Ethical and methodological issues in qualitative studies involving people with severe and persistent mental illness such as schizophrenia and other psychotic conditions: a critical review

Ing-Marie Carlsson, Marjut Blomqvist and Henrika Jormfeldt

School of Health and Welfare, Department of Health and Nursing, Halmstad University, Halmstad, Sweden

ABSTRACT

Undertaking research studies in the field of mental health is essential in mental health nursing. Qualitative research methodologies enable human experiences to become visible and recognize the importance of lived experiences. This paper argues that involving people with schizophrenia in research is critical to promote their health and well-being. The quality of qualitative research needs scrutinizing according to methodological issues such as trustworthiness and ethical standards that are a fundamental part of qualitative research and nursing curricula. The aim of this study was to critically review recent qualitative studies involving people with severe and persistent mental illness such as schizophrenia and other psychotic conditions, regarding descriptions of ethical and methodological issues in data collection and analysis. A search for relevant papers was conducted in three electronic databases, in December 2016. Fifteen qualitative interview studies were included and reviewed regarding methodological issues related to ethics, and data collection and analysis. The results revealed insufficient descriptions of methodology regarding ethical considerations and issues related to recruitment and sampling in qualitative interview studies with individuals with severe mental illness, putting trustworthiness at risk despite detailed descriptions of data analysis. Knowledge from the perspective of individuals with their own experience of mental illness is essential. Issues regarding sampling and trustworthiness in qualitative studies involving people with severe mental illness are vital to counteract the stigmatization of mental illness.

Introduction

Knowledge of mental illness is primarily established by understanding of the perspective of individuals with experience of the phenomenon investigated (Mestdagh & Hansen, 2014). One of the largest differences between research involving the general population and research involving people with severe and persistent mental illness, such as schizophrenia and other psychotic conditions, is that stigmas about mental illness are widely endorsed by the general public and by mental health professionals (Corrigan, 2000; Hansson, Jormfeldt, Svedberg, & Svensson, 2011). This constitutes specific issues regarding research involving people with schizophrenia. People with severe and persistent mental illness are generally considered, completely or partly, unable to make autonomous decisions regarding their participation in research studies (Koivisto, Janhonen, Latvala, & Väisänen, 2001). Furthermore, parts of the data-collection process, such as the recruitment of participants, are often performed by healthcare staff who select participants and sometimes choose not to ask for participation, thereby working as a kind of gatekeeper who has the power to decide who should be given a voice in research and who should not (Allbutt & Masters, 2010). Gatekeeping in the research field of caring is frequently driven by the general assumption of vulnerability of patients, combined with an emphasis on the duty to protect patients. In addition, research is often perceived as a threat to patient well-being, while the benefits seem to be overlooked (Kars et al., 2016). Changing negative attitudes about mental illness will require changes in strategies to target effectiveness and efficacy issues in the carrying through of research studies and implementation of evidence-based interventions in mental health services (Corrigan, 2000; Hansson et al., 2011). A major concern in such research is that gatekeepers prevent the patients from making their own decisions regarding research participation, thereby overriding their autonomy (Kars et al., 2016).

Attaining trustworthiness in findings of qualitative studies is of great significance and the analysis approach used should assure trustworthiness in the data analysis regarding the perspectives of the individual, which is essential for developing nursing research and practice (Elo et al., 2014). Both inductive and deductive analysis processes represent three main phases, described as preparation, organizing and reporting the data (Elo et al., 2014), starting with selecting the units of meaning in the analysis. A unit of meaning in a qualitative analysis can consist of more than one sentence and contain several...
meanings, making the use of long units of meaning in the analysis process difficult and challenging (Gra neheim & Lundman, 2004). However, too brief a meaning unit extracted from its context in the interview could result in fragmentation of the participant’s intended meaning (Elo et al., 2014). These issues become even more central when analysing data deriving from interviews with people who deliver different levels of incoherent speech or are taciturn at times despite being willing to participate and having important experiences to share. Detailed descriptions of the methodology used and the ethics considered are important to secure trustworthiness in qualitative studies to counteract stigmatization regarding mental illness.

The aim of the paper was to critically review recent qualitative studies involving people with severe and persistent mental illness such as schizophrenia and other psychotic conditions, regarding descriptions of ethical and methodological issues in data collection and data analysis.

Method

Identifying relevant studies

A search for relevant papers in was conducted in December 2016 in three electronic databases: CINAHL, PubMed and PsycINFO. To help with the search, the authors discussed search terms with an experienced librarian, who also conducted the final search. Our intention was to capture qualitative articles that used narratives or verbal data from adults diagnosed with schizophrenia or other psychotic conditions. To narrow and expand the search we used search tools such as medical subject headings (MESH), Boolean operators and truncation. In all databases, single and combined search terms included the keywords “schizophrenia”, “persistent”, “severe”, “focus group”, “interview” and “qualitative study”. Those publications defined as relevant were empirical peer-reviewed papers, published in English during 2012–2016. Inclusion criteria were articles in which people aged 18–65 years with schizophrenia participated in individual interviews. To ensure a focus on issues related to the qualitative interview dialogue between the participant and the researcher, studies excluded from this review were focus group interviews and interview studies with large sample sizes and quantitative data.

Study selection

The searches identified 598 articles, which were catalogued in EndNote®. Duplicates were then removed by automation supplemented with manual checking. Altogether, after scanning of the titles and abstracts, 495 articles remained as potentially relevant articles. At this point, we made a decision regarding the number of articles, to include only the most current articles, i.e., those published during 2016. The total number of eligible articles was 68, and the authors read the full text of all these. Articles that did not have relevance to the aim, for example, articles which interviewed relatives and healthcare professionals or focused on children and adolescents, were excluded. Finally, 15 articles were included in the present critical review (Figure 1). The authors read each method section and limitations section, if applicable, several times to become familiar with the content. Then, a summary tool was developed to extract information related to issues regarding ethics, data collection and data analysis (Table 1). Included and reviewed articles are marked with an asterisk (*) in the reference list.

Results

The results presented reflect a critical review of the ethical and methodological issues described in the studies related to the ethics, data collection and analysis of data from interviews involving people diagnosed with severe and persistent mental illness such as schizophrenia or other psychotic conditions.

Ethical issues

In most countries, the legal framework governs research activity with humans; in Sweden there is a specific law for ethical approval in research on humans (SFS 2003:460, 2003). However, there are differences between countries regarding whether ethical approval is needed or not, sometimes depending on whether a study is qualitative or quantitative. In the present critical review, most studies, but not all, had approval from research ethics committees. Some of the reviewed articles were part of a larger study and these articles did not clearly state if the actual study had ethical approval or not. The reason for this could be that the actual qualitative study was part of a larger research project that had gained ethical approval for the whole project (Burke, Wood, Zabel, Clark, & Morrison, 2016; Kidd et al., 2016; Singh, Jakhia, Amonashvili, & Winch, 2016). Two of the reviewed studies, one from Denmark (Bjerkedal, Torsting, & Møller, 2016) and one from the Netherlands (van Langen, Beentjes, van Gaal, der Sanden, & Goossens, 2016), indicated that they had consulted their ethics boards, which had replied that no ethical approval was needed. Both of these studies, however, as well as most of the others included, were conducted in line with the principles of the Declaration of Helsinki (2013) and the key ethical principles of autonomy, confidentiality, protection, do no harm and informed consent. Notable, however, regarding informed consent is that in one study the authors clearly stated that...
it was the person’s physician who gave feedback to the researcher on the person’s ability to provide informed consent, before the participant was even approached (Barut, Dietrich, Zanoni, & Ridner, 2016).

Moreover, in one of the present articles the authors acknowledged that participation in the interview study was described briefly in the personal medical records. The participants were informed, and the reason given was that the interview study was part of a larger intervention study (Bjørkedal et al., 2016).

**Issues of data collection**

All of the reviewed studies gathered data through face-to-face interviews and it was common for the research team to use semi-structured interviews. The sample size varied between seven and 30 participants. In most of the articles, the authors discuss or mention the implications of a small sample size as a limitation for the research results (Bjørkedal et al., 2016; Blixen et al., 2016; Burke et al., 2016; de Jager et al., 2016; Jones et al., 2016; Landon, Shepherd, McGarry, Theadom, & Miller, 2016; Rhodes, Parrett, & Mason, 2016; Topor, Ljungqvist, & Strandberg, 2016), whereas other authors do not discuss this issue, even if fewer than 10 participants were interviewed (Singh et al., 2016; van Langen et al., 2016).

The articles included in this review used different sampling methods such as purposive, convenience and snowball sampling. Given the complexity of sampling, Paul (2016) explicitly indicates that snowball sampling had to be used owing to difficulties in accessing or approaching participants. Other sampling strategies used to enhance recruitment included the study participant receiving a gift card or reimbursement for travel costs to participate (Barut et al., 2016; de Jager et al., 2016).

Several of the studies did not clearly outline the sampling procedure or how the participants were approached. In some cases, this was probably due to the included interview study being part of a larger study (Blixen et al., 2016; Saavedra, López, Gonzáles, & Cubero, 2016; Waite et al., 2016). Nevertheless, for most of the studies recruitment was performed by the healthcare staff or clinicians, who approached eligible candidates for the studies in their daily work (Barut et al., 2016; Bjørkedal et al., 2016; Jones et al., 2016; Kidd et al., 2016; Landon et al., 2016; Paul, 2016; Rhodes et al., 2016; van Langen et al., 2016).

Additional sources, besides healthcare staff, used to approach participants were different networks (de Jager et al., 2016), flyers, the internet, community field sites and word of mouth (Jones et al., 2016).

**Issues of data analysis**

**Using more than one author to aid understanding of the content in the material**

The method sections contained descriptions stating that the findings were scrutinized by means of discussions...
| Authors (publication year), country | Title | Aim | Method/setting | Sample/recruitment | Data analysis | Ethics | Methodological limitations and strengths |
|-------------------------------------|-------|-----|----------------|--------------------|--------------|--------|----------------------------------------|
| Barut, Dietrich, Zanoni, & Ridner (2016), USA | Sense of belonging and hope in the lives of persons with schizophrenia | To explore sense of belonging and hope in the lived experience of people with chronic schizophrenia spectrum disorders | Qualitative analysis; semi-structured interviews. A psychosis unit at the hospital | 20 participants with chronic schizophrenia-spectrum disorder. Purposive sample. The physician gave feedback on the person’s ability to provide informed consent. Those who were determined to have capacity to consent were approached. The study participant received a 25-dollar gift card. One participant became notably anxious during the interview and ended the interview early | Line-by-line analysis using ATLAS. Two of the authors participated during the analysis | Institutional review board approval. Informed consent was signed | The authors discuss that the setting, a psychosis unit at the hospital, could have affected the results |
| Bjørkedal, Torsting, & Møller (2016), Denmark | Rewarding yet demanding: Client perspectives on enabling occupations during early stages of recovery from schizophrenia | To explore how people with schizophrenia experience an occupational therapy intervention designed to enable them to carry out meaningful occupation in the early phases of recovery | Feasibility study of an intervention; qualitative interviews. A large mental health centre | 10 participants diagnosed with schizophrenia spectrum disorders. Convenience sample. Staff approached eligible candidates and then the researcher gave information | Thematic analysis. Three of the authors participated during the analysis in different steps | The Ethics Committee of the Capital Region stated that no approval was necessary. Informed consent was signed. The participants were informed that their participation would be described briefly in their medical records due to the intervention | The authors discuss interpretation bias. The recruitment strategy, sample size and that no record was written about dropouts are discussed. Only those who completed the entire intervention participated in the interview |
| Blixen et al. (2016), USA | Barriers to self-management of serious mental illness and diabetes | To assess perceived barriers to self-management among patients with both serious mental illness and diabetes to inform healthcare delivery practice | Phenomenological approach; semi-structured interviews. An urban safety-net care setting | 20 participants with a diagnosis of severe mental illness, from a larger study. Convenience sample | Qualitative content analysis | Approved by the institutional review board of the participating institution. Informed consent was assigned | The authors mention that it is a small convenience sample |
| Burke, Wood, Clark, & Morrison (2016), USA | Experiences of stigma in psychosis: A qualitative analysis of service users’ perspectives | To explore experienced, perceived and internalized/ self-stigma | Thematic analysis; semi-structured interviews. People with contact with mental health services were interviewed in their homes | 12 participants diagnosed with schizophrenia, schizoaffective disorder or delusional disorder. Data were collected as part of another study with consecutive sampling | Thematic analysis | Unclear | The authors problematize that the sample was biased towards males and white ethnicity. They also highlight that the results of social exclusion and marginalization are most pertinent for people with severe mental illness |

(Continued)
| Authors (publication year), country | Title | Aim | Method/setting | Sample/recruitment | Data analysis | Ethics | Methodological limitations and strengths |
|-------------------------------------|-------|-----|----------------|-------------------|--------------|--------|------------------------------------------|
| de Jager et al. (2016), Australia   | Investigating the lived experience of recovery in people who hear voices | To investigate voice hearers’ lived experience of recovery | Narratives; semi-structured interviews | 11 participants completed the Diagnostic Interview for Psychosis to ascertain that they met diagnostic criteria. Recruited from the Hearing Voices Network and Australian Schizophrenia Research Bank. One participant withdrew after being informed that the interview could cause distress. Reimbursement was offered for travel expenses and time spent taking part. Participants were actively involved in the generation of narrative summaries and the narratives were member checked by participants. | Narrative analysis | Ethical approval was obtained from the University of Sydney Human Ethics Committee. Informed consent was assigned. | The authors problematize the small sample size and self-selection. Participants were actively involved in the generation of narrative summaries and the narratives were member checked by participants. |
| Jones et al. (2016), USA            | “Did I push myself over the edge?”. Complications of agency in psychosis onset and development | To investigate the subjective experience of agency in the onset and early development of psychosis | Phenomenology; semi-structured interviews included participatory techniques | 19 participants diagnosed with schizophrenia spectrum and/or bipolar disorder with psychotic features. Recruited through flyers, the internet, community field sites, word of mouth and clinician referral | Grounded theory and qualitative phenomenology | Approved by the primary investigator’s ethics board. Standard consent process. | The authors claim that they did not intend to produce generalizable knowledge. |
| Kidd et al. (2016), Canada         | Locating community among people with schizophrenia living in a diverse urban environment | To provide an in-depth examination of the experiences, beliefs, behaviours and spaces that constitute community participation for a highly diverse group of people with schizophrenia | Longitudinal qualitative ethnographic design; semi-structured interviews were conducted three times over 10 months. Field notes were taken on foot or in transit in the community with participants | 30 participants with schizophrenia or psychosis spectrum mental illness. Purposive sample. Participants were recruited by care providers at hospital, community services and boarding home | Ethnographic method | Ethical approval and issues unclear | The study was conducted in a single urban setting. The participants were engaged in discussions about the emerging categories and themes. Preliminary findings were also reviewed by an advisory group of people with lived mental illness. |
| Landon, Shepherd, McGarry, Theadom, & Miller (2016), USA | When it’s quiet, it’s nice: Noise sensitivity in schizophrenia | To explore and document the experiences of noise sensitivity in people with schizophrenia | Semi-structured interview | 7 participants diagnosed with schizophrenia or schizoaffective disorder. Recruited from mental health service providers and associated networks | Thematic analysis | Ethical approval and issues unclear. Participants were invited to bring a support person to the interview but all declined. | The authors mention that the sample was small. |
| Paul (2016), India                 | Responses to stigma-related stressors: A qualitative inquiry into the lives of people living with schizophrenia in India | To shed light on conditions and factors that either promote or hinder coping with stigma among people living with schizophrenia | Qualitative interpretive design considering multiple intersectionalities; face-to-face in-depth interviews, using an open-ended interview guide | 20 participants diagnosed with schizophrenia and/or schizophrenia-related disorder. Purposive and snowball sampling strategies were used due to poor social visibility of people living with schizophrenia, and locating and recruiting them was challenging. Participants were recruited from private psychiatric clinics, mental health agencies and schizophrenia support groups | Thematic analysis | Ethical approval was received. Ethical principles were followed | Findings failed to capture experiences of those who received long-term institutionalized care. Interview notes were validated by the participants themselves. |
| Authors (publication year), country | Title | Aim | Method/setting | Sample/recruitment | Data analysis | Ethics | Methodological limitations and strengths |
|-----------------------------------|-------|-----|----------------|-------------------|--------------|--------|---------------------------------------|
| Rhodes, Parrett, & Mason (2016), UK | A qualitative study of refugees with psychotic symptoms | To examine the experiences of refugees with psychotic disorders | Interpretive phenomenological analysis | 7 refugee asylum-seekers diagnosed in a psychiatric setting with psychotic symptoms. Clinicians suggested participants. 14 participants were suggested; 4 declined to participate and 3 did not fulfill the inclusion criteria | Interpretive phenomenological analysis | Ethical approval was granted by the local research committee of the relevant London NHS Mental Health Trust | The authors problematize the small sample size and that six were male |
| Saavedra, López, González, & Cubero (2016), Spain | Does employment promote recovery? Meanings from work experience in people diagnosed with serious mental illness | To explore the meaning attributed to work activity by subjects with serious mental illness, mainly schizophrenia | Phenomenological approach | 21 participants with a diagnosed schizophrenia spectrum disorder. Participants were selected from a larger sample of a study | Social positioning analysis | Ethical approval was given and informed consent was assigned | No limitations are discussed |
| Singh, Jakhaia, Amonashvili, & Winch (2016), USA | "Finding a way out": Case histories of mental health care-seeking and recovery among long-term internally displaced persons in Georgia | To present histories of care-seeking for and recovery from mental illness and psychosocial problems in the context of protracted internal displacement | Case study; semi-structured interviews | 9 participants. Purposive selection from a larger sample. Recruited by clinicians | Grounded theory | Ethical approval is not declared. Ethics section is missing | No limitations are discussed. Credibility was used by member checks with a different subsample |
| Topor, Ljungkvist, & Strandberg (2016), Sweden | The costs of friendship: Severe mental illness poverty and social isolation | To explore the relationships between financial strain and social isolation | Grounded theory. 11 were living in their own apartment and 5 in group homes | 16 participants. Participants were recruited from their municipalities’ specialist team | Thematic analysis | The study was approved by the Regional Ethics Committee in Lund | The authors problematize the sample size |

(Continued)
| Authors (publication year, country) | Title                                                                 | Aim                                                                                                                                                                                                 | Method/setting                                                                 | Sample/recruitment | Data analysis                        | Ethics                                                                                       | Methodological limitations and strengths                                                                 |
|------------------------------------|----------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------|---------------------|--------------------------------------|---------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|
| van Langen, Beentjes, van Gaal, Nijhuis-van der Sanden, & Goossens (2016), Netherlands | How the illness management and recovery program enhanced recovery of persons with schizophrenia and other psychotic disorders: A qualitative study | To describe how the illness management and recovery programme enhanced recovery of people with schizophrenia and other psychotic disorders, from their own perspective | Descriptive phenomenological approach; one-to-one interviews                  | 14 participants were asked and 8 participated. Recruited from one outpatient unit for people with a psychiatric diagnosis. Their mental health nurse performed recruitment | Colaizzi’s data analysis method, supported by MAXQDA software. At the end of each interview, findings were summarized and checked with the participant to ensure that the accuracy of the experience was grasped | The study was conducted in accordance with the Declaration of Helsinki. The authors consulted the Dutch Central Committee on Research Involving Human Subjects and concluded that ethical approval was not needed because the participants did not receive treatment and were not asked to behave in a particular way. Informed consent was assigned. | Selection bias is highlighted since the trainers selected the potential participants |
| Waite et al. (2016), UK             | The patient experience of sleep problems and their treatment in the context of current delusions and hallucinations | To explore patients’ accounts of sleep problems and associated psychological treatment                                                                                                           | Phenomenological approach; semi-structured interviews                         | 10 participants with psychosis were recruited from a randomized control study | Interpretive phenomenological analysis                                                      | Ethical approval was obtained from an NHS research ethics committee                                                                 | The participants were a selected group in the context of a research trial                                |

NHS, National Health Service.
between authors during and after the analysis process. This process needs to maintain the original meaning of the statements when they are condensed, abstracted and labelled at a more abstract level to contribute to structured knowledge in the studied field. One of the authors in the reviewed articles was usually responsible for the main analysis and the other authors served as additional evaluators in the analysis procedure (Bjørkedal et al., 2016; Kidd et al., 2016; Paul, 2016; Rhodes et al., 2016). Others went a step further, and included more than one author to independently read the transcripts and initial analysis (Barut et al., 2016; Bliksen et al., 2016; Burke et al., 2016; Jones et al., 2016; Landon et al., 2016; Saavedra et al., 2016; Topor et al., 2016; van Langen et al., 2016; Waite et al., 2016).

Retaining the original meaning of statements through the analysis process
The findings reveal that the authors made efforts to understand the content of the interview data and to avoid misinterpretation of the interviewees’ statements. Besides the authors cross-checking and discussing the content during the analysis process, some of the included studies used member checks to ensure the accuracy of the experience and to make sure that the underlying meaning of all the statements was preserved when they were abstracted into categories and themes (de Jager et al., 2016; Kidd et al., 2016; Paul, 2016; Singh et al., 2016; van Langen et al., 2016). This was done, for example, by summarizing the findings at the end of the interview or by checking field notes with the participant (Kidd et al., 2016; Paul, 2016; van Langen et al., 2016). Participants could also review and discuss preliminary findings as well as member checks with others who were not involved in the study, such as an advisory group of people or a subsample with experience of mental illness (Kidd et al., 2016; Singh et al., 2016).

Discussion
Synthesizing and critiquing research is of importance to evidence-based practice but also with regard to ethics when human research is performed (Fothergill & Lipp, 2014). Three crucial areas regarding methodology in qualitative interview studies with individuals with severe mental illness were critically reviewed, relating to ethics, data collection and data analysis. Regarding analysis of data, two themes were described: using previous experiences to understand the content in the material, and retaining the original meaning of statements through the analysis process, which indicates awareness about the importance of interpreting the participant’s responses in accordance with his or her intentions. Thus, the importance of obtaining in-depth knowledge from the perspective of individuals with experience of the investigated phenomenon, as mentioned by Mestdagh and Hansen (2014), is well described and taken care of in some of the studied articles, for example through descriptions of member checks and the use of an advisory group of people with experience of mental illness (Kidd et al., 2016; Singh et al., 2016). In addition, attaining and reporting trustworthiness in the findings can be assured by the detailed descriptions of the analysis process in qualitative studies involving individuals with schizophrenia and other psychotic conditions, as highlighted by Elo et al. (2014).

Nevertheless, descriptions of gatekeeping and how protective power could be used by healthcare staff to restrict rather than safeguard patients’ opportunities to obtain improved services (Witham, Beddow, & Haigh, 2015) are not evident in the findings. Hence, it is noteworthy that in nine of the 15 studies recruitment was performed by the healthcare staff or clinicians (Barut et al., 2016; Bjørkedal et al., 2016; Jones et al., 2016; Kidd et al., 2016; Landon et al., 2016; Paul, 2016; Rhodes et al., 2016; Singh et al., 2016; van Langen et al., 2016).

In one study, the authors stated that it was the participant’s physician who gave feedback to the researcher on the person's ability to provide informed consent, before the participant was even approached (Barut et al., 2016), and in another study participation was described briefly in the personal medical records (Bjørkedal et al., 2016). It is remarkable that these issues of power relations related to participation in research studies are not underlined, as it is of great importance that patients are given the opportunity to identify their own needs. Given the above, it seems plausible to argue that the research society needs to reflect upon implicit authority that may be built into healthcare organizations and affects who will be invited to take part in research and who will not. The lack of recognition regarding recruitment in qualitative studies is noticeable as it is often more challenging than expected and more significant than generally acknowledged (Kristensen & Ravn, 2015). One consideration is the need for careful reporting regarding how the selection process is conducted in qualitative studies involving individuals with severe and persistent mental illness such as schizophrenia and other psychotic conditions. Regarding ethical standards, it is worth mentioning that two of the reviewed studies, one from Denmark (Bjørkedal, Torsting, & Møller, 2016) and one from the Netherlands (van Langen et al., 2016), stated that they had consulted their ethical boards and no ethical approval was needed. This is true for many judgements from ethical boards when dealing with qualitative studies. However, our standpoint is that research involving people and their mental health issues is of a sensitive nature and should be subjected to ethical approval even if it is an interview study.

Furthermore, descriptions of how stigma regarding mental illness on different levels is handled to secure an
objective, fair and equal recruitment of participants are frequently absent. Likewise, discussions of trustworthiness of findings related to internal stigmatization and other issues leading to flaws in communication skills among participants are often missing, as are descriptions of strategies and actions undertaken to control these concerns. These issues raise questions about the need for pronounced ethics regarding sampling procedures and related trustworthiness in qualitative studies involving people with severe and persistent mental illness such as schizophrenia and other psychotic conditions. Further studies regarding sampling procedures are urgently required to ensure trustworthiness in research originating from interviews with individuals who are largely dependent on decisions made by healthcare staff to be able to participate in research studies. Studies are also needed on the preparation, organization and reporting phases in the analysis of collected data to ensure the trustworthiness of findings regarding interviews involving people with severe and persistent mental illness such as schizophrenia or other psychotic conditions.

Methodological strengths and limitations

This study used systematic searches to identify relevant articles. The selection criterion of publication date was initially broad. However, during the process, we recognized the need to focus and made a decision to include the most current research in the field, i.e., articles published during 2016. This strategy limited the number of articles that could have been of interest, but enabled us to be more critical. A limitation in this review is that not all included articles could be judged sufficiently owing to a lack of information. This may have affected how we presented and critiqued an article. However, if ethical or methodological issues are lacking or vague, this must be highlighted as a limitation in research.

Conclusion

Knowledge from the perspective of individuals with experience of mental illness is essential. Thus, research requires the involvement of people with severe mental illness who can best inform the study. The main contribution of this review is to raise awareness of the importance of describing the decisions made and actions undertaken to obtain a proper sample, and finding solutions to difficulties in communication related to mental illness as well as social vulnerability among the target group, owing to dependence of care as well as inequalities in power regarding decision-making. Reporting ethical considerations and issues regarding recruitment and sampling is necessary for trustworthiness in qualitative studies to address issues of appropriateness and adequacy. Qualitative studies involving people with severe and persistent mental illness such as schizophrenia is vital to counteract the stigmatization of mental illness and improve living conditions in the community for these people.

Disclosure statement

No potential conflict of interest was reported by the authors.

References

Albutt, H., & Masters, H. (2010). Ethnography and the ethics of undertaking research in different mental healthcare settings. *Journal of Psychiatric and Mental Health Nursing*, 17(4), 210–215. doi:10.1111/j.1365-2850.2009.01493.x

Barut, J. K., Dietrich, M. S., Zanoni, P. A., & Ridner, S. H. (2016). Sense of belonging and hope in the lives of persons with schizophrenia. *Archives of Psychiatric Nursing*, 30(2), 178–184. doi:10.1016/j.apnu.2015.08.009

Bjerkedal, S. T. B., Torsting, A. M. B., & Møller, T. (2016). Rewarding yet demanding: Client perspectives on enabling occupations during early stages of recovery from schizophrenia. *Scandinavian Journal of Occupational Therapy*, 23(2), 97–106. doi:10.3109/11038128.2015.1082624

Blixen, C. E., Kanuch, S., Perzynski, A. T., Thomas, C., Dawson, N. V., & Sajatovic, M. (2016). Barriers to self-management of serious mental illness and diabetes. *American Journal of Health Behavior*, 40(2), 194–204. doi:10.5993/AJHB.40.2.4

Burke, E., Wood, L., Zabel, E., Clark, A., & Morrison, A. P. (2016). Experiences of stigma in psychosis: A qualitative analysis of service users’ perspectives. *Psychosis: Psychological, Social and Integrative Approaches*, 8(2), 130–142. doi:10.1080/17522439.2015.1115541

Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology: Science and Practice*, 7, 48–67. doi:10.1093/cpips/7.1.48

de Jager, A., Rhodes, P., Beavan, V., Holmes, D., McCabe, K., Thomas, N., … Hayward, M. (2016). Investigating the lived experience of recovery in people who hear voices. *Qualitative Health Research*, 26(10), 1409–1423. doi:10.1177/1049732315581602

Elo, S., Kääriäinen, M., Kanste, O., Pölkkö, T., Utirainen, K., & Kyngäs, H. (2014, January–March). Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, 1, 1–10. doi:10.1177/2158244014522633

Fothergill, A., & Lipp, A. (2014). A guide to critiquing a research paper on clinical supervision: Enhancing skills for practice. *Journal of Psychiatric and Mental Health Nursing*, 21, 834–840. doi:10.1111/jpm.12161

Graneheim, U.H, & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105–112. doi:10.1016/j.nedt.2003.10.001

Grant, C. (2015). The experiences of research participants living with schizophrenia. *Social Work in Mental Health*, 13(6), 332–552. doi:10.1080/15332985.2014984887

Hansson, L., Jormfeldt, H., Svedberg, P., & Svensson, B. (2011). Mental health professionals’ attitudes towards people with mental illness – Do they differ from attitudes held by people with mental illness? *International Journal of Social Psychiatry*. doi:10.1177/0001145211423176
*Jones, N., Shattell, M., Kelly, T., Brown, R., Robinson, L., Renfro, R. ... Luhmann, T. M. (2016). "Did I push myself over the edge?": Complications of agency in psychosis onset and development. Psychosis: Psychological, Social and Integrative Approaches, 8(4), 324–335. doi:10.1080/17522439.2016.1150501

Kars, M. C., van Thiel, G. J. M. W., van der Graaf, R., Moors, M., de Graeff, A., & van Delden, J. J. M. (2016). A systematic review of reasons for gatekeeping in palliative care research. Palliative Medicine, 30(6), 533–548. doi:10.1177/0269216315616759

*Kidd, S. A., Frederick, T., Tarasoff, L. A., Virdee, G., Lurie, S., Davidson, L. ... McKenzie, K. (2016). Locating community among people with schizophrenia living in a diverse urban environment. American Journal of Psychiatric Rehabilitation, 19(2), 103–121. doi:10.1080/15487768.2016.1162757

Koivisto, K., Janhonen, S., Latvala, E., & Väisänen, L. (2001). Applying ethical guidelines in nursing research on people with mental illness. Nursing Ethics, 8(4), 328–339. doi:10.1177/096973300100800405

Kristensen, G. K., & Ravn, M. N. (2015). The voices heard and the voices silenced: Recruitment processes in qualitative interview studies. Qualitative Research, 15(6), 722–737. doi:10.1177/1468794114567496

*Landon, J., Shepherd, D., McGarry, M., Theadom, A., & Miller, R. (2016). When it’s quiet, it’s nice: Noise sensitivity in schizophrenia. American Journal of Psychiatric Rehabilitation, 19(2), 122–135. doi:10.1080/15487768.2016.1162758

Mestdagh, A., & Hansen, B. (2014). Stigma in patients with schizophrenia receiving community mental health care: A review of qualitative studies. Social Psychiatry and Psychiatric Epidemiology, 49(1), 79–87. doi:10.1007/s00127-013-0729-4

*Paul, S. (2016). Responses to stigma-related stressors: A qualitative inquiry into the lives of people living with schizophrenia in India. International Journal of Culture and Mental Health, 9(3), 261–277. doi:10.1080/17542863.2016.1185134

Rhodes, J. E., Parrett, N. S., & Mason, O. J. (2016). A qualitative study of refugees with psychotic symptoms. Psychosis: Psychological, Social and Integrative Approaches, 8(1), 1–11. doi:10.1080/17522439.2015.1045547

*Saaavedra, J., López, M., González, S., & Cubero, R. (2016). Does employment promote recovery? Meanings from work experience in people diagnosed with serious mental illness. Culture, Medicine and Psychiatry, 40(3), 507–532. doi:10.1007/s11013-015-9481-4

SFS 2003:460 (2003). Law on ethics testing of human-related research. Stockholm: Social Department. Retrieved from https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningsamling/lag-2003460-om-etikprovning-av-forskning-som_sfs-2003-460

Singh, N. S., Jalkhaia, N., Amonashvili, N., & Winch, P. J. (2016). “Finding a way out”: Case histories of mental health care-seeking and recovery among long-term internally displaced persons in Georgia. Transcultural Psychiatry, 53(2), 234–256. doi:10.1177/1363461515618813

*Topor, A., Ljungqvist, I., & Strandberg, E.-L. (2016). The costs of friendship: Severe mental illness, poverty and social isolation. Psychosis: Psychological, Social and Integrative Approaches, 8(4), 336–345. doi:10.1080/17522439.2016.1167947

*van Langen, W. J. M., Beentjes, T. A. A., van Gaal, B. G. I., der Sanden, M. W. G. N.-v., & Goossens, P. J. J. (2016). How the illness management and recovery program enhanced recovery of persons with schizophrenia and other psychotic disorders: A qualitative study. Archives of Psychiatric Nursing, 30(5), 552–557. doi:10.1016/j.apnu.2016.04.005

*Waite, F., Evans, N., Myers, E., Startup, H., Lister, R., Harvey, A. G., & Freeman, D. (2016). The patient experience of sleep problems and their treatment in the context of current delusions and hallucinations. Psychology and Psychotherapy: Theory, Research and Practice, 89(2), 181–193. doi:10.1111/papt.12073

Witham, G., Beddow, A., & Haigh, C. (2015). Reflections on access: Too vulnerable to research? Journal of Research in Nursing, 20(1), 28–37. doi:10.1177/1744987113499338

World Medical Association. (2013). World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects. JAMA, 310, 2191–2194. doi:10.1001/jama.2013.281053

*Reviewed articles included in the Results section.