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How to engage people experiencing severe and persistent mental illness in qualitative research: a descriptive and reflexive analysis

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ABSTRACT

Purpose: People experiencing severe and persistent mental illness (SPMI) constitute a vulnerable population within the healthcare system and society. Similarly in research, there are perceived challenges in qualitative studies with this population due to several factors, including (self-)stigma, assessment of decision-making capacity, reduced communication skills and the (perceived) risk of adverse events, resulting in its scarcity.

Methods: In this contribution, the authors share their practical experiences of conducting qualitative research among this group of people, specifically addressing sensitive topics such as ongoing intensive care within a mental health facility and end-of-life care. Both advantageous and challenging factors that were encountered during different research phases—the preliminary phase, conducting the interviews and the concluding phase are systematically outlined.

Results: The findings highlight conscientious conducted in accordance with established standards, albeit with a deliberate embrace of non-conventional approaches while advocating an attitude of critical, ethical reflection. Adequate preparation, fostering creative approaches and adaptable communication to establish rapport and authentic interaction, thorough follow-up and support for all involved are equally crucial to sustain effective qualitative research.

Conclusion: Engaging people experiencing SPMI in research is as a cornerstone for empowerment—a feasible aspiration. Their inclusion in research endeavours is imperative, because first-hand narratives are key in shaping comprehensive and compassionate care practices for those experiencing severe and persistent mental illness.

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Introduction

Contemporary mental health care emphasize deinstitutionalization, social reintegration of patients and outpatient treatment. In Belgium, ongoing mental health reforms prioritize reducing residential admissions and reallocating financial resources to community care (Mistiaen et al., 2019). Despite these strides, some people face resocialization challenges and instead are in need of long-term and intensive treatment. This is particularly relevant for those experiencing severe and persistent mental illness (SPMI). Globally, an estimated 1% of the population lives with SPMI and is facing a striking reality of reduced life expectancy, up to 15 years shorter than the general population, primarily due to severe co-occurring somatic conditions (James et al., 2018; Oakley et al., 2018; Plana-Ripoll et al., 2020; Trachsel et al., 2016). Nevertheless, defining SPMI remains a contentious topic within mental health care and the prevalence of SPMI varies based on e.g., diagnostic criteria and geographic regions. Consensus is growing around fundamental components, in particular the 3D criteria—diagnosis, disability, and duration (Zumstein & Riese, 2020).

Accordingly, SPMI encompasses enduring and disabling mental health conditions, such as refractory

schizophrenia, treatment-resistant depression and severe bipolar disorder (Woods et al., 2008; Zumstein & Riese, 2020). This spectrum includes a substantial subgroup of people experiencing multiple concurrent disorders, posing complex challenges in terms of diagnosis, therapy and long-term management (James et al., 2018). Despite the diverse range of co-occurring diagnoses, a common thread remains: symptoms persist despite evidence-based treatments, resulting in severe impairments in daily functioning and a compromised quality of life (Zumstein & Riese, 2020). The complexities inherent in coping with SPMI underscores the pressing need for a nuanced understanding of navigating persistent and challenging mental health conditions, tailored interventions and long-term and intensive support for these people.

In Belgium, the “Oyster Care” model has emerged as an innovative approach in psychiatry tailored to people experiencing SPMI. The model is inspired by the philosophy of palliative care, focusing on quality of life and implementing a far-reaching holistic and originative approach (Decorte et al., 2020). This model focuses on creating a protective “shell” around a persons, as a metaphor for the external environmental support

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needed to experience quality of life, recognizing that full recovery or reintegration may not be attainable. Furthermore, Oyster Care addresses some of the difficulties encountered by individuals considering euthanasia when traditional treatments prove ineffective. Since the legalization of euthanasia in Belgium in 2002, there has been an increase in the number of euthanasia requests, including from individuals experiencing mental disorders. Nevertheless, recent statistics show a stabilization trend, with approximately 25 reported cases associated with SPMI in recent years, representing less than 1% of all reported euthanasia deaths (Federal Control and Evaluation Committee for Euthanasia, FCECE, 2020, 2022).

Recognizing the added value of palliative care approaches such as Oyster Care and other forms of end-of-life care in meeting the nuanced needs of people experiencing SPMI is essential for improving overall care provision. The recent integration of these aspects into mental healthcare highlights the need for additional research on how to effectively support this population within these care approaches. Moreover, the inclusion of people experiencing SPMI in research efforts overall is of high significance. Embedding their lived experiences can tailor interventions and enhance their involvement in the research process, effectively countering prevailing stigma while simultaneously bolstering the validity of research findings (Palinkas, 2014). Nonetheless, their inclusion in qualitative research raises ethical considerations, potential distress and communication issues that serve as barriers; emphasizing the need for well-defined protocols regarding participant eligibility, prevention of adverse events and effective management (Carlsson et al., 2017; de Koning et al., 2021).

This article presents a descriptive and reflexive inquiry based on the authors' experience of conducting in-depth interviews with people experiencing SPMI, exploring their perspectives on sensitive topics—such as the Oyster Care model, end-of-life care and euthanasia—to bridge gaps in research and ethical guidance. The article highlights conscientious efforts conducted in accordance with established standards, albeit with a deliberate embrace of non-conventional approaches while advocating an attitude of critical, ethical reflection. Furthermore, the article encourages critical evaluations of effective strategies and possible challenges in involving this population in research, while providing additional insights to enhance research engagement with people experiencing severe and persistent mental illness.

Methodology

This descriptive and reflexive research article is grounded in three individual studies each using a qualitative research paradigm. The three studies explored the lived experiences and perspectives of people experiencing SPMI on three topics: Oyster

Care (study 1), end-of-life care (study 2) and euthanasia (study 3). The findings from these studies have been published (regarding study 3, see Verhofstadt, 2022) or are forthcoming.

The original studies

Data for study 1 were primarily collected by the first author and data for studies 2 and 3 mainly by the last author. A total 70 in-depth interviews were completed (study 1 $N=16$; study 2 $N=19$; study 3 $N=35$) between 2017 and 2023. The studies used gatekeepers to recruit participants through purposive sampling, aiming to include individuals who were 18 years or older, proficient in Dutch (Flemish-speaking region of Belgium) and experienced severe and persistent mental illness. Additional criteria were:

- For the Oyster Care study, participants were admitted to a residential facility where Oyster Care was implemented as treatment.
- For the euthanasia study, the euthanasia request had to have been made within three years prior to the interview studies. Here, the definition of SPMI was stretched in content, as few of the euthanasia requesters were patients in a psychiatric residential facility; most were treated in a non-residential setting, although all suffered from severe psychiatric illnesses. The majority still had to undergo the euthanasia assessment phase to evaluate the criteria of irremediableness and non-alleviability of the suffering.

In all studies, a semi-structured interview guide with open-ended questions was used with a predefined interview duration of 45 minutes. The interview guides were developed by a panel of professional experts and further refined through pilot interviews. Instances where one interviewer worked in a particular setting, the respective participant was interviewed by another researcher. However, participants were informed that the transcripts would be reviewed by all researchers. Participants could involve a trustee in the interview who could provide emotional support or help them articulate their thoughts, experiences and needs. All data were transcribed, coded using NVivo and analysed according to a thematic analysis (Braun & Clarke, 2006). The analyses were conducted independently by at least two of the researchers. The results were then discussed at regular meetings with the broader research group, where different perspectives and insights were embedded to ensure the validity of the findings. The members of the research group varied depending on the study, but consistently included a mix of individuals with academic backgrounds and/or practical experience in engaging with people experiencing SPMI.

A descriptive and reflexive analysis

With their expertise in psychiatric nursing, ethics and clinical psychology, the authors of the original studies recognize the importance of first-hand narratives in shaping comprehensive and compassionate care practices for people experiencing severe and persistent mental illness. At the heart of their approach lies the guiding principle: “nothing about them, without them”. However, when engaging with people experiencing SPMI they found that existing “how-to” interview guides and principles were not necessarily suitable for gaining a deep understanding of the research topic. This experience bound the three authors together to describe their experiences, conduct a reflective analysis and disseminate their insights to others interested in similar research efforts. Regular discussions led to the identification of three main themes, each reflecting a different stage in the research process. Each theme provides a detailed account of participants’ and researchers’ first-hand experiences and responses to engaging in dialogue. Additionally, specific anonymized transcribed interview excerpts are included in the text for illustrative purposes.

A reflexive methodology in practice

Regarding the methodological framework, the “bracketing approach” was distinguished as essential. This method necessitates researchers to acknowledge and examine their pre-existing understandings while presenting an interpretive account of the participant’s world (Corby et al., 2015). In the studies, it was crucial to remain sensitive to the participants’ voices as they offered the primary understanding of the phenomenon through their experiences, descriptions, interpretations and meanings. Concerning analysis, personal reflexivity relates to how the researcher’s own background and history might have impacted the findings. To validate credibility, reflective checks with other members of the research team were undertaken (Beail & Williams, 2014).

The studies involved a group of people who are particularly vulnerable due to their severe psychiatric conditions and, especially in the case of the euthanasia study, their experiences with death ideation and death-seeking behaviour. Therefore, the researchers maintained a consistent reflexive stance during the qualitative in-depth interview process, acknowledging and documenting their preconceptions, biases and emotional responses both during and after interactions with the participants. The second author, proficient in medical ethics, took a supervisory role and ensured strict adherence to ethical guidelines throughout the research process. This expertise was critical to carefully navigate the complexities of

discussing sensitive issues with people experiencing SPMI. Incorporating monthly reflexive sessions with the broader research team into the research framework proved instrumental in meeting the ethical principles of research in all three studies. By including diverse perspectives in promoting ethical conduct and facilitating reflexive practice, these sessions enriched the research process and contributed to the generating robust, ethically sound findings. All ethical considerations were imbued with a reflexive approach that emphasized safeguarding participants’ autonomy, strictly maintaining confidentiality and prioritizing their well-being throughout the study.

For this descriptive and reflexive inquiry, scheduled sessions facilitated critical reflections on the relevance of the research paradigm, approaches to engaging participant, data collection methods and ethical considerations. This methodology prioritized navigating researchers’ backgrounds, ethical complexities and the need for transparency and reflexivity when exploring deeply personal aspects related to long-term residential Oyster Care, end-of-life care and euthanasia among people experiencing severe and persistent mental illness.

Ethics

All three studies were approved by an Ethics Committee. Study 1, the Oyster Care study, was approved by the Medical Ethics Committee of the Vrije Universiteit Brussel (VUB) approval no. EC-2021-322. Study 2, the end-of-life care study, was approved by the Research Ethics Committee UZ/KU Leuven approval no. B3222021000688. Regarding the euthanasia study, study 3, provisional ethical approval was obtained from the Ethics Review Board (ERB) on Research (cETO) of the Open University with reference U2016/03311/FRO (pending approval by a Belgian ERB). 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 143,201,939,499, 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. All participants provided written and/or verbal consent prior to enrolment in the study.

Results

The results are structured around the sequential phases of a research process: 1) the preliminary phase, 2) conducting the interviews and 3) the concluding phase. Each phase includes ethical considerations and challenges faced at that stage, in addition to

a detailed description of the methodological and data collection approaches employed, given that conventional methods of engaging this population in scientific research may prove insufficient.

The preliminary phase

The researchers anticipated challenges from **ethics committees** in obtaining approval for their study, given its focus on a vulnerable population and sensitive topics. Despite initial concerns, they found that adopting a constructive attitude towards ethical considerations facilitated the approval process. This highlights the importance of proactive engagement and a commitment to ethical principles when conducting sensitive research. For example, to mitigate potential discomfort for participants the researchers implemented additional safety measures. In obtaining approval from Medical Ethics Committees (MEC), the study on Oyster Care and end-of-life care did not encounter significant obstacles. Extra caution and additional care characterized research involving euthanasia-related studies. Proactively, the primary researcher and their lead supervisors met with the relevant MEC to present the research and discuss concerns with regard to potential adverse events on participants, such as exacerbating thoughts on mortality or self-harm behaviours.

The **selection of researchers** with a healthcare background and practical experience had a number of advantages. Their employment not only eased access to healthcare organizations, but also fostered a deeper understanding of the participants' lived experiences. For example, one benefit lies in establishing communication and maintaining a conversation with the participant. This relates to sensing the need to adapt one's own communication style to the individual's level of understanding, navigating through different levels of communication, while also being prepared for and knowing how to probe seemingly unusual expressions. Another advantage of working with researchers well versed in caring for people experiencing SPMI is their ability to adapt the **interview guide** to the specifics of the population. Moreover, the interview questions were validated by other experts and refined through pilot interviews. A semi-structured approach was adopted to allow participants to introduce other issues of relevance. To enhance comprehensibility, questions were asked in simple language and the number of questions was minimized to reduce unnecessary burden on participants.

The studies used **gatekeepers** to recruit participants. In all cases, the gatekeeper was a physician, ward manager, or therapist affiliated with a healthcare unit specialized in the care of people experiencing SPMI. During the recruitment process, the researchers communicated the desired characteristics of those to be approached, as certain settings encompassed

a broader spectrum than just people experiencing SPMI. These dialogues served the dual purpose of clarifying the specific characteristics of the target population and highlighting the crucial role of gatekeepers in providing these individuals with the necessary support to make informed choices about whether or not to participate in the study. The researchers ensured that the selection of participants was not biased in favour of those who were most articulate or had positive experiences of treatment and care. Despite using a qualitative research methodology, efforts were made to include a diverse range of voices and certainly those of the hardest-to-reach, for example people with impaired verbal ability, lower IQ or speech disorders. This was facilitated by gatekeepers who were highly committed to addressing the needs of this population—with all its subgroups—and their recognition of the potential positive impact that inclusion in research could have on practical outcomes. Additionally, the researchers argued that the treatment team has a central role in evaluating the capacity of individuals to give informed consent for participation. This recruitment method was proposed based on the researchers' pre-existing familiarity with the population and the recognition that not all individuals within this demographic are capable of giving informed consent, or at least not at any time. Subsequently, the gatekeepers recruited participants in various ways, ranging from organizing information sessions on the ward for all patients where everyone had an equal opportunity to participate, to the gatekeepers themselves putting together a selection of participants and thus enhancing the risk of selection bias.

Upon arrival for the interviews, the researchers encountered further challenges. In some facilities, participants were not informed about the study in advance, instead they were approached on the day of the research activity and asked about their **willingness to participate**. This unconventional approach raised legitimate concerns as reflected in the Informed Consent Form (ICF), with participants questioning whether they had been given enough time to consider their participation. Gatekeepers defended their departure from conventional informed consent practices by pointing to the individuals' moods, asserting that an accurately assessment of the ability to give informed consent was only feasible on the day of the study. Moreover, they claimed that pre-disclosure of study details might lead to anticipatory stress and psychological decompensation. Contrary to these assertions, the researchers' observations indicated that informing participants in advance did not diminish their enthusiasm for participation. It empowered them, enhancing their sense of autonomy and agency. In some cases, pre-informing acted as a motivational catalyst, inspiring them to actively

prepare for and look forward to their involvement in the forthcoming conversation.

When a participant expressed an interest in being interviewed, the subsequent step in the research process involved discussing and **obtaining informed consent**, a multifaceted issue that resulted in varied experiences for researchers. The research findings underscored the importance of linguistic nuances inherent in the process of securing informed consent. Some participants meticulously reviewed the ICF, highlighting specific sections and preparing questions in advance, especially regarding aspects such as: “*What is the Declaration of Helsinki all about?*” In the Oyster Care study, it occurred that the term “palliative” required additional explanation.

Articulating the complexity of the study and the content of the informed consent often demanded a considerable amount of time stemming from comprehensive pre-reviews. In all studies, some participants hesitant to sign the ICF due to various factors. For example, there were concerns about being given sufficient time to consider participation in the study. This was partly due to gatekeepers delaying information sharing, which hampered participants’ decision-making process. Also, some participants associated signing the ICF with traumatic events in the past. These events involved having to sign incomprehensible documents that led to serious consequences such as hospitalization or the sale of their property against their will. This association was particularly prevalent in clinical conditions characterized by psychosis. Acknowledging these challenges, the researchers invested considerable time and effort in explaining the ICF, strictly adhering to the principles outlined. Proactive engagement with gatekeepers and participants prior to formal consent processes had a significant positive impact on the dynamics of subsequent interviews, fostering a comfortable and non-pressured interview atmosphere. A collaborative review of the ICF allowed participants to reflect, created space to ask questions and gave them confidence in the document’s protective role. Participants were assured of their autonomy to end or withdraw from the interview without explanation with the assurance that these decisions would not affect their treatment or euthanasia procedures. Crucially, confidentiality was maintained, addressing instances where participants might have agreed to interviews to appease their healthcare providers or those overseeing euthanasia procedures, ensuring the ethical integrity of the study. In all studies, a small subgroup ($n = 5$) of potential participants regularly rescheduled appointments or simply did not show up without prior notice. Nevertheless, after signing the ICF, these individuals did spontaneously convey their story to the interviewer by email or telephone. In the Oyster Care study, one participant refused to

both signing the ICF and record his consent nor story on an audio device. Due to the person’s explicit wish to share his story with the research team, he was engaged in conversation, but his story was excluded from the analysis process.

The interview itself

Prior to the actual interview, the researchers occasionally engaged in **conversations with gatekeepers**. For example, to query some socio-demographic variables, such as duration of admission and psychiatric diagnosis. At times, gatekeepers provided comprehensive information about the participants’ unusual psychiatric symptoms and behaviours and potentially uncomfortable topics for the person, with the intention of preparing the researchers to handle them sensitively. However, there were instances where gatekeepers shared excessive information and this unintentionally introduced bias and discomfort for the researcher. Information overload sometimes shifted the focus of the interview to exploring this disclosed information, raising concerns about the participant’s privacy. The delicate balance between respecting privacy and exploiting the information needed was deemed a challenge.

Traditional conventions advocate creating a serene **interview environment** conducive to intimate one-on-one conversations, usually characterized by a tranquil and secluded environment. Some participants deviated from this norm by choosing unconventional surroundings. For example, conducting an interview in a communal space (e.g., a living room) where interruptions—such as a follow patient asking the participant for cigarettes—became inherent to the evolving dialogue. The researchers were attentive to safeguarding the participants’ integrity and privacy, recognizing that their conversations could potentially be overheard. Yet researchers did not have to intervene, as discussions on sensitive topics were naturally conducted by the participants in a subdued tone. Interviews in a communal setting also acted as a catalyst for spontaneous engagement, as passers-by occasionally interrupted the interview to inquire about their activities and express interest in participating. It should be noted that there was always consultation with the gatekeeper on whether it was appropriate for the participant to be included, considering factors such as their ability to give informed consent. Some participants preferred dynamic environments and chose to move from one place to another during the course of the interview. This was demonstrated when, in response to questions about what their personal spaces looked like, individuals physically displayed facets of their surroundings, giving the interview a tactile and spatial dimension. Similarly, questions about daily routines led participants to move to

relevant environments, such as a music room, or showing their artworks displayed in the communal living room, creating a dynamic and contextually immersive interview ambience.

P: Oh, a good day for me (...) you should take a look all these people here who are unwell (looks at peers). A good day "... look I made that! (shows knitting). So are we going to have a look at my room while you're here? You have time for that huh.

In terms of **interview duration**, the researchers opted for a duration of 45 minutes to ensure that participants were not overburdened. In practice, two contrasting interview durations were perceived, on average particularly short (25 minutes) or remarkably long (up to 2 hours). Brevity characterized the shorter interviews, reflected in condensed responses and minimal involvement in paraphrasing or asking for clarification. These interviews usually came to an abrupt end, either by direct verbal announcement or participants subtly signalling that the interview was nearing its end, such as coffee break or celebratory events they wanted to attend. Extended interviews, on the other hand, were distinguished by participants struggle to answer the questions asked and by the complexity of participants' stories which were rich in detail. In most cases, however, these long sessions seemed to stem from the participants' ability to share their experiences, thoughts or emotions candidly and extensively without restraint with an impartial person.

P: Apologies for taking so long. I did expect that and it's really heartening to be able to tell my story for once. Hopefully it may be helpful to other people.

During the interview, the researchers used commonly accepted **interview techniques** to improve the interview process, although the findings indicated limited effectiveness. For instance, the use of "humming" to facilitate fluent interviewing did not appear to be efficient. Paraphrasing answers to signal comprehension to the participant also proved ineffective as participants preferred verbatim repetition of their words. Despite efforts to avoid closed questions, researchers encountered participants' tendency towards brief or repetitive answers, potentially leading to a shift towards closed questioning.

I: You say you have already been admitted elsewhere. Then you come here, what do you think of the care you get here? P: Very good, very good. I: Can you tell what you really like? P: I do like the nurses. I: What do you like about the nurses? P: Here they help you more quickly, better and so on. (...) I: You say you like the nurses, are there other things that are good here? P: Yes a lot of things are. I: What could be better? P: No, I don't know.

Tailoring open-ended questions to participants' interests elicited more comprehensive responses, which

promoted a deeper understanding. As rapport between interviewers and participants strengthened, the researcher was able to respond to the participant's communication style and, in turn, the participant began to speak more openly and share in-depth information. One participant chose to initially convey his narrative non-verbally, formulating answers on paper before engaging in verbal discourse. Some participants introduced unique terms or logic, challenging the interviewers' comprehension. The constant dialogue allowed the researchers to identify patterns in these linguistic nuances, thus aiding in effectively interpreting the participants' accounts.

I: Are there things you lack in caring for you here? P: I wouldn't know. Friendship. Do you know why? For example, there are now people who also have claustrophobia. I was locked in the storage room of the kindergarten class, a naughty child that I was, so I was locked in the storage room and yes "... claustrophobia then. Now I hear from a girl and she also has claustrophobia. It's really a madhouse here. I mean, to me it comes across like "... that those people are all getting sick because of me. An inferiority complex. But those trainees make me happy, really, they are very sweet people. I: Tell? P: Yes, there are others who say, "You have to do that. You're going to do that now!"

The findings suggest that **attentiveness to non-verbal cues** is of great importance during interviews with people experiencing SPMI, especially those with limited verbal or intellectual capacities. Non-verbal cues served as channels of communication, complementing verbal expressions and providing nuanced insights into the emotional and psychological states of individuals who had difficulty in putting their thoughts and feelings into words verbally. Direct observations of gestures, facial expressions, body language and other non-verbal cues was essential for the researchers to understand and respond to the participants' emotions, needs and discomforts. These signals often indicated their desire for breaks, such as coffee or cigarettes, or their need for movement. In addition, responding to these cues played a key role in building trust and establishing a deeper connection; it created a supportive environment that respected individual boundaries, encouraging open communication.

In terms of **education, skills and experience**, understanding SPMI was invaluable when interviewing this population. This knowledge enabled interviewers to interpret both verbal and non-verbal cues effectively and pose questions in a direct and clear manner. They also anticipated unexpected experiences such as auditory hallucinations, dissociation or references to self-harm. They remained flexible and comfortable with unpredictability and ready to navigate unforeseen circumstances during the interviews. For instance, some participants disclosed experiencing "dissociation episodes" or "hearing voices". 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 at encouraging self-assessment of their mental state and enabling joint action, such as a visit to the nurses' office for a check-up, which ultimately proved unnecessary.

The study protocol stipulated that participants were offered the option of involving a **trustee** in their conversations. These trustees could provide emotional support or offer assistance in articulating their thoughts, experiences and needs (e.g., need for a break). It was emphasized that trustees should not influence participants to prolong the interview. Participants were free to define who would be a trustee for them, a family member, a healthcare professional or another individual. Noteworthy, participants mainly selected their designated nurse as their trustee. In practice, the involvement of participant-selected trustees in interviews introduced both benefits and challenges. One benefit was the enriched narrative depth, as their presence contributed to creating a safe interview atmosphere and often evoked more detailed descriptions of participants' lived experiences. This was due to participants sometimes viewing certain aspects of their narratives as unimportant to the research question, or possibly due to their limited understanding of (the impact of) their condition—when asked about their psychiatric condition and associated treatment and care experiences—which may have caused them to misunderstand the relevance of these details to the researcher. In response to participants' sometimes limited answers, the trustees occasionally asked nuanced questions or translated the question into the participant use of language, which revealed additional information, but also spurred further probing during the interviews. The following examples show prompts that helped uncover deeper layers of the participant's story, leading to a more comprehensive understanding of their experiences:

I: How is it here on the ward? P: Quiet. I: What do you mean by quiet, because I am not from here. P: Creating calmness, learning to use your hands, breathing, nostril in... (...) I: What do you love about this ward? P: The quietness, the tranquility. I: And where is it quiet? P: In my room. I: Can you tell something about your room? P: I always grab a cup of water from the tap, sacrifice a little, make myself happy. I: What do you mean? P: I drink that. I: Okay? P: Drinking water makes you grow, it keeps your soul awake, you grow from that "... " and from breathing. O: We also have potomania, sometimes we drink a little too much huh? P: Yes that's true, that's tough.

O: "But sometimes you do miss them [first-degree family members], right? Despite the many arguments?"

At times, participants asked the trustee nonverbally to answer difficult questions or to nuance their experience. Moreover, participants sought emotional support from their trustee while narrating, seeking a sense of reassurance or validation, which seemed to promote participants feeling comfortable in the researcher's presence as they began to narrate more openly. For instance, participants often turned their gaze to the trustee while narrating: *"At the beginning of my admission, I had no worries. That's true, right? <participant looks at trustee>".* The involvement of a trustee also brought potential drawbacks. Participants may have been reluctant to disclose specific information in front of their trustee because of concerns about trust and potential repercussions, such as increased medication dosage or restricting their freedom when being honest about their sometimes strange or negative thoughts and feelings. Additionally, there may be personal reluctance to disclose certain experiences, especially those involving past trauma or sensitive topics. Even when encouraged by the trustee, participants could choose not to elaborate further on specific topics, which was closely monitored by the researchers and respected by all parties involved. The complexities surrounding the presence of a trustee highlight the intricate dynamics at play during qualitative research interviews, demonstrating the interplay between the participant's candour and respect for their privacy, and the perspectives introduced by a trustee, which do not always align with the participant's point of view.

The use of single, verbal interviews in all studies resulted in the **underrepresentation of some sub-populations** of people experiencing SPMI, silencing their voices. These persons were unable or unwilling to communicate face-to-face for various reasons, including language barriers, privacy concerns, lack of trust or specific conditions such as severe autism or Obsessive-Compulsive Disorder (OCD). Some conditions led to the avoidance of interactions due to factors such as altered day-night rhythms, difficulties in direct social engagement or fear of being contaminated. Overall, the researchers encountered some challenges in connecting and engaging with people with the most severe health-related difficulties within the target group, despite their significance to the study. Yet, the researchers were able to include people in the study who were initially excluded. This applies to the end-of-life and euthanasia study, where people with acute symptoms of grief or substance intoxication. These exclusion criteria were deemed crucial as they could reduce an individual's mental competence to fully comprehend and appropriately sign the ICF. Despite these exclusions, certain interviews were conducted with individuals who experienced these acute symptoms. The interviewer acknowledged these symptoms, but the participants

still encouraged them to continue with the interview and emphasized its importance for their well-being and to avoid lingering feelings of guilt or grief. These interactions resulted in positive outcomes as participants openly guided discussions on managing specific circumstances and pathologic features. For one participant with acute substance abuse, an understanding was made to reschedule the interview should it prove impractical. Surprisingly, the interview exceeded expectations: it lasted almost two hours and the participant seemed to display a relatively clear cognitive state and sense of humour. In another instance, an interviewer engaging with a bereaved participant discovered a shared spiritual affinity, fostering a special connection that was potentially crucial for the interview to continue. These scenarios stress the need for flexibility and discernment regarding inclusion and exclusion criteria, especially in encounters involving substance use or acute emotional distress.

The concluding phase

The researchers were mindful of the **potential emotional impact on participants**. In residential care settings, participants had access to the care team, who were 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 general practitioner or regular practitioner if needed. Additionally, a team member with expertise in healthcare was available by phone as a resource for researchers in case of an emergency. In terms of follow-up and aftercare, the ICF allowed participants **access to support** from the interviewer if they had doubts or questions after the interview or if they experienced negative feelings. In the euthanasia study, there was 24/7 availability on the day of the interview and for a few days afterwards. If there were concrete suicidal thoughts, a psychiatrist working in a university hospital was available. This provision was used sparingly and it was not common for participants to continually contacting the researcher for casual conversation.

At the same time, the research team sought to develop **a coaching framework for interviewers**. The opportunity of debriefing sessions after each interview was facilitated, either live or remote, to discuss both positive and potentially negative experiences and adjust the interview approach if necessary. In addition, it was ensured that at least one team member was available by phone during interviews to enable researchers to seek support, ask questions and receive feedback from the team. The interviewers found comfort in discussing their experiences with colleagues, recognizing similarities in each other's

narratives and feeling reassured that certain challenges were related to the nature of interviewing people experiencing SPMI rather than solely attributed to their interviewing techniques. For example, in one case, the participant reproached the interviewer, seeing her as yet another mental health professional who might be using him for personal benefit. Consultation with the research supervisor led to the decision to partially allow this behaviour, as its nature was recognized within the context of the person's mental illness. It was made clear to the participant that this kind of behaviour might reflect doubts or discomfort about the research conditions, and that the research relationship did not extend to therapeutic or personal support outside the research context.

At the end of the interview, some participants **initiated contact with the interviewer**, posing questions such as: *"Now that I've divulged this information to you... and expressed my desire not to stay here anymore... is there a possibility for change?"* or *"Regarding the formal guidance on my euthanasia request, what is your perspective on its correctness?"* In response, the interviewer emphasized the incapacity of making changes or providing opinions based only on a single interview. This limitation was primarily guided by the directive within the ICF, which explicitly stated that the interview should have no influence on the care provided. Several individuals showed interest in **obtaining the interview transcript** for various reasons. First, to supplement information by providing additional context or adding elements that were not discussed during the interview, especially by people facing difficulties in verbal communication or cognitive abilities. Second, as preparation for discussions with their caregivers regarding the interview content. Third, as documentation to add to their euthanasia file.

Formal gratitude was extended to participants for their involvement, reciprocated by many expressing **a profound sense of gratitude** emerged from sharing personal stories. Participants believed that by sharing their experiences, they were actively contributing to advancing scientific knowledge, and providing support and care to others encountering similar challenges. Their expressions of gratitude portrayed a depth of connection that resulted from direct conversations with the interviewers, contrasting with what they often perceived as "mere conversations about them" in their daily lives. The researchers also received physical gestures of gratitude, which were intriguing as they reflected aspects of the participants' daily lives bearing personal meaning. These expressions, ranging from cards with poems and artwork, surpassed conventional forms of appreciation. Some gifts arrived months after the interview. For instance, someone sent a self-made Christmas cards inscribed with: *"This card I send to those who have been very important to me this year."*

Discussion

This paper aims to be descriptive and reflexive, based on the authors' experiences of conducting or supervising in-depth interviews with people experiencing Severe and Persistent Mental Illness (SPMI). The interview studies explored the perspectives of people experiencing SPMI on sensitive topics, such as the Oyster Care model, end-of-life care and euthanasia. Despite ongoing efforts to define exactly what constitutes SPMI, it is clear that this group of people is highly heterogeneous, with individuals having their own unique experiences. This diversity is not only reflected in working with people experiencing SPMI, but also highlights the importance of prioritizing their individual and unique preferences when engaging them in research, which often requires departing from conventional methodologies. The researchers thoroughly reflect on the issues raised in the article and their experiences of reaching and engaging this population through qualitative methods, it should be considered as enabling approaches rather than a standard approach.

The need to actively involve people experiencing SPMI in their treatment, with their values, wishes and desires playing a central role, is in line with the key beliefs of contemporary mental healthcare (Tambuyzer et al., 2014). At the same time, the advocacy for involving people experiencing SPMI in formulating policies and making decisions in mental healthcare underlines the commitment to promoting a participatory and inclusive framework (Decorte et al., 2020; Moonen et al., 2016; Woods et al., 2008). Beyond these established paradigms, the added value could become apparent when this patient population is actively involved in research, especially in the context of exploring lived experiences as a means of clarifying and informing clinical practice. Still, it is not yet common practice to involve this patient population in (different phases of) research. Because of their psychiatric issues, one could argue that this is a vulnerable population (de Koning et al., 2021), and in addition, the topics of palliative and end-of-life care are sensitive (Carlsson et al., 2017; Kars et al., 2016; Witham et al., 2015).

For example, when the studies were presented to the ethics committee, concerns were raised regarding potential adverse events for participants, particularly fear of exacerbating thoughts associated with suicidality or self-harm behaviour. However, participation in research on psychiatric illness, trauma and suicide has shown minimal immediate post-research distress (Jorm et al., 2007; Newman et al., 2017). Consistent with prior research, a meta-analysis showed a reduction in suicidal ideation after exposure to suicide-related content, especially in interview-based studies (Blades et al., 2018). As Dempsey et al. (2016) argued, the benefits of sensitive research must

outweigh the risks, as refraining from such research could be perceived as a dereliction of duty and a barrier to the empowerment of participating "vulnerable individuals". Despite some challenges, research demonstrates that vulnerable populations have much to contribute by recounting their experiences (Corby et al., 2015; Newman et al., 2017; Witham et al., 2015). Therefore, this synergistic integration of research engagement with people experiencing SPMI can not only enrich the empirical base, but also create a reciprocal dynamic whereby the insights derived from lived experiences contribute substantially to improving mental health practices.

Throughout the studies, gatekeepers played a central role in recruiting research participants. Building positive relationships with gatekeepers facilitated access to this group of people and underscored the instrumental nature of these ties in successful recruitment efforts. Gatekeeping is integral to giving voice to vulnerable populations and is accompanied by an emphasis on the duty to protect patients. Protective power can be positive and nurturing when used in times of crisis or vulnerability, but it can also devolve into paternalism, preventing choice and autonomy (Dempsey et al., 2016; Kars et al., 2016; Kirk, 2007; Witham et al., 2015). By gatekeepers, research can be easily seen as a potential additional threat to patients' well-being. For instance, one of the main reasons for not involving people facing end-of-life care in research is "not to burden them even more" (Kars et al., 2016). However, the findings consistently indicate the contrary effect, as the experience to participate in a research study was perceived as empowering by some. They were given the opportunity to tell their life stories and perspectives, while others gained fulfilment from contributing personal experiences that held significance for others, thus instilling a sense of meaningful interpersonal connection. These findings are consistent with existing research on sensitive issues and/or vulnerable groups, in which participants often perceive telling their stories as cathartic and provide a sense of emotional relief. Moreover, participants often report feeling empowered by the experience of being listened to attentively and receiving recognition. The process creates a heightened sense of purpose, attributed to an increased awareness of their stories of experience (Dempsey et al., 2016; Elmir et al., 2011; Kars et al., 2016).

Ethical challenges in interviewing participants experiencing SPMI, such as assumptions about their decision-making capacity, may also impede access to this group of people (Moureau et al., 2023; Newman et al., 2017; Witham et al., 2015), potentially neglecting their fundamental human rights including privacy, choice, dignity and social inclusion (Killaspy et al., 2009). Despite the potentially impaired decision-

making capacity attributed to psychiatric disorders, it is essential to recognize that they retain the capacity to make certain decisions (Hodel et al., 2019; Moonen et al., 2016). The findings suggest that people experiencing SPMI are capable of making choices about whether or not to participate in this kind of research. Therefore, there is a strong need for further discussion on choice, vulnerability and autonomy in light of the right of their right to make their own decisions about participation (Dempsey et al., 2016; Kars et al., 2016; Witham et al., 2015).

Preliminary findings indicate that healthcare settings with a nuanced understanding of research methodologies or with a patient-centred ethos tend to proactively inform participants about impending research agreements. Thus, by enabling people experiencing SPMI to make an informed choice whether or not to engage in research, researchers are contributing to a paradigm shift that recognizes and values the autonomy of these people. Difficulties in obtaining informed consent have led to further debate about whether it is ethical to involve vulnerable people in research at all. Many research participants do not fully understand what they are consenting to, vulnerable people may agree to participate in an interview for inappropriate reasons, or they may simply not question the document due to repeated exposure to bureaucratic treatment (Melville & Hincks, 2016). Aware of these challenges, the researchers were committed to upholding the principles of informed consent through multifaceted approaches that included understanding, voluntary participation and the capacity for autonomous consent.

Furthermore, some participants perceived barriers in the chosen research method, namely qualitative research through interviews. This could stem from the impact of mental health problems, medication, stigma or how they were taught to interact with healthcare professionals, as well as having limited vocabulary and problems with verbal comprehension and reasoning (Beail & Williams, 2014; Newman et al., 2017). Adopting alternative strategies to enhance engagement with severely ill individuals within the SPMI group becomes imperative. Repeated visits, for instance, can serve as a possible means of gradually build rapport and trust, ultimately paving the way for a more comprehensive exploration of the participant's lived experiences. The iterative nature of these interactions may allow the researcher to navigate the initial reluctance observed during the first encounter and establish a more conducive environment for open communication. Or, as Corby et al. (2015) describe, building a relationship of trust by spending time on observation and interaction prior to the interview to learn more about their communication skills and preferences. Utilizing new methods and techniques, such as

communicating through pictures, stories or symbol cards, may yield rich data not accessible through traditional conversational methods (Beail & Williams, 2014; Kirk, 2007). Moreover, an ethnographic approach or exploring future cluster research within various network circles could offer additional valuable insights into diverse perspectives, experiences and support needs, potentially shaping practical tools in end-of-life care, Oyster Care and/or euthanasia practices.

Conclusion

Engaging people experiencing severe and persistent mental illness in research is a cornerstone for empowerment—a feasible aspiration. The inclusion of people experiencing SPMI in research endeavours holds profound significance, because first-hand narratives are pivotal in shaping comprehensive and compassionate care practices. Adopting a stance of flexibility proves imperative for researchers and requires the abandonment of preconceived ideas and departing from ingrained interview techniques. Critical reflection on the role of gatekeepers and trustees to capture the authentic experiences of this population emerges as essential. Equally important is considering comprehensive support measures for both participants and researchers, encompassing the structure and significance of Informed Consent Forms, emotional support and participant well-being. Finally, embracing diverse research methodologies, including an ethnographic approach, field and cluster studies and recognizing the importance of non-verbal communication channels, is an important step in promoting inclusivity and understanding within mental health research.

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Authors' contributions

All authors contributed to the study methodology and obtained ethical approval for their individual interview studies, which serve as the foundation for this paper. MV drafted the introduction and methods sections, subsequently revised, and reviewed by CVH and LM. CVH

authored the results and discussion sections, which underwent review and editing by MV and LM. All authors contributed to the content, derived from discussions held in various online meetings. Additionally, all authors critically reviewed and revised the final manuscript.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Ethical approval

The respective research projects of the authors adhered to the Declaration of Helsinki and European General Data Protection Regulation rules. Approval for their interview studies was obtained from their respective Medical Ethics Committees.

All three studies were approved by an Ethics Committee:

- Study 1, the Oyster Care study, was approved by the Medical Ethics Committee of the Vrije Universiteit Brussel (VUB) (approval no. EC-2021-322)
- Study 2, the end-of-life care study, was approved by the Research Ethics Committee UZ/KU Leuven (approval no. B3222021000688)
- Study 3, the euthanasia study, was approved by 4 ethics committees
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