illness as well as seeking and getting support from both formal and informal systems. Maladaptive coping strategy on the other hand refers to avoiding difficult situations. These results indicate that the challenges experienced by PWMI and their families are related to individual, family and community factors. They also proved to be of importance in the development of any community-based framework and intervention that will equip PWMI and their families with the necessary skills to cope with mental illness.

4.3 Article 3: Stakeholders' views regarding their role as support system for people with mental illness and their families in rural South Africa

WHO (2013) advocates for the involvement and collaboration of "informal" mental health care providers such as, religious leaders, faith and traditional healers, police officers as well as local nongovernmental organizations as they play a crucial role in improving well-being of PWM and their families. This study explored the views of stakeholders such as the traditional leaders, traditional health practitioners (THPs), church members, police officers and home-based care groups regarding their roles as support system for PWMI and their families. Data was collected through focus group discussions with each stakeholder group.

Results of this study revealed that stakeholders based their understanding of mental illness on abnormal behaviour displayed by PWMI; this includes undressing in public, breaking things as well as aggressive acts, such as, killing a chicken with their bare hands. Stakeholders associated mental illness with multiple causes including witchcraft, substance abuse, depression as well as too much suffering as a result of poverty. The study revealed that stakeholders acknowledged that the support they provide to PWMI and their families was inadequate; this was associated with their fear and lack of skill to deal with PWMI. Stakeholders identified collaboration as a mechanism to improve working relationships, although attitudinal issues prevailed as a barrier to them providing necessary support. As a result, stakeholders suggested intervention by a third party, such as Department of Health not only to facilitate the collaborative efforts but to also provide much of the supportive role. This study highlighted aspects that were important for the development of an intervention at community level.

4.4 Article 4: A framework for a community-based programme for people with mental illness and their families in a rural setting

This article covers Phases 2 and 3. The purpose of this section was to develop and evaluate a community-based programme framework for PWMI and their families. The framework's development process was influenced by the literature reviewed and the results of the three studies conducted in Phase 1. The results in Phase 1 showed that the existing challenges were influenced by both individual and community factors, hence interventions aimed at individuals and their families as well as community levels were developed. A six module social group work educational programme was developed for PWMI and their families in conjunction with guidelines for health care professionals and stakeholders to improve provision of support to PWMI and their families. These interventions were assessed during the process of the research to determine their appropriateness and relevance to the context. The assessment results showed that these interventions were appropriate to the context.

After all amendments had been taken into cognisance, a seven step framework to guide social workers on the development and implementation of a community-based programme was proposed. In the programme framework, each step makes recommendations about factors that the social worker should take into consideration during further development and implementation processes.

5 POTENTIAL IMPLICATIONS OF STUDY RESULTS

This result of this study have a number of policy and practical implications for practitioners, stakeholders as well as policy-makers.

This study revealed that mental health services in rural areas are inadequate as most findings showed a disjuncture between policy and implementation. There is a need for policy dissemination in various health establishments around rural areas to help health care professionals reflect on their practices in terms of policy regulations and the needs of PWMI and their families.

The suggestion that health care professionals and stakeholders lack skills to deal with PWMI should imply to policy-makers that these service providers can be empowered through continuous information sharing sessions and skills development programmes. These programmes should be able to differentiate between the needs of various stakeholders and address them accordingly. Additionally, this highlights the need to incorporate mental health education in both secondary and tertiary education curriculum.

This study also revealed that there is poor collaboration between health care professionals and stakeholders. It is therefore recommended that, regular meetings be held to strengthen the working relationships and establish networks between the two groups. This also implies that policy-makers should come up with mechanisms to establish and facilitate effective collaborative efforts within communities to assist mental health stakeholders to provide proper support to PWMI and their families.

At a practical level, the framework provides practical guidelines to assist social workers to develop and implement community-based interventions that will help improve the general well-being of PWMI and their families in a rural setting. This framework is designed so that it can be modified to suit the needs of a specific target group.

6 RECOMMENDATIONS FOR FUTURE RESEARCH

The following recommendations are based on the literature reviewed and the results of the current study:

- The study was limited to health care professionals from four health establishments. It is therefore recommended that a study encompassing a large number of health establishments be conducted.

- This study limited participation to PWMI who were considered stable and the family members who had been responsible for primary caregiving. Future research therefore, should also involve the views of other family members within the same household as they form part of the family unit. Direct experiences and suggestions from other family members may give constructive feedback about living with mental illness and strategies that can be put in place to help improve their well-being.
- Another study could focus on coping strategies of families caring for PWMI who refuse to seek help resulting in them presenting persistent psychotic symptoms and disruptive behaviour.
- The establishment and management of collaborations for the improvement of mental health service delivery deserves support arising from empirical research and theoretical attention. Collaborations play a crucial role in South African mental health service delivery, but this has proved to be difficult to conceptualise and properly facilitate. This study confirms the need and possibility of collaborations, however it also highlights the barriers that may hinder any efforts to establish and manage these collaborations. Research which seeks to resolve this difficulty is likely to contribute to the existing body of knowledge and be helpful to both policy-makers and various stakeholders.
- It is also recommended that the proposed intervention aimed at the health care professionals and stakeholders should be piloted in diverse environments.

7 SUMMARY AND CONCLUSIONS

The current study is unique because its findings or primary data are from three different perspectives, namely, health care professionals, PWM and their families as well as stakeholders. This data formed the basis for the development of the community-based programme framework. Evaluation of this framework by various stakeholders indicated its relevance in a rural context.

The main contributions of this study is to enhance theoretical and practical perspective of the framework development process and the sub-processes it comprises. The quality of the framework is enhanced by the fact that it combines the efforts of other scholars, acknowledges the lived experience of PWMI and their families, policies and reorganization of existing activities in the process. In particular, the framework creates an opportunity for evidence-based practice. It also contributes to the body of knowledge

because it investigates several aspects that can be of value to the lives of PWMI and their families in rural settings. This study provides useful information that policy-makers should take into consideration while attempting to establish and strengthen partnerships and collaborations between stakeholders. A study of this nature should result in further reflections on services rendered.

In conclusion, this study recommends that social workers should work towards using this framework as a tool for guiding their efforts to develop and implement community-based programmes as they assist in lessening the workload, empowering vulnerable groups and improving the general well-being of PWMI and their families. This framework can be modified to suit the needs of any targeted population at any point in time.

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SECTION D: ANNEXURES

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ANNEXURE 23: QUESTIONNAIRE TO ASSESS INTERVENTION AIMED AT HEALTH CARE PROFESSIONALS AND STAKEHOLDERS **Error! Bookmark not defined.**

ANNEXURE 24: SOCIAL GROUP WORK EDUCATIONAL PROGRAMME..... **Error! Bookmark not defined.**

ANNEXURE 25: GUIDELINES FOR HEALTH CARE PROFESSIONALS AND STAKEHOLDERS TO IMPROVE SUPPORT TO PEOPLE WITH MENTAL ILLNESS AND THEIR FAMILIES IN A RURAL SETTING **Error! Bookmark not defined.**

ANNEXURE 26: THE SELECTED JOURNAL'S GUIDELINES FOR AUTHORS **Error! Bookmark not defined.**

International Journal of Mental Health **Error! Bookmark not defined.**

International Journal of Family Studies..... **Error! Bookmark not defined.**

Community Mental Health Journal..... **Error! Bookmark not defined.**

Southern African Journal of Social Work and Social Development**Error! Bookmark not defined.**

ANNEXURE 1: ETHICS APPROVAL



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: (018) 299-4900
Faks: (018) 299-4910
Web: <http://www.nwu.ac.za>

Ethics Committee

Tel +27 18 299 4850
Fax +27 18 293 5329
Email Ethics@nwu.ac.za

ETHICS APPROVAL OF PROJECT

The North-West University Ethics Committee (NWU-EC) hereby approves your project as indicated below. This implies that the NWU-EC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title:	"Bio-psychosocial well-being interventions for challenged marginalized and vulnerable individuals, groups and communities"																												
Project Leader:	Prof Ryke																												
Ethics number:	<table border="1"> <tr> <td>N</td><td>W</td><td>U</td><td>-</td><td>0</td><td>1</td><td>2</td><td>5</td><td>-</td><td>1</td><td>1</td><td>-</td><td>A</td><td>1</td> </tr> <tr> <td colspan="4">Institution</td> <td colspan="4">Project Number</td> <td colspan="2">Year</td> <td colspan="4">Status</td> </tr> </table>	N	W	U	-	0	1	2	5	-	1	1	-	A	1	Institution				Project Number				Year		Status			
N	W	U	-	0	1	2	5	-	1	1	-	A	1																
Institution				Project Number				Year		Status																			
Approval date:	2014/03/05																												
Expiry date:	2019/03/04																												

Special conditions of the approval (if any): None

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- The project leader (principal investigator) must report in the prescribed format to the NWU-EC:
 - annually (or as otherwise requested) on the progress of the project,
 - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-EC. Would there be deviations from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-EC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-EC retains the right to:
 - request access to any information or data at any time during the course or after completion of the project;
 - withdraw or postpone approval if:
 - any unethical principles or practices of the project are revealed or suspected,
 - it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,
 - the required annual report and reporting of adverse events was not done timely and accurately,
 - new institutional rules, national legislation or international conventions deem it necessary.

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof Amanda Lourens
(chair NWU Ethics Committee)

ANNEXURE 2: LETTER FROM MASHASHANE TRIBAL AUTHORITY



REF NO: LH 12/8/4-92
Enq: Robert Mashashane
Cell:083 446 0327/078 3603 555

Mashashane Traditional Authority
P. O Box 27
MASHASHANE
0743
11 July 2014

Mantona a Ga-Mashashane


TUMELELO YA GO DIRA DINYAKIŠIŠO TŠA BATHO BAO BA SEGO BA ITEKANELA MENAGANO

Thobela,

Re kgopela gore le amogele Mrs T.C Masea, yena o tlo dira dinyakišišo tša batho bao ba sego ba itekanela menagano mono Ga-Mashashane, yena ke moithuti go tšwa North West University, Potchefstroom Campus.

Re ka thaba ge le ka mo amogela

Wa lena


SENIOR ADMIN OFFICER

11/07/2014
DATE



ANNEXURE 3: LETTER FROM THE DEPARTMENT OF HEALTH – LIMPOPO PROVINCE



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila

Ref:4/2/2

Matsea TC
North-West University
Private Bag X6001
Potchefstroom
2520

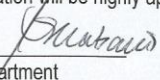
Greetings,

A community –based programme to improve the well-being of people with mental illness and their families in a rural setting.

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. 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.
 - The above approval is valid for a 3 year period.
 - If the proposal has been amended, a new approval should be sought from the Department of Health.

Your cooperation will be highly appreciated.


Head of Department


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>

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

ANNEXURE 4: LETTER FROM PRIMARY HEALTH CARE



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

CAPRICORN DISTRICT

AGANANG SUB DISTRICT

Enquiries: Mashao M.E.

Tel. No. 015 224 4083

Cell No. 0824438530

TO: MATSEA T.C.
NORTH-WEST UNIVERSITY
POTCHEFSTROOM CAMPUS

RE: THE RESEARCH PROJECT- A community –based programme to improve the well -being of people with mental illness and their families in a rural setting community.

The above matter has reference.

This office acknowledges your presence in Mashashane area to conduct a survey with regard to the above mentioned study.

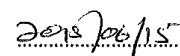
It is understood that the survey requires the participation of Professional nurses from Mashashane clinic as well as from the mobile teams within this area.

It is further understand that a consent should be obtained from the participants.

Participation of the prospective respondents is assured.

Regards.


.....
Acting Deputy Manager


.....
Date.

ANNEXURE 5: RESPONSE FROM HOSPITAL MANAGEMENT

Thabisa Matsea

From: Kholofelo.Moabelo <Kholofelo.Moabelo@dhsd.limpopo.gov.za>
Sent: 19 May 2015 08:14 AM
To: Thabisa Matsea
Subject: RE: Participation in a survey

Good morning Thabisa Matsea

I acknowledge receipt of your request and approval to participate in a survey.
We will wait for you.
Regards

Kholofelo Moabelo

-----Original Message-----

From: Thabisa Matsea [mailto:Thabisa.Matsea@univen.ac.za]
Sent: 18 May 2015 06:09 PM
To: Kholofelo.Moabelo
Subject: Participation in a survey

Dear Ms Moabelo

Please attached documents for your attention.

Your response in this matter will highly appreciated.

Yours truly
Thabisa Matsea

DISCLAIMER: This message and any attachments are confidential and intended solely for the addressee. If you have received this message in error, please notify the system manager/sender. Any unauthorized use, alteration or dissemination is prohibited. The Department of Water and Sanitation further accepts no liability whatsoever for any loss, whether it be direct, indirect or consequential, arising from this e-mail, nor for any consequence of its use or storage.

ANNEXURE 6: LETTER FROM SOUTH AFRICAN POLICE SERVICES

SAP 21



SUID-AFRIKAANSE POLISIEDIENS

SOUTH AFRICAN POLICE SERVICE

Private Bag X9428

Verwysing Reference	20/3/4
Navrae Enquiries	Brig Mulaudzi Col Machabaphala
Telefoon	015 290 6231
Faksnommer Fax number	015 290 6210

THE PROVINCIAL COMMISSIONER
SOUTH AFRICAN POLICE SERVICE
LIMPOPO
0700

2014-12-12

- A. The Provincial Commissioner
South African Police Service
LIMPOPO
- B. The Cluster Commander
South African Police Service
Seshego
- C. The Station Commander
South African Police Service
Mashashane
- D. Mrs Matsea TC
P o Box 4115
Polokwane
0699

REQUEST TO PARTICIPATE IN THE RESEARCH INTERVIEW: PHD: NORTH WEST UNIVERCSTY: TITLE: A COMMUNITY BASED PROGRAMME TO IMPROVE THE WELL- BEING OF PEOPLE WITH MENTAL ILLNERS AND THEIR FAMILIES IN A RURAL SETTING: MRS TC MATSEA.

- A. 1. Copy for information.
- B&C 1. Your office is informed that the application of Mrs TC Matsea is approved to conduct the research and that two Police officials from Mashashane SAPS be allowed to participate in the research.
- 2. Attached Mrs TC Matsea 's applications as well as letter from the University of North West .
- 3. Your request has been approved.

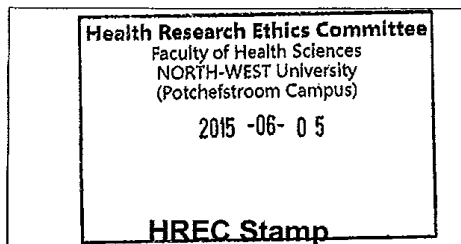

DEPUTY PROVINCIAL COMMISSIONER: LIMPOPO
DEPUTY PROVINCIAL COMMISSIONER
PHYSICAL RESOURCE MANAGEMENT
LIMPOPO PROVINCE
N.M. DLADLA

2014-12-17

ANNEXURE 7: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR PWMI-VERNACULAR



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOM CAMPUS



LETLAKALANA LA TSEBO LA BATSEAKAROLO LE FOROMO YA TUMELELO YA BATHO BA GOBA LE BOLWETSI BJA MONAGANO BJALO KA BATSEAKAROLO

HLOGO YA LENANEO LA DINYAKISISO: *Lenaneo la setšhaba la go hlabolla seemo sa bophelo sa batho bao ba fokolago monaganong le malapa a bona dinagamagaeng.*

NOMORO YA TSHUPO: NWU- 00125-11-A1

MONYAKIŠIŠI: Mohumagadi T.C. Matsea

ATERESE: Yunibesithi Ya Bokone-Bophirima, Potchefstroom

NOMORO YA MOGALA: 083 552 6706

Memo ya go tšea karolo

O mengwa go tšea karolo go dinyakišišo tšeo e tla go ba karolo ya thuto ya PhD ya bodirelaleago. Tšea nakonyana go bala segwalwa seo o se filwego e bile se hlalosago ka botlalo seo dinyakišišo di lego ka sona. Le ka botšiša monyakišiši dipotšišo ka se sengwe le sengwe seo le sa se kwešišego mabapi le lenaneo le. Go bohlokwa kudu go kgotsofala le go kwešiša seo lenaneo le dinyakišišo di lego ka sona le gore o ka kgatha tema biang.ga o gapeletšwe go tšea karolo e bile o na le tokelo ya go gana go tšea karolo gomme seo ka se go ame gampe. O na gape le tokelo ya gogela morago goba go gogela morago nako efe le efe go dinyakišišo tše.

A dinyakišišo di mabapi le eng?

Dinyakišišo di dirwa metsaneng yeo e lego bokgole bjo e ka bago dikilometara tše lesome go dikologa mošate wa gaMashashane, e bile o tla akaretša go lebelelwa ga dingwalwa le go botšiša dipotšišo go batho ka o tee o tee le dihlopha tše di ilšego gammogo le banyakišiši bao ba nago le maitemogelo e bile ba hlahliwe go tša bodirelaleago. Di tla akaretša batšeakarolo

baq e ka bago bā:lekholo le masome a mabedi (120). Karolo ye:ya dinyakišišo e tla tsinkela go dihlotswana tša batho bao ba nago le bolwetši bja monagano (ba sa itekanelago monagano) le malapa a bona, mo go lebeletšwego batšeakarolo ba e ka bago ba ba masome a mabedi (20).

Maikemišetšo a dinyakišišo tsše ke:

- Go lekodišiša seemo sa tša lephelo le hlokomelo dinagamagaeng,
- Go tšweleta kwešišo ya gore na batho ba bolwetši bja monagano le malapa a bona ba phela bjang,
- Go nyaka go kwešiša karolo yeo batšeakarolo ba go fapafapana ba e tšeago ga bjale le gore ke efe karolo yeo ba ka e bapalago go ya pele,
- Go tšweletša lenaneo la setšhaba leo le kago tliša hlabologa le leemo le lebotse la batho bao ba nago le bolwetši bja monagano le malapa a bona dinagamagaeng,
- Go tšweletša mokgwa woo le lenaneo leo badirelaleago le bašomi ba tša maphelo ba ka go di šomiša go hlabolla seemo sa batho bao nago le bolwetši bja monagano le malapa a bona.

Ke ka lebaka la eng le memilwe go tla go tšea karolo?

- O memilwe go tla go tšea karolo ka lebaka la karolo yeo le e tšeago go batho bao sa itekanelago menaganong le malapa a bona, ka go bafa thuso yeo e itšego goba le ka tša semolao.
- Ka tebelelo o na le mašwanedi a go tšea karolo goya le ka mekgwa e e šhomishwago go hlopa batšeakarolo: o magareng ga mengwaga e lesome-seswai le masome-tshela, le gona o ile a amogelwa bookelong mabapi le go se itekanele monaganong gape o saka wa wela fase dikgweding tse tshela tsa go feta.
- O ka beelwa ka thoko ge e ba ga o a itekanela gabotse go ka tšea karolo goba wa fa tumelo.

Na maikarabelo a gago ke afe?

- O lebeletšwe go tšea karolo go dihlotswana tšeo di tlogo araba pele le morago ga ge lenaneo la setšhaba le thomile le go lekwa gape morago ga dibeke tše tshela lenaneo le fedile. Dipotšišo di ka tšea tekano ya lri ye tee go ba lri le metotso ye masometharo.

A o tla hwetša moputso go o tšea karolo go dinyakišišo tše naa?

- Moputso o ka o hwetšago wa thwii ke go hwetša sebaka ka o bolela ka maitemogelo a gago. Gape o ka hwetša bokgone bja go nna o phela ka tsela e maleba le bolwetši bja monagano.
- Ka hlakoreng le lengwe dipoelo tša dinyakišišo tšeo o bilego karolo go tšona di ka šomišwa go tšwela pele go thuša batho bao ba nago le bolwetši bja monagano setšhabeng sa Afrika-Borwa ka bophara.

E ka ba go na le kotsi, yeo e lego gona ge o tšea karolo go dinyakišišo tše?

- Go ya ka maitemogelo a re na re lemoga gore dipoledišano tšeo di amago monagano di ka tsoša maikutlo a go fapafapana. Ge go le bjalo go tla ba le peakanyo le modirelaleago go thuša bao ba kago huduega goba go se ikettle. Ge o nyaka o ka emiša ka go araba dipotšišo.
- Le ge dipotšišo di ama maitemogelo a gago, leina la gago le ka se tšweletšwe phatlalatšwa, e tla ba gare ga gago le monyakišiši. Yo a tšea go karolo a ka se tšweletšwe go diphalašo go tšwa go dinyakišišong tše, ke feela sehlopha sa banyakišiši seo se tlogo šomiša tsebo yeo le re filego yona. Tsebo yeo e lego ya bonoši e ikgethilego e tla šireletšwa ya bolokwa fao e ka se fihlelelwego ke mang le mang.

Go tla diragala eng ge go o ka ikhwetša o sa lokologe e le ka lebaka la go tšea karolo ga gago mo dinyakišišong tše?

- Ge o ka hwetša go hlokagala gore o tšwele pele ka poledišano morago ga ge o emišitše ka lebaka la go se lokologe, sebaka se ka beakanywa le modirelaleago yo a ngwadišitšwego ka maleba gore o tšwele pele.

Ke mang a tlogo le tokelo ya go bala dipelo tša dinyakišišo?

- Ditaba ka moka tšeo di kgobokeditšwego mo dinyakišišong tše di tla tšeiwa bjalo ka tše bohlokwa tšeo di sa swanelago go bonwa goba go balwa ke mang le mang, le maina a batšeakarolo a ka se beiwe phatlalatša, a tla beiwa ka di nomoro tšeo di tsebagalago go banyakišiši le batšeakarolo feela.
- Ditaba ka moka tseo dikgobokeditšwego di tla tšeiwa bjalo ka tše di bohlokwa tseo di sa swanelago go bona ke mang le mang gomme monyakišiši o tšea maikarabelo a gore di bonwa ke mafapa afe. Ditaba ka moka tšeo di kgobokeditšwego di tla beiwa ka fase ga hlokomelo le taolo ya Yunibesithi ya Bokone-Bophirima, ka ge ditaba ka moka tšeo di kgobokeditšwego e le thoto ya Yunibesithi ya Bokone-Bophirima. Ditaba ka moka tšeo di kgobokeditšwego di tla beiwa tekano ya mengwa e supileng.

A batseakarolo ba tla fiwa moputsu goba ba tla lefa go tšea karolo?

Aowa, o ka se fiwe moputsu go ba motšeakarolo. Go ka se be le seo o se lefago go tšea karolo.

A e ka ba go na le se sengwe seo o lokelago go se tseba goba go se dira?

- O ka ikgokaganya le ba Health Research Ethics Committee ka Mrs Carolien van Zyl go nomoro ye ya mogala: 018 299 2089; goba go email address ya: carolien.vanzyl@nwu.ac.za
- O tla amogela setsopolwa sa ditaba tšeo di kgobokeditšwego le foromo ya tumelelano.

A o tla tseba bjang ka dipoelo tsa dinyakišišo?

Dipoelo tša dinyakišišo di ka fihlelelwa ge o ka Ikgokaganya le monyakišiši yo mogolo.

Keno ka motseakarolo

Nna, ke le....., e bile ke saenne mo fase, ke dumela go ba motseakarolo.

Ke dumela goba ke laetsa gore:

- Ke badile seo se ngwadilwego fa le foromong ya tumelelo, e bile e ngwadilwe ka leleme leo ke le kwešišago gabotsebotse.
- Ke bile le sebaka sa go botšiša dipotšišo go yo a re file.go diforomo gammogo le go monyakišiši, e bile dipotšišo tsa ka di arabilwe ka bottalo.
- Ke kwešiša gore go tsea karolo go dinyakišišo tse ke go ithaopa ga ka, e bile ga ke a gapeletswa go dira bjalo.
- Nka kgetha go tlogela go tsea kaolo nako efe le efe e bile ga go ka moo nkago bonwa molato.
- Nka kgopelwa go tlogela go ba motseakarolo pele ga ge dinyakišišo di fela ge monyakišiši a bona go šwanetše, goba ge sa šepele go ya lenaneo la dinyakišišo, bjalo ka ge go dumelelane.

Isayinwe ko ka di 20....

.....
Mosaeno wa motseakarolo

.....
Mosaeno wa paki

Keno ka monyakišiši.

Nna ke le, ke ikana gore:

Ke hlaositše dikagare tša sengwalwa se go:

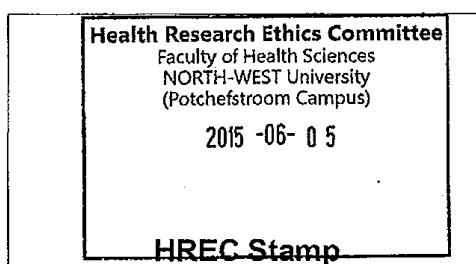
- Ke mo hlohleleditše gore a botšiše dipotšišo le gore a tšee nako pele a ka di araba.
- Ke kgotsofetše gore motseakarolo o kwešišitše dinhla ka moka tša dinyakišišo tše bjalo ka ge boledišanwe.
- Ke šomišitše mohlalosi wa ka thoko /Ga ke a šomiša mohlalosi wa ka thoko.

Isayinwe ko ka di 20....

.....
Mosaeno wa monyakišiši.

.....
Mosaeno wa paki

ANNEXURE 8: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR PWMI – ENGLISH VERSION



PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR PEOPLE WITH MENTAL ILLNESS AS PARTICIPANTS

TITLE OF THE RESEARCH PROJECT: A community-based programme to improve the well-being of people with mental illness and their families in a rural setting

REFERENCE NUMBERS: NWU- 00125-11-A1

RESEARCHER: Ms TC Matsea

ADDRESS: North West University, Potchefstroom

CONTACT NUMBER: 083 5526706

Invitation to participate

You have been invited to participate in a research study that forms part of a PhD's dissertation in social work. Please take some time to read the information presented, which will explain the details of this study. Please ask the researcher any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you did agree to take part.

What is this research study all about?

- *The study will be conducted in various villages within the 10 km radius from the chief's kraal at Mashashane and will involve surveys, individual interviews and focus group discussions. The undersigned, an experienced researcher trained in social work, and approximately 120 participants will be involved in this study. This part of the study will*

focus on semi-structured interviews with people with mental illness and their families, of which 20 participants will be included.

The objectives of this research are:

- to assess the nature of mental health care services in a rural setting,*
- to establish how people with mental illness and their families currently cope with mental illness,*
- to explore the current and potential roles of the different stakeholders in a rural setting,*
- to develop a programme for a community-based programme that will be used to improve the well-being of people with mental illness and their families in a rural setting, and*
- to evaluate the appropriateness and usefulness of the programme as a guide for social workers and other health care professionals for improving the well-being of people with mental illness and their families.*

Why have you been invited to participate?

- You have been invited to participate because you have been formally diagnosed with mental illness and you are taking treatment for mental illness in a known public health centre, and your perceptions and experiences are therefore very valuable to us.*
- You have also complied with the following inclusion criteria: You are between the ages of 18 and 60 years, and had previously been hospitalised due to mental illness and had not relapsed for the past six months.*
- You will be excluded if: You are not sufficiently well to participate or give consent.*

What will your responsibilities be?

- You will be expected to participate in semi-structured interviews before and after the community-based programme has commenced and retested approximately 6 weeks after the completion of the programme. These interviews will be conducted in your home and will take approximately an hour to one and a half hours.*

Will you benefit from taking part in this research?

- The direct possible benefits for you as a participant could be the opportunity to share your experiences with mental illness.*
- You will indirectly benefit from this study as the findings will be used for further interventions within the people with mental illness population of South Africa.*

Are there risks involved in your taking part in this research?

- From our experiences we know that the discussion of personal experiences could possibly provoke an emotional experience or response. An arrangement with a registered social*

worker will however be made to assist you if you experience any discomfort. You may also stop with the interview process at any point.

- Although the discussions will involve your personal experiences, your name will never be made known and all data will be handled as confidential as possible. No individual identifiers will be used in any publications resulting from this study and only the researcher will work with the information that is shared. All sensitive information will be protected by locking it up and storing it on a password protected computer.
- The researchers will require you to complete a mental capacity evaluation form as you need to be mentally fit and healthy to participate.

What will happen in the unlikely event of some form of discomfort occurring as a direct result of your participation in this research study?

- Should you have the need for further discussions after the above mentioned discomforts; an opportunity will be arranged for you to have a debriefing session with a registered social worker.

Who will have access to the data?

- All gathered data will be treated with confidentiality, and anonymity will be ensured by providing each participant with a participant code. Data sets will not contain participant names or any other information that could be used to identify individual participants. All of the data files will be treated as confidential, and the researcher will regulate access to data. All data will be kept confidential under secure control of the North-West University, as all raw data remains the property of the North-West University. The data will be stored for a specified minimum period of seven years.

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

No you will not be paid to take part in the study. There will be no additional costs involved for you, if you take part.

Is there anything else that you should know or do?

- You can contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 2089; carolien.vanzyl@nwu.ac.za if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

How will you know about the findings?

- The findings of the research will be shared by the researcher with you through the means of one on one discussion.

Declaration by participant

By signing below, I _____, the undersigned hereby consent to take part in the study.

I declare that:

- I have read this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions to both the person obtaining consent, as well as the researcher and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and that I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 20....

.....
Signature of participant

.....
Signature of witness

Declaration by person obtaining consent

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (*place*) on (*date*) 20....

.....
Signature of person obtaining consent

.....
Signature of witness

Declaration by researcher

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did not use an interpreter.

Signed at (*place*) on (*date*) 20....

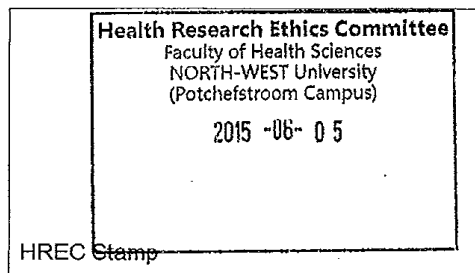
.....
Signature of researcher

.....
Signature of witness

ANNEXURE 9: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR FAMILY MEMBERS – VERNACULAR



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOM CAMPUS



LETLAKALANA LA TSEBO LA BATSEAKAROLO LE FOROMO YA TUMELELO YA MALOKO A MALAPA A BALWETSI MONAGANO BJALO KA BATSEAKAROLO

HLOGO YA LENANEO LA DINYAKISISO: *Lenaneo la setšhaba la go hlabolla seemo sa bophelo sa batho bao ba fokolago monaganong le malapa a bona dinagamaeng.*

NOMORO YA TSHUPO: NWU- 00125-11-A1

MONYAKIŠIŠI: Mohumagadi T.C. Matsea

ATERESE: Yunibesithi Ya Bokone-Bophirima, Potchefstroom

NOMORO YA MOGALA: 083 552 6706

Memo ya go tšea karolo

O mengwa go tšea karolo go dinyakišišo tšeo e tla go ba karolo ya thuto ya PhD ya bodirelaleago. Tšea nakonyana go bala segwalwa seo o se filwego e bile se hlalosago ka botlalo seo dinyakišišo di lego ka sona. Le ka botšiša monyakišiši dipotšišo ka se sengwe le sengwe seo le sa se kwešišego mabapi le lenaneo le. Go bohlokwa kudu go kgotsofala le go kwešiša seo lenaneo le dinyakišišo di lego ka sona le gore o ka kgatha tema biang.ga o gapeletšwe go tšea karolo e bile o na le tokelo ya go gana go tšea karolo gomme seo ka se go amé gampe. O na gape le tokelo ya gogela morago goba go gogela morago nako efe le efe go dinyakišišo tše.

A dinyakišišo di mabapi le eng?

Dinyakišišo di dirwa metsaneng yeo e lego bokgole bjo e ka bago dikilometara tše lesome go dikologa mošate wa gaMashashane, e bile o tla akaretša go lebelelwa ga dingwalwa le go botšiša dipotšišo go batho ka o tee o tee le dihlopha tše di itšego gammogo le banyakišiši bao ba nago le maitemogelo e bile ba hlahliwe go tša bodirelaleago. Di tla.akaretša batšeakarolo

bae e ka bago ba lekgolo le masome a mabedi (120): Karolo ye ya dinyakišišo e tla tsinkela go dihlotswana tša batho bao ba nago le bolwetši bja monagano (ba sa itekanelago monagano) le malapa a bona, mo go lebeletšwego batšeakarolo ba e ka bago ba ba masome a mabedi (20).

Maikemišetšo a dinyakišišo tše ke:

- Go lekodišiša seemo sa tša lephelo le hlokomelo dinagamagaeng,
- Go tšwelela kwešišo ya gore na batho ba bolwetši bja monagano le malapa a bona ba phela bjang,
- Go nyaka go kwešiša karolo yeo batšeakarolo ba go fapafapana ba e tšeago ga bjale le gore ke efe karolo yeo ba ka e bapalago go ya pele,
- Go tšweletša lenaneo la setšhaba leo le kago tliša hlabologa le leemo le lebotse la batho bao ba nago le bolwetši bja monagano le malapa a bona dinagamagaeng,
- Go tšweletša mokgwa woo le lenaneo leo badirelaleago le bašomi ba tša maphelo ba ka go di šomiša go hlabolla seemo sa batho bao nago le bolwetši bja monagano le malapa a bona.

Ke ka lebaka la eng le memilwe go tla go tšea karolo?

- Le memilwe go tla go tšea karolo ka lebaka la gore le dula le batho ba bolwetši bja monagano tekano ya bonnyane bja dikgwedi tše tshelago ka lapeng le tee, e bile o kgotsofatša dinyakwa tše latelago: le dutše le batho ba bolwetši bja monagano tekano ya bonnyane bja dikgwedi tše tshelago ka lapeng le tee e bile o le mohlakomedi yo mogolo letšatši le letsatši.
- O ka beelwa ka thoko ge e ba ga o a itekanela gabotse mmeleng go ka tšea karolo goba wa fa tumelo.

Na maikarabelo a gago ke afe?

- O lebeletšwe go tšea karolo go dihlotswana tšeo di tlogo araba pele le morago ga ge lenaneo la setšhaba le thomile le go lekwa gape morago ga dibeke tše tšheia lenaneo le fedile. Dipotšišo di ka tšea tekano ya iri ye tee go ba iri le metotso ye masometharo.

A o tla hwetša moputso ge o tšea karolo go dinyakišišo tše naa?

- Moputso o ka o hwetšago wa thwii ke go hwetša sebaka ka o bolela ka maitemogelo a gago. Gape o ka hwetša bokgone bja go nna le maikarabelo a ho hlokomela bolwetši.
- Ka hlakoreng le lengwe dipelo tša dinyakišišo tšeo o bilego karolo go tšona di ka šomišwa go tšwela pele go thuša batho bao ba nago le bolwetši bja monagano setšhabeng sa Afrika-Borwa ka bophara.

E. ka ba go na le kotsi yeo e lego gona ge o tšea karolo go dinyakišišo tše?

- Go ya ka maitemogelo a re na re lemoga gore dipoledišano tšeo di amago monagano di ka tsoša maikutlo a go fapafapana. Ge go le bjalo go tla ba le peakanyo le modirelaleago go thuša bao ba kago huduega goba go se ikettle. Ge o nyaka o ka emiša ka go araba dipotšišo.
- Le ge dipotšišo di ama maitemogelo a gago, leina la gago le ka se tšweletšwe phatlalatšwa, e tla ba gare ga gago le monyakišiši. Yo a tšeago karolo a ka se tšweletšwe go diphalatšo go tšwa go dinyakišišong tše, ke feela sehlopha sa banyakišiši seo se tlogo šomiša tsebo yeo le re filego yona. Tsebo yeo e lego ya bonoši e ikgethilego e tla šireletšwa ya bolokwa fao e ka se fihlelelwe go ke mang le mang.

Go tla diragala eng ge go o ka ikhwetša o sa lokologe e le ka lebaka la go tšea karolo ga gago mo dinyakišišong tše?

- Ge o ka hwetša go hlokagala gore o tšwele pele ka poledišano morago ga ge o emišitše ka lebaka la go se lokologe, sebaka se ka beakanywa le modirelaleago yo a ngwadišitšwego ka maleba gore o tšwele pele.

Ke mang a tlogo le tokelo ya go bala dipoelo tša dinyakišišo?

- Ditaba ka moka tšeo di kgobokeditšwego mo dinyakišišong tše di tla tšeiwa bjalo ka tše bohlokwa tšeo di sa swanelago go bonwa goba go balwa ke mang le mang, le maina a batšeakarolo a ka se beiwe phatlalatša, a tla beiwa ka di nomoro tšeo di tsebagalago go banyakišiši le batšeakarolo feela.
- Ditaba ka moka tšeo dikgobokeditšwego di tla tselwa bjalo ka tše di bohlokwa tšeo di sa swanelago go bona ke mang le mang gomme monyakišiši o tsea maikarabelo a gore di bonwa ke mafapa afe. Ditaba ka moka tšeo di kgobokeditšwego di tla beiwa ka fase ga hlokomelo le taolo ya Yunibesithi ya Bokone-Bophirima, ka ge ditaba ka moka tšeo di kgobokeditšwego e le thoto ya Yunibesithi ya Bokone-Bophirima. Ditaba ka moka tšeo di kgobokeditšwego di tla beiwa tekano ya mengwa e supileng.

A batšeakarolo ba tla fiwa moputso goba ba tla lefa go tšea karolo?

Aowa, o ka se fiwe moputso go ba motšeakarolo. Go ka se be le seo o se lefago go tšea karolo.

A e ka ba go na le se sengwe seo o lokelago go se tseba goba go se dira?

- O ka ikgokaganya le ba Health Research Ethics Committee ka Mrs Carolien van Zyl go nomoro ye ya mogala: 018 299 2089; goba go email address ya: carolien.vanzyl@nwu.ac.za
- O tla amogela setsopolwa sa ditaba tšeo di kgobokeditšwego le foromo ya tumelelano.

A o tla tseba bjang ka dipoelo tsa dinyakišišo?

Dipoelo tša dinyakišišo di ka fihlelelwa ge o ka ikgokaganya le monyakišiši yo mogolo.

Keno ka motseakarolo

Nna, ke le....., e bile ke saenne mo fase, ke dumela go ba motseakarolo.

Ke dumela goba ke laetsa gore:

- Ke badile seo se ngwadilwego fa le foromong ya tumelelo, e bile e ngwadilwe ka leleme leo ke le kwešišago gabotsebotse.
- Ke bile le sebaka sa go botšiša dipotšišo go yo a re file.go diforomo" gammogo le go monyakišiši, e bile dipotšišo tsa ka di arabilwe ka bottalo.
- Ke kwešiša gore go tsea karolo go dinyakišišo tse ke go ithaopa ga ka, e bile ga ke a gapeletswa go dira bjalo.
- Nka kgetha go tlogela go tsea kaolo nako efe le efe e bile ga go ka moo nkago bonwa molato.
- Nka kgopelwa go tlogela go ba motseakarolo pele ga ge dinyakišišo di fela ge monyakišiši a bona go šwanešše , goba ge sa šepele go ya lenaneo la dinyakišišo, bjalo ka ge go dumelelane.

Isayinwe ko ka di 20....

.....
Mosaeno wa motseakarolo

.....
Mosaeno wa paki

Keno ka monyakišiši.

Nna ke le, ke ikana gore:

Ke hlalositše dikagare tša sengwalwa se go:

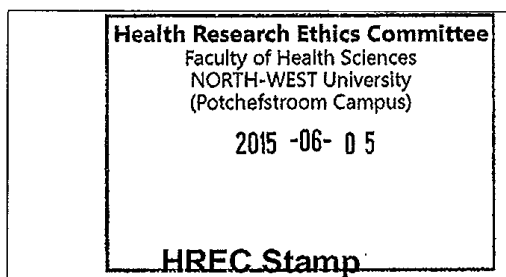
- Ke mo hlohleditše gore a botšiše dipotšišo le gore a tšee nako pele a ka di araba.
- Ke kgotsofetše gore motšeakarolo o kwešišitše dinhla ka moka tša dinyakišišo tše bjalo ka ge boledišanwe.
- Ke šomišitše mohlalosi wa ka thoko /Ga ke a šomiša mohlalosi wa ka thoko.

Isayinwe ko ka di 20....

.....
Mosaeno wa monyakišiši.

.....
Mosaeno wa paki

ANNEXURE 10: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR FAMILY MEMBERS – ENGLISH



PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR FAMILY MEMBERS AS PARTICIPANTS

TITLE OF THE RESEARCH PROJECT: A community-based programme to improve the well-being of people with mental illness and their families in a rural setting

REFERENCE NUMBERS: NWU- 00125-11-A1

RESEARCHER: Ms TC Matsea

ADDRESS: North West University, Potchefstroom

CONTACT NUMBER: 083 5526706

Invitation to participate

You have been invited to participate in a research study that forms part of a PhD's dissertation in social work. Please take some time to read the information presented, which will explain the details of this study. Please ask the researcher any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you did agree to take part.

What is this research study all about?

- *The study will be conducted in various villages within the 10 km radius from the chief's kraal at Mashashane and will involve surveys, individual interviews and focus group discussions. The undersigned, an experienced researcher trained in social work, and approximately 120 participants will be involved in this study. This part of the study will*

focus on semi-structured interviews with people with mental illness and their families, of which 20 participants will be included.

The objectives of this research are:

- to assess the nature of mental health care services in a rural setting,*
- to establish how people with mental illness and their families currently cope with mental illness,*
- to explore the current and potential roles of the different stakeholders in a rural setting,*
- to develop a programme for a community-based programme that will be used to improve the well-being of people with mental illness and their families in a rural setting, and*
- to evaluate the appropriateness and usefulness of the programme as a guide for social workers and other health care professionals for improving the well-being of people with mental illness and their families.*

Why have you been invited to participate?

- You have been invited to participate because you are staying with a person with mental illness. for a minimum period of six months in the same household, and*
- You have also complied with the following inclusion criteria: You have been staying with a person with mental illness (PMWI) for a minimum period of six months in the same household and you are involved in the day to day caring of PMWI as a primary carer.*
- You will be excluded if: You are not sufficiently well to participate or give consent.*

What will your responsibilities be?

- You will be expected to participate in semi-structured interviews before and after the community-based programme has commenced and retested approximately 6 weeks after the completion of the programme. The interview will take approximately an hour to one and a half hours.*

Will you benefit from taking part in this research?

- The direct possible benefits for you as a participant could be the opportunity to share your experiences with mental illness.*
- You will indirectly benefit from this study as the findings will be used for further interventions within the people with mental illness population of South Africa.*

Are there risks involved in your taking part in this research?

- From our experiences we know that the discussion of personal experiences could possibly provoke an emotional experience or response. An arrangement with a registered social worker will be made, to assist you if you experience any discomfort. You may also stop with the interview process at any point.*

- *Although the discussions will involve your personal experiences, your name will never be made known and all data will be handled as confidential as possible. No individual identifiers will be used in any publications resulting from this study and only the researcher will work with the information that is shared. All sensitive information will be protected by locking it up and storing it on a password protected computer.*

What will happen in the unlikely event of some form of discomfort occurring as a direct result of your participation in this research study?

- *Should you have the need for further discussions after the above mentioned discomforts; an opportunity will be arranged for you to have a debriefing session with a registered social worker.*

Who will have access to the data?

- *All gathered data will be treated with confidentiality, and anonymity will be ensured by providing each participant with a participant code. Data sets will not contain participant names or any other information that could be used to identify individual participants. All of the data files will be treated as confidential, and the researcher will regulate access to data. All data will be kept confidential under secure control of the North-West University, as all raw data remains the property of the North West-University. The data will be stored for a specified minimum period of seven years.*

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

No you will not be paid to take part in the study. There will be no additional costs involved for you, if you take part.

Is there anything else that you should know or do?

- You can contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 2089; carolien.vanzyl@nwu.ac.za if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

How will you know about the findings?

- The findings of the research will be shared by the researcher with you through the means of one on one discussion.

Declaration by researcher

I (*name*) declare that:

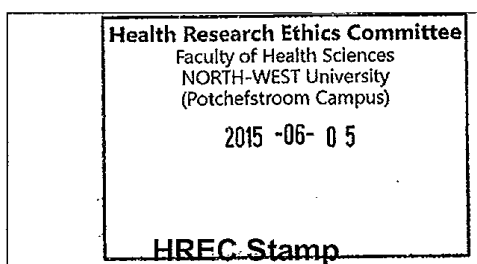
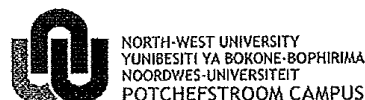
- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did not use an interpreter.

Signed at (*place*) on (*date*) 20....

.....
Signature of researcher

.....
Signature of witness

ANNEXURE 11: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR HEALTH CARE PROFESSIONALS



PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR HEALTH CARE PROFESSIONALS AS PARTICIPANTS

TITLE OF THE RESEARCH PROJECT: A community-based programme to improve the well-being of people with mental illness and their families in a rural setting

REFERENCE NUMBERS: NWU- 00125-11-A1

RESEARCHER: Ms TC Matsea

ADDRESS: North West University, Potchefstroom

CONTACT NUMBER: 083 5526706

Invitation to participate

You have been invited to participate in a research project that forms part of a PhD's dissertation in social work. Please take some time to read the information presented, which will explain the details of this study. Please ask the researcher any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you did agree to take part.

What is this research study all about?

- *The study will be conducted in various villages within the 10 km radius from the chief's kraal at Mashashane and will involve surveys, individual interviews and focus group discussions. The undersigned, an experienced researcher trained in social work, and approximately 120 participants will be involved in this study. This part of the study*

involves completion of questionnaires and will be conducted amongst health care professionals from local and mobile clinics, Seshego and Knobel hospitals. These professionals include doctors, professional nurses, social workers, psychologists and occupational therapists.

The objectives of this research are:

- to assess the nature of mental health care services in a rural setting,*
- to establish how people with mental illness and their families currently cope with mental illness,*
- to explore the current and potential roles of the different stakeholders in a rural setting,*
- to develop a programme for a community-based programme that will be used to improve the well-being of people with mental illness and their families in a rural setting, and*
- to evaluate the appropriateness and usefulness of the programme as a guide for social workers and other health care professionals for improving the well-being of people with mental illness and their families.*

Why have you been invited to participate?

- You have been invited to participate because you work in one of the health care centres that provide mental health services to people with mental illness (PMWI) and their families from Mashashane.*
- You have also complied with the following inclusion criteria: Provide input in the intervention, take part in the multi-disciplinary team meetings regarding PWMI and you are involved in either admission or discharge of PWMI.*

What will your responsibilities be?

- You will be expected to participate in a survey by completing a questionnaire and return it to the contact person whose details will be provided on the front page of the questionnaire. This questionnaire will take approximately 30 minutes.*

Will you benefit from taking part in this research?

- The questionnaire will help you as a respondent to reflect on your current practices.*
- You will indirectly benefit from this study as the findings may be used to strengthen collaborations with other mental health stakeholders in South Africa.*

Are there risks involved in your taking part in this research?

- There is minimal chance of risks involved in the survey.*
- Although the discussions will involve your personal views, your name will never be made known and all data will be handled as confidential as possible. No individual identifiers will be used in any publications resulting from this study and only the researcher will work with*

the information that is shared. All sensitive information will be protected by locking it up and storing it on a password protected computer.

What will happen in the unlikely event of some form of discomfort occurring as a direct result of your participation in this research study?

- *There are no anticipated possible forms of discomfort.*

Who will have access to the data?

- *All gathered data will be treated with confidentiality, and anonymity will be ensured by providing each participant with a participant code. Data sets will not contain participant names or any other information that could be used to identify individual participants. All of the data files will be treated as confidential, and the researcher will regulate access to data. All data will be kept confidential under secure control of the North-West University, as all raw data remains the property of the North-West University. The data will be stored for a specified minimum period of seven years.*

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

No, you will not be paid to take part in the study. There will be no additional costs involved for you if you take part.

Is there anything else that you should know or do?

- You can contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 2089; carolien.vanzyl@nwu.ac.za if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

How will you know about the findings?

- The findings of the research will be shared by the researcher with you through the means of a report submitted to the head of your health care centre.

Declaration by participant

By signing below, I _____, the undersigned hereby consent to take part in the study.

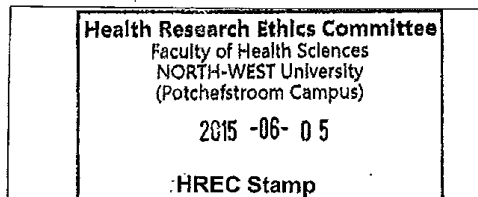
I declare that:

- I have read this information and consent form.
- I have had a chance to ask questions to both the person obtaining consent, as well as the researcher and all my questions have been adequately answered.

ANNEXURE 12: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR STAKEHOLDERS – VERNACULAR



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOM CAMPUS



LET LAKALANA LA TSEBO LA BATSEAKAROLO LE FOROMO YA TUMELELO YA BATHO BA NA LE SEABI BJALO KA BATSEAKAROLO

HLOGO YA LENANEO LA DINYAKISISO: Lenaneo la setšhaba la go hlabolla seemo sa bophelo sa batho bao ba fokolago monaganang le malapa a bona dinagamagaeng.

NOMORO YA TSHUPO: NWU- 00125-11-A1

MONYAKIŠIŠI: Mohumagadi T.C. Matsea

ATERESE: Yunibesithi Ya Bokone-Bophirima, Potchefstroom

NOMORO YA MOGALA: 083 552 6706

Memo ya go tšea karolo

O mengwa go tšea karolo go dinyakišišo tšeo e tla go ba karolo ya thuto ya PhD ya bodirelaleago. Tšea nakonyana go bala segwalwa seo o se filwego e bile se hialosago ka bottlalo seo dinyakišišo di lego ka sona. Le ka botšiša monyakišiši dipotšišo ka se sengwe le sengwe seo le sa se kwešišego mabapi le lenaneo le. Go bohlokwa kudu go kgotsofala le go kwešiša seo lenaneo le dinyakišišo di lego ka sona le gore o ka kgatha tema biang.ga o gapeletšwe go tšea karolo e bile o na le tokelo ya go gana go tšea karolo gomme seo ka se go ame gampe. O na gape le tokelo ya gogela morago goba go gogela morago nako efe le efe go dinyakišišo tše.

A dinyakišišo di mabapi le eng?

Dinyakišišo di dirwa metsaneng yeo e lego bokgole bjo e ka bago dikilometara tše lesome go dikologa mošate wa gaMashashane, e bile o tla akaretša go lebelelwa ga dingwalwa le go botšiša dipotšišo go batho ka o tee o tee le dihlopha tše di itšego gammogo le banyakišiši bao ba nago le maitemogelo e bile ba hlahlwe go tša bodirelaleago. Di tla akaretša batšea karolo bao e ka bago ba lekgolo le masome a mabedi (120). Karolo ye ya dinyakišišo e tla tsinkela go dihlotswana tše di itšego. Tsona di tla ba le ba tšea karolo ba sesupa go išha go ba seswai sehlopeng se sengwe le se sengwe. Dihlotswana tše di akaretša; magoshi, mangaka a setso,

baporofeta, badumedi, lekgotla la tekodisiso ya tsa maphelo a monagano, maphodisa le mokgatlo wa bahlokomele balwetsi ka gae.

Maikemišetšo a dinyakišišo tše ke:

- Go lekodišiša seemo sa tša lephelo le hlokomeo dinagamagaeng,
- Go tšweleta kwešišo ya gore na batho ba bolwetši bja monagano le malapa a bona ba phela bjang,
- Go nyaka go kwešiša karolo yeo batšeakorolo ba go fapafapana ba e tšeago ga bjale le gore ke efe karolo yeo ba ka e bapalago go ya pele,
- Go tšweletša lenaneo la setšhaba leo le kago tliša hlabologa le leemo le lebotse la batho bao ba nago le bolwetši bja monagano le malapa a bona dinagamagaeng,
- Go tšweletša mokgwa woo le lenaneo leo badirelaleago le bašomi ba tša maphelo ba ka go di šomiša go hlabolla seemo sa batho bao nago le bolwetši bja monagano le malapa a bona.

Na ke ka lebaka la eng le memilwe go tla go tšea karolo?

- Le memilwe go tla go tšea karolo ka lebaka la karolo yeo le e tseago go batho bao sa itekanelago menaganong le malapa a bona, ka go bafa thuso yeo e itsego goba le ka tsa semolao.
- Le ka se amege: ntle le tumelelo ya lena.

Na maikarabelo a gago ke afe?

- O lebeletšwe go tšea karolo go dihlotswana tše di itsego. Di ahlaahlo di lebeletšwe go tšea iri e tee go išha go iri le seripa.

A o tla hwetša moputso ge o tšea karolo go dinyakišišo tše naa?

- Moputso wa gago o le motseakarolo e tšaba go oketsa tsebo ya gago ka kwešišo yeo e tseneletsego ka bolwetse bja go se itekanele monaganong.
- Ka hlakoreng le lengwe dipoelo tša dinyakišišo tše o bilego karolo go tšona di ka šomišwa go tšwela pele go thuša batho bao ba nago le bolwetši bja monagano setšhabeng sa Afrika-Borwa ka bophara.

E ka ba go na le kotsi yeo e lego gona ge o tšea karolo go dinyakišišo tše?

- Ga gona le sebaka se se itsego gore o ka ba kotsing ka go ba motseakarolo go dihlotswana tsa dinyakišišo.
- Le ge dipotšišo di ama maitemogelo a gago, leina la gago le ka se tšweletšwe phatlalatšwa, e tla ba gare ga gago le monyakišiši. Yo a tšeago karolo a ka se tšweletšwe go diphalatšo go tšwa go dinyakišišong tše, ke feela sehlopha sa banyakišiši seose tšago šomiša tsebo yeo le re filego yona. Tsebo yeo e lego ya bonoši e ikgethilego e tla šireletšwa ya bolokwa fao e ka se fihlelelwego ke mang le mang.

Go tla diragala eng ge o ka ikhwetša o sa lokologe e le ka lebaka la go tšea karoelo ga gago mo dinyakišišong tše?

- Ge o ka hwetša go hlokagala gore o tšwele pele ka poledišano morago ga ge o emišitše ka lebaka la go se lokologe, sebaka se ka beakanywa le modirelaleago yo a ngwadišitšwego ka maleba gore o tšwele pele.

Ke mang a tlogo goba le tokelo ya go bala dipoelo tša dinyakišišo?

- Ditaba ka moka tšeo di kgobokeditšwego mo dinyakišišong tše di tla tšeiwa bjalo ka tše bohlokwa tšeo di sa swanelago go bonwa goba go balwa ke mang le mang, le maina a batšeakarolo a ka se beiwe phatlalatša, a tla beiwa ka di nomoro tšeo di tsebagalago go banyakišiši le batšeakarolo feela.
- Ditaba ka moka tseo dikgobokeditšwego di tla tšeiwa bjalo ka tse di bohlokwa tseo di sa swanelago go bona ke mang le mang gomme monyakišiši o tsea maikarabelo a gore di bonwa ke mafapa afe. Ditaba ka moka tšeo di kgobokeditšwego di tla beiwa ka fase ga hlokomelo le taolo ya Yunibesithi ya Bokone-Bophirima, ka ge ditaba ka moka tšeo di kgobokeditšwego e le thoto ya Yunibesithi ya Bokone-Bophirima. Ditaba ka moka tšeo di kgobokeditšwegodi tla beiwa tekano ya mengwa e supileng.

Na o le motseakarolo o tla lefa goba wa gona le ditefelo tseo di akareditswego?

- Aowa, o ka se lefelwe go ba motšeakarolo go dinyakišišo mohlomongwe go ka ba le dino le dijo go dihlotswana tsa dinyakishisho. Efela, batseakarolo bao ba lefelago dinamelwa ba tla putswa.

A e ka ba go na le se sengwe seo o lokelago go se tseba goba go se dira?

- O ka lkgokaganya le ba Health Research Ethics Committee ka Mrs Carolien van Zyl go nomoro ye ya mogala: 018 299 2089; goba go email address ya: carolien.vanzyl@nwu.ac.za
- O tla amogela setsopolwa sa ditaba tseo di kgobokeditšwego le foromo ya tumelalano.

A o tla tseba bjang ka dipoelo tsa dinyakišišo?

Dipoelo tša dinyakišišo di ka fihlelelwa ge o ka lkgokaganya le monyakišiši.

Keno ka motseakarolo

Nna, ke le....., e bile ke saenne mo fase, ke dumela go ba motseakarolo.

Ke dumela goba ke laetsa gore:

- Ke badile seo se ngwadilwego fa le foromong ya tumelalo, e bile e ngwadilwe ka leleme leo ke le kwesisago gabotsebotse.
- Ke bile le sebaka sa go botsisa dipotšišo go yo a re file go diforomo gammogo le go monyakišiši, e bile dipotšišo tsa ka di arabilwe ka botlalo.

- Ke kwešiša gore go tsea karolo go dinyakisiso tse ke go ithaopa ga ka, e bile ga ke a gapeletswa go dira bjalo.
- Nka kgetha go tlogela go tsea kaolo nako efe le efe e bile ga go ka moo nkago bonwa molato.
- Nka kgopelwa go tlogela go ba motseakarolo pele ga ge dinyakišišo di fela ge monyakišiši a bona go šwanetse , goba ge sa šepele go ya lenaneo la dinyakišišo, bjalo ka ge go dumelelane.

Isayinwe ko ka di 20....

.....
Mosaeno wa motseakarolo

.....
Mosaeno wa paki

Keno ka monyakišiši.

Nna ke le ke ikana gore:

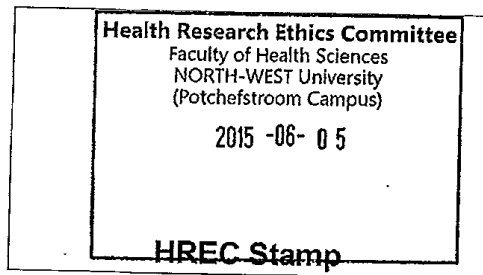
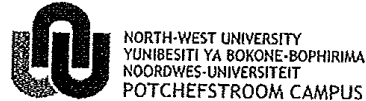
- Ke hlalositše dikagare tša sengwalwa se go:
- Ke mo hlohleleditše gore a botšiše dipotšišo le gore a tšee nako pele a ka di araba.
- Ke kgotsofetše gore motšeakarolo o kwešišitse dinhla ka moka tša dinyakišišo tše bjalo ka ge boledišanwe.
- Ke šomišitše mohlalosi wa ka thoko /Ga ke a šomiša mohlalosi wa ka thoko.

Isayinwe ko ka di 20....

.....
Mosaeno wa monyakišiši.

.....
Mosaeno wa paki

ANNEXURE 13: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR STAKEHOLDERS – ENGLISH



PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR STAKEHOLDERS AS PARTICIPANTS

TITLE OF THE RESEARCH PROJECT: A community-based programme to improve the well-being of people with mental illness and their families in a rural setting

REFERENCE NUMBERS: NWU- 00125-11-A1

RESEARCHER: Ms TC Matsea

ADDRESS: North West University, Potchefstroom

CONTACT NUMBER: 083 5526706

Invitation to participate

You have been invited to participate in a research project that forms part of a PhD's dissertation in social work. Please take some time to read the information presented, which will explain the details of this study. Please ask the researcher any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely, voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you did agree to take part.

What is this research study all about?

- *The study will be conducted in various villages within the 10 km radius from the chief's kraal at Mashashane and will involve surveys, individual interviews and focus group discussions. The undersigned, an experienced researcher trained in social work, and approximately 120 participants will be involved in this study.*

- *This part of the study involves focus group discussions of various stakeholders, of which 6 to 8 participants will be included in each focus group. These stakeholders include traditional leaders, traditional healers and faith healers, church members, Mental Health Review Boards, police officers and home-based care groups. Also involved in this part of the study is the research assistant who will be responsible for administration.*

The objectives of this research are:

- *to assess the nature of mental health care services in a rural setting,*
- *to establish how people with mental illness and their families currently cope with mental illness,*
- *to explore the current and potential roles of the different stakeholders in a rural setting,*
- *to develop a programme for a community-based programme that will be used to improve the well-being of people with mental illness and their families in a rural setting, and*
- *to evaluate the appropriateness and usefulness of the programme as a guide for social workers and other health care professionals for improving the well-being of people with mental illness and their families.*

Why have you been invited to participate?

- *You have been invited to participate on the basis of the role you play on people with mental illness with their families, either in the form of assistance or law enforcement.*
- *You will be excluded if you have no previous experience in dealing with people with mental illness and their families.*

What will your responsibilities be?

- *You will be expected to complete a survey and to participate in a focus group discussion. The survey will take approximately thirty minutes and the focus group discussion will take approximately an hour to one and a half hours.*

Will you benefit from taking part in this research?

- *The benefit for you as a participant will be an opportunity to reflect on stakeholder's role concerning people with mental illness and their families.*
- *You will indirectly benefit from this study as the findings may be used for strengthened collaborations with other mental health stakeholders in South Africa.*

Are there risks involved in your taking part in this research?

- *There is minimal chance of risks in the focus group discussion and survey. Due to diversity of participants in the focus group, differing views may erupt. Ground rules will be set in order to prevent this from happening.*

- *Although the discussions will involve your personal views, your name will never be made known and all data will be handled as confidential as possible. No individual identifiers will be used in any publications resulting from this study and only the researcher will work with the information that is shared. All sensitive information will be protected by locking it up and storing it on a password protected computer.*

What will happen in the unlikely event of some form of discomfort occurring as a direct result of your participation in this research study?

- *There are no anticipated possible forms of discomfort in the focus group discussion, however should you have the need for further discussion you will be referred to a relevant professional.*

Who will have access to the data?

- *All gathered data will be treated with confidentiality, and anonymity will be ensured by providing each participant with a participant code. Data sets will not contain participant names or any other information that could be used to identify individual participants. All of the data files will be treated as confidential, and the researcher will regulate access to data. All data will be kept confidential under secure control of the North-West University, as all raw data remains the property of the North-West University. The data will be stored for a specified minimum period of seven years.*

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

No, you will not be paid to take part in the study but refreshments may be provided during the focus group interviews. However, participants' transport cost will be reimbursed.

Is there anything else that you should know or do?

- You can contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 2089; carolien.vanzyl@nwu.ac.za if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

How will you know about the findings?

- The findings of the research will be shared by the researcher with you through the means of a group discussion.

Declaration by participant

By signing below, I _____, the undersigned hereby consent to take part in the study.

I declare that:

- I have read this information and consent form.
- I have had a chance to ask questions to both the person obtaining consent, as well as the researcher and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and that I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 20....

.....
Signature of participant

.....
Signature of witness

Declaration by person obtaining consent

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (*place*) on (*date*) 20....

.....
Signature of person obtaining consent

.....
Signature of witness

Declaration by researcher

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did not use an interpreter.

Signed at (*place*) on (*date*) 20....

.....
Signature of researcher

.....
Signature of witness

ANNEXURE 14: INTERVIEW GUIDES FOR PWMI



THEME/ARTICLE 2:

The circumstances and coping of people with mental illness and their families

INTERVIEW SCHEDULE: PERSON WITH MENTAL ILLNESS

(Semi-structured interview)

INTRODUCTION

Thank you for agreeing to participate in this research project. My name is Thabisa Matsea. I am a researcher from the North-West University and I would like to get a better understanding about your circumstances and coping with mental illness. I will be using this information to develop a protocol for a program that will help improve the current circumstances of people with mental illness and their families in the future. Therefore, I would like to ask you several questions with regards to how you have been living with the illness.

ETHICAL ASPECTS

- You have signed an informed consent form as an indication that you have agreed to take part on this project. The signing of this informed consent form does not necessarily mean you are forced to participate; therefore you are welcome to withdraw at any point during the interview. This withdrawal will not bear any consequences.
- I would like to assure you that you will remain anonymous and that the records of the interview will not have your name on them. The information shared during the interview will be kept confidential.
- I would like to remind you that should you have the need for further discussions in the unlikely event of some form of discomfort occurring as a direct result of your

participation in this research study; an opportunity will be arranged for you to have a debriefing session with a registered social worker.

- I would like to request your permission to record this interview for the purpose of analysis.

SECTION A: DEMOGRAPHIC QUESTIONS

1. Gender

Male	Female
------	--------

2. Age distribution

18 – 26 years	27 – 35 years	36 – 44 years	45 – 52 years	52 - 60 years
---------------	---------------	------------------	---------------	---------------

3. Your age during first diagnosis

18 – 26 years	27 – 35 years	36 – 44 years	45 – 52 years	52 - 60 years
---------------	---------------	------------------	---------------	---------------

4. Education level.

Never went to school	Primary education	Secondary education	Tertiary education	Other*
-------------------------	----------------------	------------------------	--------------------	--------

* In the case of “Other”, please
specify: _____

5. Marital status

Never married	Married	Divorced	Widowed	Other*
------------------	---------	----------	---------	--------

* In the case of “Other”, please
specify: _____

6. Number of children

None	1 – 2	3 – 4	5 – 6	7 - 8	9 +
------	-------	-------	-------	-------	-----

7. Age(s) of your children

0 – 1 year	2 – 5 years	6 – 10 years	11 – 15 years	16 – 20 years	21 years +
------------	-------------	--------------	------------------	------------------	---------------

8. Relationship with the carer?

Mother	Father	Brother	Sister	Spouse	Other*
--------	--------	---------	--------	--------	--------

* In the case of “Other”, please

specify:_____

9. Source of income

Employed	Social grant	Carer	Other*
----------	--------------	-------	--------

* In the case of “Other”, please

specify:_____

SECTION B: QUESTIONS

1. What is the current diagnosis of your mental illness?
2. What is your understanding of your mental illness?
3. How is it for you as a person with mental illness in this community?
4. What support systems are available in this community to help you and your family cope with mental illness?
5. What makes it possible for you to get the support you need?
6. What makes it difficult for you to get the support you need?

SECTION C: INTERVIEWER NOTES AND OBSERVATIONS

ANNEXURE 15: INTERVIEW GUIDE FOR FAMILY MEMBERS



THEME/ARTICLE 2:

The circumstances and coping of people with mental illness and their families

INTERVIEW SCHEDULE: FAMILY MEMBER OF A PERSON WITH MENTAL ILLNESS

(Semi-structured interview)

INTRODUCTION

Thank you for agreeing to participate in this research project. My name is Thabisa Matsea. I am a researcher from the North-West University and I would like to get a better understanding about your circumstances and coping with mental illness. I will be using this information to develop a protocol for a program that will help improve the current circumstances of people with mental illness and their families in the future. Therefore, I would like to ask you several questions with regards to how you have been living with a person with mental illness.

ETHICAL ASPECTS

- You have signed an informed consent form as an indication that you have agreed to take part in this project. The signing of this informed consent form does not necessarily mean you are forced to participate; therefore you are welcome to withdraw at any point during the interview. This withdrawal will not carry any consequences.
- I would like to assure you that you will remain anonymous and that the records of the interview will not have your name on them. The information shared during the interview will be kept confidential.
- I would like to remind you that should you have the need for further discussions in the unlikely event of some form of discomfort occurring as a direct result of your

participation in this research study; an opportunity will be arranged for you to have a debriefing session with a registered social worker.

- I would like to request your permission to record this interview for the purpose of analysis.

SECTION A: DEMOGRAPHIC QUESTIONS

9. Gender

Male	Female
------	--------

10. Age distribution

18 – 26 years	27 – 35 years	36 – 44 years	45 – 52 years	52 - 60 years
---------------	---------------	---------------	---------------	---------------

11. Education level.

Never went to school	Primary education	Secondary education	Tertiary education	Other*
----------------------	-------------------	---------------------	--------------------	--------

* In the case of “Other”, please specify: _____

12. Marital status

Never married	Married	Divorced	Widowed	Other*
---------------	---------	----------	---------	--------

* In the case of “Other”, please specify: _____

13. Number of children

None	1 – 2	3 – 4	5 – 6	7 - 8	9 +
------	-------	-------	-------	-------	-----

14. Age(s) of your children

0 – 1 year	2 – 5 years	6 – 10 years	11 – 15 years	16 – 20 years	21 years +
------------	-------------	--------------	---------------	---------------	------------

15. Relationship of the carer with the person with mental illness?

Mother	Father	Brother	Sister	Spouse	Other*
--------	--------	---------	--------	--------	--------

* In the case of "Other", please

specify: _____

16. Source of income

Employed	Social grant	Carer	Other*
----------	--------------	-------	--------

* In the case of "Other", please

specify: _____

SECTION B: QUESTIONS

1. How long have you been taking care of the person with mental illness?
2. What is the current diagnosis of his/her mental illness?
3. What is your understanding of his/her mental illness?
4. How is it for you to take care of a person with mental illness in this community?
5. What support systems are available in this community to help you cope with caring for the person with mental illness?
6. What makes it possible for you to get the support you need?
7. What makes it difficult for you to get the support you need?

SECTION E: INTERVIEWER NOTES AND OBSERVATIONS

ANNEXURE 16: EXAMPLE OF A FOCUS GROUP PROTOCOL



THEME/ARTICLE 3

The views of stakeholders regarding their role as a support system for people with mental illness and their families

FOCUS GROUP PROTOCOL: POLICE OFFICERS

SECTION A: INTRODUCTION AND EXPLANATION

- Details about interview
 - Researcher: Mrs. T. Matsea
 - Research assistant: Ms. M. Magagane
 - Date of interview:
 - Time & duration:
- Welcome and thank you for agreeing to participate in this research project. My name is Thabisa Matsea, a researcher at North-West University. Working with me is Mahlodi Magagane and she will be responsible for recording the proceedings of today.
- You have been invited to complete a short survey and to participate in a focus group discussion to help us understand your views with regards to your role in supporting people with mental illness and their families. We will be using this information to develop a protocol for an intervention that will help improve the wellbeing of people with mental illness and their families in rural areas. This discussion will also provide invaluable information about how mental health service providers can provide better services in the future.
- The group discussion is scheduled to last approximately 60 - 90 minutes and will include questions about your understanding of mental illness, your roles in helping people with mental illness, health promotion as well as your interaction with other stakeholders.
- You are welcome to ask the researcher any questions about any part of this project that you do not fully understand.

ETHICAL ASPECTS

- You have signed an informed consent form as an indication that you have agreed to take part in this project. Signing of this informed consent form does not necessarily mean you are forced to participate; therefore you are welcome to withdraw at any point during the discussion. This withdrawal will not carry any consequences.
- We would like to assure you that you will remain anonymous and the records of this focus group discussion will not have your name on them. The information shared during the interview will be kept confidential.
- We would like you to know that confidentiality during the focus group meeting cannot be promised, but that ground rules are set to protect it as far as possible. Please read the ground rules section for this aspect.
- We would like to request your permission to record this discussion for the purpose of analysis.

GROUND RULES

- Remember that everyone has something to contribute; therefore your active participation is very important.
- Please note that there is no right or wrong answer. Also note that all ideas are important and will be treated as such. Therefore, do not hesitate to speak up when you have a point that you would like to make or concerns to raise.
- Please answer all questions as honestly as possible.
- We would like to request you not to disclose any information discussed and the names of people participating in this focus group discussion.
- Please note that what you say during focus group discussion is your responsibility. Regard the group discussion as a public meeting.

SECTION B: THE SURVEY

This survey comprises of two parts. Part 1 requests basis demographical information to establish a participant profile. Part 2 focuses on available resources, support given to people with mental illness and/ their families as well as collaborations with other stakeholders.

PART 1: COMPOSITION OF GROUP

Instructions: **Please tick only one box per question except for where indicated.**

16. Gender

Male	Female
------	--------

17. Age group

25 – 30 years	31 – 35 years	36 – 40 years	41 – 45 years	46 - 50 years	50 years+
------------------	------------------	------------------	------------------	------------------	-----------

18. Rank

Constable	Sergeant	Warrant officer	Lieutenant	Other*
-----------	----------	-----------------	------------	--------

* In the case of "Other", please specify: _____

19. Number of years as a police officer

0 – 1 year	2 – 5 years	6 – 10 years	11 – 15 years	15 years +
------------	-------------	--------------	---------------	------------

20. Education level.

Never went to school	Primary education	Secondary education	Tertiary education	Other*
----------------------------	----------------------	------------------------	--------------------	--------

* In the case of "Other", please specify: _____

PART 2: RESOURCES AND SUPPORT

AGREE OR DISAGREE

Instructions: To what extent do you agree or disagree with each of the following statements?

Question	1.	2.	3.	4.
Mental health resources are available within this community.	1. / strongly disagree	2. / disagree	3. / I agree	4. / strongly agree
Mental health resources in this community are easily accessible	1. / strongly disagree	2. / disagree	3. / I agree	4. / strongly agree
Mental health resources make it possible for me to use them	1. / strongly disagree	2. / disagree	3. / I agree	4. / strongly agree
Other stakeholders make it possible for me to work with them	1. / strongly disagree	2. / disagree	3. / I agree	4. / strongly agree
I am satisfied with the current state of collaborations with other stakeholders	1. / strongly disagree	2. / disagree	3. / I agree	4. / strongly agree

HIGH AND LOW

Instructions: Please indicate on a scale of 1-5 (5 being the highest) how you would score the following:

Please make a cross ☒ in the appropriate block regarding the availability of the following professionals to work with you on matters relating to people with mental illness.	1. <i>Never available</i>	2. Almost never available	3. Some of the time available	4. Almost always available	5. Always available
10.1 Doctors	1	2	3	4	5
10.2 Nurses	1	2	3	4	5
10.3 Occupational therapists	1	2	3	4	5
10.4 Psychologists	1	2	3	4	5
10.5 Social workers	1	2	3	4	5

11 Please make a cross ☒ in the appropriate block regarding the availability of the following stakeholders to work with you on matters relating to people with mental illness.	1. <i>Never available</i>	2. Almost never available	3. Some of the time available	4. Almost always available	5. Always available
11.1 Health care professionals	1	2	3	4	5
11.2 Traditional health practitioners	1	2	3	4	5
11.3 Church members	1	2	3	4	5
11.4 Home-based caregiver	1	2	3	4	5
11.5 Traditional leaders	1	2	3	4	5

GIVING SUPPORT

12. Please make a cross ☒ in the appropriate block regarding the kind of support police officers give to people with mental illness and their families. You may tick the two main supports.	1. Emotional support	2. Material support	3. Psych o- social suppor t	4. Spiritual support	5. Other (please specify): _____ _____ _____ _____
--	--------------------------------	-------------------------------	---	--------------------------------	--

THANK YOU FOR COMPLETING THIS SURVEY

SECTION D: INTERVIEW SCHEDULE

- a. What is your understanding of mental illness?
- b. What support systems are available for people with mental illness and their families in this community?
- c. To what extent do people use these resources?
- d. How do you as police officers view your role in supporting people with mental illness and their families?
- e. Various stakeholders such as health care professionals, traditional health practitioners, church members, home-based caregivers and traditional leaders are involved as support systems for people with mental illness and their families. How do you think you can improve working with these people to improve mental health services?
- f. Would you like to add anything else to this discussion to bring more understanding?

SECTION E: INTERVIEWER NOTES AND OBSERVATIONS

ANNEXURE 17: QUESTIONNAIRE FOR HEALTH CARE PROFESSIONALS



NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOM CAMPUS

Private Bag X6001, Potchefstroom
South Africa 2520
Tel: (018) 299-4900
Web: <http://www.nwu.ac.za>

ASSESSMENT OF MENTAL HEALTH SERVICES QUESTIONNAIRE

1. Introduction

People with mental illness and their families often consult your organization with their mental health needs. Because you are involved in the rendering of such services, you have been selected to take part on a survey that covered the nature of your organisations mental health services (see information leaflet attached).

2. Purpose

The purpose of the study of which this questionnaire forms a part, is to assess the nature and state of mental health services in general and especially those pertaining to rural areas. Through your participation, you will especially help us to make recommendations on how the service to these clients and their families can be improved.

3. Instructions for completing this Questionnaire

It is important to complete the following questionnaire **honestly** and **in full**. Your honest professional and personal views are crucial in helping me/us to come up with best recommendations for the service.

The questionnaire is divided into three sections. Section 1 is about demographic information, your qualifications and experience. Section 2 focuses on giving information about the health facility whereas section 3 focuses on the mental health services you render.

3.1 Answer all the questions.

3.2 Except for where indicated (Question 1 in Section 3), mark only one answer per question.

3.3 Mark all the answers on this questionnaire by making a cross in the appropriate blocks.

3.4 Complete the questionnaire on your own.

This questionnaire does not contain any questions that will identify you as a person. Please not to *write your name anywhere on it*. By completing this questionnaire you give permission that the data may be used for research purposes.

4. Submission of a completed questionnaire

When you have completed the questionnaire, please return it to the contact person, who will seal it in an envelope and hand it over to the research team.

*Contact
person:*

Sr. Mpho Rametsi
Cell: 0723560197

*Researcher
:*

Ms Thabisa Matsea,
Cell: 0835526706

Regards

SECTION 1: DEMOGRAPHIC AND RELATED INFORMATION

Instructions: *Please tick only one block per question.*

Please indicate your **gender**

Male	Female
------	--------

Please indicate your **race**

Asian	Black	Coloured	White	Other*
-------	-------	----------	-------	--------

* In the case of "Other", please specify: _____

Please indicate your **profession/ occupation**

Doctor (medical)	Psychologist	Social worker	Occupational therapist	Nurse	Other*
------------------	--------------	---------------	------------------------	-------	--------

* In the case of "Other", please specify: _____

Please indicate your highest **qualification**.

Higher certificate	Diploma	Bachelor's degree	Postgraduate qualification	Other*
--------------------	---------	-------------------	----------------------------	--------

* In the case of "Other", please specify: _____

Please indicate your **work experience** (total number of months/years worked in current occupation)

0 – 6 months	6 – 12 months	1 – 2 years	3 – 5 years	6 years +
--------------	---------------	-------------	-------------	-----------

Please indicate number of months/years employed at your current place of work.

0 – 6 months	6 – 12 months	1 – 2 years	3 – 5 years	6 years +
--------------	---------------	-------------	-------------	-----------

SECTION 2: INFORMATION RE YOUR ORGANISATIONAL SETTING

Instruction: *Please tick only one block per question.*

1. In which level of care do you work?

1.1 Primary care level	2.2 Secondary care level	3.3 Tertiary care level
------------------------	--------------------------	-------------------------

2. The type of health care centre where you predominantly work?

2.1 Hospital	2.2 Clinic	2.3 Mobile clinic	2.4 Other*
--------------	------------	-------------------	------------

* In the case of "Other", please specify: _____

3. Would you describe the setting where you work as predominantly urban or rural?

3.1 Urban	3.2 Rural
-----------	-----------

SECTION 3: SERVICES RENDERED

This section covers the mental health services rendered by you and/or your organisation. It consists of eight parts. Each part has a number of questions that you need to answer.

General instructions: Part 1 has two formats of questions, please follow instructions as indicated. Other parts have questions in a *Likert*-scale format, please tick only one box. Please answer the questions as honestly and accurately as possible.

3.1 COMPREHENSIVENESS

Comprehensiveness focuses on the range of services that are provided to clients. It also focuses on collaborations within the organization.

3.1.1 Which of the following best describes the services you **predominantly** render?

Instruction: ***You may tick the three main services.***

Rehabilitative services	Preventative services	Crisis intervention	Support services	Counselling	Health promotion	<input type="checkbox"/> Other*
-------------------------	-----------------------	---------------------	------------------	-------------	------------------	---------------------------------

* In the case of "Other", please specify: _____

3.1.2 Please indicate level of comprehensiveness of your service including collaborations with other systems during the past three.

Instructions: ***Please tick only one box per question.***

3.1.2.1 In the past three months, how often did you talk to your clients about other issues of concerns besides what they consulted for?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.1.2.2 In the past three months, how often did you collaborate with other health care professionals to develop care plans for people with mental illness?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.1.2.4 In the past three months, how often did you refer a person with mental illness to other members of the multidisciplinary team?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

What are the most important strengths regarding comprehensiveness of your service?

.....

.....

.....

.....

What are the most important weaknesses regarding comprehensiveness of your service?

.....

.....

.....

.....

3.2 ACCESSIBILITY OF SERVICE

This subsection covers the level of accessibility of your service to people with mental illness and their families. Please indicate level of accessibility of your service during the past three months.

3.2.1 Do you render a 24 hour service?

Yes	No
-----	----

If the answer is no, in the past three months, how often did you make arrangements for people with mental illness and their families to access your services during crisis situation after hours?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.2.2 In the past three months, how often did your clients have to wait for more than an hour to consult with you?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.2.3 In the past three months, how often did you give patients information about how to prevent further problems with mental illness?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.2.4 In the past three months, how often did you experience language barriers when assisting a person who needed your service?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

What do you regard as the most important strengths of the accessibility your service?

.....

.....

.....

.....

What do you regard as the most important weaknesses of the accessibility of your service?

.....

.....

.....

.....

3.3 SERVICE COVERAGE

This subsection focuses on the proportion of population covered for health care on a particular period. Please indicate level of service coverage during the past three months.

3.3.1. In the past three months, how often did you conduct outreach services specifically for people with mental illness?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.3.2. In the past three months, how often did you assist people with mental illness from areas that do not fall under your jurisdiction?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.3.3. In the past three months, how many people with mental illness and their families did you attend to?

0	1 - 10	11 - 20	21 - 30	>30
---	--------	---------	---------	-----

What do you regard as strengths of your service coverage?

.....

.....

.....

.....

What do you regard as weaknesses of your service coverage?

.....

.....

.....

.....

3.4 CONTINUITY OF CARE

This subsection focuses on the continuous interaction between the service provider and the people with mental illness and their families. Please indicate level of continuity of care during the past three months.

3.4.1. In the past three months, how often did you attend to the same person with mental illness?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.4.2. In the past three months, were there times when a client refused to be attended to by some of your colleagues and requested to be attended by you only?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.4.3. In the past three months, how often did you provide service to a client referred by other health care professional without any information?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.4.4. In the past three months, how often did you ask the clients to give information that should be in their/your records?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.4.5. In the past three months, how often did you follow-up on people with mental illness who have missed their appointments?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.4.6. How often do you follow-up on referrals to ensure that people with mental illness receive proper service?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

What do you regard as the most important strengths of the continuity of your service?

.....

.....

.....

.....

What do you regard as the most important weaknesses of the continuity of your service?

.....

.....

.....

.....

3.5 QUALITY OF SERVICE

This section focuses on aspects that are important for service providers to improve quality and ensure effectiveness of their service.

3.5.1 In the past 12 months, how often did you attend training on mental illness and other mental health related issues?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.5.2 In the past 12 months, how often was your performance assessed?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.5.3 In the past six months, how often did you receive technical support or supervision for service delivered to people with mental illness and their families?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.5.4 In the past six months, how often did you benchmark from other institutions delivering the similar service?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

What do you regard as the most important strengths the quality of your service?

.....

.....

.....

.....

What do you regard as the most important weaknesses of the quality of your service?

.....

.....

.....

.....

3.6 PERSON-CENTEREDNESS

This section focuses on the extent in which health care professionals involve people with mental illness on decisions about different aspects of care.

3.6.1 In the past six months, how often did you involve people with mental illness and their family in decision making with regards to treatment choices?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

3.6.2 In the past six months, how often did you involve people with mental illness and their families when making plans to change some aspects of your service?

Never	Rarely	Sometimes	Mostly	Always
-------	--------	-----------	--------	--------

What do you regard as the most important strengths the person-centeredness of your service?

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What do you regard as the most important weaknesses of the person-centeredness of your service?

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3.7 COORDINATION

Coordination focuses mostly on the interaction between service providers with the aim of providing better service to people with mental illness and their families.

3.7.1 In the past six months, how often did you encourage your clients to attend programs in the community that could help them cope with mental illness?

Never	Rarely	Sometimes	Mostly	Always
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3.7.2 In the past six months, how often did you engage voluntary groups in the community to provide support to people with mental illness and their families?

Never	Rarely	Sometimes	Mostly	Always
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3.7.3 In the past 12 months, how often did you attend mental health case conferences on or off-site?

Never	Rarely	Sometimes	Mostly	Always
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3.7.4 In the past six months, have you created networks with other mental health stakeholders such as traditional health practitioners, traditional leaders, home-based care groups, church members, as well as police officers, in order to improve referrals, strengthen linkages and expand resources?

Never	Rarely	Sometimes	Mostly	Always
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3.7.5 In the past six months, how often did you refer clients or receive referrals from the above stakeholders?

Never	Rarely	Sometimes	Mostly	Always
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What do you regard as the most important strength of coordination of your service?

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What do you regard as the most important weakness of coordination of your service?

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3.8 ACCOUNTABILITY AND EFFECTIVENESS

This part focuses on the management of mental health services by making sure standards are upheld and that the organization’s goals and objectives are achieved in the past 12 months. Please indicate level in which you agree with the following statements.

3.8.1 The service you render is audited to identify the opportunities and priorities for improving care?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
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3.8.2 Management allocates resources relevant to the delivery of service to people with mental illness.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
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3.8.3 There are mechanisms in place to identify and act on professional needs.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
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3.8.4 Management invests on training staff members.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
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3.8.5 Management places a priority on hiring and retaining skilled staff.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
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3.8.6 Communication channels are used to engage staff members on a regular basis to discuss changes regarding service delivery.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
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3.8.7 There are clear standards, procedures and protocols that guide mental health services delivery.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
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What do you regard as the most important strengths of the general management?

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What do you regard as the most important weaknesses of the general management?

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SECTION 4: ANY OTHER COMMENT

What other concerns do you think I should be aware of in order to better understand the level of your service?

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THANK YOU FOR PARTICIPATING IN THIS SURVEY

ANNEXURE 18: EXAMPLE OF A TRANSCRIPT FOR PWMI

Researcher: God morning uncle. I would like you to tell me what this research is all about.

Participant: This research is about mental illness, people with mental illness, those that are retarded.

Researcher:

Why have you been invited to participate in this research?

Participant: It is because we want to know if our life/ well-being is taken care of.

Researcher: But, do you understand that this research involves you and your family?

Participant: Yes, this can help us when we are able follow them the way we are supposed to.

Researcher: Okay, thank you. I would now like to start with our questions.

Participant: It's okay, let's start.

Researcher: My first question is, what did they say was the diagnosis of the illness you have?

Participant: They said the illness I have is....., in English they say its mental illness.

Researcher: Oh, what kind of mental illness is it because there are different kinds of mental illness? What type do they say it is amongst the many types of mental illness?

Participant: It is Schizophrenia.

Researcher: Oh. Do you understand what Schizophrenia is?

Participant: Yes, it requires that one must take treatment correctly.

Researcher: What else do you understand or know about Schizophrenia? **Participant:**

It is important that a person with Schizophrenia consults with the doctor every six months.

Researcher: Is there anything else that you would like to tell me about Schizophrenia?

Participant: Schizophrenia is a very dangerous illness, therefore one must keep taking medication continuously. Schizophrenia

Researcher: Where did you get the knowledge/ information you have about Schizophrenia?

Participant: I get this information from the nurses in the hospital and the clinic.

Researcher: Ooh.

The interview was interrupted when the participant's mother.

Researcher: Let us/ Can we continue with our interview?

Participant: Yes.

Researcher: How is it for you to live with mental illness in the community? **Participant:**

No, people here know about people with mental illness. They don't treat us badly.

Researcher: May I ask, do you have any friends now?

Participant: No, I do not have female friends/ girlfriends.

Researcher: Other friends?

Participant: I have male friends. I do not have any female friends/ girlfriend.

Researcher: Did you have any girlfriends or just friends before you became ill

Participant: I used to have girlfriends when I was in Gauteng.

Researcher: What challenges do you come across as a person living with mental illness?

Participant: Problems that people with mental illness encounter are related to non-compliance to the doctor's orders.

Researcher: Where do you get support? Is there any group or organization within the community that gives you support so that you can live well?

Participant: We do not get support. The only thing we get is the reminder that we should not forget to take treatment.

Researcher: Is there nowhere where you get support?

Participant: No.

Researcher: Isn't there any help you get from the clinic?

Participant: They do not even allow us in the clinic. When we consult there, they tell us to go and get a referral letter from the mobile clinic. They tell us to get referral letter from the mobile clinic if we consult there.

Researcher: How difficult is to get the support you need from the community?

Participant: They treat us well here at home. They always remind us to take treatment. That is the only support we get.

Researcher: Is there anything else that you would like me to know largely about mental illness? Something that will make have a better understanding about mental illness.

Participant: No

Researcher: There are other questions that I'd like to ask you. The first one is your gender: Are you a male? ,

Participant: Yes

Researcher: How old are you?

Participant: 51

Researcher: How old were you when you were first diagnosed with mental illness?

Participant: I could not accept that I had mental illness because I was embarrassed, refusing to even take treatment properly.

Researcher: How old were you then?

Participant: I was already 30 years old.

Researcher: In other words you have been living with mental illness for 21 because you are now 51 years.

Participant: Yes, because it was in 1993 when I learned that I have mental illness.

Researcher: Where were you then?

Participant: I was here at home.

Researcher: Le yile neng Gauteng? When did you go to Gauteng?

Participant: I went to Gauteng in 1982. I stayed in for December and that was the time we were staying at ga-Chuene. Just after arrival here in 1987. I went back to back to Gauteng and returned home in 1991.

Researcher: At what grade did you leave school?

Participant: I did ABET level 4.

Researcher: Before ABET, did you not go to school?

Participant: I have never been too school. I only attended ABET.

Researcher: Are you married or have you been married?

Participant: I never married.

Researcher: Do you have children?

Participant: No.

Researcher: How are you related to your caregiver?

Participant: She is my younger brother's wife (sister-in-law).

Researcher: What is your source of income? Do you work or is there money that you are getting or you are supported by your caregiver?

Participant: Ke hwetša grant. I receive a social grant.

Researcher: So you get a grant?

Participant: Even though I did not go well last month.

Researcher: What was the reason you did not go well?

Participant: You know, usually I withdraw money in the shop by first buying but last month they robbed me money for sekete because when I withdraw from the machine I use a pin number.

Researcher: But was the money deposited?

Participant: Yes, it was deposited but when I checked the money on the slip it was different from what should be in the account.

Researcher: Did they not explain what happened?

Participant: I explained to them and they issued the slip for the third. The slip was showing that I withdrew all the money whereas the one I had was telling a different story then I went to SASSA and they told me to do an affidavit.

Researcher: When are you receiving your grant?

Participant: On the 5th.

Researcher: Thank you uncle. We have reached the end of our interview. I'll come again for the papers I spoke about. You'll learn about the results and the commencement of the six weeks programme after I have concluded this research.

Participant: Yes.

Researcher: Is there anything you would like to know or ask?

Participant: No. We'll wait for you.

ANNEXURE 19: EXAMPLE OF A TRANSCRIPT FOR A FAMILY MEMBER

Researcher: Ke ya leboga ka gore o tsee nako ya go tsea karolo mo dinyakisisong tse. Re tlo thoma ka depotsiso tsa rona. Karolo ya mathomo e mabapi le wena, ya bobedi e nyakisisa ka ge o le mohlokomedi wa molwetsi. Re ka thoma?

Participant: Ee

Researcher: Mengwaga ya lena ke e mekae?

Participant: Mengwaga ya ka gane jwatse ke sa e tseba. Mhm, a ke e tsebe.

Researcher: Le fihlile kae kua sekolong?

Participant: A se nke key a sekolong.

Researcher: le nyetse?

Participant: Ee, ke nyetswe.

Researcher: How many children do you have? Lena le bana ba bakae

Participant: Ntse ba le some ga tloga ba babedi, gane jwale go setsi ba seswayi.

Researcher: Molwetši le eng le yena?

Participant: Ke morwa waka, o latela wa boraro.

Researcher: Bjale le iphediša ka eng?

Participant: Ke gola motente, le yena ke motsentshitse oa gola.

Researcher: Alright, karolo ya mathomo re e feditše, re ya karolong ya bobedi.

Participant: Ee.

KAROLO YA BOBEDI/ SECOND SESSION

Researcher: Le na le nako e kae le hlokomela molwetši?

Participant: Ke kgale ngwana ka, ga ne jwatse, yhoo, ke kgale man. Go ka tseba mokgalabe yo. Nna dilo tse dia ngakantsha. Le sesi ya bona ge e nkabe a le gona o be a tla tseba mara ga a gona o mo Matshipi.

Researcher: Ba re bolwetsi ke eng?

Participant: Bolwetsi ge bothoma, ba rile motho o na le badimo. Ba re o na le badimo. Ra napa ra tloga ra ya mosading yo mongwe kua fase.

Researcher: Ok ma, ko sepetlele ba re bolwetis bo ke eng?

Participant: Kua sepetlele ba rile a fiwe dihlare, ba re a hlabiwe a fiwe dihlare

Researcher: Ba rile ke kalafo ya eng?

Participant: Ba rile dihlare tse, bolwetsi bo, dihlare ke tsa gore tlhogo e se ka tswenya.

Researcher: o na le tsebo e kakang ka bolwetsi bo?

Participant: Ke kgale man ke kgale.

Researcher: Se ke nyakago go se tseba ke gore o tseba eng ka bolwetsi bjo?

Participant: Nna bolwetsi bjo a ke bo tsebe ke no bona batho ba bangwe ba sepela ka mo ntle. Nna a ke bo tsebe nie, ke mathomo ke bo bona ka ngwana yo. A ile mmerekong kua Tswetla, ge a boya napile a boya a le ka mokgwa o.

Researcher: O tsea kalafo e jwang?

Participant: Be ke mo isa toropong, di ngaka tsa re aowa gane jwale a ka boya mo gae. Go tla re ka nako ye engwe la tla mo toropong. Bona ba beile nako ya bona. Ba tla ba mmona ba ba le dipotsiso le yena.

Researcher: Kalafo e a e hwetsago e mo thusa jwang?

Participant: Nna ke bona e mo thusa ngwana ka. Ka gore matsatsi a o right kudu. Nako e la ya kgale o be o tla mmona a jikajika gona mo motseng a bolela a sa fetsi. O be a se sa tsea dihlare. Tsona di ya mo thusa kudu, di mo swere gabotse. Le yena o a thusa ka mo gae kudu.

Researcher: Le nagana gore ke eng e hlotseng bolwetsi?

Participant: He ai, nna nka se tsebe, ka nnete a ke tsebe ke no bona ge ngwana a boya a le ka mokgwa o. O be a bereka Tswetla kua fasi kua, ra napa ra mmona a tsena le dilo tsa gagwe. Rena, hi, na go dia jwang Jacky, molato ke eng? A re mmele waka a ke o kwe gabotse, ke ya lwala, mmele o bohloko. Ka thoma ka mo isa di ngakeng, aowa ka bona go sa thusi selo. Ka morago ke rile ke dutse motho a re ke badimo. Ge ba re ke badimo ka mo tsea ka mo isa ka kua, go mosadi o mongwe wa ngaka. Re dutse ampuru ngwaga ka moka ke na le yena.

Researcher: Gona bjale le phela bjang mo setshabeng bjalo ka mohlokomedi wa molwetsi.

Participant: Aowa, a ke bone bothata. Le batho mo ba mo hlompha kudu. Ke re kgane ba mo hlompha ka gore o feditse ngwaga a thwasiswa a le mo malopong. Le gore le yena ga tswenye motho.

Researcher: Go hlokomela ga ga go molwetsi yoo, go sitisha jwang go tsea karolo go mesomo ya setshaba?

Participant: Le ra go thusa ge gona le mebereko e tswana le mahu?

Researcher: Ee.

Participant: Ee, aowa ke be ke ya ka nako e la ya kgale mara gane bjale ke ya palelwa ka gore ke ya lwala. Kgale be ke no palelwa go tsamaya ke ya kgole ka go tshaba gore a gona motho yo a ka hlokomelago molwetsi. Le yena di nako tse dingwe o wa thusa.

Researcher: Go jwang go hlokomela molwetsi?

Participant: Awu ngwana ka, ke tla reng. Gona go boima kudu kudu ge a thoma go lwala, o no bona go esa, ke gore ke mathata. Mara ge a enwa dihlare go ba kaone kudu, e bile yena o thusa nna.

Researcher: Ke e e feng thekgo e le ye humanago gona mo setshabeng?

Participant: Thekgo ya mohuta mang?

Researcher: Thekgo engwe le engwe.

Participant: Aowa a e go.

Researcher: E re ke le fe mohlala. Go na le thekgo e le e homanago go ba bereke ba tsa maphelo kapa ba direla leago?

Participant: Aowa, e no ba go humana dihlare tsa molwetsi?

Researcher: Le tsena kereke?

Participant: Ee

Researcher: Ke e feng thekgo e le e humanago kerekeng?

Participant: Aa ngwana ka, go ka kwagala nkare ke rekisa kereke yaka, mara thekgo ye ba mphago yona ke ye kgolo. Wa tseba ba tla mo ba tlo re rapelela.

Researcher: Ka mo gae le humana thekgo?

Participant: Le lapa le ke ikeme ka lona ka gore o wa bona gane jwale ke ya lwala akere, a ke sa kgona go dira dilo tse dintsi. Jwale ke thekgwa ke bona.

Researcher: Ee.

Participant: Ke gore ka gore le yena molwetsi o thekga kudu. Aowa ngwana ka mogae thekgo e kgona.

Researcher: Le kgona jwang go kgotlelelana le mathata a go hlokomela molwetsi?

Participant: Aowa ka gore ke ngwanaka nka se mo lahle, ke tla mofa mang. Le gore ke motho wa kereke jwale ke ya rapela nako e ntsi. Akere le molwetsi ga tswenye?

Researcher: Re fihlele mafelelong a dipotsiso tsa rena, go na le se sengwe se le ka ratago go se oketsa gore ke kgone go kwisisa ka hlomelo ya molwetsi wa monagano?

Participant: Aowa.

Researcher: Kea leboga ma.

Participant: Go le boga nna ngwana ka.

ANNEXURE 20: EXAMPLE OF A TRANSCRIPT FOR FOCUS GROUP DISCUSSION

POLICE OFFICERS TRANSCRIPT

Researcher: Question number 1: What is your understanding of mental illness? Anyone can start answering. What is your understanding of mental illness? We can mix English and Sotho, its fine.

Participant 1: I think mental illness is the mental disturbance caused maybe by stress, divorce or domestic violence. Sometimes it may affect one to maybe have mental illness.

Researcher: What do others think? What is your understanding of mental illness? Kwesiso ya gago ka bolwetsi ba monagano ke ye efeng or o kwesisa eng ka bolwetsi ba monagano?

Participant 2: My answer is not too different from that of the first speaker; I can say it's people who are disabled/ disturbed mentally and it could be because of problems.

Participant 3: I can also bring this other one, culturally it is believed that a person with mental illness is bewitched to be in that kind of state, but personally I think it's because of stress or other circumstances that a person ends up in such a state.

Participant 4: Or maybe we can even say according to my understanding or knowledge I have that people or individuals are using any types of drugs may end up having mental illness. Comparing to this area that we are working in, drugs in most villages is their everyday use (food). In other words we have most cases of drug use and there are a lot of mentally ill people.

Researcher: What support system is available in the community for people with mental illness and their families?

Participant 5: It seems that the responsibility to support these people lies with the government. Even in the government the treatment or support is not enough. So there is no support in the community, because when the family is experiencing problems with the ill individual, they call government officials which are police and paramedics.

Participant 1: There is no support for these people. I think the support we can give mostly is that, if we as police can conduct workshops and ask people with mental illness, doctors, nurses and paramedics (as already stated) do an awareness whereby we can

ask for the mentally ill from the community and gather them then call the medical doctors and nurses maybe we can achieve something.

Participant 3: I think as for support, there is not much support from the community. If you look at the family you'll find that the person caring for the ill individual is not well equipped to understand how s/he thinks when he is in a different situation. For instance you may find that I as a carer I start acting weird around this person maybe by showing fear as a result he ends up frustrated and the situation gets worse. People are just not equipped, even the community does not know how to treat this person. There is no information as far as mental illness is concerned so we need education.

Participant 2: there is no support from the family because you find that every individual who is mentally ill has one person with whom he gets on well among the family members. We are not able to see where we are who the mentally ill person understands. If the family or community could just identify and use the person who the PWMI gets on well with so that he can get help.

Participant 3: Another thing about support, sorry to get in there. There is this issue is that there is no support in the families. You'll find that most people we as police officers take to hospital to get injection are also given pills but when they get home they don't take (drink) them they just pack them. You'll find that next time you go the family they will say he is not taking his medication only to find the pills are just piling up.

Participant 4: Okay, to add on that, the only problem is one; the disability grant. In most cases the only thing that most families only care about is this grant for the PWMI. They are not interested in giving any help to the ill individual. So that is why most times they don't lock them as a result they end up confused because they are not taking treatment.

In most cases people with mental illness get support from HBC. Caregivers get scared when they realize that they are pushing for the ill individuals to get that care where the family is not helping. What the caregivers do is to take them to the mobile clinic to get their treatment and also check them on daily basis to see if they drink it. If they fail to visit then PWMI do not get their treatment because the family fails to force ill individuals to take their treatment. So I can say they only get support from HBC, the family don't take their wellness into consideration but is only interested at mndende (grant).

Researcher: How do you view your role as police officers?

Participant 5: If I can just try to answer that, we as police officers when we are called to attend to a mentally ill patient we go there because we think there maybe harm to the community. That's the only thing that concerns us, making sure that the person does not cause any harm. When we arrive at the scene we call the paramedics to handle the situation.

Participant 2: Our role is to combat crime and protect the community as a whole. Meaning there is somewhere somehow where we as police officers do not fit in. We assist the community when the patient is too violent or involved in any criminal activities because of his mental status. The challenge is that the community does not understand that our role is not to collect/transport the patient to the hospital or to get medical assistance but to protect the community from the mentally ill who is violent and may cause harm to the community members.

Participant 5: You see what I can say is that as for us police to work/deal with the mentally ill is a problem because we are not well trained about people with mental illness. We just go there physically so but we have to be cautious. We go there physically so. Remember a police officer is a human being. Our role is to remove this person from the community. Our aim of going there is based on protecting the community.

It would be better if there was a course that we attend to educate us about how to calm the situation down. As I have said that we go there physically, somebody can get harmed either the person with mental illness or the police officer. We are trying to play the role it but we are not equipped.

Researcher: Probe: How do you deal with the case where you feel that it should not be attended to by you? E.g. you find that the person is not violent.

Participant 2: Normally when we arrive there we assess the situation and the conditions of the patient. The family will not be happy if we leave before giving them assistance. (Therefore) Meaning we liaise with the paramedics to check how far are they because we are waiting for them to take the patient.

Participant 1: To add on that, normally we call the right one in order for the family to be satisfied that we did something.

Researcher: To what extent do you work with other stakeholders?

Participant 4: Maybe I can say from my side or according to me from the office of social crime prevention, in most cases we engage the home-base caregivers for assistance when we do door to door campaign to go and identify any patient who will need help. But with paramedics there is nothing you can do, but if maybe possible there can be an ambulance based at each and every police station to work with us when we go to attend such cases and also attend to other medical cases. You know with police officers we are jacks of all trades, if there is a snake at a home they call us knowing very well that we don't work for SPCA. They call us when there is mentally ill person knowing that we are not well trained. So having an ambulance on site would help because we would go together to the scene to assist. If we work like this I believe that we can reduce this thing.

Participant 2: What stakeholders are you talking about? **In response to this question the researcher outlines various stakeholders.**

Participant 2: We only work with emergency services (ambulance). Isn't it?

Participant 4: We work with home-based caregivers who do regular door to door visits and also assist by going with ill individuals to mobile clinic.

Researcher: What can you do to improve the working relationship between you and other stakeholders?

Participant 1: I think maybe if we can get small training together with EMS so that when we come across a case of a person with mental illness, we can assign the responsibility to one of the trained constables and he can also work together with the well trained paramedics.

Participant 2: if it was possible the EMS should be close to us, they should be stationed closer to the police station. EMS comes from far, they come from one direction and we as police officers come from another direction. That is why when we go somewhere to attend to a case we spend too much time waiting for them or they waiting for us. So if they are nearby we can render the service at the same time.

Participant 4: Socially we do communicate with other stakeholders and therefore I can say we do have that relationship only that we are distant from each other, this lead to failure to deliver the needed service at the same time. Due to distance stakeholders may delay to get to the scene as a result one who came first may be unable to wait for the

other stakeholder to arrive. A message for other stakeholders to call when they arrive at the scene may be left with the family members. This becomes a cycle that impacts badly on service delivery. We would like for the facilities to be at the same place or closer to each other it will be easier when going to attend a case.

Participant 2: EMS comes from +/- 100km away, which is very far. You find that you wait there for a long time. While waiting you get reports for a more serious emergency as a result you end leaving. When that other one arrives they can approach the ill individual in the absence of police. This ends up being an up and down. It would really be nice to have all stakeholders who render essential services the community be housed in one place so as render a speedy service.

Researcher: Anything you would like to add to help me understand your role better?

Participant 2: There is a problem that we wish can be solved. These people go to hospital and you find that their files are thick but they are not referred to the relevant mental institution like Sekutupu or Thaba Moopo. Hospitals take time before taking/referring the patient to mental hospitals. Sometimes they refer when the ill individual already has a case and it becomes out of hand that way. They should look at it differently.

Participant 4: One more thing, if it's possible why don't they use injections rather than pills for violent patient because this people don't take pills? If health professionals can just use their categories and give other MI injection. To be honest these people stop taking their pills.

Researcher: Aowa, ke ya leboga

ANNEXURE 21: EXAMPLE OF FIELD NOTES

EXPANDED FIELD NOTES

The setting was okay. Due to lack of space, we were forced to conduct the interview in the car. While in the middle of the interview, the participant's mother came looking disturbed. She mumbled something about her daughter in law. The participant tried to find out what the problem was and the mother asked us if we had said anything to the daughter-in-law as she appeared to be angry. We told her that we had not spoken with her daughter-in-law yet. She started saying other aspects that could not be linked with anything. So the participant requested her to leave as we wanted to continue with the interview. He, however promised that we would attend to her after the interview. After this incident, the participant also complained about his mother who likes to make an issue out of nothing. He also mentioned that he understood that it was because of her age.

The participant spoke highly of treatment and seemed to know what is expected. He said: *"We are often told to take treatment correctly. I know it's important because it has helped me. I used to look horrible with very long dirty hair and nails, even my clothes were very dirty. Since taking treatment, I can differentiate between what's right or wrong."* He spoke about people who do not seem to take their treatment seriously and mix it with alcohol. The participant spoke about those who do not want to accept their status hence most of them remain ill for a very long time.

Besides treatment, he appeared to be someone who is aware of what is going on in his village and also participates in most social activities. He narrated several stories that show that he considers himself a responsible member of the community. He also spoke about his interest in education and mentioned that he wished to continue with ABET so that he can get a Grade 12.

Reflection from the interview: it started well but I nearly forgot to include the demographic information in the interview. I noticed that the participant could have more to offer because he seemed to be aware of what was going on around him.

ANNEXURE 22: QUESTIONNAIRE TO ASSESS INTERVENTION AIMED AT PWMI AND THEIR FAMILIES



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EVALUATION OF A SOCIAL GROUP WORK EDUCATIONAL PROGRAMME FOR PEOPLE WITH MENTAL ILLNESS AND THEIR FAMILIES IN A RURAL SETTING

*Please respond to the following statements and questions as honestly as possible.
Your views are crucial in helping me/us improve this educational programme.*

Are the goals of this educational programme clear and well-founded? *Please explain.*

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To what extent is the content clear, concise and relevant?

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How applicable are the outlined activities to the intended target groups?

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Evaluate the potential of this programme to provide capacity to social workers to educate people with mental illness and their families.

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What are the possible constraints that can hinder the implementation of this educational programme?

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What other aspects do you think should be included in this educational programme?

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.....

THANK YOU FOR PARTICIPATING

ANNEXURE 23: QUESTIONNAIRE TO ASSESS INTERVENTION AIMED AT HEALTH CARE PROFESSIONALS AND STAKEHOLDERS



Private Bag X6001, Potchefstroom
South Africa 2520
Tel: (018) 299-1900

EVALUATION OF GUIDELINES FOR HEALTH CARE PROFESSIONALS AND STAKEHOLDERS TO IMPROVE PROVISION OF SUPPORT TO PEOPLE WITH MENTAL ILLNESS AND THEIR FAMILIES IN A RURAL SETTING

*Please respond to the following statements and questions as honestly as possible.
Your views are crucial in helping me/us improve these guidelines.*

Are the goals of the guidelines clear and well-founded? *Please explain.*

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To what extent is the content clear, concise and relevant?

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How applicable are the outlined activities to the intended target groups?

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Evaluate the potential of these guidelines to provide health care professionals and stakeholders with the capacity to support people with mental illness and their families.

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.....

What are the possible constraints that can hinder the implementation of these guidelines?

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What other aspects do you think should be included in the framework?

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THANK YOU FOR PARTICIPATING

ANNEXURE 24: SOCIAL GROUP WORK EDUCATIONAL PROGRAMME

FIRST SESSION: WELCOMING AND INTRODUCTION

Session objectives

- To welcome the participants into the group
- To facilitate participants' introduction
- To discuss the aim and the objectives of the programme
- To establish expectations
- To establish ground rules
- To contract with the participants
- To evaluate the session

Session activities

First session serves as a general welcome and introduction to community-based programme (CBP) and its purpose. This provides an opportunity for the facilitator and the participants to meet. In order to ensure that the participants reveal relevant information during the introductions, the facilitator guides them by firstly introducing herself and briefly explains what is expected of them (Toseland & Rivas 2012:199).

The first session is often characterised by fear and feelings of uncertainty especially when participants are not familiar with each other. It is therefore important to create a climate and set the tone that would make all participants comfortable and feel that they belong to the group. At the stage the facilitator has to steer the group to the right direction (Toseland & Rivas 2012:207). There is, however a possibility that some participants who are from the same village or neighbouring villages know each other. This lessens the fear as most participants create the atmosphere that makes those who do not know others feel comfortable. The facilitator welcomes the participants into the group. Although all participants already know who the facilitator is, she has to introduce herself once again and request participants to introduce themselves to each other.

After the general introductions, the facilitator explains the purpose of this group. Prior to the explanation, the facilitator gives a brief background about the findings of the study conducted with the participants as this forms basis for the purpose of the group.

Participants are allowed to ask questions or get clarity about the findings and the study in general. After this explanation, participants are divided into smaller groups of three to discuss their expectations and establish the ground rules. Although due to the small number of the group and the fact that majority of participants maybe familiar with one another, each small group must have one person who is not known by others. Participants from the same household are not allowed to be in the same group. After this exercise, participants present their expectations and ground rules. The facilitator adds her expectations and some ground rules. The whole group reaches an agreement about these.

Following the presentation of expectations, the facilitator informs the participants that their contract has to be reviewed. Contracting focuses mainly on administrative aspects such as day, time, venue and frequency of the meetings as well as transport arrangements for those who were staying far from the chosen venue. The session ends with session evaluation and planning for the next session.

SECOND SESSION: MENTAL ILLNESS

Session objectives

- To discuss about mental illness.
- To discuss treatment for mental illness.
- To explain the benefits of treatment and the importance of adherence.
- To evaluate the session

Session content and activities

This session begin by acknowledging the participants have lived experiences with mental illness. Therefore, following suggestions by Sands (2003:7), Toseland and Rivas, (2009:24) and Ramaprasad and Kalyanasundaram (2015:17), the facilitator starts where the participants were in terms of their knowledge regarding mental illness. This would help them to link new information with the existing knowledge. After the introduction of the session, participants are divided into small groups. Each group is expected to discuss what they know about mental illness. After 15 minutes, each group gives feedback to the house about their understanding of mental illness. This affords them an opportunity to talk about their daily challenges, ways of coping and how they solve these challenges. It

also provides an opportunity for participants to get support and constructive advices from others.

The facilitator gives a presentation on what mental illness is. This presentations focuses on discussing the myths about mental illness and different types of mental illness. More emphasis is put on the diagnosis of the participants and some of the most common types of mental illness within the province. It has to be emphasised that anyone can suffer from mental illness.

Participants are given an opportunity to talk about the treatment they are taking, its advantages and disadvantages. This gives them to share their experiences about treatment and how it changed their lives. Although it is commonly known that most participants experience side effects, especially from injection, talking about treatment will put emphasis on the importance of adhering and therefore encourage others to stick to their treatment. This also serves as a motivation to other PWMI and their family members who might be having doubts to the effectiveness of treatment.

At the end of the session the facilitator summarizes topics that were discussed. Following this summary, the participants evaluate the session focusing on which information was useful and which was not useful in terms of their expectations. They also have to evaluate processes followed for presentations. After the evaluation, the facilitator briefs the participants about the topics to be discussed in the next session.

THIRD SESSION: MANAGING EMOTIONS

Session objectives

- To equip participants with skills on how to deal with their emotions.
- To discuss the impact of emotional over-involvement.
- To evaluate the session

Session content and activities

The facilitator begins the session by explaining to the participants about the topics of the day. Questions are posed to the participants about their understanding of managing emotions. Participants are allowed discuss amongst themselves first and to answer this question. Prior to the explanation about emotion management, the facilitator gives examples of common emotions that we as human being experience under certain

circumstances. For instance, fear of rejection has a negative impact on PWMI as it prevents them from taking charge of their lives. For these people, fear is a result of perceived rejection or past experiences with stigma. As a result they tend to isolate themselves. Anger is also identified as one of the common emotions that most participants experience.

The facilitator makes a presentation about the impact of most emotions and how to deal with them. The main focus is on anger management, identifying triggers of emotional disturbances and dealing with fear. The following suggestions are made:

- Engage in physical activities
- Getting information about illness
- Join support groups and try to spend time with positive people
- Slowly engage in social activities in order to learn to be around people
- Learn to ignore negative comments
- Educate people about mental illness
- Identify aspects that trigger certain emotions e.g. anger.

Next, the facilitator makes a presentation on over involvement of family members into the lives of PWMI. The aim of this presentation is not to blame but to create awareness of the impact it has presently and in the future of the person with mental illness especially because most caregiving family members are over the age of sixty. This discussion is prompted by the finding from the study, which indicate that caregiving family members' worry about the future in which they indicated the worry about who would take care of the PWMI when the caregivers are no more. Participants are given a platform to discuss this issue. It is anticipated that caregiving family members may find it difficult to just let go due to their past experiences. It is important to emphasize the importance of allowing PWMI to exercise independence. Some of the questions that can be asked to the participants include:

- What will happen to the person when you are no more?
- What makes it difficult for you to let go?

Following this brief discussion, the facilitator summarizes the topics discussed and the views of the participants about over involvement. More emphasis is put on learning to

take responsibility on the side of PWMI whereas family members are urged to slowly learn to let go. The session is evaluated.

SESSION 4: MAKING ENDS MEET

Session objectives

- To discuss budgeting and prioritising on expenses
- To discuss saving options
- To evaluate the session

Session content and activities

As an introduction, participants are asked to analyse how they spend their finances by categorising their expenses according to the needs and wants. Participants will also have to discuss things that they feel are important to them but cannot get due to financial difficulty. Thereafter the facilitator makes a presentation distinguishing between the needs and wants. The focus is on prioritising the needs over wants. In addition, the presentation focuses on the importance of budgeting. Participants are asked to share their understanding of budget and how they do it on a monthly basis. The focus is on making budget and stick to it. Emphasis is put on the importance of living within ones means.

The next discussion focuses on saving for the rainy day. Participants will work in pairs and discuss different ways in which they are currently saving as well as other ways of saving that they feel should be explored. Their discussion is guided by the following questions:

- ✓ How often and how much do you save?
- ✓ Why do you save?
- ✓ How often do you withdraw your savings?
- ✓ Does saving your money benefit you in any way?

Thereafter, participants will give feedback of what they have discussed. The facilitator will make a presentation on the importance of saving. Various saving options in both formal and informal institutions are explored. This includes burial societies and stokvels as saving options. Benefits of saving are discussed. Participants are informed of reputable institutions in which they can save their money. They are also warned of the

“fly by night” schemes that promise them unbelievable interests. Given the costs of traveling to town, the facilitator and participants look into the ways of keeping some money at home and avoid temptations of using it for other things besides what it is meant for. Participants will evaluate the session. The facilitator will conclude and brief participants about the following session.

SESSION 5: COMMUNICATION SKILLS

Session objectives

- To discuss various effective communication skills and their importance
- To discuss how to handle difficult situations
- To discuss the importance of socializing – claiming your role in the community.
- To discuss the importance of establishing social networks
- To prepare for termination
- To evaluate the session

Session content and activities

The purpose of this session is to equip participants with communication skills. The facilitator introduces the topic and ask the group about their understanding of communication. Types of communication are discussed. Emphasis is put on the importance of communication skills to facilitate effective communication through information sharing. Participants are divided into pairs to brainstorm about important communication skills that can be used to solve a problem and ways in which they can improve communication. The discussion focuses on the following aspects of communication:

- ✓ The importance of listening
- ✓ Benefits of good communication
- ✓ The challenges associated with poor communication.

Given the fact that participants tend to avoid potential difficult situations, the main purpose of learning problem solving will help them to develop and enhance social skills necessary for dealing with interpersonal problems. Avoidance is discouraged and participants are encouraged to address their problems. Particular emphasis is put on addressing the situation in an assertive manner. Participants are advised to consider planning their strategy as this will help them avoid to use impulsive and aggressive

methods. Socializing is identified as an important aspect that can help participants improve communication and also reclaim their position in the community. This will help them to interact with people and initiate conversations. By so doing, they will get exposed to how other people handle various situations, especially difficult situations. This will also help them make informed choices about social activities that are more beneficial to them.

The facilitator highlights creating support networks as an important aspect that helps improve communication. Networks create opportunities for individuals and groups to come together, share ideas and establish a common goal. Before evaluation and ending the session, the facilitator reminds participants that the programme is nearing its end. Participants are encouraged to consider applying the skills learned from the beginning of the programme. Participants evaluate the session.

SESSION 6: SUMMARY OF THE PROGRAMME AND TERMINATION

Session objectives

- To review topics discussed in the previous sessions.
- To establish/ set short-term and long-term goals.
- To evaluate the session and the programme

Session content and activities

This serves as the last session of the CBP. The facilitator elaborates on some of the topics that were discussed in the previous sessions. Participants are asked to give summaries of the topics that they think made impact on them and the skills that they are most likely to practice. Particular emphasis is put on the importance of reclaiming the position in the community. Participants are encouraged to take the first step in changing the mind-set of the people around them.

Following this review, the facilitator introduces the topic about short term and long term goals. Emphasis is put on the importance of setting realistic goals that are achievable within a certain period of time. Participants are asked to write their short and long term goals in a piece of paper and give a brief overview of how they plan to reach them. This session ends with a review of the skills presented. Particular emphasis is directed at strengthening continued application of skills learned during the programme. Participants

are encouraged to work towards achieving their goals. The facilitator summarizes the session.

Participants are asked to evaluate the programme focusing on the sessions, topics discussed and the procedures followed. They are also asked to fill the programme evaluation form that consists of the following open-ended questions:

- What did you find most helpful/ beneficial about participating in the group?
- What did you find least helpful/ beneficial about participating in the group?
- What changes would you recommend for future groups?
- Any other comment?

After the evaluations, the facilitator reminds participants of the follow-up visits to assess the impact the programme. The programme ends.

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ANNEXURE 25: GUIDELINES FOR HEALTH CARE PROFESSIONALS AND STAKEHOLDERS TO IMPROVE SUPPORT TO PEOPLE WITH MENTAL ILLNESS AND THEIR FAMILIES IN A RURAL SETTING

1. INTRODUCTION

Acknowledging and understanding the critical aspects associated with mental illness is important for effective intervention to improve the well-being of people with mental illness (PWMI) and their families. The collaboration of health care professionals with stakeholders including families, religious leaders, traditional health practitioners, school teachers, police officers as well as local non-governmental organizations, as formal and informal systems for providing support to PWMI and their families within the community is essential. Results of a situational analysis conducted at Mashashane show that both formal and informal systems provide inadequate support to PWMI and their families. This lack of support was associated with lack of skills, fear due to lack of knowledge about mental illness, perceptions that PWMI are dangerous, lack of resources for mental health service delivery as well as poor collaboration among stakeholders.

The purpose of this document is to recommend guidelines to various health care professionals and stakeholders on how to provide support to PWMI and their families. These guidelines were developed based on an extensive literature reviewed and results of a situational analysis conducted at Mashashane. The study focused on the following key areas:

- Individual and family support
- Collaboration among stakeholders
- Individual and family involvement in supporting efforts
- Awareness training for all stakeholders.

2. BACKGROUND

Evidence suggests that mental illness has devastating impact on various levels (Robinson, Rogers & Butterworth 2008:4; Gamm, Stone & Pittman 2010:100; Ziller, Anderson & Coburn 2010:216). People with mental illness experience stigma every day of their lives. This deprives them the opportunity to participate in societal activities and decisions that affect their lives resulting in low self-esteem, withdrawal and social isolation (Larson & Corrigan, 2008:88). In addition, they have to deal with severe health challenges caused by treatment side effects (Mavundla, Toth & Mphelane 2009:361).

According to O'Connell, Boat and Warner (2009:65), family is a primary source of support and the socializing agent of people with mental illness. The existence of mental illness shapes the social network of the family as the new caregiving demands are thrust upon them without knowledge and skills (Botha, Koen, Oosthuizen, Joska & Hering 2008:272). The provision of psychosocial support to people with mental illness who sometimes do not even notice the efforts made by family members result in high levels of stress (Mavundla, et al. 2009:361). This high level of stress may result in health problems and increase the risk of mental illness among family members (Robinson, et al. 2008:9). It can also be a result of financial challenges experienced due to travel costs to access specialized services (Botha, et al., 2008:272; Mayosi, Flisher, Lalloo, Sitas, Tollman, & Bradshaw, 2009:934), impulsive spending behaviour adopted by PWMI (Byaruhanga, Cantor-Graae, Maling and Kabakyenga 2008:117) and payment of damages to property caused by PWMI during manic episodes (Mavundla 2009:360).

There is growing evidence of the impact of support on general health outcomes, maintaining good mental health and enhancing resilience (Ozby, Johnson, Dimoulas, Morgan III, Charney & Southwick, 2007:35; Reblin & Uchino 2008:204). Given the multifaceted nature of challenges posed by mental illness, providing support is crucial. Therefore, there is a need for joint efforts of health care professionals and stakeholders to provide support to improve quality of life and well-being. South African National Mental Health Policy and Strategic Plan 2013-2020 (DoH 2012:26) and WHO (2013:13) recognize the vital role played by both formal and informal care providers in improving the well-being of PWMI and their families. As a result, emphasis is put on the active involvement of stakeholders and their collaboration health care professionals. The collaboration is especially crucial in resource constrained areas as it contributes to improved mental health services delivery (Adelman & Taylor 2007:3).

Supporting the view of stakeholder involvement, O'Connell, et al. (2009:19) present three perspectives that strengthen the need for multi-level intervention to improve well-being of PWMI and their families. The public health context understands health as a result of interaction of various factors that are beyond the individual. It therefore calls for the involvement of various stakeholders to address intertwined factors affecting mental health. Economic perspective calls for public sector intervention in mental illness impose costs not only on the individual but the society. According to the political science perspective, government should intervene on aspects of shared interests that require shared solutions (O'Connell 2009:20).

It can be concluded that receiving support within the community setting may reduce the burden of care for families and improve well-being of both PWMI and their families. Both formal and informal systems can also benefit from the joint efforts through increased access to resources, sharing expertise as well as strengthen relationships.

3. GUIDELINES FOR SUPPORT

Given the inadequacies in the mental health services and poor support provided by both health care professionals and stakeholders to PWMI and their families, the proposed guidelines are intended to improve their support efforts.

3.1 Individual and family support

The presence of mental illness is challenging not only to the person with illness but the family as a whole. It is recommended that health care professionals and stakeholders consider the following aspects when providing support:

- Inform the individual and family about the availability of support.
- Assign a health care professional or stakeholder to a specific individual and family in order to ensure consistency and provision of culture sensitive support.
- Educate the family about signs and symptoms of illness and relapse.

3.2 Collaborations among stakeholders

It is recommended that the following aspects are put in place as part of collaborative support efforts:

- Establish a task team consisting of representatives from each group of stakeholders.
- Identify a supporter for a specific individual and family.
- Develop measures to engage other stakeholders and families.
- Develop measures to evaluate the quality of the support and its impact on individuals and family.
- Foster agreement between health care professionals and stakeholders regarding the extent and limits of support they can provide.
- Conduct planned regular meetings to share ideas, provide information and address support related issues.
- Recognize and agree on roles to be played by each health care professional and stakeholder.
- Establish clear lines of communications.

3.3 Training for all stakeholders

Knowledge and skills are important in dealing with PWMI and their families hence it is important to provide relevant training to both health care professionals and stakeholders. It is therefore recommended that training focuses on the following aspects:

- The meaning of mental illness.
- Understanding the challenges faced by individuals and their families.
- Understanding the impact of mental illness on the individuals and their families.
- Dealing with the individual and family affected by mental illness.
- Understanding and recognizing treatment and its complications on people with mental illness.
- Train health care professionals so that they can provide culturally sensitive support.

3.4 Individual and family involvement

It is important to involve individuals and families in various processes if the project is to succeed. To allow and enhance individual as well as family involvement, it is recommended that the following aspects be considered:

- Involve individuals and families in the planning processes.
- Ensure active participation of individuals and families in activities regarding their support.
- Identify and draft individual and family roles and responsibilities in support activities.
- Formulate processes for interacting with individuals and families.

4. CONCLUSION

The well-being of PWMI and their families is not always taken into consideration despite their many needs that require collaborative efforts. These guidelines are an attempt to facilitate collaboration between health care professionals and stakeholders with the aim of providing adequate support that will improve the well-being of PWMI and their families in rural areas.

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ANNEXURE 26: THE SELECTED JOURNAL'S GUIDELINES FOR AUTHORS

International Journal of Mental Health

Aims & scope

The International Journal of Mental Health features in-depth articles on research, clinical practice, and the organization and delivery of mental health services around the world. Covering both developed and developing countries, it provides vital information on important new ideas and trends in community mental health, social psychiatry, psychiatric epidemiology, prevention, treatment, and psychosocial rehabilitation.

Peer Review Policy: All articles in this journal have undergone rigorous anonymous double-blind peer review, based on initial editor screening and anonymous refereeing by two to four anonymous referees.

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read them and follow the instructions as closely as possible.



Should you have any queries, please visit our [Author Services website](#) or contact us at authorqueries@tandf.co.uk.

Instructions for Submission of Manuscripts

International Journal of Mental Health receives all manuscript submissions electronically via its Editorial Manager site located at <http://www.editorialmanager.com/mimh>. Editorial Manager allows for rapid submission of original and revised manuscripts, and facilitates the review process and internal communication between authors, editors, and reviewers via a web-based platform. Editorial Manager technical support can be accessed at <http://www.editorialmanager.com/rohohelp/10.1/index.htm>. If you have any other requests, please contact Karen Rothman, Assistant Editor, at Karen.Rothman@nyumc.org.

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Authors of papers that have been accepted for publication must complete and sign the form "Consent to Publish/Transfer of English-language Rights," and provide it to the Editor with the final copy of his/her paper. The software and formats used for the text and graphics files should be identified.

All tables and charts or other art should be submitted in separate files from the main text of the manuscript and the diskettes must indicate the program used to create them. DO NOT embed them in the main text of the manuscript.

DO NOT use the automatic footnoting feature in your word processor. Notes should be indicated by a superscript number in the text, and the note text should be placed as regular running text at the end of the manuscript or in a separate file.

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References

The reference list should be provided at the end of the paper. The references should be numbered and arranged by appearance in the article, putting the last name of the first author or editor first. All articles, books, etc., referred to in the article (but only those cited) should be indicated in the text by consecutive numbers in square brackets (or parentheses if brackets are not available). If authors are mentioned in the text and there is more than one, use an ampersand (&) as a connective instead of “and”; if there are three or more authors, a comma precedes the ampersand (e.g., Collins & Smith; Jones, Wing, & Harmon). When referring to a work by more than three authors, use “et al.,” such as “Connors et al.” If you cite a number of works for a particular statement, consecutive numbers may be expressed as a span connected by an en-dash (e.g., “A number of investigators [5, 16–19] have found . . .”). References should be provided as follows.

References to Items in Periodicals

These should take the form: author(s), title, journal (italicized), volume and issue numbers, date, inclusive pages. For all authors, last names are given first; likewise for editors, with the names followed by “ed.” The name of the last author ends with a period. More than two authors are separated by semicolons. The date is given in parentheses. Example:

Notes

17. T.H. Davenport and M.C. Beers. (1995). “Managing Information About Processes.” *Journal of Management Information Systems* 12, no. 1: 57–80.

18. John Smith. (1999) “Why Economics?” *New York Times*, April 25.

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Davenport, T.H., and Beers, M.C. (1993) Managing Information About Processes.” *Journal of Management Information Systems* 12, no. 1 (summer 1995): 57–80.

Smith, John. (1999) "Why Economics?" *New York Times*, April 1: 25.

References to Books

Author(s) are specified in the same style as for periodicals. In the title, all principal words are capitalized and the title is italicized or underlined. The title ends with a period and is followed by city, ":", publisher, year. Example:

Notes

19. J. Nonaka, *The Knowledge-Creating Company* (New York: Oxford University Press, 1995), 65.

References

Nonaka, J., and H. Takeuchi. *The Knowledge-Creating Company*. New York: Oxford University Press (1995).

Figures and Tables

Figures should be submitted as original drawings, complete, and ready for photo reproduction. Tables submitted as cleanly printed copy may also be reproduced photographically. All lettering and figure elements should be large enough to be readable when the figure has been reduced to fit the journal page. All figures and tables must be specifically referred to in the text. All figures and tables should have brief, descriptive captions. If figures are provided on diskette, they should be in their original software (e.g., Excel, JPEG, TIFF, EPS), rather than pasted into a word-processing document. All figures must be submitted in camera-ready condition, preferably in black and white. We do not have the staff to produce or otherwise repair figures.

International Journal of Family Studies

1. General guidelines

Manuscripts are accepted in English. Any consistent spelling and punctuation styles may be used. Please use double quotation marks, except where “a quotation is ‘within’ a quotation”. Long quotations of 40 words or more should be indented without quotation marks.

- A typical manuscript will be 5000-8000 words including tables, references, captions, footnotes and endnotes. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgements as well as Funding and grant-awarding bodies); abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
- [Abstracts](#) of 150 words are required for all manuscripts submitted.
- Each manuscript should have 3 to 10 [keywords](#).
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#).
- Section headings should be concise.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Biographical notes on contributors are not required for this journal.
- Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate paragraph, as follows:

- *For single agency grants:* "This work was supported by the [Funding Agency] under Grant [number xxxx]."
- *For multiple agency grants:* "This work was supported by the [Funding Agency 1] under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding Agency 3] under Grant [number xxxx]."
- Authors must also incorporate a [Disclosure Statement](#) which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.
- Authors must adhere to [SI units](#). Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors must not embed [equations](#) or image files within their manuscript

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