

# Experiences of Persons Living with Severe and Persistent Mental Illness

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## Abstract

The mental healthcare needs of individuals suffering from mental illness, especially those with severe and persistent mental illness, are neglected and often misunderstood in South African rural communities. The purpose of the study was to explore and describe experiences of persons living with severe and persistent mental illness and those of their families in respect of mental health services provided by primary healthcare facilities in rural Eastern Cape, South Africa. A qualitative, descriptive, exploratory research design was utilised. Convenience sampling was used to select primary healthcare facilities in the rural Emalahleni sub-district of the Chris Hani Health District in the Eastern Cape. Purposive sampling was used to recruit persons living with severe and persistent mental illness ( $n = 18$ ) and their family members ( $n = 11$ ). A total of 29 in-depth, unstructured individual interviews were conducted using an audio recorder. Tesch's thematic analysis was used to identify themes from the data. Two central themes emerged from the data, namely the challenges in accessing primary healthcare services, and the inadequate provision of mental healthcare. Primary healthcare in rural South Africa needs to be better prioritised by national government to deal with mental healthcare. Improvements in infrastructural and staff capacity are needed to improve access and availability of mental healthcare services in rural communities. Nursing education programmes should better integrate mental healthcare into curricula, especially rural mental healthcare. Cost-effective, evidence-based, culturally-sensitive

mental health innovations focusing on the mental health needs throughout the person's life course should be implemented.

**Keywords:** mental healthcare; mental illness; primary healthcare; rural health; South Africa

## **Introduction and Background Information**

Generally, people with mental disorders have limited access to the appropriate healthcare services (Caldas de Almeida and Killaspy 2011). This is especially the case in many low- and middle-income countries, including South Africa, where reporting on mental health indicators that include both public and private sectors remains a challenge. It therefore remains unclear whether people with mental illness in these countries do receive appropriate treatment for their mental illness (World Health Organization 2018). Accurate statistics on the subject are lacking in South Africa. However, a research study conducted in the Eastern Cape (urban and semi-rural sample), South Africa, found that 43 per cent of people with depression did not seek mental health services (Andersson et al. 2013, 439).

Although mental health services and resources are limited in urban areas of most developing countries, it is significantly more the case in rural areas (Health Systems Trust 2017). Efforts to deal with this treatment gap in South Africa have included a number of strategies, such as the decentralisation of mental health services by integrating mental health services into primary healthcare (PHC) (Health Systems Trust 2017).

Persons living with severe and persistent mental illness (SPMI) are expected to fulfil their roles, responsibilities and self-care demands. In order to do so, extensive psychosocial rehabilitation is required. Further, continuing assistance in terms of treatment, housing and social support is required (Uys and Middleton 2010, 53). However, challenges facing persons living with SPMI, especially those in rural areas where the access to mental healthcare is limited, include the lack of education or information about their diagnosis and the treatment regimen, stigmatisation, and the lack of available and accessible resources (Giandinoto and Edward 2014, 730; Masunga, Kajula, and Yahya-Malima 2016, 6).

Families often care for persons living with SPMI in the community, which frequently causes a burden to them emotionally, physically and financially (Janardhana et al. 2015, 184), leading to poverty, discrimination and stigma, depression, emotional trauma and poor or interrupted sleep (Ae-Ngibise et al. 2015). Further, the necessary caregiving for a person living with SPMI is diverse and complex, which may exacerbate how caretakers feel and react to their role. Carers in Australia reported that caring for a person living with SPMI is more stressful than caring for a person with a physical disability (Brodaty and Donkin 2009, 217–218). In the same study, family members

also indicated that they lack the social contact, support and knowledge on how to meet the mental health needs of the person living with SPMI (Brodaty and Donkin 2009, 217–218).

## **Statement of the Problem**

The first author, who has been a psychiatric nurse at a PHC facility providing mental health services in the rural area of the Emalahleni sub-district of the Chris Hani Health District in the Eastern Cape province, became aware of the gradual increase in the numbers of persons living with SPMI whose conditions worsen when they are discharged into the community. The rural area of the Emalahleni sub-district is one of the poorest districts of the province. It covers an area of 3 442 square kilometres and has a population of 807 826 people, with a population density of 22.4 persons per square kilometre (Massyn et al. 2017). There are a total of five hospitals and 35 PHC facilities in the Emalahleni sub-district. Only a small proportion of the population has access to healthcare facilities within five kilometres of their home (Massyn et al. 2017).

The majority of the people in Emalahleni sub-district are Xhosa speaking. Emalahleni settlements (homes) are predominantly dispersed, traditional rural villages, the majority of which lack roads, electricity and safe drinking water (Massyn et al. 2017). The majority of people in the Emalahleni sub-district live in poverty due to the lack of employment—the unemployment rate is 39.0 per cent—and of further education opportunities. As a result, most households rely on government social grants and remittances from family members working elsewhere (Massyn et al. 2017).

Persons living with SPMI often reside far from the nearest PHC facility that offers mental health services and are cared for by their families. Little is known about the experiences in rural Eastern Cape of people living with SPMI, and those of their family members, regarding mental health services provided by PHC facilities. There is therefore insufficient information on whether the healthcare needs of persons living with SPMI are being met comprehensively by PHC facilities. It appears, however, that affected families are not provided with adequate information. This article therefore focuses on the experiences of people living with SPMI, and also those of their family members, in rural Eastern Cape.

## **Aim of the Study**

This research study aims to explore and describe how persons living with SPMI and members of their families experience mental health services provided by PHC facilities in the rural Eastern Cape province, South Africa.

## **Research Methodology**

### **Design**

A qualitative, descriptive, exploratory research design was implemented to advance understanding of the experiences of mental health services provided by PHC facilities in rural South Africa for persons living with SPMI and their families.

### **Sampling Strategy**

Convenience sampling was used to select 11 PHC facilities, as only a few of the 35 primary health facilities in rural Emalahleni sub-district are accessible by vehicle. The first author, a psychiatric nurse in various PHC facilities in the area, had good knowledge of facilities that were accessible. Furthermore, the 11 PHC facilities identified were widely dispersed, which ensured a better representation of the population.

Thereafter, purposive sampling was utilised to recruit persons living with SPMI and one of their family members that was willing to participate. The nursing manager of each PHC clinic assisted in identifying persons living with SPMI that could be included in the research study. The inclusion criteria for persons living with SPMI comprised the following: the ability to communicate in English or Xhosa; a legitimate DSM 5 schizophrenia diagnosis but in a stable phase of their treatment during the time of data collection; history of SPMI for at least 2 years; between 30–45 years of age; and living with a partner or relative in the same home. The inclusion criteria for a family member of persons living with SPMI comprised the following: the ability to communicate in English or Xhosa; familial relative (partner, blood family member or in-laws) to the person living with SPMI; and residing with the person living with SPMI for at least six months. Persons living with SPMI and their family members were telephonically contacted and a date and place for the interview was selected that were suitable for both the participants and the researcher.

### **Data Collection**

In-depth, unstructured interviews were conducted by the first author who, at the time of the study, was employed as a lecturer at a local nursing college and a holder of a Master's degree in Psychiatric Nursing Science. The researcher did not have an established relationship with the participants before the study commenced, which reduced researcher bias. A total of 29 unstructured individual interviews were conducted to collect data from the participants, comprising persons living with SPMI (n = 18) and one family member (n = 11) that were available and willing to participate. Family members of seven (n = 7) persons living with SPMI declined participation for personal reasons.

The interviews were conducted in Xhosa, the language of discourse preferred by the participants, at their home (which was the place the participants felt comfortable in). A

single open-ended question was asked of all participants—although the question was rephrased slightly to focus on the relatives of persons living with SPMI. This question was: “Tell me about your experience of mental healthcare provided to you at the clinic?”/“Ndichazele ngamava akho ngenkonzo yempilo oyifumanayo eclinic?” Beyond the opening question, the researcher did not set additional questions, but probed for explanation if something was not clear. A pilot test was conducted with one (n = 1) participant from each group and, as no amendments needed to be made, the results of the pilot study were included in the main study.

Before each interview the participants were provided with information about the purpose of the research, how confidentiality would be maintained, and their right to withdraw from the study. Thereafter a consent form was signed by both the participants and the researcher. An audio recorder was used to capture verbatim the verbal interactions. Each interview took approximately 35–50 minutes to complete. Data collection ended once data saturation (Creswell 2014) was achieved. Field notes were taken after each interview to record reflective data. No follow-up interviews were required.

The researcher transcribed the Xhosa audio recordings verbatim. Transcriptions were then translated into English by the researcher. A Xhosa-speaking person familiar with the context of the research setting, but independent to the study, assisted in back-translation, interpreting the translated English transcripts back to the original language of Xhosa so as to ensure accuracy of interpretation.

### **Data Analysis**

Tesch’s eight steps of thematic analysis (Creswell 2014, 198) were used to analyse the data. An independent co-coder, together with the first three authors, analysed the data. The independent co-coder was sent a data analysis guide including the interview schedule, transcribed text and a brief discussion of Tesch’s eight steps of thematic analysis in order to optimise the depth of the analysis. Once completed independently, a consensus discussion resulted in well-refined themes. The emergent themes were recontextualised within existing literature to identify support for, or dismissal of, features revealed during the analysis.

### **Trustworthiness**

To optimise the trustworthiness of the research study the researcher applied Guba’s concepts of transferability, credibility, dependability and confirmability (Guba 1981 in Brink, Van der Walt, and Van Rensburg 2012, 171–173). Strategies included peer reviews of the interview schedule; member checking; the authority of the first author in the light of her extensive experience in the field (credibility); a detailed audit trail, involving description of sources and techniques of data collection and analysis (transferability); the use of an independent coder and a translator that translated the

transcribed texts (dependability); and triangulation of multiple data-gathering methods (conformability).

### **Ethical Considerations**

Once the first author had gained ethical approval from the Research Ethics Committee: Human (REC-H) at the Nelson Mandela University (H09-HEA-NUR-001), the following persons were approached to gain permission for access to the research population: the District Manager for the Eastern Cape Department of Health, the District Manager for the Chris Hani Health District, and the nursing managers of PHC clinics in the Emalahleni sub-district of the Chris Hani Health District. The right to privacy, confidentiality and anonymity were adhered to by recording pseudonyms rather than the real names of the participants for the interviews. The data collected were available only to the authors. Requirements for informed consent of the participants were adhered to. The participants were offered counselling free of charge in the event that they experienced any emotional discomfort as a consequence of the research interviews. This offer was not taken up by any of the participants as none of them reported experiencing emotional discomfort.

### **Results**

Two central themes emerged from the data related to persons living with SPMI and their families. Firstly, the results showed that there are challenges in accessing PHC services. Secondly, the results showed that there is inadequate provision of mental healthcare. Themes are outlined in Table 1 and discussed below.

**Table 1:** Research themes

<b>Theme</b>	<b>Sub-themes</b>
Challenges in accessing primary healthcare services	Specialised and emergency treatment is limited and largely unavailable Stigmatisation prevents help-seeking Long queues and extended waiting periods result in frustration
Inadequate provision of mental healthcare	The inconsistent supply of psychotropic medication leads to non-adherence and relapse Mental health information is inadequate in serving mental health needs Rural primary healthcare facilities lack supportive programmes

#### **Theme 1: Challenges in Accessing Primary Healthcare Services**

The participants highlighted that their most significant concern was that of inaccessible and largely unavailable mental health services. The sub-themes below elaborate on this particular concern for both patients and family members.

### *Specialised and Emergency Treatment is Limited and Largely Unavailable*

The participants expressed a need for a responsive emergency transport ambulance service in the event of mental health emergencies. However, the participants indicated concerns regarding the ambulance services' unwillingness to respond to distressed patients in the community because of poor infrastructure, as in the following statement:

Ambulances do not want to come to our villages. They claim that our roads are bad. It becomes a problem really. The government must build this road for us. (Person living with SPMI)

Police officers are also experienced as unhelpful in the event of an emergency, as their actions portray a lack of knowledge and skills related to managing persons living with SPMI. The result often leads to humiliation and shame for both the person living with SPMI and their families:

My son had a bad experience being taken off in a police van as a criminal. Meanwhile he is sick [SPMI]. The police officer actually handcuffed his feet together as well as his hands while he is in the police van. (Relative)

Owing to the lack of responsiveness from emergency and police services, families are faced with the challenging task of using public transport to take disturbed and agitated persons with SPMI for treatment. Public transport is unaffordable for most people.

One is to hire a vehicle from a community member, which is quite expensive. They say it is a 'special trip'. (Person living with SPMI)

More importantly, the participants felt that public transport places passengers at risk of injury on the way to the hospital when travelling with a psychotic and/or aggressive mental healthcare user:

Sometimes I have to take the public transport, which places other passengers at risk for injury when dealing with a mentally ill person en route to the hospital. (Person living with SPMI)

The participants indicated that referral to a hospital outside of their local community—whether for comprehensive mental status examination and treatment or any other service (such as social or employment services)—is inconvenient and costly. Participants highlighted the need for critical members of the multidisciplinary team to be present at each clinic, specifically referring to medical doctors and social workers:

There is no doctor and no social workers in this clinic. We need to have them visiting at least once a month so that we do not go to hospital, as travelling to hospital is expensive and you have to wake up early and stay the whole day in hospital and come back late. (Person living with SPMI)

### *Stigmatisation Prevents Help-seeking*

The stigmatisation of mental illness is an additional burden that persons living with SPMI report having to bear. Consequently, the participants of this study reported that they are reluctant to attend social gatherings or contribute to discussions in their community for fear of being stigmatised and discriminated against by fellow community members:

As mentally ill patients, we are not given a chance to talk in the meetings or social gatherings like funerals. I think, because we are mentally ill, people think we cannot make sense. (Person living with SPMI)

It is evident from this study that the inability to sustain positive relationships with people in the community had a further negative impact on family life. Persons living with SPMI felt their family was, by default, stigmatised through association. Thus, family and friends remain unsupportive of the needs of the person with SPMI who, as a result, goes through life with a deep sense of sadness and loneliness.

You know, what worries me most is that some people are still judgemental, and that does not help. He had wonderful friends and family members, but they do not come anymore. That is not supportive. It is very hard to deal with mental illness alone—I mean, just to come and visit for a friendly talk with him. (Relative)

My daughter does not like that. She always complains that people do not listen to them, as if what they say does not make sense. This is painful. (Relative)

Furthermore, community stigma negatively affects the ability of persons living with SPMI to secure employment, as outlined in the following statement:

My husband is unemployed, although he is experienced in teaching. Because he is mentally ill now, and they think that he cannot teach anymore, regardless of the skills that he has. (Relative)

It was clear from the various interviews that there is a considerable amount of stigma that emanates from the community, which consequently affects important areas of the study participants' social and occupational life. However, in addition to stigma from the community, the participants indicated that health professionals stigmatise them, leading to persons living with SPMI avoiding seeking healthcare, as outlined in the following statements:

Nurses at times also shout at them to say that they are dirty. It is not easy for us to wash these people. [...] Sometimes they [nurses] do not listen to them because they think they do not make sense. (Relative)

Nurses also shout at them. I wish nurses treat them [persons with SPMI] like everybody else, or treat them first because people become uncomfortable around them. (Relative)



I also wish that nurses give him love and care because sometimes he becomes reluctant to go to the clinic, stating that nurses are silly, they are shouting at him. That is a problem to us as a family. (Relative)

### *Long Queues and Extended Waiting Periods Result in Frustration*

The participants expressed great dissatisfaction with the amount of time spent waiting in long queues at the clinic before being examined. Most of the participants travelled long distances to get to the clinic, leaving home early in the morning only to wait for extended periods of time before they could see a nurse and leave for home again, as explained below:

A person has to wake up early to go to the clinic, because you have to be in a queue with other patients that are sick with other diseases, like diabetes and hypertension and others, [and] some have come for wound dressing and so on. This takes a long time before a person gets help. You have to sit in a long queue with so many patients, and the sisters will take a long time to help you. (Person living with SPMI)

Although sometimes you find that there is only one sister on duty in the clinic, which makes us to wait for a long time before you are helped. Sometimes when you go to the clinic you have to stay the whole day. (Person living with SPMI)

Such circumstances were explained as being challenging for a person living with SPMI, as they can become easily agitated and unpredictable.

## **Theme 2: Inadequate Provision of Mental Healthcare**

Some of the most significant barriers to the provision of mental healthcare in rural PHC services in South Africa emerge as a result of insufficient resourcing for SPMI, which results in inadequate provision of mental healthcare for both persons living with mental illness and for their families, particularly in rural areas in South Africa.

### *The Inconsistent Supply of Psychotropic Medication Leads to Non-adherence and Relapse*

The study participants stated that there is unavailability or inconsistent supply of medication in the PHC facilities in the rural clinics of Emalahleni. After travelling long distances to acquire their prescribed psychotropic medication, people are sometimes told the clinic is out of stock. Apart from the disappointment and frustration of those affected, the study participants reported that the inconsistency of supply of medication results in high rates of non-adherence to medication regimens, and, consequently, relapse in some cases due to being unable to take their medication regularly.

That is why I say government should try by all means that medication is available at all times at the clinic. Also nurses to order medication regularly and in time. I have to fight with nurses [because] they do not have enough medication for my son. (Relative)

I wish my son can get his treatment, because it takes a long time for the treatment to be available. Sometimes we go to the clinic and we are told that his treatment is not available. Or we get only one type of tablets and we are told that other tablets are out of stock. (Relative)

### *Mental Health Information is Inadequate in Serving Mental Health Needs*

The participants of this study indicated that there was inadequate health education given to them regarding their treatment, mental health issues and what to do when a patient relapsed.

I would have liked the information about her mental illness and some guidance on what the family should do when she becomes ill. No information was given to me by nurses and doctors, except the interviews that they normally conduct when somebody reports illness. (Relative)

The participants indicated that there was a lack of access to health information and education for both patients and family members regarding their mental illness, treatment, and strategies for coping. The family members reported that they often felt frustrated and powerless as a result of not knowing where to find help when coping with mental illness of a relative, as described by one relative:

For the first few months I did not know how to interact with her anymore. The family members became trapped with little or no information to help to handle the situation. Right now, I am not sure about the causes of her mental illness. I am just in the dark. I do not go through a day without questioning what is happening. (Relative)

### *Rural Primary Healthcare Facilities Lack Supportive Programmes*

Promoting family inclusive practices encourages recognition by health professionals of the need to support and work in partnership with families. Families of persons living with SPMI reported that they often feel scared, disempowered and isolated. The findings of this study show that families were dissatisfied with their level of involvement in their mentally ill relatives' treatment and felt left out of the treatment process.

The service that we are getting is inadequate because there is no programme to provide to families to be involved in the treatment plan of their mentally ill family members. This becomes painful to us, here at home. (Relative)

Severe mental illnesses affect all aspects of family functioning, and all family relationships and roles are altered—sometimes permanently. These alterations affect finances, employment, social life, physical health and family relationships. As one participant explained:

I think the only thing I need to do is to accept the situation by being close to my husband. He has changed now from being our breadwinner and giving us all the support to now being on the edge of mental illness. (Relative)

Some of the families of mentally ill persons left their employment to take care of their mentally ill relatives. Since family members often lack social contact and support, sometimes they sacrifice their leisure and hobbies.

My hands are full and I have never been able to socialise with friends. I really think I have done the best I can do and I am getting old and cannot do much. I worry about the future of my other children. I have never taken any holiday because I see my role as an extended one. (Relative)

It was evident from the findings that persons living with SPMI were a burden of care to their families in terms of financial assistance, emotional support, medication, compliance with medication and daily activities of living. The participants stated that family inclusion in the treatment plan of the mentally ill persons could help to alleviate the perceived burden. Mental health professionals need to work in partnership with families of mentally ill persons in the care of a family member who is mentally ill.

According to the participants in this study, rural PHC clinics are not initiating support groups or any supporting programmes focusing on the needs of the mentally ill persons and their families. The participants expressed feelings of being bored, lonely and isolated. The findings showed that, owing to a lack of community resources, persons living with mental illness were not occupied constructively. As one participant reported:

I just stay at home with my mother doing nothing. (Relative)

## **Discussion**

Persons living with SPMI and their families expressed similar experiences related to mental health services offered at PHC facilities in rural South Africa. Gaining access to PHC services for mental healthcare was experienced as a challenge for both groups of participants. In this study the inaccessibility of responsive emergency transport ambulance services due to poor infrastructure, and the lack of knowledge and skills of police officers to deal with persons living with SPMI in case of emergencies, were mentioned by the participants. Similar issues have been identified elsewhere (Canadian Mental Health Association 2003; Shaban 2009). This can be contributed to the fact that even in countries where the majority of the population live in rural areas, the resources are concentrated in the cities (Health Systems Trust 2017).

It is further stated that rural areas commonly have difficulties with transport and communication, and they almost all face challenges linked to a shortage of nurses and other health professionals providing specialised and emergency treatment, such as social workers, doctors and psychologists (Panagariya 2014, 126). Furthermore, global data

have shown that mental illness often accounts for loss in the gross domestic product, thereby driving households further into poverty. This also affects the accessibility to care, especially when, for example, persons living with SPMI are not able to afford to travel long distances to access health services (Bloom et al. 2012; Lund et al. 2013, 850). Survey results indicate that the degree of unmet treatment needs for SPMI may be higher in rural areas (Gamm, Stone, and Pittman 2004, 1712).

According to the Constitution of the Republic of South Africa (Republic of South Africa 1996) and the Mental Health Care Act (Republic of South Africa 2002), access to healthcare, including emergency medical services is a human right. This requirement is reflected in the Department of Health's National Mental Health Policy Framework and Strategic Plan 2013–2020 (Department of Health 2013). The healthcare discrepancies highlighted by this research into the experiences of persons living with SPMI and of their families need to be the focus of government intervention. Furthermore, training should be provided to police officers on how to deal with persons living with SPMI.

Stigmatisation from the community and healthcare professionals was also mentioned as a challenge for the study participants, making appropriate levels of PHC services for mental health inaccessible to them. It is evident from relevant literature that stigma and discrimination against mentally ill people are a major concern, especially in rural areas, and have negative implications for the prevention and treatment of mental disorders, as well as for the quality of life of those suffering from mental illness (Schierenbeck et al. 2013, 111; Rural Mental Health Campaign 2015).

The participants of this study also highlighted that the waiting time and long queues to receive appropriate services caused frustration and were experienced as costly and inconvenient. Other authors confirm that long waiting times and poor access to clinics affect the patients' access to mental healthcare and their help-seeking behaviour (Andersson et al. 2013, 439; Willie 2011, 167). Such conditions remain a great challenge to appropriate healthcare for people living with SPMI and their families and should be dealt with by the appropriate authorities.

Inadequate provision of mental health services was also reported in this study in terms of the inconsistent supply of psychotropic medication, leading to non-adherence to and relapse of the treatment regime by persons living with SPMI. Access to psychotropic medication is a major facilitator for integrating mental healthcare into PHC. However, problems sometimes occur in supplying and distributing these medications directly to PHC facilities. In this study, non-adherence and relapse to the treatment regime occurred owing to the unavailability of psychotropic medication. Similar conditions were found in a study by Liu-Seifert et al. (2010). In this study, it was also found that the majority of patients admitted to mental hospitals were linked to non-adherence to treatment.

The participants also indicated that the mental health information provided to them at the PHC facility was inadequate in serving their mental health needs. Access to tailored

health information and education regarding mental illness, treatment, and strategies for coping should be provided for both patients and family members. As the family often is the main caretaker for persons living with SPMI, promoting family inclusive practices, done in agreement with the person living with SPMI, would provide the required support to all parties and would better meet mental health needs. This is upheld by McCann, Lubman and Clark (2011, 381–388), who counsel that families of persons living with SPMI should be prepared for the long-term role change of becoming caregivers. During counselling the long-term role change should be included in the health information provided to the persons living with SPMI and their families.

The participants expressed feelings of being bored, lonely and isolated. Almost all the participants reported that they do not attend support groups because no support groups are offered by the PHC facilities in the rural areas. People living with SPMI need to belong to a group that offers assistance and care. Support programmes could assist in achieving this. Group-based support in communities is especially important as nurses at the PHC facilities are unable to facilitate this owing to limited staff members available (Mnisi 2011, 61). As many participants indicated they were unemployed, support groups could assist in preventing them from being bored and giving them a sense of belonging, and have the potential to make people living with SPMI feel that they are making a contribution to society.

Although there has been a move towards the integration of mental care services into PHC in South Africa, stigmatisation of patients by both the community and health professionals has been found to be a major challenge (Reddhi 2008). To improve the situation, awareness should be created among communities as well as health professionals by providing information about mental health problems and how they affect persons living with such conditions. One option would be awareness campaigns led and supported by health professionals.

Mental health information sharing is cited as a priority activity for nurses so as to reduce stigma and improve the lives of persons living with mental illness (De Haan, Denil and Vasuthevan 2011). This study highlighted that health education given to persons living with SPMI and their families was felt to be inadequate. Good health education programmes that are family focused and tailored to the person living with SPMI should therefore be implemented with the purpose of communicating with affected people and giving them information they specifically need to be able to attain good health.

The participants of this study indicated a need for critical members of the multidisciplinary team to be present at each PHC facility. This can assist in reducing waiting times and travelling to other facilities to obtain the required (specialised and emergency) mental health services.

An important role of nurses in health education is to motivate the community to participate in improving its mental health status (Rural Health Africa Project 2015).

PHC nurses should therefore offer regular mental health education, conducted at community events and gatherings, to inform families at large about the nature of mental illness and the need for sustained treatment (Van Rooyen et al. 2014, 371). This could also avoid the high rates of non-adherence to medication, as well as relapse in treatment. To support sustained treatment, sufficient stocktaking and budgeting should be put in place as non-availability was associated with the non-adherence to regimens by the participants in this study.

There appears to be a need for community support programmes that benefit mentally ill persons. Support groups facilitate the sharing of ideas and advice, as well as information on coping mechanisms (Reddhi 2008). The participants of this study expressed similar views about the need for support programmes in which mentally ill patients could engage in various activities, such as gardening, handwork and involvement in support groups.

In conclusion, it is recommended that the general access to and availability of mental health services in rural communities be increased by, for example, upscaling of infrastructural and capacity staff regarding skills in providing mental health services. Further, nursing training programmes could better integrate mental healthcare—especially in respect of rural mental healthcare—into their curricula. Cost-effective and innovative methods that are evidence-based and culturally sensitive could be used to improve access to mental health services provided by PHC facilities for persons living with SPMI.

## **Limitations**

Some limitations in the study were observed. The initial plan was that unstructured individual interviews be conducted at the homes of the persons living with SPMI and their families, but the homes of some potential participants were not accessible due to them being in deep rural areas with no accessible roads. The study was therefore restricted to accessible rural areas, so certain viewpoints of possible eligible participants may have been missed.

## **Conclusion**

It can be concluded, based on the findings of this study, that improvements in mental health services provided by PHC facilities in rural South Africa need to be prioritised by national government. There is a need for the implementation of cost-effective innovative methods, especially since the lack of resources plays such a significant role in dealing with the challenges to effective mental healthcare in rural communities. For example, technology could be used through low-data applications on mobile phones. This could provide services such as one-on-one therapy through video and text, behaviour trackers that may indicate an approaching mental health crisis, or smart software to be used by PHC nurses to indicate at-risk patients from their medical

records. Such cost-effective mental health innovations need to be based on best practices and culturally-sensitive, dealing with mental health needs throughout the person's life course (Patel et al. 2013).

Finally, in-depth research is required to further explore the experiences of persons living with SPMI and their families and how improvements to their access to mental healthcare should be made. For example, further consideration could be given to the provision of education regarding possible services and/or analysis of what services and innovations would most benefit users.

## Acknowledgements

The authors would like to thank all the participants for their participation and also Vicki Igglesden for editing the article.

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