Society of Medical Education & Research

Ethical Challenges in End-of-Life Care for Individuals with Severe and Persistent Mental Illness: A Qualitative Study

Vanessa Machado[1,2,3], Carlos Laranjeira[3,4,5], Ana Sintra Delgado[3,4,6], Maria Pia Ferraz[3,4], Ana Botelho[2*]

[1]Psychiatric and Mental Health Service, Local Health Unit of the Leiria Region—Hospital of Santo André, Rua das Olhalvas, 2410-197 Leiria, Portugal.
[2]Faculty of Medicine, University of Porto, 4200-319 Porto, Portugal.
[3]Centre for Innovative Care and Health Technology (ciTechCare), Rua de Santo André-66-68, Campus 5, 13 Polytechnic University of Leiria, 2410-541 Leiria, Portugal.
[4]School of Health Sciences, Polytechnic University of Leiria, Campus 2—Morro do Lena, Alto do Vieiro—Apart. 4137, 2411-901 Leiria, Portugal.
[5]Comprehensive Health Research Centre (CHRC), University of Évora, 7000-801 Évora, Portugal.
[6]Center for Health Technology and Services Research (CINTESIS), NursID, University of Porto, 4200-450 Porto, Portugal.

*E-mail ✉ Anabotelho@gmail.com

Abstract

People living with severe and persistent mental illness (SPMI) constitute a small yet highly vulnerable group within mental health care. Their care raises complex ethical challenges due to factors such as the intensity of their conditions, limited social support, communication difficulties, impaired decision-making, and, occasionally, disruptive behaviors. Despite these challenges, research on ethical issues in this population remains limited. This study explores the ethical considerations involved in providing care to individuals with SPMI, including end-of-life care. It examines the types of ethical dilemmas that arise, approaches used by care teams, decision-making processes, and ethical frameworks or practices applied in real-world settings. We conducted 73 qualitative interviews with a diverse group of participants, including care recipients, family members, caregivers, care managers, and subject-matter experts in the Flemish region of Belgium. The interviews were analyzed using content analysis to identify recurring themes and ethical practices. Although many institutions have formal ethics resources, such as guidelines or committees, these are often unfamiliar to frontline staff or perceived as difficult to access. Ethical dilemmas are mostly managed at the team level, with some organizations employing ethics reference persons, peer support mechanisms, or informal discussion forums ("ethics pubs"). Euthanasia was the most frequently discussed ethical issue. Other concerns included neglect in home care, delays in palliative care initiation, and safeguarding autonomy. Resource allocation, both at organizational and societal levels, also emerged as a significant concern. Caregivers reported tensions between individualized care and institutional rules, while families emphasized collective responsibility in making care decisions. Providing ethical care for individuals with SPMI requires careful attention to autonomy, collaboration, and fair resource distribution. Enhancing access to ethical support structures and adopting tailored approaches can help reconcile recovery-focused and palliative care needs, ensuring dignity and respect for this vulnerable population.

Keywords: Severe and persistent mental illness (SPMI), Ethics, End-of-life care

Introduction

Individuals living with severe and persistent mental illness (SPMI) represent a small but highly vulnerable population within mental health care. While there is no

universally accepted definition, SPMI is often described using the "3 D's"—disease, duration, and disability [1]. This group includes people diagnosed with severe conditions such as schizophrenia, bipolar disorder, or major depression, which typically follow a chronic course and may respond minimally—or sometimes negatively—to medical and therapeutic interventions [2]. Beyond the symptoms of illness itself, the resulting disabilities significantly affect daily functioning and quality of life. Globally, estimates suggest that around 1% of the population experience SPMI, depending on the criteria applied [3]. Individuals with SPMI also face markedly reduced life expectancy—up to 15 years shorter than the general population—largely due to severe comorbid somatic conditions such as obesity or dysphagia [4–7]. These factors underscore the importance of considering end-of-life care for this population.

Interest in end-of-life care for persons with SPMI has grown in recent years. Central topics include the development of "palliative psychiatry" [6, 8], the provision of standard palliative care [9, 10], the use of a broader palliative care approach [11, 12], and challenges related to medical assistance in dying [13]. While some concepts, like palliative care, are directly associated with care at the end of life, others, such as a palliative care approach, emphasize the underlying philosophy guiding care provision.

Delivering high-quality care to individuals with SPMI—both generally and at the end of life—raises complex ethical issues, including assessing decision-making capacity, managing disruptive behavior, addressing self-stigma, and navigating fragmented care systems [14]. Ethics consultations can help teams, patients, and families manage these dilemmas by clarifying ethical concerns, exploring values, and guiding decision-making, ultimately supporting patient-centered and ethically sound care.

In Belgium, as elsewhere, hospitals—including psychiatric institutions—are legally required to maintain ethics committees. These bodies typically provide guidance on ethical issues in care, review research involving human participants, and offer advice on individual cases [15]. Within hospitals or collaborative facility networks, ethics experts may coordinate ethics activities, provide training, and facilitate structured moral case deliberations, where teams discuss ethical issues using specific methods under a trained facilitator [16].

Despite growing literature on ethical challenges and end-of-life care in SPMI, few studies directly involve care users, their families, or frontline caregivers [14, 17]. This study addresses this gap by examining the experiences, needs, and expectations of care users, relatives, and caregivers, as well as the perspectives of managers and experts in ethics and palliative care.

In Flanders, these issues are particularly pressing due to the legal framework allowing euthanasia for unbearable and irremediable psychiatric suffering since 2002 [18] and the development of the Oyster Care Model. Belgium is among the few countries where psychiatric conditions may legally justify euthanasia. In practice, however, numerous ethical, legal, and medical questions remain, including whether a psychiatric condition can truly be considered irremediable and how the disorder affects decision-making capacity for euthanasia [19, 20]. Studies indicate that many psychiatrists approach euthanasia requests cautiously, with concerns about legal liability and professional responsibility influencing practice [21]. Consequently, the number of euthanasia cases for psychiatric reasons remains small, although it is gradually increasing [22].

Methods

Interviews lasted between half an hour and over two hours, averaging around 60 minutes. Participants were purposefully recruited from seven mental health organizations across the five provinces of Flanders, Belgium, covering a variety of care settings, including residential facilities, assisted living, and outpatient services. Recruitment was coordinated through designated contacts at each organization (e.g., head nurses, therapists, or physicians), and interested participants reached out to the research team directly to schedule interviews. Only two care users withdrew, reporting difficulty in sharing their experiences. Some participants chose to have a trustee present during the interviews.

Ethical approval was secured from both central and local ethics committees associated with the participating facilities. All participants provided informed consent prior to participation. Interviews were audio-recorded, fully transcribed, and pseudonymized. Researchers LM and MV independently analyzed the transcripts using a mix of inductive and deductive thematic content analysis in Qualicoder software [18]. Disagreements in coding were resolved through discussion, with input from the

study supervisor AL. Data collection continued until thematic saturation was achieved, although additional interviews were conducted to ensure a diverse sample in terms of age, gender, and professional background. In two cases, participants requested transcripts for review, but no feedback was returned. Limited post-interview notes were taken but were not used in the analysis.

Results

While findings on end-of-life care are reported elsewhere [23], this paper focuses specifically on ethical aspects of care, which emerged in two main areas: 1) ethics support, and 2) substantive ethical dilemmas. The study included 73 participants: 17 care users, 12 family members, 24 caregivers, and 20 managers or experts. Demographic details are provided in Supplementary Appendix S1.

Ethics support at organizational and team levels

All participating facilities offered some form of ethics support. Each hospital maintained a legally required ethics committee and employed an ethics expert. Written guidelines, especially regarding euthanasia, were available; however, these were primarily utilized by management or staff with specialized ethics or spiritual training. Caregivers and family members rarely referenced these resources, and when they did, it was typically to clarify procedural steps for euthanasia in cases of unbearable psychiatric suffering.

Despite frequent encounters with ethical dilemmas, consultation with committees or ethics experts was uncommon. Several reasons emerged: some participants had not considered contacting the committee, others addressed ethical concerns within team meetings instead, and in some cases, the responsibility for formal consultation was assigned to a manager or physician, delaying engagement. Additionally, the perceived slow response time from committees made them less practical for urgent ethical issues.

Barriers and facilitators of ethics consultation

Some caregivers highlighted challenges in accessing ethics support, particularly in urgent or complex cases. For instance, one nurse described a situation involving a patient with a tumor who refused treatment. The nurse explained that while medical procedures like a biopsy were necessary, legal and ethical considerations, along with limited availability of the ethics committee and

physicians, slowed decision-making. The nurse noted the difficulty in balancing patient rights with timely medical intervention:

"We currently have a patient with a tumor who refuses treatment, which makes things very challenging. A biopsy is needed, but we don't yet know whether the tumor is benign or malignant. Back when I started, coercion was more common, but now that isn't possible. We have an ethics committee, yet we're still waiting for guidance. Our doctor is busy, and the matter has to be escalated to the central organization's ethics team. Questions arise: can we sedate the patient to proceed, or must it be voluntary? These delays mean the tumor continues to grow, though the patient remains stable for now." (nurse).

Several physicians reported feeling isolated when navigating ethical dilemmas, despite occasional opportunities for peer discussion: "You often have to make decisions on your own. Sometimes intervision sessions are organized, which can be helpful, but for many patients, you are left to manage alone." (psychiatrist).

Despite these obstacles, there were instances where ethics consultation proved beneficial. Caregivers recalled cases in which input from an ethics expert or committee provided fresh perspectives, especially in complex scenarios. Euthanasia was the most frequently discussed topic, although other dilemmas, such as refusal of care or organizational policies, were also raised: "In situations where we've reached our limits, consultation with the ethicist brings completely new ideas and opens an honest discussion. Without this input, we might rely solely on rational or pragmatic thinking, but the conversation becomes richer with someone who is not involved in daily care." (nurse).

Family members also acknowledged the value of ethics committees, citing cases where guidance helped navigate particularly complicated end-of-life trajectories.

Ethics support initiatives at care facilities

Facilities in the study have implemented a range of measures to integrate ethics into daily practice. Some organizations appointed departmental ethics focal points or reference persons who coordinate moral case deliberation and peer consultation sessions. These individuals often receive additional training in ethics and facilitate structured discussions among staff: "For our staff, I lead a weekly session called 'time for

ourselves,' where team members share struggles, reflections, and positive experiences. It can cover anything, from challenging patient interactions to moments of joy or growth. It helps the team process experiences collectively." (therapist).

In addition, some organizations provide voluntary peer support for colleagues after particularly difficult events, such as patient aggression or suicides. Working groups within facilities also address specific ethical topics, including end-of-life care, advance care planning, and organizational policies. These groups aim to reduce barriers to ethics support by bridging everyday care with formal ethics committees. One facility hosted an "ethics pub," a regular informal forum where staff, patients, and families could discuss ethical issues openly under the guidance of an ethics expert.

Ethical themes in care for persons experiencing SPMI

The most frequently discussed ethical theme in this study was euthanasia. Although care users and family members occasionally mentioned it, caregivers and managers raised it most often. Ethical dilemmas around euthanasia were multifaceted, including questions about the patient's consideration of the request, its acceptability, its emotional impact on staff, and the preferred setting for its execution:

"With this patient, I felt torn; she was so young with so much potential, yet her suffering was intense." (counsellor).

"A 30-year-old woman requested euthanasia. Initially, we thought we could buy time to see if she changed her mind, but the request persisted, so we explored it seriously." (therapist).

"Linking euthanasia with the ward setting is difficult. It gives the impression that the patient was 'put to sleep' here, but dying in a familiar environment can also be more comforting for the individual." (nurse).

Ethical challenges in end-of-life care, care refusal, resource allocation, and the oyster care model

Physicians often described euthanasia as a particularly difficult topic, though some expressed understanding of why patients with SPMI might request it. One psychiatrist reflected:

"I struggle deeply with euthanasia. I feel that the patient is seeking someone who believes in their life's value and does not give up on them."

Another physician noted:

"After so many years of suffering, I can understand why a person might want to end their life. Perhaps I also have a role to play in supporting that decision."

These discussions frequently revolved around the tension between respecting patient autonomy and safeguarding vulnerable lives while ensuring quality care. Similar dilemmas arose in situations where patients with life-threatening conditions refused treatment. For example, a psychologist recounted a case where a patient declined a DNR order because he did not grasp the severity of his condition. In such cases, ethics experts were consulted to involve the team, family, and legal guardians in decision-making.

Refusal of care also emerged as a recurring ethical concern beyond end-of-life contexts. A psychiatrist described the case of a patient with chronic psychiatric and substance use conditions who consistently refused home visits and support from the mobile care team. Despite repeated attempts to engage the patient, he ultimately passed away, highlighting the ethical tension between respecting patient autonomy and providing necessary care:

"These situations are frequent. We try to intervene, but ultimately the patient can make their own decisions. It raises the question of whether additional independent oversight could be useful for care teams working with persons experiencing SPMI."

Resource allocation was another key ethical theme, particularly in palliative scenarios. One ward coordinator explained the dilemma of dedicating significant time and attention to a single patient, potentially limiting support for other residents:

"A lot of effort goes into one patient, which reduces time for the others. We try to involve the patients themselves in the process, but ethically it remains challenging to balance individual and collective needs."

Palliative sedation also arose as an ethically complex intervention. A case involving a woman with severe juvenile dementia illustrated how ethics committee guidance was crucial. Palliative sedation was ultimately chosen due to her extreme suffering and isolation, which had a profound emotional impact on both family members and caregivers.

Ethical questions were also raised in relation to the Oyster Care model, particularly regarding adherence to institutional rules, balancing caregiver proximity and distance, and tailoring care to individual needs. Some staff expressed concerns about the model's divergence from recovery-oriented care principles:

"Many of our approaches conflict with hospital policies or standard quality procedures in other departments." (psychologist)

"I sometimes feel I am exceeding my own professional boundaries, though the special bonds we form with patients make it difficult not to." (nurse)

"'Oyster Care' seems to focus heavily on cocooning. For me, an open cocoon is acceptable—patients can retreat and return—but too much restriction may reduce their autonomy." (psychiatrist)

Interestingly, these perspectives were echoed by some persons experiencing SPMI themselves, who occasionally reported feeling under-stimulated or excluded in communal settings:

"There isn't much for me to do here. Caregivers often spend time with each other, and I don't get to engage with other residents meaningfully." (care user)

Ethical responsibility in care for persons experiencing SPMI

Participants highlighted that caring for persons with SPMI, as a particularly vulnerable group, is an ethical duty. Many emphasized that such care should not be guided by market principles or cost-benefit calculations. Instead, society bears a moral obligation to provide support, regardless of the associated "costs."

This perspective closely aligns with the experiences shared by family members, who often described the process of securing appropriate care as challenging and emotionally taxing. Several noted a strong desire for relief from the exclusive responsibility of caring for their relatives with SPMI. One mother explained: "Finding suitable care for my son was incredibly difficult, even though I am familiar with the healthcare system. It took years. I no longer wanted to carry this responsibility alone. What affected me deeply was how many people, including family members, failed to understand the situation and eventually stopped contacting me."

Discussion

Ethics support systems

Ethics are a foundational aspect of care at organizational, team, and individual levels. Ethical and professional responsibilities are embedded in healthcare practice from the outset, reflected in guiding principles such as the Hippocratic Oath for physicians, the Florence Nightingale Pledge for nurses, and Beauchamp and Childress' four principles of biomedical ethics [24].

Our study found that all participating facilities had established ethics structures. Each was connected to a local ethics committee and had a central expert overseeing ethics policies, often supported by advisory documents. Despite these frameworks, staff and other stakeholders were not always aware of or actively utilizing these resources. While some facilities employed reference persons, working groups, or other accessible ethics initiatives, significant barriers to consultation remained, even in complex or urgent cases. Many participants indicated that informal team discussions were the primary method for resolving ethical issues, though some, particularly physicians, reported feeling isolated.

These findings suggest that organizations should continue efforts to reduce obstacles to ethical discussion, for instance, by embedding ethics reference roles within teams, fostering in-team ethics expertise, and providing informal opportunities for reflection and discussion. Reference persons and working groups can serve as bridges between everyday care practices and formal ethics committees, enhancing mutual functioning and awareness. Promoting awareness and visibility of these initiatives may further improve utilization.

Ethical dilemmas and themes in SPMI Care

As the study explored both end-of-life care and broader ethical concerns, it is unsurprising that many dilemmas identified by participants were linked to palliative and end-of-life situations. Euthanasia emerged as the most prominent theme. Its high visibility in public and media discourse may contribute to its prominence in care settings. Requests for euthanasia often had a strong impact on care teams, prompting ethical deliberation or peer consultation. Attitudes among participants varied, with some caregivers struggling to reconcile the request with their professional and personal values. Teams frequently sought guidance from specialized organizations such as LEIF, Vonkel, or Reakiro to navigate these complex cases.

The findings indicate that euthanasia, consistent with other research, remains a divisive issue with substantial emotional and ethical implications for caregivers [20, 21]. Recommendations include enhancing understanding of relevant legislation, fostering communication among

all stakeholders, and providing structured ethics support to balance patient autonomy with the duty of care.

Beyond euthanasia, ethical challenges also arose in palliative care contexts. Psychiatric facilities are sometimes insufficiently equipped to provide optimal support for palliative patients, raising questions about fairness in resource allocation and the involvement of other care users. Collaborative approaches, including partnership with mobile palliative care teams, development of somatic and palliative care expertise within psychiatric facilities, and temporary additional personnel, were seen as potential solutions. Physicians, such as general practitioners or specialists in somatic care, can play a critical bridging role in supporting these processes [25, 26].

Ethical considerations in palliative care and the oyster care model

Some participants described instances where uncertainty existed around whether to begin palliative care or proceed with palliative sedation for a family member. These cases indicate that knowledge about palliative care in mental health settings may sometimes be limited, but they also highlight the central role of ethical deliberation in decision-making. End-of-life decisions for individuals with SPMI are particularly sensitive, as difficulties in communication and limited decision-making capacity can add complexity [9].

While many ethical challenges focused on end-of-life care, other dilemmas were also highlighted. Caregivers often felt frustrated when individuals refused or neglected essential care, which mirrors findings from international research [9].

Regarding the Oyster Care model—a long-term care approach for persons with SPMI informed by palliative care principles such as creativity and quality of life—four main ethical subthemes emerged.

The first relates to societal responsibility: participants emphasized that caring for highly vulnerable individuals constitutes a moral duty. Some viewed the framing of care within a strict "market logic" as inappropriate or ethically concerning.

The second subtheme involves the tension between institutional rules and individualized care. Participants questioned how far regulations could be adapted or bypassed to enable creative, personalized interventions consistent with a palliative approach.

The third subtheme centers on the relationship between caregivers and care users. Given the long-term nature of SPMI care, relationships often become close, creating potential challenges with maintaining professional boundaries and managing disruptive behaviors, including conflicts between residents.

The fourth subtheme concerns the adequacy of care and the extent to which it meets the specific needs and preferences of care users. Autonomy was highlighted, with some participants noting that care was not sufficiently tailored. Family members frequently described the process of finding appropriate care as burdensome and expressed a desire to share or relieve their caregiving responsibilities.

Overall, these findings indicate the need for further examination of the Oyster Care model, particularly regarding its alignment with recovery-oriented principles and applicable regulations. Ethics support at the local level—through guidance on departmental rules, client participation, treatment planning, and behavioral management—warrants continued attention.

Strengths and limitations

A key strength of this study is its inclusion of multiple stakeholders, including care users, family members, caregivers, managers, and palliative and psychiatric care experts. This broad approach provides a nuanced understanding of the experiences, needs, and ethical issues surrounding care for persons with SPMI, both in routine and end-of-life contexts. By capturing diverse perspectives, the study sheds light on care practices in Flanders and offers insights that can inform improvements at individual, team, and organizational levels.

Another strength is the focus on a population that is often overlooked. Ethical issues and end-of-life care for individuals with SPMI remain underexplored, and this study contributes valuable knowledge on topics such as euthanasia, advance care planning, Oyster Care, and palliative approaches within psychiatric settings.

The study has limitations. First, its geographic focus on Flanders, Belgium, may reduce generalizability to regions with different cultural, legal, or healthcare contexts. The Belgian euthanasia framework is unique and may not reflect practices elsewhere.

Second, the sample size for care users and relatives was limited. Although thematic saturation was achieved, their perspectives may be underrepresented, as care users often

preferred to focus on daily activities rather than end-of-life discussions. In contrast, caregivers and experts may dominate the ethical discourse, potentially biasing the findings. Future research should engage larger and more diverse care user populations to amplify their voices.

Third, semi-structured interviews, while valuable for exploring complex issues, may have resulted in variability in responses due to differing interpretations of questions. Incorporating additional qualitative methods, such as focus groups, could strengthen the depth and comparability of findings.

Finally, the study predominantly examined residential care settings. Experiences in community-based or nonresidential contexts may differ, limiting the generalizability of findings. Future studies should include a broader range of care environments to capture a more comprehensive picture of care for persons with SPMI.

Ethical considerations in palliative care and the oyster care model

Some participants described instances where uncertainty existed around whether to begin palliative care or proceed with palliative sedation for a family member. These cases indicate that knowledge about palliative care in mental health settings may sometimes be limited, but they also highlight the central role of ethical deliberation in decision-making. End-of-life decisions for individuals with SPMI are particularly sensitive, as difficulties in communication and limited decision-making capacity can add complexity [9].

While many ethical challenges focused on end-of-life care, other dilemmas were also highlighted. Caregivers often felt frustrated when individuals refused or neglected essential care, which mirrors findings from international research [9].

Regarding the Oyster Care model—a long-term care approach for persons with SPMI informed by palliative care principles such as creativity and quality of life—four main ethical subthemes emerged.

The first relates to societal responsibility: participants emphasized that caring for highly vulnerable individuals constitutes a moral duty. Some viewed the framing of care within a strict "market logic" as inappropriate or ethically concerning.

The second subtheme involves the tension between institutional rules and individualized care. Participants questioned how far regulations could be adapted or bypassed to enable creative, personalized interventions consistent with a palliative approach.

The third subtheme centers on the relationship between caregivers and care users. Given the long-term nature of SPMI care, relationships often become close, creating potential challenges with maintaining professional boundaries and managing disruptive behaviors, including conflicts between residents.

The fourth subtheme concerns the adequacy of care and the extent to which it meets the specific needs and preferences of care users. Autonomy was highlighted, with some participants noting that care was not sufficiently tailored. Family members frequently described the process of finding appropriate care as burdensome and expressed a desire to share or relieve their caregiving responsibilities.

Overall, these findings indicate the need for further examination of the Oyster Care model, particularly regarding its alignment with recovery-oriented principles and applicable regulations. Ethics support at the local level—through guidance on departmental rules, client participation, treatment planning, and behavioral management—warrants continued attention.

Strengths and limitations

A key strength of this study is its inclusion of multiple stakeholders, including care users, family members, caregivers, managers, and palliative and psychiatric care experts. This broad approach provides a nuanced understanding of the experiences, needs, and ethical issues surrounding care for persons with SPMI, both in routine and end-of-life contexts. By capturing diverse perspectives, the study sheds light on care practices in Flanders and offers insights that can inform improvements at individual, team, and organizational levels.

Another strength is the focus on a population that is often overlooked. Ethical issues and end-of-life care for individuals with SPMI remain underexplored, and this study contributes valuable knowledge on topics such as euthanasia, advance care planning, Oyster Care, and palliative approaches within psychiatric settings.

The study has limitations. First, its geographic focus on Flanders, Belgium, may reduce generalizability to regions with different cultural, legal, or healthcare contexts. The Belgian euthanasia framework is unique and may not reflect practices elsewhere.

Second, the sample size for care users and relatives was limited. Although thematic saturation was achieved, their perspectives may be underrepresented, as care users often preferred to focus on daily activities rather than end-of-life discussions. In contrast, caregivers and experts may dominate the ethical discourse, potentially biasing the findings. Future research should engage larger and more diverse care user populations to amplify their voices.

Third, semi-structured interviews, while valuable for exploring complex issues, may have resulted in variability in responses due to differing interpretations of questions. Incorporating additional qualitative methods, such as focus groups, could strengthen the depth and comparability of findings.

Finally, the study predominantly examined residential care settings. Experiences in community-based or nonresidential contexts may differ, limiting the generalizability of findings. Future studies should include a broader range of care environments to capture a more comprehensive picture of care for persons with SPMI.

References

1. Zumstein N, Riese F. Defining severe and persistent mental Illness—a pragmatic utility concept analysis. Front Psychiatry. 2020;11.
2. Coulter A. Schuermeyer, Isabel, Sola, Christopher. Evaluating ineffective treatments: A proposed model for discussing futility in psychiatric illness. Harv Rev Psychiatry. 2021;29(3):240–5.
3. James S, Abate D, Abate K, Abay S, Abbafati C, Abbasi N, et al. Global, regional, and National incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the global burden of disease study 2017. Lancet. 2018;392:1789–858.
4. De Hert M, Cohen D, Bobes J, Cetkovich-Bakmas M, Leucht S, Ndetei DM, et al. Physical illness in patients with severe mental disorders. Ii. Barriers to care, monitoring and treatment guidelines, plus recommendations at the system and individual level. World Psychiatry. 2011;10(2):138–51.
5. Donald EE, Stajduhar KI. A scoping review of palliative care for persons with severe persistent mental illness. Palliat Support Care. 2019;17(4):479–87.
6. Trachsel M, Irwin SA, Biller-Andorno N, Hoff P, Riese F. Palliative psychiatry for severe and persistent mental illness. Lancet Psychiatry. 2016;3(3):200–200.
7. Woods A, Willison K, Kington C, Gavin A. Palliative care for people with severe persistent mental illness: A review of the literature. Can J Psychiatry. 2008;53(11):725–36.
8. Levitt S, Cooper RB, Gupta M, Kirby J, Panko L, Rosenbaum D, et al. Palliative psychiatry: research, clinical, and educational priorities. Annals Palliat Med. 2024;13(3):542–57.
9. Butler H, O' Brien AJ. Access to specialist palliative care services by people with severe and persistent mental illness: A retrospective cohort study. Int J Ment Health Nurs. 2018;27(2):737–46.
10. Ebenau AF, Dijkstra BAG, Huurne C ter, Hasselaar GJ, Vissers KCP, Groot CM. palliative care for patients with substance use disorder and multiple problems: a qualitative study on experiences of healthcare professionals, volunteers and experts-by-experience. Bmc Palliat Care. 2020;19(1):8–8.
11. Decorte I, Verfaillie F, Moureau L, Meynendonckx S, Ballaer KV, Geest ID et al. Oyster care: an innovative palliative approach towards SPMI patients. Front Psychiatry. 2020;11.
12. Strand M, Sjöstrand M, Lindblad A. A palliative care approach in psychiatry: clinical implications. BMC Med Ethics. 2020;21(1):29–8.
13. van Veen SMP, Ruissen AM, Beekman ATF, Evans N, Widdershoven GAM. Establishing irremediable psychiatric suffering in the context of medical assistance in dying in the Netherlands: A qualitative study. Can Med Association J (CMAJ). 2022;194(13):E485–91.
14. Moureau L, Verhofstadt M, Liégeois A. Mapping the ethical aspects in end-of-life care for persons with a severe and persistent mental illness: A scoping review of the literature. Front Psychiatry. 2023;14:1094038–1094038.
15. Koninklijk besluit (1994, 12 augustus) tot wijziging van het koninklijk besluit van 23 oktober 1964 tot

bepaling van de normen die door de ziekenhuizen en hun diensten moeten worden nageleefd. Belgisch Staatsblad, 27 september 1994. [Internet]. Available from: http://www.ejustice.just.fgov.be/cgi_loi/c hange_lg.pl?language=nl&la=N&cn= 1994081264&table_name = wet.

16. What is Moral Case Deliberation [Internet], Amsterdam UMC. Available from: https://www.vumc.nl/research/ethiek-recht-humaniora/dienstverlening-sup port/ethiek-support-ethics-support/wat-is-moreel-beraad-what-is-moral-case-deliberation.htm#:~:text=Een%20Moreel%20Beraa d%20is%20een,met%20 behulp%20van%20een%20gespreksleider

17. Carlsson IM, Blomqvist M, Jormfeldt H. Ethical and methodological issues in qualitative studies involving people with severe and persistent mental illness such as schizophrenia and other psychotic conditions: A critical review. Int J Qualitative Stud Health Well-Being. 2017;12(Suppl 2):1–10.

18. Verhofstadt M, Pardon K, Audenaert K, Deliens L, Mortier F, Liégeois A, et al. Why adults with psychiatric conditions request euthanasia: A qualitative interview study of life experiences, motives and preventive factors. J Psychiatr Res. 2021;144:158–67.

19. Verhofstadt M, Moureau L, Pardon K, Liegeois A. Ethical perspectives regarding euthanasia, including in the context of adult psychiatry: A qualitative interview study among healthcare workers in Belgium. BMC Med Ethics. 2024;25:60.

20. Nicolini ME, Kim SYH, Churchill ME, Gastmans C. Should euthanasia and assisted suicide for psychiatric disorders be permitted? A systematic review of reasons. Psychol Med. 2020;50(8):1241–56.

21. Verhofstadt M, Audenaert K, Van Den Broeck K, Deliens L, Mortier F, Titeca K, et al. Belgian psychiatrists' attitudes towards, and readiness to engage in, euthanasia assessment procedures with adults with psychiatric conditions: A survey. BMC Psychiatry. 2020;20(1):374–374.

22. EUTHANASIE – Cijfers. van 2023 [Internet]. FCEE; Available from: https://overle gorganen.gezondheid.belgie.be/nl/documenten/pers bericht-fcee-euthanasi e-cijfers-van-2023

23. Moureau L, Verhofstadt M, Hoe CV, Vandenberghe J, Van Audenhove C, Liégeois A. Discussing end-of-life care for persons experiencing severe and persistent mental illness: A qualitative study among stakeholders in Flanders. Annals Palliat Med. 2025;14:114–27.

24. Beauchamp TL, Childress JF. Principles of biomedical ethics. 8th ed. New York: Oxford University Press; 2019.

25. den Boer K, de Veer AJE, Schoonmade LJ, Verhaegh KJ, van Meijel B, Francke AL. A systematic review of palliative care tools and interventions for people with severe mental illness. BMC Psychiatry. 2019;19(1):106.

26. Moureau L, Tansens A, Desimpele L, Verdeé T, Delepeire J. Omgaan Met Zorgweigering Bij Een persoon Met Een Ernstige psychiatrische Aandoening En Een Levensbedreigende ziekte: Een casusbespreking. Tijdschrift Voor Geneeskunde En Gezondheidszorg. 2024;80:156–66.