

Mental health consumers and caregivers as instructors for health professional students: a qualitative study

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Abstract

Purpose The purpose of this study was to explore the self-reported effect of consumer and caregiver-led education for pharmacy students and to explore the goals, challenges and benefits of mental health consumer educators providing education to health professional students.

Methods Five focus groups (mean duration 46 min, SD 22 min) were held with 23 participants (11 undergraduate pharmacy students, 12 mental health consumer educators) using semi-structured interview guides. The focus groups were digitally audio-recorded, transcribed verbatim and thematically content analyzed using a constant comparison approach.

Results Three major themes emerged from the data; raising awareness about mental health, impact on professional practice and impact on mental health consumers.

The students reported decreased stigma, improved attitudes toward mental illness and behavior changes in their professional practice. The primary reason for becoming an educator was to raise awareness and reduce mental health stigma. However, educators also benefited personally through empowerment, improved confidence and social skills.

Conclusion Providing students the opportunity to have contact with consumers with a mental illness in a safe, educational setting led to decreases in stigma, the fostering of empathy and self-reported behavior changes in practice. Sharing personal stories about mental illness is a powerful tool to decrease mental health stigma and may be an important aspect of a person's recovery from mental illness. Contact with mental health consumers in an educational setting is recommended, particularly for future health care professionals. Appropriate training and support of consumers is crucial to ensure the experience is positive for all involved.

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Introduction

Stigma is a negative attitude based on prejudice and misinformation and the presence of stigma can lead to discrimination in all aspects of a person's life [1, 2]. Stigma has been described as a major barrier to receiving effective mental healthcare and consumers with psychotic disorders self-report high rates of discrimination [2, 3]. Stigma can originate from healthcare professionals as well as the public, and may lead to a reluctance to seek help for mental

health symptoms and hinder recovery [4]. There is growing evidence to support the involvement of mental health consumers in anti-stigma campaigns and educational programs [5–7]. The World Health Organization recognizes that good communication skills are essential for all mental healthcare workers and that consumers should be engaged in the development of mental health education [8].

Personal contact with mental health consumers has been described as the single most important factor influencing public attitudes and behavior [5]. Contact with consumers with a mental illness can reduce stigma, but whether this contact is of a voluntary (contact with friends) or involuntary (workplace contact) nature may have an influence [9, 10]. Education about mental illness may need to be multi-faceted and on-going to address stigma and result in behavior change. It has been suggested that mental health consumers should have active involvement in education sessions as co-facilitators rather than guest speakers [5].

Medications are the major modality of treatment for most mental illnesses. In United States, the number of people aged 6 years and older treated with an antidepressant during a calendar year increased from 13.3 million in 1996 to 27 million in 2005 [11]. In Australia, more than 11% of prescriptions were mental health related in 2007–2008 [12]. Pharmacists are among the most accessible health professionals and are frequently consulted for advice on psychotropic medications [13]. Services provided by pharmacists such as medication counseling and medication reviews have been shown to increase adherence to psychotropic medications and resolve medication related problems [14–16]. While most pharmacists are able to correctly identify mental illnesses, pharmacists have similar negative beliefs to the public and may underestimate the risk of suicide [17, 18]. These suboptimal attitudes and lack of knowledge about mental health conditions may act as a major barrier to the professional practice [19, 20].

Involving mental health consumers in educational programs may reduce mental health stigma and improve empathy and attitudes among participants [6, 7, 9, 21]. However, little is known on the impact this involvement has on the consumers themselves. Walters identified positive outcomes for patients after their involvement in teaching medical students which included improved self-esteem and empowerment, which can be an important aspect of recovery in mental illness [22, 23]. However, this involvement was also distressing for some patients [24].

The aims of this study were to explore the self-reported effect of consumer and caregiver-led education for pharmacy students and to explore the goals, challenges and benefits of mental health consumer educators providing education to health professional students.

Materials and methods

Study design

Focus groups were conducted with both students and mental health consumer educators (MHCEs). A consumer educator in mental health care is a person who has previously received mental health care and works, often on a voluntary basis, to inform and educate professionals, students and the wider community on mental illness and its effects on individuals, families and society. The Schizophrenia Fellowship of New South Wales (SFNSW), through their Remind Training and Education program, train consumers to share their lived experience with mental illness [25].

In July 2008, all third year pharmacy students ($n = 258$) participated in one of ten consumer-led educational sessions with trained MHCEs. The MHCEs gave a brief introduction about themselves and their history with mental illness and the medications they take. Students then had an opportunity to interview the MHCEs, with a focus on medication history and medication counseling. The MHCEs rotated around the small groups of students to facilitate the students' gaining a variety of perspectives and experiences. Following the intervention all students and MHCEs were invited, by email and in person, to participate in a focus group conducted 6–8 weeks after the sessions. Over the period of December 2008 to October 2009, five focus groups involving 11 students and 12 MHCEs were conducted. Separate focus groups were conducted with students (three sessions) and MHCEs (two sessions). The focus groups with MHCEs also involved the presence of three mental health care workers (MHCW) from SFNSW. The MHCWs co-ordinate the Remind Training and Education program at SFNSW. The mean duration of the focus groups was 46 min (SD 22 min). The focus groups were conducted at either The University of Sydney or the offices of SFNSW in Sydney, NSW.

The mean age of the pharmacy students was 21 years and the majority were female. Of the 12 MHCEs (6 female), ten MHCEs had a diagnosis of a psychotic disorder (schizophrenia, bipolar disorder or schizoaffective disorder) and had a history of antipsychotic medicine use. The other two MHCEs were currently suffering from depression and taking antidepressant medicines, while also being the primary caregiver for a family member with schizophrenia. The caregivers spoke to the students about both their own experiences with mental illness and their experience in living and providing care to someone with schizophrenia.

Focus groups

Two purpose-designed semi-structured interview guides were developed. The student guide asked about their general thoughts on the use of MHCEs, any impact on their attitudes or likely behavior change toward consumers with a mental illness and if and how it changed their understanding of mental illness. The MHCE guide asked about their reasons for becoming an educator, and the benefits and challenges of participating in training programs. All study authors contributed to the development of the two interview guides used in the study. The focus groups were moderated by two of the study authors (COR and TC) as the MHCEs had previously worked with the study authors and were comfortable discussing their role as a MHCE with them. The role of the study authors was as neutral facilitators. COR was present at all focus groups and TC was present at three of the five focus groups. COR led the discussions in all focus groups.

Data analysis

The focus groups were digitally audio-recorded and transcribed verbatim. Each transcript was repeatedly read by a researcher while listening to the audio files. The constant comparison approach, a method where data is continually compared with data previously collected and their coding, was used to identify emerging patterns and key themes with single words, sentences or groups of sentences were coded to a particular theme [26, 27]. Key themes and interpretation of the data were iteratively discussed. The content analysis was managed using the qualitative data software program NVivo (Version 8, QSR International, Doncaster, Australia).

Ethics approval

This study was approved by The University of Sydney Human Research Ethics Committee.

Results

Three major themes emerged from the data; raising awareness about mental health, impact on professional practice and impact on mental health consumers.

Raising awareness about mental health

All MHCEs nominated reducing mental health stigma as a primary reason for becoming a MHCE. All reported personal experience with mental health stigma at some stage of their illness and were motivated to share their personal

stories and to educate the community about mental illness. They felt that their own personal stories had a much greater impact on reducing stigma and improving attitudes toward mental illness in the community than standard educational methods. In particular, the MHCEs wanted to demonstrate that they were “real people” rather than “patients with a mental illness”. They also wanted to dispel a common misperception that all individuals with a mental illness were violent and dangerous. Overall, they were motivated to break down the stereotypical myths about mental illness and wished to be less marginalized by the society.

‘Tell a real story, and people take whatever part of that story back, and remember really unique things about it that sit with them. And that is something that then attaches to their ongoing attitude change or their approach to the general community.’ (MHCW, focus group 4)

‘I think it’s about education and breaking down barriers and eliminating stigma. I think the more people become aware of how normal schizophrenia can be... then they’re more likely to be less prejudiced and judgmental toward people with schizophrenia and mental illness.’ (MHCE, focus group 5)

‘...people who have a mental illness are no more violent than anyone else in the community, which is such a big misnomer. I know sometimes when I mention I have a mental illness to some people you can see them recoil’. (MHCE, focus group 4)

The contact the students had with the MHCE provided them with a greater insight into what it is like to suffer from psychotic symptoms and the challenges people face in managing their mental illness.

‘I found the educators... to be a really useful and insightful experience. It often feels that a lot of the terminology and concepts we learn have little relevance, however when it came to actually encountering people who were suffering from such conditions it suddenly became meaningful.’ (student, focus group 1)

All of the students felt that the sessions with the MHCEs had contributed to a decrease in their mental health stigma and enabled them to see that they are real people suffering from an illness that can be treated. Many of them had preconceived ideas about what a person with a mental illness looks like or how they should act, and this helped eliminate some of these ideas.

‘I think everyone has preconceptions. In the media they’re portrayed as something and there is a stigma attached to it so it was good to get rid of that stigma

and see that it is an actual person that you are talking to and they are exactly the same as us.’ (student, focus group 3)

‘I had always thought that I was quite open minded... however meeting these people pushed my comfort zone and I had to re-evaluate. I was able to actually see first-hand what it means to be mentally ill and as a result I was able to formulate a true opinion.’ (student, focus group 2)

Impact on professional practice

The MHCE appreciated that the students derived benefit from their joint participation in the educational sessions, via feedback from the students. They also indicated that this may positively impact on the students’ future professional practice as pharmacists. The real-life experience they gained from face-to-face contact with consumers with a mental illness in an educational setting may help them to be more sensitive and understanding to the needs of consumers with a mental illness in their practice.

‘I think actually it will make them better pharmacists, generally I think their approach to people with a mental illness are hopefully if not understood before is understood a little bit better.’ (MHCE, focus group 4)

‘It’s certainly an advantage for them to get some firsthand experience rather than just something from a textbook.’ (MHCE, focus group 5)

Students’ reported that contact with the consumers helped contribute to a change in their attitudes toward mental illness and a number of students indicated that they had made some changes to their practice since participating in the educational session. It made them aware of the impact their behavior may have on consumers, which they reflected on when they returned to the pharmacy workplace.

‘I noticed that I changed my habits in the way I interacted with a few patients (since the consumer-led session) because I used to be a little bit careless.’ (student, focus group 2)

‘Just being more understanding, more patient, just more accepting I think in general... yes perhaps somewhat to a degree, my behavior has changed.’ (student, focus group 2)

‘It has changed the way I practise and think about patients and how they feel a little more’. (student, focus group 1)

Confidence in communicating with consumers with a mental illness also improved following the consumer-led

session with students commenting it had helped improve their ability to counsel consumers about their psychotropic medications.

‘When you ask the patient, when you counsel, make it open-ended and listen to them. One thing that’s important for them might not work for another person.’ (student, focus group 1)

Students also gained an understanding of the importance of being non-judgmental and that consumers want advice from pharmacists about their psychotropic medications, contrary to the belief that consumers will not feel comfortable discussing their illness with a pharmacist. However, some MHCEs did express the importance of maintaining privacy in a busy pharmacy environment.

‘Just being more understanding, more patient, just more accepting I think in general.’ (student, focus group 2)

‘A very practical thing that I brought up was a number of pharmacies when they give you the drugs sometimes they put it in clear plastic bags and that can be a problem.’ (MHCE, focus group 4)

While a number of students commented that they would feel less cautious or scared in the pharmacy setting when dealing with a consumer with a mental illness, others still found it was a confronting experience in the educational setting and in real-life practice. It was reported as being an emotional experience for some of the students who thought they should be able to do more to help consumers with a mental illness and it gave them insight into what they have experienced. There was also an uncertainty about what information was too personal to ask about, during the educational session as well as in real-life practice, and to what extent they could ask them about their illness and its effect on their lives.

‘If anything I would say that I would be less cautious of it whereas previously if someone came in with a script for an antipsychotic, you were cautious of the patient.’ (student, focus group 3)

‘At first it was a bit confronting but once we got to talk to all the different patients, you got more comfortable with asking questions of them.’ (student, focus group 1)

Impact on MHCEs

In addition to the impact on the professional practice of the participants, the MHCEs themselves reported experiencing a number of personal benefits from their role. They all reported feeling empowered in their role of sharing their

personal knowledge and experiences of mental illness. It gave them great joy and strength to see the impact they had on people's views about mental illness.

'It is empowering when I know I've educated a large number of people in my audience, and like a domino effect they go out and educate others.' (MHCE, focus group 5)

'When I speak I gain inner strength and inner fortitude which is reflected in every other area of my life.' (MHCE, focus group 5)

The interaction with people through their role as a MHCE led them to reflect and review the management of their own illness. Through speaking about their experiences and illness it has also enabled them to see that their recovery process is going well and to see how far they have come.

'I find that it helps me to sometimes even review my own management skills through the questions that I get because each group of people they may come up with different questions. So that brings a perspective that maybe I never thought of.' (MHCE, focus group 4)

'Every time I finish doing the talk and I go home and just reflect on what I've said, it always affirms that my recovery is still quite positive, and that is a good reminder that I am doing well.' (MHCE, focus group 4)

MHCEs commented that often they were asked very personal or confronting questions which they have had to develop the confidence and skills to be able to handle.

'You don't know basically what is going to be thrown at you until it is asked. But you could get a question that could take you back and get you thinking about something that you haven't really thought about before. You go home and think, well you know that was a significant question and I haven't really thought about that, so you kind of analyze it and think how you can maybe change that or do it better.' (MHCE, focus group 4)

Significant improvements in confidence and public speaking skills were reported by all MHCEs. Many also commented that these benefits extended to social skills outside their role as a MHCE and that it helped them in everyday social situations as well. They also enjoyed the social aspects of their role that involved meeting other consumers, as many of them had been through similar experiences.

'It helps me with public speaking. It helps me to realize that I'm not the only person in the universe

with an illness and that the world doesn't revolve around me, but there's a lot of other people out there that are eager to hear what I've got to say and who are interested in my contribution to the world.' (MHCE, focus group 5)

However, some MHCEs found their role to be challenging due to a fear of social situations or paranoia. While participating as a MHCE has helped to control these symptoms of their illness it is still an ongoing challenge to overcome these fears to be able to fulfill their role.

'I get a lot out of public speaking. I get a lot of self confidence... when I get it right. When I'm talking to people... I don't know. It's quite a challenge for me speaking to people in public.' (MHCE, focus group 5)

'Sometimes I still have trouble... with the feelings that people are saying bad things about me...and part of my reasoning for being a part of Remind is to aggressively deal with something like that. It put me in a position... that you're dealing with people and you're trying to communicate what you know and feel about the illness, and the way that people should be treated, and answering questions and...part of my motivation was to meet that sort of thing face to face.' (MHCE, focus group 5)

Discussion

No other published studies have investigated the impact of involving mental health consumers in an educational setting on both the student participants and the consumers themselves. The contact with mental health consumers in a safe, educational setting provided the pharmacy students with a greater insight into the challenges surrounding mental illness, contributed to a self-reported decrease in their mental health stigma and it also led to self-reported behavior changes in their professional practice in the pharmacy. Both the MHCEs and participants identified these attitude and behavior changes would not occur with standard didactic forms of mental health education. While training of health professional students in the area of mental health has traditionally focused on the technical or clinical aspects of therapy (e.g. criteria for diagnosing mental illnesses or pharmacotherapy treatment options), studies in medical and pharmacy students have shown that these methods may have limited impact on reducing mental health stigma [7, 28, 29]. Although challenging, this highlights the importance of also addressing the social and communication aspects required for the delivery of optimal mental health care. Contact with consumers in an educational setting for pharmacy students can lead to sustained

decreases in mental health stigma and improvements in attitudes toward providing pharmaceutical services for mental health consumers [6, 7, 21]. Furthermore, the conditions of contact with consumers with a mental illness appear to be important [30, 31]. Contact in the workplace alone appears not to be enough to reduce mental health stigma [32]. Furthermore certain conditions such as equal status between groups, common goals, support of the authorities and the structure and setting of the interaction need to be considered for the contact to be successful [31, 33]. The mechanism by which contact reduces stigma remains unclear, but it is thought to disconfirm stereotypical beliefs about mental illness which may result in positive behavior change [34, 35]. In addition, the reversal of the typical hierarchal structure of a professional–patient interaction allowed for a greater sense of equality between participants [36]. Fostering opportunities for students to experience contact with a mental illness a safe, non-confrontational setting is essential to ensure the optimal care of consumers with a mental illness.

The primary reason for becoming a MHCE was to raise awareness about mental health and to reduce mental health stigma. However, the MHCEs also benefited in many other ways by sharing their personal stories such as a feeling of empowerment and strength when they saw the impact they made to people's views about mental illness. Sharing personal narratives has shown to be an important and unique domain in a person's recovery from mental illness [37]. Furthermore, empowerment is an important aspect of recovery in mental illness and involvement in consumer organizations has shown to be associated with recovery [22, 23]. Empowerment has also been shown to be associated with decreased levels of self-stigma in schizophrenia [3]. While involvement in consumer organizations is an important empowerment strategy, other factors should also be considered including collaborative treatment plans and encouraging a focus on recovery [38].

Talking honestly and candidly to strangers was at times challenging for the MHCEs, but they did this to break down stereotypical views which enabled the students to relate and reflect in a safe learning environment. This challenging and confronting nature of their role led many to reflect and review their own management of their illness. It also helped to reaffirm their recovery process when positive feedback from participants was received. Significant improvements in confidence and social skills were gained by all educators and these benefits extended beyond their role as an educator into their personal lives. These benefits of improved self-esteem and empowerment are consistent with previous research involving mental health consumers in the teaching of undergraduate medical students [24]. However, Walters and colleagues [24] found that participation in their study was distressing for some

consumers. In our study, no consumers were distressed by the confronting nature of the questions and this may be due to the training they receive from the Schizophrenia Fellowship enabling them to comfortably respond to challenging questions. It is important that this is a positive experience for all participants, with the consumer as an equal.

An important strength of the study was the use of focus group methodology which allowed us to obtain in-depth information from our participants regarding their attitudes about mental health and the involvement of consumers in mental health educational programs [39, 40]. Qualitative research studies do not necessarily require a large random sample because generalizability is not the objective [41]. All consumers and caregivers who participated in the education program participated in the focus groups ($n = 12$). A comparable number of pharmacy students also participated in the focus groups ($n = 11$). However, it is possible that the small sample size of pharmacy students meant that the experiences of specific groups of pharmacy students were not fully captured, including those with specific cultural backgrounds or those with a mental illness themselves. The educational sessions were only conducted with undergraduate pharmacy students and the results from the participants may not be extrapolated to other study populations.

Conclusion

Providing students the opportunity to have contact with mental health consumers in a safe, educational setting led to decreases in stigma, the fostering of empathy and self-reported behavior changes in practice. Sharing personal stories about mental illness is a powerful tool to decrease mental health stigma and may be an important aspect of a person's recovery from mental illness. Contact with mental health consumers in an educational setting is recommended, particularly for future health care professionals. Appropriate training and support of MHCEs is important to ensure the experience is positive for all involved.

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