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ORIGINAL PAPER

Stakeholders' Views Regarding Their Role as Support System for People with Mental Illness and Their Families in Rural South Africa

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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 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. Seven focus group discussions were conducted with various stakeholders. This qualitative study employed content analysis to allow for comparison of stakeholders' views. 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 · Families · Mental illness · People with mental illness · Rural area · Stakeholders · Support system

Introduction

There has been a growing interest in stakeholder involvement in mental health and related issues. This is based on the perception that the fight against mental illness and promotion of mental health are regarded as everybody's business (Skeen et al. 2010). 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 (Grifitths et al. 2008).

Given the disparities in rural mental health services and the cultural beliefs that influence the acceptability and utilization of this 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, traditional leaders (TL), traditional health practitioners (THPs) such as faith and traditional healers, school teachers, police officers (PO) and non-governmental organizations as well as non-profit organizations such as home-based care groups (WHO 2013). Stakeholder involvement can be associated with the biopsychosocial approach which attributes mental illness causation to biological, psychological and social factors (Dogar 2007). Cultural, economic, political and environmental factors are additionally classified as determinants of mental illness (WHO 2013).

Majority of stakeholders are directly or indirectly involved with people with mental illness (PWMI) and their families. Studies show that PWMI and their families consult either traditional or faith healers based on the belief of what caused mental illness (Nsereko et al. 2011; Ndetei et al. 2013). This is influenced by THPs accessibility as they are usually in the same community as their clients. Their locality makes it easy for them to conduct home visits as part of the treatment practices and extension of support to families. It also reduces the burden of high transport costs that are incurred when seeking help from mental health services (Ndetei et al. 2008, 2013; Nsereko et al. 2011). Given that faith healers are mostly associated with the church, people

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who get healed end up joining the same church resulting in a long-term relationship with more benefits. Magezi (2010) and Faull (2012) point out that the church plays a crucial role in promoting health, enhancing general well-being and promoting social functioning of individual members of the community.

HBC are an essential extension of health care that have been recognized for their role in providing social, emotional and material support to ill individuals and their families (Mahilall 2009; Ama and Seloilwe 2011). Although the initial view of HBC came as a result of providing relief to health care system that was overburdened due to the increase of HIV/AIDS cases (Friedman 2005), changes in mental health policy that resulted in de-institutionalization of PWMI increased the demand for HBC to provide care and support to ill individuals and their families (Ama and Seloilwe 2010; Mamba and Ntuli 2014).

The South African legislation recognizes TL as custodians of African culture that play a significant role in health, welfare, safety and security in the communities (Ross 2010; Knoetze 2014). A study conducted in Zimbabwe revealed that TL 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, PO are in constant contact with PWMI. They are usually the first people to be called when an individual with mental illness displays violent behavior (Livingston et al. 2014).

Although there is substantial evidence on stakeholders' pathways of care, treatment practices and management of PWMI (Sorsdahl et al. 2009; Magadla and Kolwapi 2013; Mamba and Ntuli 2014), their supportive role remains largely unexplored. Additionally, no studies have explored the role of TL within the context of mental illness. To date, no research has included THPs, church members, PO, home-based care groups and TL 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.

Methods

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 to fully understand the views of various stakeholders (Babbie and Mouton 2012; Creswell and Clark 2007; Yin 2003).

Study Sample

The study population from which a purposive sample of 41 stakeholders was selected, comprised of THPs (n = 6), TL (n = 4), CM (n = 11), HBC (n = 15) and PO (n = 5) from Mashashane. 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 (Babbie and Mouton 2012). Each group of stakeholders was recruited differently. The principal investigator wrote letters to and met with authorities from various churches, the tribal authority, THPs and HBC groups to request for permission for some members to participate in the study. The researcher met and recruited the recommended people. As for THPs and PO, the researcher met them as a group and explained the purpose of the study.

Data Collection

A short survey to source a demographic profile of the participants preceded the focus group discussions. The main data was sourced through focus group discussions. Due to the diverse nature of these stakeholders and to increase the level of participation, the focus group discussions were conducted with each group. Seven focus groups consisting minimum of four to a maximum of eight participants were conducted. An interview guide was developed to ease the discussion process. Some of the questions asked include the following: *What is your understanding of mental illness? How do you 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 (Babbie and Mouton 2012). The discussions were conducted in Sepedi and English. All focus group discussions were recorded.

Data Analysis

Data was analysed according to qualitative methods. Content analysis was used to compare different views from the participating stakeholders, which is usually performed by extracting themes from a textual data (Pierce 2009). 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. Researchers categorized data

according to the topics discussed during discussions. They read each transcript to identify passages that showed similarities or differences in stakeholders' views.

Findings

Findings presented here 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. Because faith healers did not participate, the findings and discussion use TH to represent traditional healers, rather than THPs as appropriate.

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, TH, TL and PO had more than 6 years working experience. Participating PO included four constables and a lieutenant. Of the CM who participated, five were from an independent church while the other six members were from traditional churches. All participating TH were diviners, while three TL were indunas and one councilor. Except for 2 TH, majority of participants were literate with education level ranging from primary school to tertiary education.

Understanding of Mental Illness

Participants had various understanding of mental illness. For participants, people's reaction towards PWMI influences their behavior. The TLs, HBCs and TH 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:

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

PWMI's behavior was also used as a determinant of stakeholders' understanding of mental illness. Most participants regarded PWMI as otherwise fine but for some reason may behave in a manner that is regarded as abnormal and socially unacceptable. The most frequently reported abnormal behaviors were mood swings, aggression, poor hygiene and personal care, mumbling as well as walking naked in public. One participant described the behavior of PWMI:

> A person with mental illness does things that are not expected to be done by a normal person. (HBC5)

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. Except for TH, participants stated that 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. In African culture, we believe that one is bewitched. (CM2)

These findings indicate that participants based their understanding of mental illness on expected reaction towards PWMI, the causes of mental illness and the behavior that PWMI display. Although the participants acknowledged that various factors can cause mental illness, their interpretation is mostly based on traditional beliefs with witchcraft as a dominating cause of mental illness.

Views on Available Systems in the Community

Participants identified the family, community, PO, clinic and HBC, health as well social services professionals as systems that should provide support in the community. However, 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 provide support:

> I don't see any support for these people because in our communities. People are scared of PWMI, and even their families reject them. (HBC7)

Another participant's observation:

> It seems that the responsibility to support these people lies with the government, but this is also 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:

> 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 because they visit homes to check on the PWMI (PO4)

These findings indicate that both formal and informal support systems are available in the community but they do not provide adequate support. Fear of PWM is a contributing factor, whereas families' lack of support is attributed to financial gain.

Views About Roles of Stakeholders

All stakeholders acknowledged that that they have an important role to play as support systems. TH claimed they provide PWMI with remedies to help with their illness. This includes staying 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 conduct home visits to check if they administer treatment as instructed, in that way I prevent any relapse. (TH3)

Whilst some TL reported the inability to know about incidences regarding PWMI and provide support due vastness of their area of jurisdiction, some indicated that they play broker, mediation and advisory roles. One participant explained:

> Even if they do not need anything, I give advice. 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 CM acknowledged that they are supposed to provide spiritual, emotional and material support, however, only a few members reported doing this. Some reported that they conduct outreach programmes in various villages focusing not only on PWMI but every community member who needs support. Participants reported assisting by linking PWMI and their families with relevant resources. Some reported that they help PWMI and their families to accept their situation. They also encourage them to join the church so that they can keep an eye on them and determine their spiritual growth. One 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. We also need to give them direction and invite them to church to fellowship with us so that we can monitor their spiritually growth. (CM4)

HBC 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. I encourage them to take their treatment and also save part of their grant. (HBC2)

PO reported that they are often called to attend to PWMI. They mentioned that 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, but if the person 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. To be honest, I work with PWMI but I am scared of them. (TH1)

Another participant reflected:

> You see as for us police officers, we are not well trained about handling PWMI. Our aim 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:

> Sometimes we make it a point that they get medication 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 and lack of skills to deal with PWMI contributes to this.

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. Majority emphasized the need to form a coalition to improve working relationships and help them understand one another's roles. They suggested forming a committee to facilitate activities for 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 like Social Development or Health must take the first step. They must call a gathering in which a committee is established. (CM2)

From PO' perspective, having a one-stop center would quicken the response to service users. They reported that the distance travelled by emergency services to get to Mashashane during times of crisis results in delay and disintegration of service rendered to PWMI. One participant stated:

> EMS comes from far. 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. (PO3)

Although some stakeholders reported working well with other stakeholders, some did not seem keen to work with TH. The business oriented nature of TH and the Christian belief systems were reported as the reasons for the unwillingness to work with TH. As reflected in the following comment traditional healing was associated with darkness hence the hesitation to form collaboration with them:

> The bible says that darkness can never mix with the light. (CM3)

TH 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. (TH1)

Another TH added:

> They [health care professionals] won't allow us to work in the same environment with them because our things are dirty. (TH3)

These findings highlight the need for collaborations. However, negative attitudes and lack of understanding of other stakeholders' roles seem to be a barrier for collaborations. It was evident that TH experience inferiority complex that prevents them from attempting to work with other stakeholders.

Discussion

The aim of this study was to explore the views of 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 TH as cultural experts to identify witchcraft as the cause of mental illness (Sorsdahl et al. 2010), the present study revealed that TH based their understanding of mental illness on the social approach where they emphasized on reaction towards PWMI. 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. Furthermore, the findings also revealed the ineffectiveness of formal and other informal systems in providing support. 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 (Ganasen 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.

Similarly, majority of stakeholders acknowledged certain roles that they play and should play as support system. TH support was based on biomedical intervention as they provide remedies to heal PWMI. 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 by shopkeepers.

Although PO 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 PO normally refuse to do as 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 PO, they are not well equipped to deal with PWMI. This is consistent with findings of previous study (Magadla and Kolwapi 2013) that reported that police office officers lack the necessary skills to deal with PWMI. This lack of skill may have an impact on how PO interact with PWMI. As Watson et al. (2008) pointed out that this lack of skill may result in PO 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 ill individuals, 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 (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 and provision of support require 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 TH. 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 TH may hamper the South African government's efforts to strengthen collaborations with various stakeholders 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.

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 PO, TL and TH. No faith healers participated in the study. Their views might have given insight on how they use their religious background to provide support. Furthermore, each focus group discussion was conducted with only once; it is possible that stakeholders would have reported additional instances of support efforts had they participated multiple times. Therefore, the findings from the study could not be generalized to all stakeholders in the country even those that are in the province.

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 provided third party intervenes to facilitate collaborations. This has implications for government's active involvement and facilitation of collaborative efforts. Research is needed to establish collaboration between stakeholders thus improving provision of support to PWMI and their families in rural settings.

Compliance with Ethical Standards

Conflict of interest Authors declare that there are no known conflicts of interest.

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 Informed consent was obtained from all individual participants. Participants were reimbursed for transportation.

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