



Shared decision making: People with severe mental illness experiences of involvement in the care of their physical health



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ABSTRACT

Addressing the poor physical health of people with severe mental illness (SMI) occurs within a complex mix of individual requirements. People with SMI often have demanding health and illness management workloads, which they are required to perform on a daily basis. Most clinical studies lack information on how much people are affected by the side effects they experience and how to manage these problems. Mental health staff often consider that their primary target is to reduce psychotic symptoms rather than health promotion. Therefore, the objective of this qualitative study was to describe the current experience of people with SMI, with the view to exploring ways that they might be involved in managing their physical health. Thirty-two people with lived experience of mental illness within a defined geographic area in Queensland, Australia, participated in semi-structured face-to-face interviews. Data were digitally recorded, transcribed verbatim and analysed using qualitative content analysis. Four key areas in which people with SMI were able to be involved in their health were identified: care continuity within a fragmented care system; medication management; credibility and being mastered; and self-mastery and self-managing health. Shared decision making in mental health care can contribute to equality, control and recovery. Involving people with SMI in shared decision making will contribute positively to their overall health. However, substantial changes are required to shift the health system from a traditional “health professional as expert” approach to one with the patients in the centre.

1. Introduction

The poor physical health of people with severe mental illness (SMI) is well recognized and has been described as a “silent scandal” by Gray (2012). Mental illnesses, such as schizophrenia, bipolar disorder, and depression, are linked with undue medical morbidity and mortality, and there is a persisting gap in life expectancy with a 15- to 30-year shorter lifetime compared with the general population (Saravane et al., 2009; Suetani, Rosenbaum, Scott, Curtis, & Ward, 2016). Furthermore, mental health clinicians commonly believe that the mortality gap is due to preventable medical conditions caused by the side effects of psychotropic medication (Gray (2012). Medications, i.e. antipsychotic agents, mood stabilizers and antidepressant medications, can predispose people to physical illness and have well-established side effects (Cuijpers & Smit, 2002; Lawrence, D'Arcy, Holman, Jablensky, & Hobbs, 2003). The prevalence of obesity and other risk factors such as hyperglycaemia are increasing in the general population; however, patients with SMI have an increased prevalence of overweight and obesity, hyperglycaemia, dyslipidaemia, hypertension, and smoking

compared with the general population (Newcomer, 2007; Tomiyama, 2014).

Covell et al. (2007) examined prevalence and perceived distress from self-reported side effects attributed to psychotropic medications among individuals with SMI and found that over half (52%, n=916) of the study participants reported embarrassment with weight gain and, of these, 74% (n=678) were bothered moderately and 57% (n=999) were bothered a lot. Furthermore, the life expectancy of people with SMI is shorter than that of the general population, primarily due to premature cardiovascular mortality; the increased risk can include non-disease-related factors such as poverty and reduced access to medical care (Newcomer, 2007). Furthermore, people with schizophrenia have 2- to 5-fold higher risk of type 2 diabetes than the general population, and antipsychotic medications increase the risk of type 2 diabetes both directly by affecting insulin sensitivity and indirectly by causing weight gain (Suvisaari, Keinänen, Eskelinen, & Mantere, 2016). Excessive weight gain also has several deleterious effects on psychiatric patients, including stigmatization and non-compliance with medication (Goeb et al., 2010). Severity of mental illness is one of the

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Table 1
Characteristics of the study participants.

Variable	Participants (N=32)
Gender	
Female	15
Male	17
Age (years) (range)	24–66
Time since diagnosis of their mental illness (years), mean (range)	27 (1–40)
Bipolar affective disorder	
Schizophrenia (ICD9 code 296)	
Non-affective psychoses schizophreniform	
Schizoaffective disorder	
Paranoid psychotic disorder	

most significant factors predicting social distance and social withdrawal (Gaebel, Zasko & Baumann, 2006). Other factors that may account for poor health among people with SMI include unhealthy lifestyle behaviours such as smoking, abuse of alcohol, unhealthy eating habits and low physical activity levels (Table 1).

Often people with SMI have demanding health and illness management workloads, which they are required to perform on a daily basis (Shippee, Shah, May, Mair, & Montori, 2012). Most clinical studies lack information on how much people are affected by the side effects they experience and how to manage these problems. Mental health staff often consider that their primary target is to reduce psychotic symptoms rather than health promotion. Understanding from clinicians regarding the subjective distress due to side effects among individuals is vitally important to have a holistic approach towards people's health. Generally the health care system has improved physical health care, however there is strong evidence that this improvement has not included people with SMI (Hultsjö & Syren, 2013). People with SMI have been shown to have poorer access to physical health care than the population in general (Druss, Zhao, Esenwein, Morrato, & Marcus, 2011; Thornicraft, 2011). One explanation for this unequal treatment is that negative attitudes and social distance towards individuals with mental illness are not only found among the public but also among mental health professionals (Lopez-Ibor, Cuenca, & Reneses, 2005; Thornicraft, 2011; Lauber, Anthony, Ajdacic-Gross & Rossler, 2004; Uçok, Polat, Sartorius, Erkok & Atakli, 2004; Sartorius, 2002).

In mental health service delivery, the response to active patient involvement includes concepts such as shared decision making (SDM) (Borg, Karlsson, Tondora, & Davidson, 2009; Wills & Holmes-Rover, 2006). SDM has been defined as “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (Elwyn et al., 2010). Engaging in SDM and including processes to design care that meets the needs of patients from their perspective are central to active patient involvement (Lutz & Bowers, 2000; McCormack, 2003). A prerequisite of the active involvement of patients in their care is to ensure that meaningful and actionable inputs are co-produced with caregivers at all levels (Steiger & Balog, 2010). Earlier studies in several areas suggest that patient-centred care and SDM improve patient outcomes (Chong, Aslani, & Chen, 2013; DeWitt et al., 2014; Phillips & Morgan, 2014; Wilson, 1994).

Numerous interventions, improvements and community-based services have been implemented with the intention of improving the health of people with SMI (Happell, Davies & Scott, 2012). Although patients' preferences are highly regarded in theory, in practice the voice of people with SMI regarding their experience of physical health care is still frequently absent. Understanding how people with SMI experience their physical health and their interaction with professionals, i.e. social workers, mental health staff, and general practitioners, could help improve mental health service.

The aim of this study was to investigate the current experience of people with SMI with regard to their physical health. The study sought to answer the research question: What is the experience of people with SMI regarding professionals engaging them about their physical health?

2. Methods

A qualitative approach with interviews was used. The purpose of a qualitative interview is to understand the participant's point of view and to uncover their lived experience before scientific explanations. An interview is a professional conversation whereby two people converse about a topic and knowledge is constructed during the interaction between the interviewer and the interviewee (Kvale & Brinkman, 2008). This qualitative study took place in a metropolitan region in Queensland, Australia. Participants were recruited indirectly from non-government mental health service providers and public mental health services. Data were collected using semi-structured individual interviews. Content analysis according to Hsieh and Shannon (2005) was used to analyse the data. Ethics approval for this research was fully reviewed and approved by the Human Research Ethics Committees of the relevant university and health departments.

2.1. Recruitment of participants

Clinicians in each organization were provided with written information regarding the research, which they distributed to people with SMI. Participants were eligible for inclusion if they had more than 12 months lived experience of SMI. Participants were excluded if they had required hospitalization for mental health care for more than 6 of the previous 12 months. This exclusion criterion was based on the assumption that lengthy hospitalization indicated potential instability and greater risk of harm to the participant to be involved in the study. Participants were provided with a consent form, which they had the option to either read independently or to have read to them; they were informed that they could withdraw from the interview at any time.

Fifteen women and 17 men (N=32) aged between 24 and 66 years participated in a face-to-face interview during a 2-week period in November 2013.

2.2. Data collection

Participants who consented to participate in the research were interviewed at a time and place that was convenient for them, usually in a private room in a familiar service provider organization. The interviews lasted between 20 and 60 min and were recorded after informed consent from the participants. An interview guide was developed by one of the researchers in the study. It was scrutinized by the other researchers with a background in nursing and psychology.

Qualitative in-depth individual interviews with an open-ended structure that investigated participants' current experience of involvement in their care were used. Interview questions included the following: What issues are you are facing with your physical health? What would make it easier for you to manage your physical health? How do you feel about talking to your doctor about your physical health? What are your experiences of information and discussions with your doctor or other people about your physical health? What do you think is missing or could improve with regard to managing your physical health?

2.3. Data analysis

All interviews were digitally recorded and transcribed verbatim. Data were analysed using qualitative content analysis (Hsieh & Shannon, 2005). The analysis of the interviews involved the following steps: both authors (1) independently read all the transcripts several

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