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Challenges in accessing and interviewing participants with severe mental illness.

Abstract

Background

Interviews are widely used in qualitative research to collect data. However, little has been written about interviewing people with severe mental illness (SMI).

Aim

To report and analyse an experience of addressing the ethical and practical challenges of interviewing people with SMI.

Discussion

Semi-structured interviews were conducted as part of a doctoral study to explore how service users and healthcare professionals built relationships with each other.

Conclusion

Although interviewing participants with SMI was challenging, rich data illustrating their experiences were gathered. Careful planning around ethical considerations, such as obtaining informed consent, was required to maximise the opportunities to gather in-depth information during the interviews. The relationship established between researcher and the participants assisted with sensitive disclosures and allowed participants to tell their stories.

Implications for research

This paper provides strategies to help guide researchers planning interviews with vulnerable populations, including those with SMI. These strategies include how to discuss sensitive issues

and promote engagement. Listening to participants' life stories is an intense experience, requiring support for the interviewer to stay neutral during interviews. It is also important to be aware of the differences between the roles of nurse and nurse researcher before undertaking in-depth qualitative interviews, particularly with vulnerable participants

Keywords: Ethical, Relationship, Semi-structured interviews, Severe Mental Illness and Vulnerable Populations

Introduction

Approximately one in five people will experience a mental health problem over their lifetime (Centre for Behavioural Health Statistics and Quality, 2015). It is expected that an additional two million people will experience a mental health problem in 2030 than in 2013 (Mental Health Foundation, 2013). Consequently, the need to explore how people experience mental health problems and services is increasing. Additionally, the levels of knowledge regarding Severe Mental Illness (SMI) such as Schizophrenia is limited amongst professionals and the general public (O'Reilly et al. 2015). SMI can be defined as people who experience emotional, behavioural or mental health problems (excluding addiction and developmental issues) that substantially limits one or more major life activity. It is estimated that 4.1% of adults experience SMI (Centre for Behavioural Health Statistics and Quality, 2015).

Currently, the momentum driving the interest in service users' experience of mental health problems is recovery. Recovery is an emerging concept in mental health practice (Higgins and McGowan, 2014). Recovery is a personal journey that belongs to and is completed by service users (Watts and Higgins, 2016). The overarching themes of recovery can be described through the CHIME acronym of Connectedness, Hope, Identity, Meaning and Empowerment (Leamy et al. 2011). Recovery advocates for a deeper analysis of the mental health service and how power is disturbed (Higgins and McGowan, 2014). Service user involvement in healthcare research is important in achieving recovery oriented practice, as their experience can influence healthcare research and service provision (Callard and Rose 2012).

The aim of this article is to report and analyse a personal experience of addressing the ethical and practical challenges of interviewing people who experience SMI. This experience was drawn from a research study which explored how service users and healthcare professionals built relationships and communicated with each other. The rationale for the study arose from an

integrative literature review which explored service users' experience of mental health services (Newman *et al.* 2015). The relationship between service users and healthcare professionals emerged as important for planning care and interactions. The main finding from this review is whilst people may express satisfaction with mental health services; there are issues around poor communication, service user involvement, decision making and limited treatment choice (Newman *et al.* 2015).

The research study

To investigate how relationships were built between service users and healthcare professionals, a qualitative case study was undertaken. The overall aim was to explore how service users and healthcare professionals built relationships and communicated with each other. The rationale for using a qualitative case study methodology was twofold. The research question was formed as a 'how' question i.e. how service users and healthcare professionals built relationships and communicated with each other. Yin (2014) states that qualitative case studies are an effective mechanism to answer 'how' questions. Additionally, as the focus of the study related to contemporary issues such as how relationships are now being built, qualitative case studies allowed the researcher to gather in-depth explanations of these social behaviours and interactions (Yin, 2014).

A typical characteristic of qualitative case studies is the use of multiple sources of data (Yin, 2014). In this research project semi-structured interviews and focus groups were used to gather data. Qualitative interviews allow insights into what participants perceive as relevant and important to them (Bryman 2012). In this study, eight service users and sixteen healthcare professionals were interviewed. Service users were interviewed first and healthcare professionals who had a role in their care were then invited to participate. This was followed by 5 focus groups. Focus groups were held with healthcare professionals (n=18). Data were

collected between October 2014 and June 2015. Data were collected by the first author (the interviewer).

In relation to participants, there has been much debate regarding how to describe persons who use mental health services and the emotions they experience (Dickens and Picchioni, 2012). During the interviews, participants were addressed by their name and the term 'Service user' is used in this paper to denote the perspective of the participant. All terms are potentially problematic; however, service user is seen as an improvement from previous concepts (Armes *et al.* 2011 and McLaughlin 2009). Seven of the eight participants described themselves as experiencing schizophrenia/psychosis while one described experiencing bi-polar disorder. The six men and two women who consented to be interviewed were aged between 25 and 60. They have engaged with mental health services for between 10 and 30 years. The interviews lasted between 30 and 90 minutes.

What follows is an analysis of the learning gained which centres on the ethical and practical challenges of conducting semi-structured interviews with people who experience SMI.

Ethical challenges when interviewing participants with SMI

The role of research ethics is to protect human participants from harm (Sieber and Tolich, 2013). There were several ethical issues that arose during the interview process such as dealing with sensitive disclosures, empowering participants to tell their stories and ensuring informed consent was given.

Informed consent is a fundamental requirement of ethical research (World Medical Association, 2013). Strategies were required that allowed potential participants to be sufficiently informed about the interviews. As part of this process, an information leaflet for participants who experience SMI was distributed to the sample population. Remenyi *et al.* (2011) supports this approach as potential participants may find a leaflet less daunting than a

formal letter. Two exploratory interviews were conducted and these participants commented that whilst the leaflet was useful, it was too word heavy. Changes were made so the leaflet communicated its message clearly and in a less complex manner. Additionally, potential participants were made aware of their rights when the leaflets were distributed and prior to the interview itself. Providing both written and verbal information about the study removed barriers to engagement as it allowed potential participants the opportunity to understand the study prior to giving consent. It enabled participants to ask further questions about the study, the interviewer and the research process. In practice, these conversations were positive. It enabled trust to develop as it demonstrated the first concern of the study was maintaining participants' autonomy and respect. The extra step of giving both verbal and written information provided participants with the knowledge to give informed consent. Both written and verbal consent were documented or recorded via Dictaphone.

Empowering participants to tell their story freely was central to the experience the interviewer wanted to create. This is important in all situations but vital when interviewing participants who experience SMI. Some participants' experienced barriers to communication arising from the consequences of mental distress, medications, stigma and how they have learned to interact with healthcare professionals i.e. passiveness (Healy 2015, National Institute of Mental Health 2015 and Wahl 2012). Participants were empowered in several ways. Firstly by making the interview process as relaxed and informal as possible, it made participation less stressful. It was important to respond to each individual's need by constructing questions using the clearest possible language, thus promoting engagement (See Box 1). To implement this approach, the interviewer met with each participant for approximately fifteen minutes prior to the interview. This time allowed for the consideration of their needs (if any) and to promote confidence by reassuring them that their input and expertise was important. This also empowered participants to set boundaries around the discussion (Dickson-Swift *et al.* 2015). Participants were open to

discussing their life story and these actions empowered participants to tell their story as they wished and helped the interviewer to adjust to their needs or anxieties.

Box 1: Examples of questions used during the interviews

- So can you tell me about your experiences in the mental health service up to now?
- Can you tell me about the services and care you are currently receiving from the mental health services?
- From your experience can healthcare professionals do things differently?
- When you are in a meeting with a healthcare professional discussing an issue, what are the most important elements about how that conversation develops?

Managing the disclosure of sensitive information was also a significant ethical challenge. Just three minutes into interviewing one participant, he disclosed experiencing intrusive thoughts about assaulting women (See Box 2). Not knowing how to respond to this disclosure, the interviewer moved on to another line of conversation, which in retrospect was a lost opportunity. One should expect the unexpected, which at that point the interviewer failed to do. By focusing on the participant, the interviewer was able to respond to the disclosure at a later point. Other disclosures were addressed by acknowledging the pain that participants expressed while being prepared to terminate the interview if necessary (Dickson-Smith *et al.* 2008). The use of interpersonal skills such as active listening assisted in the management of most situations encountered during the interviews (Mealer and Jones 2014).

Box 2: Dealing with sensitive disclosures

Interviewer: Ten years and why have you been using the service?

SU 1: [Because] I was obsessed about harming a girl I used to work with.

Interviewer: Ok, ok and um.... what's been your experience being in the mental health services until now?

SU 1: How do you mean?

Interviewer: How do you find the services?

SU 1: Good, yeah.

Later in the interview:

Interviewer: Did anyone help you with these thoughts?

SU 1: X (Name) I suppose and X (Name)

Interviewer: So nurses were particularly helpful to you when dealing with this issue?

SU 1: Yeah.

Interviewer: What did they for you that others didn't?

SU 1: When I was under the care of XHe gave me advice on how to look after myself and that. '

The ethical aspects of the research were just the first steps in the data collection process. The interviews themselves required one to be flexible and create the circumstances so the interviewer could fully capitalise on the opportunity to obtain the participants' experiences of the phenomenon.

Enhancing the interview process.

The first priority of any research study is safety. It is important to emphasise that the participants posed no risk. The interviewer never felt unsafe and acknowledge the contributions of participants. To prepare for the interviews, a risk assessment was performed i.e. having discussions with the participating clinical teams about risk and assessing sites for hazards such as doors that lock automatically (Barr and Welch, 2012). A number of precautions were implemented including choosing a neutral place to interview participants (Social Research Association, 2006). An unexpected issue which arose was how the participating organisations viewed risk in the clinical setting. For example, after commencing an interview, a professional knocked on the door and rushed in to give the interviewer an alarm. This could have unsettled the participant, highlighting the potential risks associated with him. However, through the use

of interpersonal skills i.e. humour, the interviewer defused the situation and refocused the interview back on the participant. This example demonstrates that organisational concerns should be considered when developing a safety protocol, which was an initial oversight on the interviewer's part (Roguski and Tauri, 2013).

The main priority of the study was protecting participants from harm. It was important to become aware of subtle changes in behaviour during the interviews (Parahoo, 2014). For example when a participant became emotional about his deceased mother, the interviewer comforted and empathised with him. On a practical level, the interview settings had a quiet space if required by participants. Additionally, at the end of each interview, some time was spent with the participants to gain their perspective and they reported feeling uplifted by the experience.

An outcome of spending time with participants prior to the actual interview was building a brief relationship with them. The effect of this brief relationship was enhanced communication and trust. These conversations provided details regarding the type of service the person used, which helped the flow of the interview. Additionally, this time spent with participants allowed the interviewer to assess each situation. Sometimes doing nothing and adjusting to the participant's communication style was the best approach. For example, a participant began to communicate with voices he experienced during an interview. At first, the interviewer intervened by asking the participant to focus on his perspective. However, this disrupted the participant and how he communicated. By reverting back to how the participant originally communicated, this enabled him to become more relaxed and improved communication for the rest of the interview. During this situation, the interviewer became aware of his own prejudgements and preconceptions.

The role of body language became central to communicating the interviewer's acceptance of participants' communication styles. To demonstrate this, Egan's (2010) SOLER acronym (Sit Straight, Open Posture, Lean Forward, Eye Contact and Relax) was used. This technique was successful in unifying overall communication; however, it was tiring to maintain due to the many issues needing to be considered during each research interview.

The second advantage of this brief relationship was the development of trust. Trust is an issue in every interview but vital due to the personal and sensitive experiences being described such as a participant's first experience of mental distress (Corbin and Strauss, 2015). Trust was built through self-disclosure and setting boundaries around the relationship. The interviewer's self-disclosure began with the information leaflet. Being a PhD student allowed trust to develop quickly for some, as he was separate from the service. Willingness to listen to their concerns also assisted in building trust. Additionally, this created a less intimidating environment between the interviewer and participant (Elmir *et al*, 2011). Box 3 demonstrates the value of trust, which enabled this participant to provide a personal insight into the question posed.

Box 3: An example of how trust enabled participants to fully explore their experiences

Interviewer: How have your mental health problems affected your life –do you think?

SU 6: Socially, I missed the boat when all my other friends were going off to college, I missed that step. Although I did go to college. However, I wasn't really able to cope by the time I got there, and it really had an effect on my education. My family, it had a bad effect on my family.....My younger sister and I, ... before my first admission to a psychiatric unit,... we were best of friends, but then she found it hard to cope. So, from somebody who was really caring and who cared about her a lot and showed her great attention – all that kind of fizzled away, so she was left wondering what's going on. However, she lives abroad now,

and I don't see her very often and I miss that. I miss that because I'd like for things to be patched up, but because she's so far away, I don't see how that can actually happen.

The interview process was enhanced by pre planning and learning from experiences of interviewing participants. The following will outline some reflections and discuss the key learning gained during the data collection process.

Discussion

The interview as a method of data collection has been debated and examined. Interviews are a part of our life from the clinical setting to job applications. The interview process outlined the need for reflection in order to collect the highest quality data. Overcoming the anxieties and additional ethical requirements of engaging with so-called vulnerable populations such as persons who experience SMI and enabling them to tell their stories freely was the key learning gained from this experience (Edwards and Holland, 2013). This affected how the interviewer contributed to and reflected upon the interview process and the necessity to engage with people from hard to access groups such as people who experience SMI.

The interviewer failed to anticipate the personal impact that participants' stories would have on him. Box 2 described how the interviewer steered the conversation away from a participant's line of thought. This mistake was based on the assumption that training as a psychiatric nurse equipped him with the skills needed to address most situations. This assumption was incorrect, as Ashton (2014) advises previous nursing experience does not prepare one for the role of a researcher.

Ashton (2014) also discussed the blurred roles between the nurse and nurse researcher and the use of the nursing role within the research interview. The main difficulty the interviewer experienced was separating being a nurse to that of being a nurse researcher. As a nurse,

delivering services with a service user was a process of ‘getting to know’ the person’s story over time. In the research interview setting, the interviewer needs to uncover the participants’ life story within a short timeframe. As a nurse, one would develop a plan with the service user to address their issues. In the researcher role at times one felt helpless, as all he could do was listen. In addition, without the distractions of having a list of duties to complete it gave him time to reflect on how, at times, we disappoint those who come to us for assistance. Listening, good communication and being impartial were key competencies one developed during the data collection process. Being impartial or self-control as Ashton (2014) described it was the most difficult skill to learn. It was difficult being fully engaged in each interview while trying to gain an overall perspective on what issues and ideas were emerging without involving personal emotions. The interviewer had to truly understand and internalise the purpose of being a nurse researcher, i.e., investigate a phenomenon to identify solutions to clinical problems, before he could use his nursing experience as an asset to improve participants’ engagement with the research process (Polit and Beck, 2012).

This paper has described the key skills necessary for any interview to succeed, particularly those that involve so-called vulnerable populations, who are defined as persons considered being at a higher risk of harm (Parahoo, 2014).

Firstly, there is evidence to suggest that vulnerable populations can benefit from participating in research (Biddle *et al.*, 2012). Similar issues as those described in this paper such as participants being unfamiliar with the research process can occur with other vulnerable groups which can impede their participation (Mcgrath *et al.* 2013). Strategies to address interview skills and ethical considerations as described in this paper are similarly outlined when interviewing newly migrant women (Merry *et al.* 2011). In that study, Merry *et al.* (2011) outlined that the context of the interview was important. In addition, Hlavka *et al.* (2007) review of women’s’ who experience violence documented similar ethical procedures such as

interviewers immersing themselves in the topic. Additionally, the interviewer should be reflective and assess how the interview affected them personally (Scerri *et al.* 2012).

Ensuring robust ethical processes around informed consent and improving communication are essential in all studies. When interviewing participants who experience SMI one must try to recognise its impact on them as individuals and adapt to their context. This article provides some 'real life' experiences and learning when interviewing participants who experience SMI. Recovery advocates that service users are an integral part of research (Office of the Nursing and Midwifery Services Director and Health Service Executive, 2012); therefore, it is important that they are empowered and supported to fully engage in research on their own terms.

Conclusion

The process of interviewing participants who experience SMI was valuable. The experience participants shared emphasised the need to involve them in research and showed that they have much to contribute by recounting their experiences. The strategies this paper describe can be adapted to other situations in which persons who are considered vulnerable are interviewed. The key points of learning are the need for interviewers to immerse themselves in the topic area in order to develop strategies to establish a reciprocal relationship for the purpose of gathering research data. Data collection plans need to recognise salient ethical issues such as informed consent and responding in real time to the needs of vulnerable participants. Secondly, the role of the nurse and nurse researcher are distinct. Nurses plan care based on an assessment of need, whereas researchers gather information normally with no further involvement required. Overall, those planning to research phenomena involving vulnerable groups must ensure that participants receive the opportunity to tell their stories freely and on their own terms.

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