Barriers to community mental health IT users' access to information needed to deal with mental health problems in the Western Cape, South Africa

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Abstract

The most important advancement in the healthcare industry in the 21st century is the application of information technology (IT) in health care. While integrated IT is critical in transforming mental health care, IT infrastructure in mental health lags behind other sectors. This study explored community mental health users' barriers to accessing information in dealing with mental health problems. Semi-structured individual interviews were conducted with 11 mental health users and their family members, and two focus group discussions were held with eight mental health consumers and family members of each. Major barriers to accessing information were long waiting times for services; inadequate mental health education and information sessions; and lack of a support club to share information and experiences with people with similar mental problems. Empowering mental health users with adequate and appropriate mental health information helps to improve their care. Use of IT such as tele-health communication, email and text messages using computers was proven to improve access to information and quality of care provision.

Keywords: Mental health support, inadequate resources, information inhibitors, poor access to health information

Introduction

Information is a key element within all healthcare processes. Advanced information technology (IT) empowers consumers and families and assists healthcare providers to deliver best care (New Freedom Commission, 2003). Health information sharing plays a critical role in addressing quality of care and the cost and access challenges of the healthcare system (Vest, Zhao, Jasperson, Gamm & DOhsfeldt, 2011). Furthermore, investment in a Health Management Information System (HMIS) and information sharing could have multiple benefits, such as detecting and controlling emerging endemic health problems;

monitoring progress; empowering individuals and communities with timely and driven improvement in quality of services; strengthening the evidence base for effective health policies; enabling innovation through research; mobilising new resources; and ensuring accountability (World Health Organization, 2004). The quality of clinical care depends on the collection, exchange and transfer of information between clinicians and mental health users in flexible form at each and every point of patient contact (McClelland, Lewis & Elphick, 2002). Most consumers and families want up-to-date information about the mental disorders, systems, treatment and supportive services for the mentally ill person they are caring for; however, such information is seldom available when people need it most (New Freedom Commission, 2003). Evidence has shown that use of IT such as tele-health and e-health technologies is of great importance in improving access to mental health care in many rural and remote communities (New Freedom Commission, 2003). E-health technologies such as use of computer technology in sending email reminders, transmitting results by email or telephone, and assisting healthcare providers with follow-up to underserved and remote communities, can significantly improve care for individuals with chronic health conditions, including severe mental illness (New Freedom Commission, 2003).

Public expectations of health services and how the public interact with these services are changing (Cotton, Hyatt & Patrick, 2012). Enhancing information exchange between mental health consumers and healthcare professionals improves their discussion about treatment options and promotes more informed decisions (New Freedom Commission, 2003). Transforming mental health services through the use of IT provides the potential for self-care and peer support within a well-governed, safe, immediately accessible and stigma-free environment (Cotton et al., 2012). Through the use of IT, mental health consumers are becoming more active and informed about their health care and decisions. More and more people now use online resources to check symptoms, to find out information about the services and treatment options, and to obtain feedback about the services they use in public forums (Cotton et al., 2012). The use of information resources not only improves efficiency but also transforms the nature of mental healthcare itself (Cotton et al., 2012). Transparency and sharing health information is an important step in improving the efficacy and fairness of healthcare globally (Eldessouki & Smith, 2012). However, the great majority of claims by service users against healthcare providers and recurring incident enquiries concern failed communication of information (McClelland et al., 2002). The evidence is that optimal care and treatment of patients within a modern health environment is highly dependent upon the availability, quality and accuracy of information; professional access to, use and management of information about individuals; and the use of information to enhance the effectiveness of professional practice (McClelland et al., 2002). Nevertheless, present evidence indicates a substantial failure and lack of information flow

within health and social care, as well as poor analysis of information (McClelland et al., 2002). Although efforts have been made to improve information sharing and harmonise health technology assessment across countries, there are many barriers such as different languages, lack of transparency, fragmentation of the available information and limited resources impeding information flow (Eldessouki & Smith, 2012). Moreover, quality of care and the outcomes of health care suffered due to patient health information residing in fragmented locations, for instance in the office of primary care physicians, hospitals, clinics, laboratories and radiology centres, health plans, pharmacies, nursing homes, and even with the patients themselves. The aim of this study was to explore community mental health users' barriers to accessing information in dealing with mental health problems.

Methodology

The study employed a qualitative approach to explore the information needs of mental health consumers. This study was conducted in the Cape Town Metro area in the Western Cape province of South Africa. Ethical approval for the study was obtained from the University Senate Ethics Committee. Permission to use the health facilities for study was granted from the provincial Department of Health. Prior informed consent was sought from each participant. The participants were allowed to ask questions for clarity before they signed the consent form. Eleven mental health users and family members were selected for individual interviews, and 16 participants were selected for two focus group discussions (FGDs) (eight participants in each).

A data collection protocol was developed to keep an account of the data collection process and analysis, and pilot tested to ensure trustworthiness. The individual interviews lasted 40 to 45 minutes each. The FGDs lasted for an hour and a half each. The interview guide included questions covering issues such as barriers of information needs; information sharing with mental healthcare providers and/or other support groups; and barriers to mental health information sharing. When no new information was generated during data collection and analysis, data saturation was achieved. The researcher transcribed the audiotapes from the interviews and FGDs and coded the data pool with reference to the research question. Data were analysed using thematic content analysis, whereby themes were generated through repeated reviews of the interview data. The data underwent several stages of analysis. Reading and rereading of the transcript numerous times took place to obtain a general overview of all the text, jotting down notes and reflective comments in the margin and/or highlighting text with different colours. This included counting, connecting words or theme occurrence, and measuring information in the content. Translating participants' ideas into metaphors and development of themes was done by immersion in the data to understand it and seek further explanations. Finally, the themes were

discussed with colleagues, and member checking took place to scrutinise the trustworthiness and validity of the data and to substantiate the results. Ensuring trustworthiness of the study was also achieved by peer-review of the analysis and probing for researchers' bias; exploring meanings; checking the steps and process of analysis; leaving an audit trail; and consulting experts in the field. The field notes and audiotapes were kept as evidence, and inputs from peers and senior researchers were used to ensure dependability of the research.

Results

Throughout the discussions three major themes emerged: long waiting times for services affected access to information; lack of mental health education and information sessions; and lack of a support club to share experiences with people with similar problems.

Theme: Long waiting times for services affected information needs of mental health users

The long waiting times for services affected accessing information and the quality of service provision, such as consultation time with healthcare providers; and information sharing about the illness, such as diagnosis, treatment, and how to handle restless/uncooperative patients. The respondents reported that the long waiting times for services in the community health centres and day hospitals are stressful. They also affect their consulting time with doctors or mental health nurses, because the doctors and nurses are always in a hurry to see all of the patients, and the patient is also rushing to join another long queue at the pharmacy. They do not have time to discuss their stressing health problems with the doctor or mental health practitioner. The following extract was from FGD participant (P2):

> "Most of the time I wait long here by the receptionist for the folder, by the doctor or nurse and by the chemist to get the monthly pills, and it is not only me, others also complaining for sitting too long for services. . .. Some people wait from 5 a.m. in the morning till 5 p.m. in the afternoon. It is not right. Yes, it is the truth. It is very true."

The participants reported that mental health patients become very irritable due to the nature of their illness and become worried when they are not attended to on time. In an individual interview Mrs H illustrates this: *"I am now sitting and worried about when I am going to get my tablets, it is frustrating me. How long I am going to be sitting and waiting."*

The majority of the respondents reported that the existing limited health facilities and staff are not coping with the ever-increasing patient numbers. The

complexity of medical problems and the shortage of clinical staff become major problems in providing quality information for patients. As already noted, consultation time with clinical staff is very short, or limited to handing out prescriptions. Mrs R reported: *". . . the staff are overbooked, feel rushed to see all patients, and they have no time to talk to the patient or share information about their illness, as they only have three to five minutes to write prescriptions."* Unlike other medical patients, psychiatric patients require more consultation time. FGD participant P4 reported that *". . . the way we go to wait in front, before your name is being called, wait by sister or doctor for your name to be called again, then you wait ages, two to three hours, by the dispensary for your medication."*

The pressure on the staff is considerably high, because sometimes there is only one doctor for the whole health facility, and the next month there may be no doctor at all. Participant Ms S expressed the following:

> *". . . the pressure on the doctors or nurses were very high, so you will wait for quite long hours, they haven't got time to explain exactly what is going on or why this pill is not working, they just give you the pills and tell you to go. You can do nothing, we cannot fight them."*

Another participant, Ms M, stressed the problem of lack of consultation time: *"I think the only thing that is lacking in any public health facility is the time, which still remains the major issue".* FGD participant P1 reported that he did not know his own diagnosis, but was taking tablets: *". . . well, I don't know my diagnosis, nobody told me saying look here you are suffering from this or that".* Another FGD participant P5 said: *"I get hyperactive without the tablets and tablets basically cool me down, so I am waiting for long hours to get my tablets".*

Similar responses came from FGD participants P7 and P3 respectively:

> *". . . they didn't provide proper information about the type of illness, when we see he is becoming aggressive, we just leave him, because we want to know how to handle him, he doesn't want any visitors or his own sisters to visit him, now what do I do in case like that?"*

> *"The doctors don't really like when you ask information, they either give you high medical terms that people don't understand. If you ask doctor what did you just say now, he gets irritated because you are wasting his time, he got another ten patients waiting outside, it is almost lunch time, he needs to go . . . you know my father died of the wrong medication, you know it is your body and you feel you have the right to have the right information about medication."*

Moreover, FGD participant P9 reported that the information received from the healthcare providers on how to handle persons with mental conditions at home was not sufficient. The information could assist them to know more about the nature of the illness, the treatment, and what should be done to prevent a relapse, and how to handle or make the patients calm when they were in an aggressive state. The following statements illustrate this:

> *"I don't think you get much information here, but when I belong to the club, the doctor used to come and inspect us and share very important information about mental illness, but . . . otherwise I can't say that the information given here has helped."* (Ms F)

> *". . . in the service there is no information, nobody explains anything to you. If you don't help yourself, you are going to get nowhere; you tend to be like a dummy. You want to know the side-effects of the medication . . . there is very little help offered, . . . for people who have mental illness put on medication are left alone."* (Ms O)

Furthermore, participants were of the view that in order to resolve the problems highlighted above, there is a need for more staff and facilities that could improve the relationship between patients and healthcare providers, and a need to share information that could help the clients. The participants expressed their dissatisfaction with the current mental health service delivery. The shortage of health facilities and health workers appears to contribute to the long waiting times and short healthcare consultations with health workers. Waiting for too long at each service point is stressful and frustrating for people seeking help, particularly for those with mental health conditions. It is also important to note that providing adequate consultation time and information sharing has a significant therapeutic effect on people with mental health problems.

Theme: Mental health education and information sessions at the health facility

The participants stated that mental health education and information sessions in the patient waiting area in the community health centres are not effective. Mental health has a broad spectrum, meaning that there are many types of or categories of mental illness, which makes it difficult to provide health education and information sessions about it. As Ms S said:

> *"Health education in a big group in a waiting area is not working, because nobody is listening or keeping quiet, . . . you find some of us are listening but everybody else eventually starts to talk, and it does make me mad because I think it's so rude. You know, even if they don't want to listen they should keep quiet."*

The participants reported that the best place for mental health education and information sharing would be during the consultation time. Said Ms A:

> *"The sister should provide health education and share information about mental illness, because a lot of people . . . every patient would prefer the privacy, so they prefer the health education in the doctor or nurse's office rather than in the waiting area."*

They added that even nurses or doctors cannot manage to stand and talk to the group in a very noisy waiting area, as it is always too noisy and people are not interested in listening to other people's health problems. The mental health information session in a waiting area does not seem to be effective in promoting mental health. However, some participants stated that more time for the patient and some health education upfront is important. Others suggested that information on pamphlets which were sometimes handed to the patients or caregivers could help, but they hadn't seen any such pamphlets recently. In addition, information sharing using telephone calls or even email was suggested as an option for those who could access these technologies. Some participants stressed that mental health nurses, in the past, had phoned them at home, asking how they were doing with the treatment and about any problems relating to the medication; however, these telephone calls to patients had stopped a long time ago. A one-on-one session with the doctor or nurse, combined with handing out information pamphlets, may be the best way of sharing information and communication. However, based on the evidence identified in this study, nurses and doctors are already overwhelmed by their workloads and the complexity of the medical problems. It would be a challenge for them to have to take on the responsibility of information sharing without addressing major hurdles such as the shortage of clinical staff and resources.

Theme: Information on handling uncooperative patients and a support club

Information sharing about the type of mental illness and skills to handle aggressive patients are important for the caregivers to manage their own mentally ill family member at home. However, most of the family caregivers reported that they were not getting sufficient information from the healthcare providers. This led to the caregiver being unable to provide appropriate care for the family member with a mental condition. Some of the respondents stated that, although they were a caregiver for the family member with a mental condition, they also had mental problems themselves and were on treatment. The majority of participants reported that they had limited knowledge and understanding about how to manage their own illness. The participants needed adequate information about the course on mental illness, treatment and prognosis. Ms W illustrates this:

> *"We need more information about how we can handle a person with aggressive behaviour; in this case, we need information and skills in dealing with mental illness."*

Such support and information sharing is important, not only for the caregiver's welfare, but also for the patient; for example, due to lack of information on how to handle an aggressive patient, Mr B stated that: *". . . we would fight back if the patient became aggressive or even send the patient away from home as the patient is seen to be a danger to our family."*

The participants perceive that the doctors are not willing to provide them with proper answers to their questions about their patients, and in some cases the doctors use medical terminology which the family or patient cannot understand. FGD participant P11 states:

> *"Like I said, they never give you the right information. With me it also happened, you know, when I also see a doctor myself I ask them what is here by my hands, my hands are skew can you see; they can't give me the right information."*

Participants reported that they had had support clubs in the past, where they could share their experiences and information about their illness, and how to care for their mentally ill patients. However, the support clubs are no longer available at health facilities or at community level for people with mental conditions. Such support groups were useful to share personal experiences, emotional matters and other important related information. Since the abandonment of such support clubs, there has never been any strategic measure to offer emotional and other needed support from the health workers, as they are always busy. Besides, they have cited lack of financial and other necessary resources. These sentiments were expressed by FGD participant P12 as follows:

> *". . . a couple of years ago we had a support club here, where we used to meet once a week. we had an intern psychologist who used to sit in groups with us when she had the time, and that seemed to help the people, but then they decided to stop the support club, because there was no money and things changed. And you know we got attached with the stigma, we can't come in here on the weekend because there is mostly other staff, and they don't want to help you, they are scared of you. When you feel depressed you come in, you talk to people, share information about your illness, and you feel much better. It lasts a couple of days, that`s what happens."*

The majority of the participants reported that the current health service system is failing to respond to their mental health information needs. They stressed that the

current mental health services are worsening the condition of mental health patients, because delaying in attending to patients' problems may result in deterioration of their condition. This also affected mental health users' satisfaction with the service provision. They reported that mental health patients need more dignified mental health services through an improved healthcare delivery system. The following are extracts from FGD participants P1 and P14 respectively:

> *"I am suggesting that as mental health patients we are not demanding special treatment, because of our conditions we tend to get angry. Sometimes the nurse on duty they know me, but they acted as if they don't know me, then they treat me very badly. You don't feel nice even to ask the information you need . . .."*

> *". . . now in this discussion we do have the opportunity to express ourselves, to say how we feel, now we are expressing it, but it is not possible to change. We have got to accept, we are not forcing it."*

The participants felt that the current health systems are very weak and require changes, especially for those people with mental conditions. The participants believe that the lack of information creates dissatisfaction with services because of the shortage of health facilities and health workers – that the health facility is not coping with the influx of patients. Participants suggested that they need more health facilities and more staff because the population of patients with mental mental health problems is growing all the time. As Ms V said:

> *". . . the system they are working is very weak, we understand that they have shortage of health facilities and staff and, now we are already broken, they are breaking us more, . . . they [government] must consider to improve the health system."*

It seems that there are problems in terms of providing the right information to caregivers or family members regarding patient behaviour and treatment, and to empower them with skills on how to deal with patients who have different kinds of strange or uncooperative behaviour. Support groups for sharing experiences and information seem to have worked for people with mental conditions in the past.

Discussion

This study demonstrates barriers to mental health consumers' access to information needed to deal with their mental conditions. Long waiting times for services; inadequate mental health education and information sessions; lack of a support club; and information on handling uncooperative patients are the major

problems experienced by those involved with mental health. Although very few studies on the information needs of the public/community and information-seeking behaviour of health professionals have been reported, the literature indicates a critical need for comprehensive, coordinated and accessible information to meet the needs of public consumers and the health workforce (Revere, Turner, Madhavan, Ramo & Bugni, 2007).

The major barriers to community access to information include lack of time; lack of resources; trustworthiness or credibility of information; and information overload (Revere et al., 2007). Similarly, this study identifies lack of time as a barrier to accessing information, because of having to wait too long to get help at each service point. There is a long queue at reception to get the folder, then to be seen by a doctor or a psychiatric nurse, and then to get the necessary pills from the pharmacy. By the time the patient sees the doctor or a nurse, they are already exhausted and worried about the next queue at the pharmacy – they therefore hold back the very important information about their health that they had wanted to discuss with the healthcare provider. The doctors are always in a rush to see all of the patients and refill their prescriptions, and therefore no queries are entertained. Waiting for the whole day for services also increases the stress levels of the patients with mental problems.

A study on barriers to community access to information indicated that unavailability of Internet sources in a rural environment, inadequate equipment and lack of organised information session services are cited as environmental barriers to meeting information needs of public community and health professionals (Knight, Pedersen, Bina & Anderson, 2001; Lee, Giuse & Sathe, 2003). Another study has shown that information communication using different technological devices, such as email, text messages, the telephone, as well as personal contact, have improved mental health problems (Buntin, Burke, Hoaglin & Blumenthal, 2011). Resources are a major problem in all aspects in developing countries. Things that had been running well at one time and had shown significant results in improving health, currently had completely collapsed due to lack of resources. This study identified inadequate mental health education and information sessions as well as lack of a support club for people with mental problems that could have helped them to share information and experiences with people with similar mental problems. The support club had been well supported by the mental health community in previous days, and the collapse of this programme was a major concern for many of the study participants.

Tele-health communication was another important area that was supported by the participants in this study, but was recently discontinued for unknown reasons. Information communication using email or text messages had never been practised in this study setting.

Health IT has the potential to improve the health of individuals, facilitate health providers' performance, quality of care and patient engagement in their own health care (Buntin et al., 2011). The application of behavioural and psychological intervention strategies through the use of technology can address behavioural, cognitive and affective targets that support physical, behavioural and mental health (Mohr, Burns, Schueller, Clarke & Klenkman, 2013). Furthermore, clinical information provides new opportunities to many healthcare providers, including the ability to analyse and better understand their case practices, costs and effectiveness based on information captured in patient charts (Mohr et al., 2013).

The public health community meets its information needs by using information resources that are easy to access and use, up-to-date, flexible, free or at low cost, and public health professionals rely on timely, up-to-date information (Revere et al., *2*007). However, the importance of the information needs of mental health consumers were undermined due to structural health system problems. Information is the laboratory through which to diagnose, treat and follow up mental health problems. Therefore improving information infrastructure is the cornerstone to improving the information needs of the mental health community.

Limitation

The study has some limitations. Owing to time constraints and limited funding, it was not possible to involve more research sites in the study to include more participants. Due to the qualitative nature of the study, it was limited to a small sample size. Therefore, the results of the study cannot be generalised to a larger population. However, all efforts were made to ensure the rigour of the study and data saturation.

Recommendations

The quality of mental health services depends on the quality of information sharing between mental healthcare providers and mental health users. The effective use of IT such as tele-health, email and text messages using computers and smartphones will help to address the barriers to information access. The long waiting times for services requires political intervention to increase the number of health facilities and mental health clinicians at primary care level. Online information communication and sharing, as well as 'home visits' using telephone calls may help to minimise the workload and long waiting times for services. It is important to strengthen what is already working rather than looking for something new to start. Community mental health education and information sessions using public mass media and social networking are an important area that should be considered in order to address the barriers of community mental health users' access to information.

Conclusion

The findings of this study have shown the major barriers to community mental health users: long waiting times for services affect access to information, inadequate mental health education and information sessions, and lack of a support club to share information and experiences with people with similar mental problems. Empowering mental health users with adequate and appropriate mental health information helps to improve the care given to people with mental conditions. The use of IT such as tele-health communication, email and text messages using computers and smartphones has the potential to improve information needs and the quality of care provision. Quality of care depends on the quality of information transfer between clinicians and mental health users. Encouraging the use of online services, treatment information and obtaining feedback improves the knowledge and skills of mental health users to care for their own health. This study also identified that a support club that previously existed in the health facilities had been helpful to share experiences and information on how to manage persons with mental conditions. It is a great concern that such an important programme was discontinued at some study facilities.

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