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Discussing end-of-life care for persons experiencing severe and persistent mental illness: a qualitative study among stakeholders in Flanders

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Background: End-of-life care for persons experiencing severe and persistent mental illness (SPMI) is a complex topic that deserves more attention. Despite growing awareness within international scientific research, topics such as palliative psychiatry, the provision of palliative care, and ethical dilemmas, including medical assistance in dying, remain under-researched. The aim of this study is therefore to qualitatively explore the views of different stakeholders on these issues to inform care providers about current challenges and opportunities in care.

Methods: A qualitative study in Flanders, Belgium, involving 73 participants—including care users, caregivers, managers, and experts—explored experiences, needs, challenges and dilemmas regarding end-of-life care for persons experiencing SPMI. Semi-structured interviews were conducted, transcribed, and thematically analyzed.

Results: Explored themes included advance care planning, suicide risk and prevention, euthanasia, the provision of palliative care, bereavement care, and the use of a palliative care approach. Challenges in standardizing advance care planning were noted. Euthanasia requests were rare but ethically complex. The provision of palliative care within familiar settings was favored but posed challenges related to expertise and staffing. Farewell rituals emphasized strong bonds between caregivers and care users. The study highlights the importance of advance care planning, the relative absence of discussions about suicide and euthanasia, and the challenges in providing palliative care. It underscores the need for education, ethical support, and collaboration with palliative care networks.

Conclusions: End-of-life care for persons experiencing SPMI demands a comprehensive approach that addresses ethical considerations, advance care planning, suicide risk, and the provision of palliative care. Policy recommendations include investing in education, establishing ethical support mechanisms, and fostering collaboration with palliative care networks to ensure dignified and compassionate care for this vulnerable population.

Keywords: End-of-life care; severe and persistent mental illness (SPMI); palliative care; euthanasia; Oyster Care

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Introduction

Persons experiencing severe and persistent mental illness (SPMI) form a small yet vulnerable group within mental healthcare. Although there is no consensus on a definition for SPMI, some researchers describe it using the "3 D's"—disease, duration, and disability (1). persons experiencing SPMI are diagnosed with one or more severe mental illnesses, such as schizophrenia, bipolar disorder, or severe depression. These conditions typically follow a chronic course, with medical and therapeutic interventions offering little to no improvement in quality of life, or even worsening it (2). In addition to the illness itself, the disability it causes leads to significant suffering and challenges in daily life. Globally, depending on the indicators used, approximately 1% of the population lives experiencing SPMI (3). Statistically, persons experiencing SPMI face a significantly reduced life expectancy—up to 15 years shorter than the general population, largely due to severe co-occurring somatic conditions (4-7). This observation highlights the critical importance of addressing end-of-life concerns and providing comprehensive and dignified care throughout the dying process in the context of mental health care, where this is not always self-evident.

Recently, end-of-life care for persons experiencing SPMI, in several ways, has indeed garnered more attention in international scientific literature. Central to the debate are topics like the need for 'palliative psychiatry' (6,8), the provision of 'regular' palliative care (9,10), the potential application of a 'palliative care approach' (11,12), as well as the challenges of whether or not to facilitate medical assistance in dying (MAID) (13). Most of these concepts, like palliative care, are directly related to care in the dying process; while others, like 'the palliative care approach', are more loosely related to the end-of-life. The conceptual framework and related working definitions are further outlined in Appendix 1.

Delivering high-quality care to persons experiencing SPMI at the end of life involves numerous ethical challenges, including assessing decision-making capacity, managing disruptive behavior and self-stigma, and navigating a fragmented care landscape (14).

Despite the growing body of literature offering reflections, recommendations, and highlighting difficulties, very little research has directly involved care users, relatives, and caregivers themselves. This study seeks therefore to address this gap by exploring the experiences, needs, and expectations of care users, their relatives, and caregivers in relation to end-of-life care. It also aims to capture the perspectives of ethics and palliative care content experts.

In Flanders, Belgium, these issues are particularly pressing due to the legal framework permitting euthanasia based on unbearable psychiatric suffering since 2002 on the one hand (15); and the development of the Oyster Care Model on the other. The number of euthanasia requests, as well as the number of performed euthanasia cases in Belgium, has been steadily increasing for several years (16). This also applies to cases where psychiatric suffering is identified as the primary diagnosis. Additionally, in Belgium, euthanasia has become to some extent 'normalized' and holds an almost equivalent position alongside palliative care as a possible end-of-life decision (17,18). The Belgian situation, as the societal backdrop of this study, is therefore rather exceptional in an international context, with the exception of a few countries such as the Netherlands.

The Oyster Care Model complements recovery-oriented care and uses the metaphor of a shell to represent a palliative approach for persons experiencing SPMI, focusing on quality of life, creativity, and a holistic view of the person (11). The model is, parallel to palliative care, based

Highlight box

Key findings

- This study reveals significant barriers and challenges in facilitating end-of-life care for persons experiencing severe and persistent mental illness (SPMI) in Flanders. Many participants reported difficulties in the provision of palliative care, advance care planning and medical assistance in dying (MAID), highlighting a need for improved caregiver training and support.

What is known and what is new?

- Existing literature acknowledges the ethical complexities of end-of-life care for persons experiencing SPMI, including challenges in decision-making and communication.
- This manuscript adds to the discourse by providing firsthand insights from care users, relatives, caregivers, and experts, emphasizing the importance of tailored communication strategies and the need for systemic support in palliative care settings.

What is the implication, and what should change now?

- Findings suggest a pressing need for organizations to implement comprehensive training for caregivers, enhance communication protocols, and foster collaboration with external partners such as palliative care networks.
- A call for further research is necessary to explore effective strategies for addressing end-of-life concerns, including the development of guidelines for ethical practices in care and the integration of user-friendly communication tools.

on four pillars: physical care adequately responding to the somatic impairments of these patients; psychological care changing the scope of therapy by focusing on mental comfort and wellbeing; social care providing a structure of daily activities and contacts; existential care enhancing the experience of life as valuable and meaningful. The mission of the Oyster Care Model is to adapt the environment as much as possible to the care user, rather than the other way around. For instance, a care recipient's hoarding tendencies are tolerated or sublimated to a certain extent. This approach also aims to reduce the use of restrictive or coercive measures. The model is dynamic, with care being scaled up or down according to the care user's rhythm. Developed in the context of euthanasia legislation, the model seeks to provide a full-fledged alternative equivalent to palliative care in the somatic healthcare sector. While this approach offers numerous benefits, it also raises ethical concerns, such as the risk of adopting a paternalistic or insufficiently recovery-oriented perspective (19). A careful balance must be struck to avoid adding stigma while acknowledging the complexity and severity of the suffering experienced by this population (20).

Given the scarcity of studies that amplify the voices of all relevant stakeholders, we undertook a qualitative study in Flanders. Our main research question was how end-of-life care for persons experiencing SPMI is addressed, and what experiences and challenges are associated with it. By involving users, relatives, caregivers, managers, and experts, we aimed to contribute to the ethical obligation to include persons experiencing SPMI in qualitative research, despite the additional challenges this may represent (21,22). These challenges included, for example, demonstrating extra flexibility when scheduling interviews or allocating more time than usual to review the information documents step by step with the participant. We present this article in accordance with the COREQ reporting checklist (available at https://apm.amegroups.com/article/view/10.21037/apm-24-157/rc).

Methods

Sample, duration, participants characteristics and researchers' background

A total of 73 participants, including 12 next-of-kin, 17 care users, 24 caregivers, and 20 managers and experts, were all interviewed once about their experiences, needs, and expectations regarding end-of-life care for persons experiencing SPMI. Appendix 2 outlines study participant demographics. Efforts were made to establish representative socio-demographic characteristics distribution amongst all target groups. The interviews were conducted in Dutch by two researchers (L.M., MA, male and M.V., PhD, female), with a background in care ethics and psychology respectively, from July 2022 to May 2023. Interviews ranged from 30 minutes to over two hours, averaging around one hour. We reported about our experiences elsewhere (22). Both researchers conducting the interviews received training in qualitative research, while one had extensive experience in conducting interviews with persons experiencing SPMI, both as a doctoral researcher and as a volunteer. Interviewees were not known by the interviewers. The interviewers also have subject matter expertise and familiarity with this population given prior research and professional activities. Assumptions and expected results of the qualitative research were noted beforehand, while researchers discussed similarities and differences afterwards.

Interview location, topic guide and inclusion criteria

Participants chose the interview locations, which were typically the ward or organization where they worked or lived—often for several years in the case of care users. The semi-structured interviews followed a pre-constructed topic guide, covering themes such as care approaches, end-of-life care needs, ethical considerations, and existential questions. The pilot tested interview guides are provided in Appendices 3,4. For caregivers, managers, and experts, there was direct experience with end-of-life issues. However, for relatives and care users, the experiences were not always as explicit, though some relatives reflected on the care and death of a family member experiencing SPMI. Occasionally, care users had experiences with advance care planning, requests for MAID, or severe illnesses like cancer; while for others, end-of-life discussions were more hypothetical. The inclusion criteria can be found in Appendix 5.

Recruitment and organizations characteristics

Participants were purposely recruited from seven mental healthcare organizations across the five Flemish provinces, representing varied care settings including residential care, assisting living, and ambulatory services within a broad geographic range. These organizations operate from various therapeutic and existential frameworks, all of them providing some form of long-term and protective care for persons experiencing SPMI, mostly in a residential setting. Some, but not all, of these organizations were familiar with the Oyster Care Model. On all campuses, a care team—including a psychiatrist—is always present or on call. The organizations were initially contacted via email and phone, and a contact person (e.g., a head nurse, therapist, or physician) was appointed to facilitate recruitment. Interested participants contacted the researchers directly to arrange interviews. Of all the participants, only two dropped out of the study. These two care users ultimately found it too difficult to bring their stories. In some cases, care users preferred to have a trustee present.

Ethical statement

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the central ethics committee of KU Leuven, Belgium (No. B3222021000688) and informed consent was obtained from all individual participants.

Data analysis

The interviews were audio-recorded, transcribed verbatim, and pseudonymized. Researchers L.M., M.V., and C.V.H. independently analyzed and coded the transcripts using a combination of deductive and inductive thematic content analysis in Qualicoder software (23,24). Differences in interpretation were discussed, and disagreements were resolved with input from the study supervisor A.L. Data collection continued until thematic saturation was reached. However, interviews did continue to ensure sufficient diversity in terms of age, gender and professional background. In two cases, the transcript was requested by the interviewee for review, but no further feedback was provided. The researchers made limited notes after the interviews, but these were not used further in the study.

Results

The results of the research are categorized according to the following themes, closely following the structure of the interview guide: advance care planning and discussions about end-of-life; suicide risk and suicide prevention; provision of palliative care; euthanasia; the use of a palliative care approach for the target group; and bereavement care. All of these themes were highly prominent in the interviews, and each topic was mentioned to some degree by the majority of participants. Below, we will delve deeper into each of these themes, illustrating them with quotes from the interviews. We aim to provide a broad overview of the topics discussed, structured by stakeholder, concerning end-of-life care in a general sense. Our focus lies in highlighting some of the key best practices, experiences, and points of attention, while also striving to demonstrate the significant variety and nuances present in the extensive source material. Regarding each topic, a wide range of opinions and experiences emerged. Sometimes, there was relatively strong coherence within a particular facility or department, while in other cases, there was considerable diversity in opinions.

With regard to each topic, we start out by offering the perspectives of the care users and next of kin. Next, we provide insight into the views of caregivers and managers and experts.

Advance care planning and talking about end-of-life

In various healthcare settings, including elderly care, advance care planning is quite common for these discussions to take place with almost all care users in the first months or even weeks after admission (25).

For almost all the caregivers interviewed in our study however, death and the end of life was something they did not deal with or talk about much. As one care user puts it when asked if he ever thought about end-of-life:

> "*No, that's not something I'm thinking about!*" (care user P7).

This kind of response was very common among care users in our interviews. Likewise, most family members admit to have given relatively little thought about the topic. Moreover, some family members mention that discussions about end-of-life might be too complex for their loved ones, or might trigger responses of misunderstanding and fright. A spouse says the following about her husband and advance care planning:

> "*No, we never discussed it in the past. And now it wouldn't work anymore. He would immediately think that something really serious is happening and would become very anxious.*" (spouse F2).

From this study, it appears that in many organizations providing care for persons experiencing SPMI, these conversations are not conducted in a systematic manner, although most of the care users do live and stay on the ward for a long time (i.e., several years and, for some, until death). Instead, they are typically initiated only when there is a specific indication to do so, like the diagnosis of a severe somatic illness, or otherwise in a very informal way, often related to a death or serious diagnosis in someone in the circle of acquaintances or someone in the media. As one caregiver puts it:

> "*Sometimes something happens in the media or in the ward. And then you already have to bring that up or use an opportunity to say something about it. Or the situation of a fellow patient who is sick at some point or is having a difficult situation with it. Using it as an entry point. If someone is concerned, I ask: and what about yourself? And what would you want? And what do you actually think is important about it?*" (psychologist Z16).

For some caregivers and care users, talking about death and end-of-life was not that difficult. As one psychiatrist told us:

> "*I think that actually goes smoothly. It also depends on yourself as a counselor. I certainly don't avoid that subject '...' including the subject of euthanasia or suicide.*" (psychiatrist Z4).

Other caregivers however indicated that these discussions are difficult for them to have and to initiate. On the one hand, they mentioned that they may lack experience or feel uncomfortable initiating them. On the other, they expressed that care users may not be receptive or may not always have the cognitive/communication skills necessary for such discussions, or fear they may do harm. According to some healthcare providers and relatives who participated in the study, some persons experiencing SPMI also do not always have sufficient insight into the illness to make these considerations effectively. As one physician puts it:

> "*When I think about the profile of the patients of (the ward), for example, to what extent that those people are all able to assess that. And make correct decisions about that. Either they are cognitively still good but have been influenced in their decision by psychosis, for example, or they are cognitively no longer strong enough.*" (physician Z11).

Caregivers also mention that due to the good and long-standing relationships they have built with care users, they often have a good understanding of their wishes and can bring them up in discussions within the caregiving team if needed. In cases of serious somatic illness or in a terminal phase, if family or other close relatives are involved, they are also included in the decision-making process.

In some settings, efforts are made to systematically address conversations about advance care planning, and for some care users, this process unfolds smoothly. For others, it's more difficult or not really a primary concern:

> "*I was doing this the other day with my assigned patient. And some colleagues and patients find it easy, but others say: 'what are you doing? That's way too early, isn't it?' I say: yes, but, it's better that it's planned. You never know. It's better to know what you want, instead of doing it at the last minute. So we know what you want and what not.*" (nurse Z5).

Suicide risk and suicide prevention

From the various interviews with caregivers and family members it could be concluded that suicidal thoughts, suicidal ideation and suicide attempts had often been present at an earlier stage in life. Family members indicated that this was very difficult for them to deal with, and often expressed feelings of powerlessness and lack of understanding about this. In all cases, however, there had been some stability around this issue in the recent past.

It is notable that each care setting where we interviewed, has a prevention policy in place, usually applicable to the entire facility. Despite meticulous administration and careful monitoring of suicide threats, many caregivers also indicate that the issue is not as prominent for this target group as it may be on some other wards or with other populations:

> "*It's a topic much less prominent than where I came from. Right now I think out of 30 people who are here there are about three where there is some risk. Or where the word suicide is mentioned. Not so much that they have a death wish, but if they didn't wake up tomorrow that wouldn't be so bad, or so they say. But that's not acute.*" (nurse Z7).

For instance, one caregiver mentions that most care users feel quite well on the ward and many of them live "day by day". According to some caregivers, suicide threats are more likely to arise in contexts where care users disagree with prescribed medication or treatment, although the actual risk of attempted or completed suicides is relatively rare in practice:

> "*This is less common here and I have not yet experienced it. I have experienced patients cursing it out. Like: I'm going to put a stop to it... But rather out of anger at the time, because if you ask them afterwards: would you really do that, they'll say no. But rather when the anger has subsided and you can have a quiet conversation.*" (nurse Z20).

Other caregivers mention that certain care users, who are more capable of reflecting on their lives and have built significant aspects of their lives outside of psychiatry, sometimes do experience suicidal ideation. Often, these thoughts are expressed in the context of a request for medically assisted dying, specifically euthanasia, on which topic we come back below.

Euthanasia

A significant portion of the care users that were willing to discuss the topic, shared a rather negative attitude towards euthanasia, stating that "*life should be lived as it comes*" (P3); while others insisted that caregivers should always take a request regarding euthanasia seriously:

> "*I think caregivers should always take a request seriously and never just shove it off the table*." (care user P10).

Most relatives and next-of-kin had a rather positive attitude toward euthanasia, especially in situations of unbearable and hopeless physical suffering. One brother indicated that euthanasia would have meant a more dignified end of life for him than the lengthy course of palliative sedation his sister had gone through. Euthanasia in the context of psychiatric suffering was generally considered a very complex issue, and none of the interviewees saw this as a practice that would be applicable to their family member.

The experiences of caregivers regarding this issue within the target group of persons experiencing SPMI vary greatly. Some caregivers state that the request for euthanasia rarely arises within this group, while others can cite several cases. Although most caregivers display a certain openness towards this issue, there are others who clearly indicate that they do not support euthanasia in the context of mental healthcare.

> "*I think the question has come very rarely, and I will tell you honestly that euthanasia is not my favorite topic. And I know that here in Belgium there will be people who will resent me for saying this, but should we not opt for quality end-of-life counseling? And that's what I'm trying to say to people. Comfort care, rather than taking the step of: an injection, done*." (physician Z11).

Similarly to the theme of suicide, some caregivers note that the request for euthanasia is often expressed by certain care users during times of intense emotions or when they resist proposed treatments or medications. The request may then quickly dissipate.

> "*I haven't talked yet, for example, about our patients who sometimes want or request euthanasia. And sometimes that's really from psychiatric suffering. For example, one of our patients has been drinking excessively and is temporarily put in the secluded part of the ward. She then says: I want euthanasia. But actually she just doesn't want those two days in seclusion. She can't go out shopping then and for instance go buy her favorite snacks. It's then about those things actually. And she expresses that by saying she wants euthanasia, but she's actually mad at us. So I do find those situations difficult*." (nurse Z13).

For other care users, according to some caregivers, the request is more enduring, and in some cases, a procedure may be initiated. Nearly all caregivers mentioned that this is a difficult and ethically charged matter, requiring team discussions and ethical support. One therapist recalls the following about a case where euthanasia was requested and eventually carried out:

> "*That was the first time. That was pretty intense, too. We didn't see that coming either. She was also only 30 years old, or even just 29. And with her, we really took that seriously. We did try to buy some time, but it kept coming back. And for the staff we did need a lot of support. Because it was very drastic for us as well*." (therapist Z1).

In several interviews, caregivers, experts and other stakeholders mentioned LevensEinde InformatieForum (LEIF), Vonkel and Reakiro[1] as partners in helping to identify the needs of the person requesting euthanasia, and providing practical support:

> "*But yes, one chooses to refer, especially to LEIF. That's almost standard*." (ethicist M14).
>
> "*It is fortunately not very common. Currently, however, we hear more and more of this demand for euthanasia. Because of psychiatric suffering. And we are glad that we can appeal to a Reakiro. So we feel a little more supported*." (ward coordinator M1).

Some caregivers, managers and experts involved in the study indicated that euthanasia had indeed been carried out. The underlying issues were sometimes somatic, but sometimes also on the basis of psychiatric suffering. An important point of discussion was the location of the procedure, as caregivers also wanted to consider the well-being of other care users. As one caregiver recounts:

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[1] LEIF (end-of life information forum) is, according to their own website, an open initiative of people and associations striving for a dignified end of life for all, with respect for the patient's will being paramount. LEIF also trains healthcare professionals, including physicians, to engage around end-of-life questions. Vonkel presents itself as a drop-in house and meeting place for those dealing with death, dying, and grief. REAKIRO is, according to their website, a place you can go as a person with a desire for euthanasia because of unbearable mental suffering due to a psychiatric condition. All three organizations operate in the Flemish region, Belgium.

> "*I find that a difficult question. What I think: if it happens here, then you link the two with each other: euthanasia and the ward. Then you always have that image of: this person has been put to sleep here. Now, it's more comfortable for the person themselves I think. To die in a place that they're used to.*" (nurse Z21).

Certain caregivers also observed that some care users experienced very little quality of life, but they may not possess the cognitive and verbal abilities to request euthanasia, let alone undergo a prolonged and complex procedure.

> "*Or like the lady with schizophrenia, she has too little language for that, and she is too sick and too psychotic to ask that question. Because I know in the past, also from hearsay, that there has been a case here, and it has been a very long procedure. This person had to look up a lot of things by herself. For instance, she had to look for doctors who are not connected to the hospital, and she had to travel long distances. So yes, I think it's a very difficult procedure anyway, and what I think is it is necessary, but at the same time my feeling is that for some people I think it's unfortunate. Because the people who have been here for so long and have been so incredibly sick for so long and where you can ask questions about quality of life, don't have the language to be able to say that, so another kind of pathway should exist.*" (nurse Z6).

Provision of palliative care

One extensively discussed topic was palliative care in the case of severe and lethal somatic conditions in care users. In the vast majority of cases, all stakeholders were in favor of providing palliative care within the familiar care setting—often the psychiatric hospital—if the patient wished it so, except in instances of excessive care complexity. The primary argument for this was the strong familiarity with and strong relation of trust in the ward and the staff, who often serve as a kind of surrogate home environment and family respectively.

Both caregivers and close family members expressed their trust in the caregivers, with whom they have often built up a long-term relationship. Also, both groups told that they considered good medical follow-up and treatment important, as well as the use of pain medication in case of (severe) physical pain.

However, the decision to offer palliative care within the context of the psychiatric hospital is not without challenges according to several caregivers, experts and managers. Teams often lack experience in somatic care and administering pain medication, also due to the low frequency of patients dying of natural causes in the psychiatric hospital environment:

> "*One has 10 wards here in this hospital. That means that sometimes there is a situation here and then only a few months later or even a little longer in another department. Fortunately, it does not happen very often. But of course that also means that the experience in each individual department is very limited.*" (physician Z4).

Additionally, the staffing is often too limited to guarantee standard care for other care users at the same level as usual. Some participants noted that fellow residents or patients displayed varying levels of understanding and involvement, with some being very supportive and engaged, while others were less understanding. One manager formulated this an important ethical dilemma:

> "*A lot of time goes into this. And the time goes to one person. It's not going to the 43 others that are hospitalized in the ward. We then tried to counter that, by involving patients in it as well.*
>
> *And that in itself was a great story. But on the other hand, we made the following reflection: can or can't you do this from an ethical point of view? Burden patients with this, following that process together?*
>
> *Also, you could say: let the patients choose for themselves. But the whole ward gets a piece of involvement anyway. Even people who don't choose for it.*" (ward coordinator M8).

Some participants also indicated that certain team members doubted the team's capacity to provide palliative care on the ward. Expert support from external ambulatory palliative care teams within the region was often sought, and this collaboration was unanimously viewed as highly positive. As a psychiatric nurse recalls:

> "*That went very well at the time. You notice that that team really has the expertise to follow people up to the end in the home situation. And then you really feel the support from their expertise: then you really feel: together we can handle this.*" (nurse Z15).

Additionally, having palliative care consultants within the ward or at least within the hospital was seen as good practice. Having someone who performs a liaison function between psychiatry and general care, such as one family physician or an internist, can make a very big difference in the quality of care:

> "*So just to point out that it was somebody who had affinity with that target population. And who actually also trusted us as a team. If we made an assessment at some*

> *point....*
>
> *Also in terms of somatics ... He took that seriously. And he wasn't going to give us short shrift. So it was a very important bridging function.*" (nurse Z2).

Another aspect highly appreciated by caregivers was the temporary deployment of additional staff, for example, from other departments, to support care and provide quality end-of-life care.

> "*So how do we do that? By trying to provide maximum care, and then in the final phase I have to add an extra night shift, for example. You then have to add staff to carry that.*" (hospital manager M3).

Although it was often mentioned that family members are generally not very involved with care users, the loved ones of the care user often became more involved during this phase, leading to positive discussions.

The initiation of palliative care could also lead to ethical dilemmas in some situations, as several caregivers indicated, when the care user, due to their condition (e.g., psychosis), did not recognize the seriousness of the situation and care was refused. In those cases, extensive interdisciplinary discussions, discussions with family members and legal guardian and ethics support were introduced, to reflect on the best way to organize care.

Finally, when healthcare providers were questioned about their experiences with palliative care units in general hospitals, varying experiences emerged. On the one hand, it may be the choice of the care user themselves to be treated there, or the somatic care needs may simply be too complex to address in a psychiatric setting. In such cases, according to some participants, it can be helpful to schedule regular visits from the psychiatric team, or even other care users. As one nurse recalls:

> "*Then we worked out a system that we went there every day. The staff was limited of course. So you don't have as many staff resources. So we couldn't always go ourselves. But also fellow patients then carried that very strongly, and that's actually been a great story as well, I think.*" (nurse Z20).

However, some participants also reported negative experiences and stigma with general hospitals, where insufficient consideration was given to the psychological vulnerability of the care users and insufficient expertise was built around this. One of the caregivers told us:

> "*There is a lot of stigma, even among caregivers. They think, 'it's that drunk again, it won't be that bad.'*" (nurse Z8).

Two caregivers even recall a situation where a person experiencing SPMI was not welcome in the palliative care ward of the general hospital, because this person was on a kind of 'blacklist' or, because the care user was hospitalized already (i.e., a psychiatric hospital) and in a care environment, so a transfer to a palliative care unit was supposedly not needed.

Bereavement care and farewell rituals

The topics of bereavement care was hardly discussed by caregivers or their loved ones, who did show a broad spectrum of religious involvement. The theme was strikingly prevalent, however, in many conversations with caregivers and managers, specifically with regard to the care devoted to organize appropriate farewell rituals after the passing of a care user or resident. An important reason cited for the importance of these rituals of caregivers is the special bond often developed over a long period between the care user and caregiver. Several participants, caregivers as well as care users, describe this bond as "a kind of family". After the passing, the entire team and other care users are often given the opportunity to pay their respects to the departed person. Additionally, a special space is often set up with photos and other mementos, and those involved can, if they wish, write and leave a message or farewell wish.

Often, within teams, debriefings are held to support the care users. It also happens that caregivers, in the absence of involved family members, have to arrange the entire funeral themselves.

> "*For example, I had a client who was really alone. He really had no network at all and he suddenly died. And he got a minimalistic, state provided funeral. But that's really nothing. No letters or cards. That's just a cremation and a scattering. I felt very sorry for the person. And then the organization allowed me to put together a celebration. With cards and a photo and so on. We then held a celebration in the chapel that attracted quite a few people. People who had known him in the past and so on. And that was nice. Then you can share that with others, your grief. And that helps. It's not standard and I don't do that for everyone. But you want something more for that person. They didn't deserve that. I didn't think that was humane. And I think it's the same for my colleagues.*" (therapist Z16).

The role of pastoral/spiritual care workers was also frequently mentioned, particularly regarding their involvement in providing rituals, conversations, and presence with both care users and the team, as well as their role in organizing funerals or prayer services afterward. As one participant told us:

"*That may be very strange, but the pastoral care worker, whether he was involved in the dying process or not, that depended from situation to situation, what the patient's wish was regarding that. Yes. When he was always involved, was afterwards. Because ultimately, people have died, but you're left with a lot of wounds. Within a team, within the patient population. (...) But he managed to institute a very strong ritual to remember the person on the one hand. But on the other hand also to heal those wounds in some way*." (ward coordinator M11).

The use of a palliative care approach

For care many care users, a palliative care approach embodied through the Oyster Care Model brought a sense of safety, being certain that they could stay in a homely and trusted environment, together with the caregivers they trust and like:

"*I am glad that I can stay here. I can always retreat to my own room and find peace. I know that the caregivers are there for me. In the past, I was never sure if I could stay*." (care user P5).

This feeling was shared in some regard by many of the family members, for whom the search for appropriate care had often been a major concern for many years. Many family members indicated that this relief and knowing that they would not be called upon at an unexpected moment (for example, in the case of an incident involving their loved one, such as a car accident, an aggression incident, financial problems or situations caused by substance abuse) was very important.

"*Because that is, in fact, let's say, the search for the family is both challenging and burdensome, as it is difficult for them to find a place and to ensure that their loved ones are in the right place and receiving the proper care*." (brother, F1).

For next of kin, a palliative care approach evokes the image of intensified care, putting comfort first and looking for small steps towards recovery, side by side—also outside the psychiatric hospital:

It really should be possible to invest more in teams that can provide much more intensive post-admission support. Maybe it does exist. But if you see what it represents qualitatively, and there I see a piece that comfort care or what you say. In very small things. In what presents itself day to day. Being there for people and searching together. (mother, F9).

When the advantages and disadvantages of this model were discussed with stakeholders, it became apparent that many had heard of the model but often lacked a deep familiarity with its specifics. Many caregivers identified their own work with some aspects of the model. Most participants associated the model with a focus on the quality of life for the care user and the importance of allowing sufficient time to build a personal bond between the care user and caregiver. One nurse defined the model as follows:

"*I think Oyster Care encompasses a lot of beautiful things: being a nurse, giving warm care and then also thinking, acting and acting ethically toward the patient. Looking at what the patient needs to experience quality, even if they have a very heavy backpack or serious issues. Looking at where we can commit to quality and make each day as beautiful as possible*." (nurse Z6).

Some participants however expressed concerns about the potential unintended association the model might evoke with the dying process and other negative connotations. As a pastoral care worker puts it:

"*I fear it is rather mixed or even has a negative connotation. Because it is something that refers to the end. I think that if that is included or discussed, it is better that other words are used. Because palliative care might also have other connotations. Like, for example, not taking pain seriously. Or, we let the suffering exist based on certain principles. Whereas, of course, in reality, we want something completely different to be heard. But I fear that for too long it has stood for something with a different connotation. So palliative care can be seen as something that stretches a situation that is actually no longer dignified*." (pastoral care worker M12).

Others were worried about its relationship with recovery-oriented care and the importance of still seeking opportunities to move forward, alongside the patient, in their recovery journey. A psychiatrist gave word to her concerns:

"*Oyster to me implies a little too much encapsulation or freezing of the situation. But maybe it's just me misunderstanding the word. But of course this now goes against the way I've worked with so many SPMI patients already. For so many patients, I've often still seen a little more quality of life or at some point an opportunity to do something else that gave a bit more autonomy. Whereas Oyster Care is much more about cocooning. If that's an open cocoon, that's ok with me. If that's a cocoon that people can go to and back out of, that's ok for me.*

Oyster Care, to me however, does not include enough possibility of change. I've had patients who were on a ward for 20 years who went into sheltered living anyway at 50.

> *I'm still so pleased that that worked out. Those people too, life was really different for them. So a lot is still possible.*" (psychiatrist Z22).

Another caregiver said the following about the relationship between Oyster Care and recovery:

> "*Oyster Care is the true recovery for the patients we have. For our patients, Oyster Care is the recovery of the situation as it is at that moment. We have our patients with their issues, and we try to work towards recovery by providing warm care and by being the shell. Sometimes offering a bit more support, and sometimes letting go a little, allowing the patient to exist in the best possible way. It is recovery, but not in the grand sense of the word. We won't be able to fix everything, but we can glue the small cracks in the day.*" (nurse Z5).

Discussion

Below, we will discuss the results of the six subtopics in sequence. Our objective was to better understand the experiences, needs, challenges, and potential ethical dilemmas surrounding end-of-life care for persons experiencing SPMI in Flanders. For each main topic, we will highlight key points for care, emphasizing both best practices and potential pitfalls, and suggest directions for further research.

Advance care planning

One important finding from this study is the significance of conversations about advance care planning with this target group. Previous research has shown that, despite challenges, these conversations are both possible and valuable for persons experiencing SPMI (10). Some participants reported encountering few or no issues with these discussions, and various organizations aim to integrate these conversations more systematically in care settings. However, a substantial number of participants found these conversations difficult. Notably, their attitude may not differ as much from the general population (26). Some participants did not see the conversations as relevant, while certain caregivers questioned the capacity of care users or felt uncomfortable discussing topics such as suffering and dying.

Improving caregiver training to reduce discomfort around these conversations could foster a more open culture. Additionally, the development of task forces to create templates and guidelines for advance care planning discussions, and systematically including such conversations on care agendas, could be beneficial. As several participants suggested, specific triggers—such as a serious illness or death within the care environment—could provide natural opportunities to initiate these discussions. Given that many participants reported facing barriers, it would be useful to explore how communication about illness and dying can be better tailored to this target group, and how role models can be introduced to support these conversations.

Suicidality and euthanasia

Another notable finding is the relatively limited experience with cases of suicide or euthanasia in this target group, despite both topics being frequently mentioned in the interviews. Organizations have implemented policies related to these issues, such as advisory texts and preventive measures. Previous research has shown that suicidality plays a significant role in the deaths of persons experiencing SPMI over their lifetime (27). Some participants in our study did encounter cases of suicidality, but many caregivers may perceive these situations as rare due to their low absolute numbers, which is distinct from the relative figures. It is also possible that rates vary between populations receiving residential care and those who do not. More research regarding this topic in this populations seems warranted.

Several interviewees noted that thoughts of suicide or euthanasia often diminish over time or arise temporarily, especially during conflicts between care users and caregivers about treatment or approach. Some participants suggested that care users' limited cognitive and verbal abilities, or their illness severity, may prevent them from focusing on these topics in care settings. This situation may be comparable to other populations, like persons with dementia or mental disabilities. Others questioned the complexity of the euthanasia procedure, both legal and in practice. This observation accords with another recent study, involving caregivers in the Netherlands (13). While this barrier to access can be problematized on one hand, it can also be argued on the other hand that it is actually beneficial to have a certain level of protection in place for vulnerable groups. On a more positive note, it was suggested that the quality of care and the strong personal bonds between care users and caregivers might improve quality of life, thereby reducing the prominence of these issues. Further research into this topic, e.g., regarding tools that enhance nonverbal communication, seems warranted.

When suicide or euthanasia do become central concerns, they have a significant impact on caregivers. Investments in team meetings, supervision, and moral support, such as through moral deliberation or ethics committee consultations, were cited as good practices. Throughout the interviews, caregivers, experts, managers, relatives, and care users often mentioned organizations such as LEIF, Vonkel, and Reakiro, which focus on making end-of-life issues more discussable and, in the case of the first two, provide support for euthanasia requests. These organizations were regarded as important and positively evaluated. It is crucial for organizations providing care to persons experiencing SPMI to maintain strong collaboration with these initiatives when addressing questions related to medically assisted dying. An open, reflective, and respectful attitude from caregivers was frequently emphasized, although, as noted in other research, views on euthanasia among caregivers and other participants remain divided (28).

Palliative care

Regarding palliative care, there is a notable trend toward enabling care within the care user's familiar (residential care) environment, as long as the care user chooses this option. However, this approach presents challenges, such as resistance from the care team and fellow residents, or from care users who may not fully understand the seriousness of their situation, as well as issues related to knowledge and staffing. We have previously discussed barriers to providing quality palliative care in psychiatric hospitals in Flanders, Belgium, and the potential role of ethics support (29). From our qualitative study, several good practices emerge. First, close collaboration with external palliative care networks can support local caregivers and provide training on issues such as pain management. Second, investing in experienced internal palliative care consultants within psychiatric facilities—essentially a palliative support team—is essential. In many cases, lack of knowledge leads to caregiver anxiety and suboptimal care. In organizations with such teams, participants spoke highly of them. Third, providing additional staff support during palliative care can relieve the team, allowing for greater presence during the final phase of life and ensuring continuity of care for other users. Lastly, better coordination between mental healthcare organizations and general hospitals or palliative care units—such as through a liaison person—could help reduce stigma and barriers between healthcare sectors, improving access to quality palliative care for vulnerable groups. Both care organizations and government funding bodies play crucial roles in addressing these issues.

Bereavement care and farewell rituals

Many participants emphasized the importance of bereavement care and farewell rituals, which likely stem from the strong bonds between care users and caregivers. This bond was frequently cited as both a source of strength and a cause of exhaustion. We also observed that spiritual care workers and pastoral staff provide significant support for both care users and teams during and after the dying process. Family members, even if not heavily involved during the care user's stay, are often engaged in the final stages of life, leading to positive conversations.

A palliative care approach

Finally, we reflect on the "Oyster Care" Model, which translates the palliative care approach for this target group in Flanders. While caregivers often associate the model with positive aspects, such as quality of life and building personal bonds, it is not always well understood. Positive associations are linked to the quality of life, while negative associations focus on a perceived lack of attention to recovery. A potential policy recommendation is for organizations working with the model to invest in greater education about it, and elaborate on its relationship with recovery-oriented care. Further reflection could also focus on the specific relationship between this approach and the improvement of quality of life on one hand, and (chronic) suicidality, physician-assisted death, and euthanasia on the other.

Strengths and limitations of the study

One of the strengths of this study is the inclusion of a broad range of stakeholders, including care users, their relatives, caregivers, managers, and experts in palliative and psychiatric care. This comprehensive approach allows for a nuanced understanding of the experiences, needs, and ethical dilemmas associated with end-of-life care for persons experiencing SPMI. By capturing the perspectives of a large group all relevant stakeholders, the study provides a well-rounded picture of the current state of care in Flanders and offers valuable insights for improving care at multiple levels—from individual care interactions to institutional policies.

Another strength lies in the study's focus on a highly vulnerable and often overlooked population. End-of-life care for persons experiencing SPMI remains an underexplored area in both psychiatric and palliative care literature. This study contributes significantly to filling that gap by highlighting the unique challenges and opportunities involved in providing compassionate, ethical care to persons experiencing SPMI at the end of their lives. The ethical dilemmas surrounding euthanasia, advance care planning, and palliative care in psychiatric settings are especially valuable for shaping future research and policy development.

However, the study is not without limitations. First, it is geographically limited to Flanders, Belgium, meaning that its findings may not be generalizable to other regions or countries with different legal, cultural, or healthcare frameworks. The unique legal landscape in Belgium, particularly regarding euthanasia, may not reflect the experiences of other countries where assisted dying is not legally permitted.

Another limitation is the relatively small sample size for certain subgroups, particularly care users and their relatives. While the study reached thematic saturation, the voices of care users may be underrepresented, especially given the reluctance of many care users to discuss end-of-life issues in depth. It was notable that, despite participating voluntarily and being informed about the topics to be discussed, care users often preferred to touch only briefly on the subject of end-of-life. During the interviews, they tended to focus more on daily care, hobbies, and social relationships. This could lead to a bias in the findings, where the perspectives of caregivers and experts may carry more weight. Future research should aim to engage a larger and more diverse group of care users to ensure their voices are more prominently included. In general, we also observed that the results for caregivers and managers/experts were closely aligned, as the latter are often deeply involved in care and frequently have experience working as caregivers themselves; some caregivers also have (limited) management responsibilities.

Additionally, the study relied on semi-structured interviews, which, while valuable for exploring complex issues, may limit the comparability of responses across participants. Participants may have interpreted questions differently, leading to variations in the depth and type of responses provided. A more structured approach to data collection, or the inclusion of additional qualitative methods such as focus groups, could have enhanced the richness of the data.

Finally, the study primarily involved residential care settings, meaning that the experiences of persons experiencing SPMI in non-residential or community-based settings may not be fully captured. This limits the study's ability to provide a comprehensive overview of end-of-life care for all persons experiencing SPMI, regardless of care setting. Future studies should aim to include a broader range of care environments to ensure that the findings are applicable to all persons experiencing SPMI, regardless of their living situation.

Conclusions

This study provides critical insights into the complexities of end-of-life care for persons experiencing SPMI. It highlights the significant challenges faced by both care users and providers in navigating ethical, emotional, and practical aspects of care. The need for structured and proactive advance care planning is evident, as many care users are hesitant or ill-prepared to engage in these discussions, while caregivers often struggle with initiating them. Standardizing these conversations could help ensure that the wishes of persons experiencing SPMI are respected and that care is aligned with their needs and preferences.

In addition, the findings emphasize the importance of a tailored approach to suicide prevention. While the risk of completed suicides may be lower in some care settings, the potential for suicidal ideation remains significant, requiring targeted interventions and support systems that take into account the unique characteristics of this population.

The study also sheds light on the complex and ethically charged issue of euthanasia. While legal frameworks in Belgium allow for euthanasia based on psychiatric suffering, the emotional and ethical burden this places on caregivers and care users cannot be overstated. Greater ethical support and clearer guidelines are needed to navigate these difficult cases.

Moreover, the provision of palliative care in familiar psychiatric settings is strongly preferred by care users and caregivers alike, but the lack of somatic expertise and staffing shortages pose significant challenges. Collaborative efforts with external palliative care teams and the strategic use of additional resources are necessary to ensure that persons experiencing SPMI receive high-quality palliative care and stigma is reduced.

The study also highlights the role of bereavement care and farewell rituals in supporting both care users and caregivers during times of loss. These rituals, facilitated by pastoral care workers, provide closure and help prevent emotional burnout among caregivers.

Finally, this study also points out potential benefits and pitfalls regarding the use of a palliative care approach for this target population. Although most actors are positive about this model, we see that there is still much ambiguity surrounding the concept, and questions regarding its relationship with the recovery approach.

In conclusion, addressing the end-of-life care needs of persons experiencing SPMI requires a holistic, compassionate, and ethically grounded approach. Policy-wise, more attention needs to be given to the topic of end-of-life care in mental healthcare, where it clearly receives less notice than in somatic medicine. In particular, advance care planning, palliative care, and palliative care models like Oyster Care deserve more attention in policy, practice, and scientific research, as the current focus is often primarily on physician assisted death and euthanasia. By focusing on the unique challenges this population faces and fostering collaboration between mental health and palliative care providers, we can work towards ensuring that persons experiencing SPMI receive dignified, respectful, and high-quality care in their final stages of life.

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Footnote

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