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Qualitative Research on the Topic of End-of-Life Care and a Palliative Care Approach in Persons with Severe and Persistent Mental Illness: Reflections and Take-Home Messages

ABSTRACT

Persons experiencing severe and persistent mental illness (SPMI) constitute a small but vulnerable population in healthcare and society. Nonetheless, it is advocated to involve people with SPMI in research to improve how care is provided to them. However, qualitative research with this population is challenging due to several factors, including (self-) stigma, assessment of decision-making capacity, reduced communication skills, and the (perceived) risk of adverse events, resulting in relative scarcity in academic interest and scientific publications.

In this contribution, the authors share their practical experiences in conducting qualitative research among this group of people, specifically focusing on sensitive topics including end-of-life care and palliative care approaches. Both beneficial and challenging factors encountered across the different research stages are systematically delineated and reflected upon.

Qualitative research involving persons with SPMI necessitates a different perspective on methodology and requires specific competencies from researchers. As might be expected, adequate preparation, thorough follow-up, and support for all involved are critical success factors. Additionally, however, it may also require adopting a somewhat unconventional approach to qualitative interviewing, encouraging creativity and ethical reflection as guiding principles. Exploring alternative methodologies and non-conventional engagement in research could provide a much-needed voice to individuals who are currently unrepresented in the research discourse.

Keywords: Severe and persistent mental illness, qualitative interviewing, palliative care approach, end-of-life care

Introduction

Persons with severe and persistent mental illnesses (SPMI) constitute a small, vulnerable group within society and the healthcare system. Although there is no consensus definition around "SPMI," it is characterized by 3 elements: disease, duration, and disability.[1] Common diagnoses include schizoaffective disorder, bipolar disorder, or major depression; often, these people have a dual or triple diagnosis, resulting in a long course of illness and numerous problems in their social lives. Generally, these individuals have a limited social network and experience numerous admissions to mental healthcare facilities and treatments that have no lasting positive impact on their quality of life. Their life expectancy is significantly lower as a result of side effects of medication, poor lifestyle, suicide risk, difficult access to specialized care, etc.[2] Lately, there has been increased attention to care for people with SPMI, particularly expanding palliative psychiatry and integrating palliative care principles into these people's treatment.[3-5]

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Similar to other vulnerable groups, their inclusion in scientific research is difficult, especially when qualitative research is involved. There are several reasons for this: persons with SPMI are not always able to communicate fluently (verbally), doubts occur regarding their decision-making skills (and thus their ability to give informed consent), and certain negative perceptions or even stigma are present among researchers regarding possible aggressive or 'difficult' behavior.[6,7]

As caregivers and researchers, we recognize the importance of amplifying the voices of vulnerable populations by providing agency to those directly impacted by the subject of research. In the context of our studies regarding end-of-life care and palliative care approaches in Flanders, Belgium, we have adopted an inclusive approach, considering not only the perspectives of healthcare providers, families, and policy stakeholders but also those of people directly affected by palliative care approaches and end-of-life care decisions.

In doing so, we aspire to contribute to the ongoing dialogue surrounding palliative care approaches and end-of-life care practices, while simultaneously committing to elevate the voices of those who are often overlooked. We noticed that there was little literature available that could provide guidance on how qualitative research could be done with this target group or how it was even discouraged in several studies for the reasons mentioned above.[8] Therefore, we would like to give readers an insight into our experience of conducting an interview study with persons with SPMI, indicate the difficulties we encountered, and offer advice to future researchers. It may be that qualitative research with this target group cannot always be conducted in a completely conventional way and that researchers need to be creative and flexible to "get the job done."

However, we are convinced that qualitative research with persons suffering from SPMI is not only feasible but even imperative, and that our findings may be applicable in other international contexts or even with other vulnerable populations.

Short Description of the Research

The second and third authors conducted seventy in-depth interviews with persons experiencing SPMI in Belgium, aimed at capturing their perspectives and experiences concerning Oyster Care—a palliative care approach in mental healthcare (N = 16); end-of-life care, including palliative care (N = 19); and euthanasia (N = 35). Besides care-users, caregivers, managers, and family members or loved ones were also interviewed in each study. These interviews were undertaken between 2017 and 2023 in the Flemish-speaking region of Belgium. The first author was involved in preparing the research and analysis. All authors have experience with the target group, either from their educational background or as professionals. Each of the 3 studies was conducted within the framework of a research group that included experts in mental health and end-of-life care and with the approval of central and local ethics committees. The results of our research are published elsewhere.[9,10] In summary, our study provides a good idea of the lived experiences of care actors involved in caring for persons with SPMI in coping with end-of-life issues. We identified good practices and limiting factors and made recommendations toward care and key stakeholders. Definite approval was obtained from the Medical Ethics Committee of the Vrije Universiteit Brussel (VUB) with reference B.U.N. 143201628847. Additionally, approval was obtained from the Medical Ethics Committee of the Brussels University Hospital with reference BUN 143201939499, from the Medical Ethics Committee of Ghent University Hospital with reference 2019/0456, and from the Medical Ethics Committee of the Brothers of Charity with reference OG054-2019-20.

In terms of research methodology, a semi-structured, in-depth interview approach was employed, guided by a set of research questions and a topic list with corresponding prompts. All interviews were conducted at a single point in time.

The primary research questions addressed in our study, focusing on psychiatric care and end-of-life care, were as follows:

- How do participants perceive their past, present, and future psychiatric trajectories? What type of care do they wish to receive in the event of a life-threatening illness? What aspects of their care have been successful, and what areas require improvement? What are the sources of strength that give their lives meaning? What existential needs and desires do they have? How do they describe the impact of their psychiatric experiences on their mental state and social relationships?

In the specific context of euthanasia, additional research questions included*:*

How do participants describe the nature and extent of their suffering? What motives do they have for requesting euthanasia, how does this relate to suicide, and what factors might prevent them from considering a hastened death? How do they describe the impact of the euthanasia procedure on their mental state, clinical trajectory, and social relationships? Regarding the theoretical framework, when a topic is being explored for the first time, qualitative research designs often precede quantitative ones. This is because qualitative research is better suited to provide a comprehensive understanding of new topics, offering deeper insights into human mental states and behaviors that quantitative methods cannot match. By focusing on not just what participants think and feel, but also on how they articulate these thoughts and feelings, qualitative research allows for the unraveling of complex issues from first-hand perspectives.

Our research was grounded in the framework of "critical social constructionism" as proposed by Berger and Luckmann.[11] This approach offers a nuanced perspective that diverges from acknowledging an objective reality, instead examining the interplay of personal, social, and societal dimensions within the studied phenomena. This necessitates an acknowledgment of the layered complexities influencing our understanding.

The data interpretation was influenced by social constructionism, recognizing the role of internalized societal norms in shaping personal perceptions of reality over time. Furthermore, we adopted a contextualist epistemology as described by Braun and Clarke,[12]

MAIN POINTS

- *Qualitative research in persons with severe and persistent mental illnesses (SPMI) requires an out-of-the-box approach.*
- *Vulnerable populations, like persons with SPMI, should be given a voice in academic research.*
- *Further research into how to include the most vulnerable in academic research is needed*

acknowledging the contextual influences on knowledge formation among researchers and participants. This methodological approach aimed to capture diverse lived experiences and perspectives, including varied attitudes toward end-of-life care based on specific relationships with clinicians, other caregivers, family members, friends, and peers. Consequently, a reflexive stance was maintained regarding the potential impact of the researchers' individual experiences and identities on their analyses and interpretations.

Our Experiences: the Good, the Bad, and the Unforeseen

When we started our research effort, our main objective was to adhere to ”state-of-the-art” methodologies, driven by the determination of rigorous work in our endeavors.

At the same time, based on our collective experiences as a nurse, psychologist, and care ethicist working directly with the target population, we recognized the need for increased sensitivity and creativity to engage with this population in a research context. Through collaborative dialogue with the broader research group and learning from existing literature, it became clear that interviews with persons with SPMI required a distinct approach to ensure comprehensive and insightful data collection.

Firstly, it was decided to have the interviews conducted by individuals who had experience both in qualitative research and in working with individuals with SPMI; thereby facilitating tailored communication towards the target group. We also chose to make the vocabulary of our questions in our interview guides as simple as possible and to limit the number of questions, avoiding unnecessary participant burden.

The study was submitted to the central ethics committees, as well as to the local ethics committees associated with the organizations that had agreed to participate in the study. In 2 of the 3 studies, this step presented no significant obstacles, but in the euthanasia study, additional questions of due diligence were raised. Members of the central ethics committee believed that research on this topic could potentially increase suicidal risk and therefore asked for additional safeguards toward follow-up of the participants, which we did.

Working with the usual information and consent forms (ICF), we, as researchers ran into a major hurdle with this target group: a subgroup hesitated to sign these papers, often prompted by negative experiences with signing (legal) documents in the past. It was also noticeable that several participants, in contrast to most participants in qualitative research, asked very pointed questions about certain terms in the documents, such as “palliative” or the “Declaration of Helsinki.” The researchers thus had to allocate sufficient time to properly explain the documents and thoroughly explain the benefits and risks of the study. However, some participants were only willing to give verbal agreement, which was recorded. We realized that the legal basis here is ambiguous, leading to decisions in certain instances to forego the interview process or, in the case of individuals who really wanted to share their story, not to use the interview for data analysis. Involvement of a legal representative and adequate advance notice of the potential participant regarding the research design by the local gatekeepers are factors that could contribute to a balanced informed consent procedure.

The researchers always felt safe while conducting the interviews. They had experience with the target group and had a very realistic, open-minded, and positive attitude towards them. The researchers' expertise also instilled confidence among the participating facilities in the ethically sound execution of the study.

Participants for the study were selected via gatekeepers, based on the criteria provided by the researchers. In all cases, this gatekeeper was a physician, ward manager, or therapist affiliated with a care unit specializing in the care of individuals with SPMI. Working with gatekeepers facilitated the study, e.g., with regard to building relations of trust and facilitating the practical execution of the interviews. However, this also did present a risk of potential bias: would gatekeepers possibly not include persons with the greatest vulnerability or with certain negative views around the care provided? In our experience, the above is partially true: a certain subgroup of the least verbally strong individuals with SPMI was not reached, yet participants regularly related to care very critically.

The interviews always took place in the environment chosen by the participants. Although most participants chose to be interviewed in a private room, some participants preferred a more public space, such as the communal living room. Given the home-replacement context that the ward provides for many of these individuals, we respected the person's preferences. Additionally, we offered the participant the option of having a trustee present at the interview. Notably, when this occurred, each time a caregiver was chosen. This partly underlines the fact that many persons with SPMI have little involved family, and caregivers often act as proxy family for these people.

Involving trustees or continuing an interview in a semi-public space created specific dynamics researchers had to creatively and flexibly relate to. On the one hand, it opens up the possibility of bias and interjection, but on the other, it opens up the possibility of engaging with people on topics that are otherwise not accessible. For instance, the fragment illustrates the dynamics going on between the interviewer, patient, and caregiver/trustee:

Interviewer: “And do you have good contact with your parents?”

Patient: “Yes, I do, yes, because I see them every week and we email each other every day.”

Caregiver/trustee: “But can you talk to your parents about anything?”

Patient: “No, unfortunately not, like with that wish for euthanasia, both Mom and Dad don't want to hear about that, so that's hard though. Allez, not only Mom and Dad, the whole family doesn't want to hear about it. But I'm still working on it, so much so that it's a disappointment to wake up the next day. It's always like that…”

The duration of the interviews proved to be remarkably variable, showing the rich diversity in the interview population. Some interviews lasted very short (25 minutes) because some participants responded little or not at all to open questions or requests for clarification. Often, participants interrupted the interviews in favor of, for example, meals or a coffee break. In contrast, the extended interviews (over 2 hours) were distinctive, occasionally presenting challenges in adhering to posed questions and stemming from the intricacy of participants' narratives, rich in detail. However, in most instances, these prolonged sessions resulted from the participants' opportunities to share their experiences, thoughts, or emotions candidly and expansively, without any restraint.

Throughout their education, the interviewers had learned various interview techniques to enhance interview flow, such as using "humming" to maintain the interview's rhythm or employing paraphrasing signaling comprehension to the interviewee. While these techniques are commonly endorsed, our interviews revealed discrepancies: the use of "humming" did not appear efficient, and the practice of paraphrasing interviewee responses proved ineffective, as participants preferred verbatim repetition of their words. Despite efforts to avoid closed questions, researchers encountered participants' tendencies toward brief or repetitive answers, potentially leading to a shift toward closed questioning. Tailoring open-ended inquiries to participants' interests elicited more comprehensive responses, fostering deeper understanding. As rapport between interviewers and participants strengthened, individuals shared nuanced information, enriching the research. Some participants introduced unique terms or logic, challenging the interviewers' comprehension. However, ongoing dialogue allowed the researchers to identify patterns within these linguistic nuances, aiding in effective interpretation. One participant chose to formulate responses on paper before engaging in verbal discourse.

Attentiveness to non-verbal cues held paramount significance during the interviews, especially with those individuals with limited verbal or intellectual capacities. Non-verbal cues served as crucial channels of communication, complementing verbal expressions, and providing nuanced insights into the emotional and psychological states of individuals struggling to articulate their thoughts and feelings verbally. Moreover, these cues played a pivotal role in establishing trust and ensuring the patient's safety, allowing interviewers to create a supportive environment that respected the individual's boundaries and encouraged open communication. For instance, some patients disclosed experiencing "dissociation episodes" or "hearing voices" before the interview began. They guided the interviewer by expressing: "If you notice any signs of distraction in me, would you kindly inquire if I require medication?" This proactive approach aimed to prompt self-assessment of their mental state or enable joint action, like visiting the nurses' office for a medicine check-up, which ultimately turned out not to be necessary.

Regarding departures from the study's strict boundaries, reflection centered on exclusion criteria outlined in the ICF, particularly concerning acute symptoms of grief and substance abuse. These criteria were initially deemed crucial as they might diminish an individual's mental competence to fully comprehend and appropriately sign the ICF, and to ensure the safety of all those involved. Despite these exclusions, however, certain interviews were conducted with individuals experiencing acute symptoms, e.g., grief for a lost family member. The interviewer acknowledged these symptoms, yet the interviewees themselves encouraged the continuation of the interview, emphasizing its significance for their well-being and preventing persistent feelings of guilt or grief. These interactions resulted in positive outcomes as interviewees openly guided discussions on managing specific circumstances and pathological features.

Gratitude was always expressed to participants for their involvement, reciprocated by many participants expressing thanks to the researcher for engaging with them. A profound sense of gratitude emerged from sharing personal stories. Participants believed that by sharing their experiences, they actively contributed to advancing scientific knowledge and extending support to others encountering similar challenges. As one interviewee told us: "Don't mind that it took longer. I expected that and it's gratifying to be able to tell my story for once. Hopefully it can help other people."

The expressions of gratitude portrayed a depth of connection resulting from direct conversations with the interviewers, contrasting with what they often perceived as "mere conversations about them" in their daily lives. These gestures of gratitude were intriguing, as they reflected aspects from the participants' daily lives holding personal significance, surpassing conventional forms of appreciation; ranging from cards and poems to artwork.

As a research team, we sought to develop a coaching framework for interviewers. We facilitated debriefing sessions after each interview, either live or remote, discussing both positive and potentially negative experiences and adapting our approach if necessary. Moreover, we ensured that at least one team member was always available by phone during interviews, enabling researchers to seek support, ask questions, and receive feedback.

As researchers, we were mindful of the potential emotional impact on participants. In residential care settings, participants had access to the care team, which was informed about the conversations and research themes. In outpatient contexts, providing aftercare was more challenging. Researchers shared contact information and could refer participants to their primary care physician or regular practitioner if needed. Additionally, a team member with expertise in healthcare delivery was available by phone as a resource for researchers in emergencies.

Conclusion and Take Home Messages

Conducting qualitative research among persons with SPMI poses specific challenges to researchers. It is important that even the most vulnerable people have a voice in scientific research and that researchers are not deterred by stigma and prejudice. We found many people willing to engage in conversation even on sensitive topics such as end-of-life and palliative care.

To make the research rigorous and ethically sound, one needs to prepare well, work with healthcare organizations and ethics committees, be flexible, and perhaps sometimes dare to "think outside the box." We recommend: employing experienced researchers (both in the field of qualitative interview techniques as well as with mental health services); collaborating with local gatekeepers and seeing how selection bias can be mitigated; putting participants at ease by providing tailor-made information; choosing an appropriate location for the interview; including trustees; paying attention to non-verbal responses during interviews and building a certain level of trust with the participant. This requires creativity and adaptability on the part of researchers, with regard to anticipating suspicion around signing information and consent documents, or suddenly shifting interview dates due to crises or emotional fluctuations.

It is important to mention that all interviews were conducted safely and that researchers experienced much gratitude, both from the participants themselves and from their caregiving context. As a research team, we felt it was important to be easily accessible to each other and to be accessible to our participants.

As researchers, we also reflect on the fact that we were not able to give each person with SPMI a voice. Some persons turned out to be too seriously ill to allow conversation. We therefore advocate for further research into nonverbal ways of conducting research with vulnerable populations and the importance of field research. Even though we realize that our study and its description in this essay have several limitations, we hope it encourages researchers to give qualitative research with persons with SPMI and other vulnerable populations a chance, sharing their experiences.

Availability of Data and Materials: *All data generated or analyzed during this study are included in the article.*

Ethics Committee Approval: *Definite approval was obtained from the Medical Ethics Committee of the Vrije Universiteit Brussel (VUB) with reference B.U.N. 143201628847. Additionally, approval was obtained from the Medical Ethics Committee of the Brussels University Hospital with reference BUN 143201939499, from the Medical Ethics Committee of Ghent University Hospital with reference 2019/0456, and from the Medical Ethics Committee of the Brothers of Charity with reference OG054-2019-20.*

Informed Consent: *Written informed consent was obtained from the patients who agreed to take part in the study.*

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