

Ensuring High Quality Oyster Care for People Experiencing Severe and Persistent Mental Illness – A Three-Phase Development of a Quality Monitoring Tool

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Abstract

Introduction: Mental healthcare is moving toward de-institutionalization, focusing on community-based care. However, people with severe and persistent mental illness (SPMI) often require long-term, intensive support. The Oyster Care model, developed as an innovative approach based on palliative psychiatry, aims to address the complex needs of this population. This study seeks to develop and validate a monitoring tool for assessing the quality of care provided under the Oyster Care model.

Methods: A mixed methods study was conducted between 2021 and 2023 to develop a quality monitor for Oyster Care. The research was structured into three phases. In the first phase, a literature review and qualitative study explored the experiences of key stakeholders to develop a quality framework. The second phase involved a Delphi expert consensus process to develop and validate operational indicators. In the final phase, experts selected the most important validated indicators to establish a minimal set for use as a practical monitoring tool for mental health services in Flanders.

Results: An iterative process using various methods resulted in the development of 78 indicators of high-quality Oyster Care. These indicators were grouped into 24 sub-themes, each containing three to five indicators, which were then organized under eight overarching themes: The care process, The somatic pillar, The psychological pillar, The social pillar, The existential pillar, End-of-life care, Team vision, culture, and development, and The living environment. The SCV-I demonstrated 97% for clarity and 93% for relevance of these indicators.

Discussion: The final monitoring tool is designed for use in Flemish mental health hospitals and psychiatric nursing homes, allowing teams to objectively assess and improve their practice. A planned pilot study, scheduled for April 2024 to April 2025, will evaluate the monitor's implementation and future research could measure the impact on health outcomes, aiding in resource allocation and treatment decisions.

Conclusion: A practice monitor was developed and validated for Oyster Care in this study, addressing three main objectives: creating a quality framework, formulating and validating operational indicators, and developing a practical monitoring tool. The tool provides a structured mechanism for teams to implement the care model as intended, engage in continuous reflection and improvement of their practices, and rigorously evaluate care outcomes.

Keywords: severe and persistent mental illness; palliative psychiatry; palliative care approach; long-term mental health care; quality improvement

Introduction

A movement toward de-institutionalization has emerged in mental healthcare, with a focus on the social (re)integration of patients and outpatient care. A similar trend is evident in Belgium's mental health system, with a reduction in residential admissions and the redirection of financial resources toward community care [1]. However, some people find social reintegration challenging and are in need of long-term and intensive treatment. This is particularly relevant for those experiencing severe and persistent mental illness (SPMI). Globally, an estimated 1% of the population lives with SPMI. These people face a striking reality of reduced life expectancy, which is up to 15 years shorter than the general population, mainly due to severe co-occurring somatic disorders [2- 5]. Accordingly, SPMI encompasses long-term and disabling mental health conditions, such as refractory schizophrenia, treatment-resistant depression and severe bipolar disorder [6, 7]. This population shares the characteristic of experiencing persistent symptoms despite undergoing evidence-based treatments, resulting in significantly impaired daily functioning and reduced quality of life [7]. Traditional therapeutic interventions aimed at cure often prove ineffective for SPMI, leading caregivers to either persist with futile therapeutic approaches or in some cases discontinue care altogether. Also, in this specific population with refractory symptoms, the usual approaches of recovery and psychosocial rehabilitation alone are often not sufficient to improve wellbeing [8]. This group of people, described as chronic and resistant to treatment, requires less conventional, disease-focused interventions and a shift to more person-centered care [9, 10].

There is growing evidence that palliative psychiatry holds promise for addressing the needs of people experiencing SPMI [5, 6, 10, 11]. Based on the palliative philosophy, the innovative model of 'Oyster Care' was developed. Oyster Care adopts a holistic approach in caring for this group of people based on four pillars: physical care addresses somatic conditions, psychological care focuses on comfort and well-being, social care provides structure through activities and connections and existential care promotes a sense of meaningful living. Unlike traditional approaches aimed at healing or restoring health, yet complementary to the recovery paradigm, the Oyster Care model focuses primarily on reducing symptom burden and improving the quality of daily life. As in regular palliative care, it places great value on interpersonal relationships and creative, out-of-the-box thinking by caregivers to go beyond standard protocol in caring for these people to improve their sense of meaning and well-being. Oyster Care represents a relatively new approach to caring for people experiencing SPMI and initial feedback from both caregivers and care users has been positive. Caregivers report a heightened sense of well-being, which is also reflected in care users through reduced suffering and enhanced quality of life [8]. As in several mental health institutions in Flanders, the Oyster Care model has demonstrated its ability to improve outcomes for care users, however, these results are derived primarily from the initial experiences of various stakeholders.

Consequently, as the implementation of the Oyster Care model progresses, there is a recognized need for an evidence-based tool that can translate the model's philosophy into practice to effectively guide caregivers in its principles, to evaluate the quali-

ty of care provided and to assess whether expected outcomes are being achieved. By enabling teams to compare their current practices to an idealized model, such tool can provide valuable insight into areas for practice improvement. In addition, it can promote scientific research, increase awareness of the model of care and improve adherence [12]. In the Netherlands, Active Recovery Triad (ART) and Flexible Assertive Community Treatment (FACT) have already developed tools that allow teams to continuously evaluate their practices to ensure quality of care for people experiencing severe psychiatric disorders [13, 14]. However, Oyster Care emphasizes specific aspects of quality care for this population, necessitating the development of a distinct monitoring tool tailored to its unique focus. The tool could improve the quality of care in mental health care by providing teams with a structured approach to assess and refine their practices in accordance with the principles of the Oyster Care model. By creating a feedback loop, the tool allows teams to gain insight into their current practices, which can then be used for improvements. This process helps ensure that care delivery remains consistent with the philosophy of the model, ultimately leading to better quality mental health care.

The aim of this study is to report on the development and validation of a practice monitor tool for Oyster Care. The three underlying sub-aims are: 1) to develop a quality framework for Oyster Care 2) to develop and validate operational indicators for the Oyster Care monitor and 3) to develop a practical tool for quality monitoring. By informing teams of the core components that contribute to high-quality Oyster Care, the tool can support their implementation of the care model as intended, facilitate regular reviews of their practice and improvement efforts, and enable thorough evaluations of outcomes.

Methodology

Design

The researchers undertook a mixed methods study consisting of three phases, conducted between 2021 and 2023, to develop a quality monitor for Oyster Care [15]. The first phase entailed a literature review and a qualitative study focused on understanding the care model based on the experiences of those involved, in order to develop a quality framework for Oyster Care. The second phase comprised a Delphi expert consensus process aimed at developing and validating operational indicators relevant to Oyster Care. In the final phase, experts were tasked with selecting the validated indicators most important to Oyster Care in order to establish a minimal set of indicators that could be a practical monitoring tool for mental health services in Flanders. By using a mixed methods approach, the study was able to develop a quality monitor that was both theoretically sound and practical, adapted to the specific imperatives of Oyster Care and applicable in the real context of mental health services in Flanders.

Setting and Study Population

The study was conducted in collaboration with eight mental health facilities across Flanders, namely three psychiatric hospitals, three psychiatric nursing homes, a walk-in centre for people with a death wish due to severe mental health problems and a psychiatric outpatient team. A ninth facility, a psychiatric nursing home, withdrew from participation prior to the start of the study, citing that they had not yet implemented the Oyster Care model in their practice and therefore felt unable to provide relevant insights regarding its use. The study population consisted of various stakeholders Oyster Care intends to reach: people experiencing severe and persistent mental illness; next of kin; and professionals and policy makers who engage with people experiencing SPMI and are familiar with the Oyster Care model.

Methods

Phase 1: Developing a Comprehensive Quality Framework for Oyster Care

Initially, a theoretical quality framework for Oyster Care was developed based on existing literature on the care needs of people

experiencing SPMI and care grounded in palliative care principles to respond to the care needs of this population. However, recognizing the limited scope of research specifically addressing this topic, a qualitative research design was subsequently selected. This approach was deemed appropriate for addressing the identified gaps in the literature while allowing for a more focused exploration of the Oyster Care model through the lens of experienced evidence.

Literature review: In December 2021, the researchers conducted a comprehensive literature search on palliative care approaches for people experiencing SPMI and the care needs of this population, excluding articles related to euthanasia and assisted suicide. The search yielded 18 relevant articles, which were analyzed with a focus on the care needs of people experiencing SPMI and how palliative care approaches can meet these needs. The analysis identified ten major themes: the care process, somatic care (needs), psychological care (needs), social care (needs), existential care (needs), end-of-life care (needs), team processes, the environment, ethical and legal aspects of care, and team structure. Each theme was further divided in sub-themes.

Qualitative interviews: Between January 2022 and November 2022, a qualitative study was conducted in two concurrent phases. Phase 1a explored the characteristics of Oyster Care from the perspectives of healthcare professionals, managers and policy makers. A total of 44 participants were interviewed through focus groups or individual interviews. Phase 1b focused on understanding the care needs of people experiencing SPMI and their next of kin, along with their experiences with Oyster Care and the extent to which the model does or does not address their needs. We argue that involving people experiencing severe and persistent mental illness in research efforts stands as a cornerstone for empowerment - a feasible aspiration. We underscore the importance of respectful and inclusive practices when engaging with this population, thereby enhancing the quality and relevance of research outcomes and facilitating more effective healthcare interventions tailored to their needs. Sixteen people experiencing SPMI and eight next of kin were interviewed one-on-one. A contact person at each participating facility supervised the recruitment process and additional precautions were taken during the recruitment of people experiencing SPMI to minimize participant burden (see Table 1). A semi-structured interview guide with open-ended questions was employed. The data were transcribed, coded using NVivo13 and analyzed according to a thematic analysis [16]. Eight main themes emerged, encompassing the somatic pillar, psychological pillar, social pillar, existential pillar, end-of-life care, the care process, the team and infrastructure. Each main theme included several sub-themes with slight variations among the different groups of participants, providing complementary insights and enhancing the understanding of each theme.

Table 1: Supportive measures to include people experiencing SPMI in research

Interviews with patients are conducted only in real life.
The gatekeeper, in consultation with the treating psychiatrist, assesses the patient's decision-making capacity (impact of research) and the extent to which they can provide informed consent.
Interested patients cannot directly contact the researcher. They can express their interest to the gatekeeper
Considering the patient's SPMI, the researcher contacts the local contact person on the day of the interview to discuss whether it is appropriate to proceed with the conversation.
The interview duration is limited. Conversations last a maximum of 45 minutes to reduce participant burden
Patients may choose to have a trustee to join the conversation. The trustee can offer emotional support or assist patients in articulating their experiences. Support persons cannot compel the patient to continue the conversation. If the patient indicates a desire to end the conversation, the researcher concludes the discussion.
Care providers and departmental leaders are informed of the nature, location, and timing of the conversation to mobilize a safety net within the department. Patients are asked if the local contact person or another care provider can accompany them back to the department after the conversation to offer additional support if needed.

Integration of findings: Both the literature review and the qualitative research employed an inductive analysis, allowing themes to emerge organically from the data collected. This open approach facilitated the development of a theoretical quality framework that responded to new insights. Consequently, the themes identified in relation to the research questions revealed strong connections with those in the conceptual model of Oyster Care, highlighting the relevance of the model while also accommodating emerging concepts. The themes that emerged from both the literature review and qualitative interviews were largely consistent, although the sub-themes varied and complemented one another. This process led to the development of a quality framework, which was subsequently face-validated during an ad hoc expert meeting. Five experts from three different settings participated in the four-hour live session, along with two members of the research team and one of the founders of the care model. During this session, subthemes were removed if the content was covered by other themes, divided into smaller themes or reorganized across the larger themes. Additional content and nuance were incorporated into the quality framework and some (sub)themes were renamed. A significant change was the removal of the theme 'Ethical and legal aspects of care', as these aspects were considered integral to any theme within the Oyster Care model, and the theme 'team structure' was removed due to insufficient content to justify its inclusion.

Phase 2: Developing and Validating Quality Indicators Based on Expert Consensus

Phase 2 started with the research group translating the content of the (sub)themes within the quality framework into operational indicators to measure the provision of high-quality Oyster Care. A total of 192 quality indicators were developed, distributed across 37 sub-themes within eight overarching themes. Since Oyster Care is a new intervention, and scientific research on positive outcomes is lacking, collecting expert opinions through a modified Delphi study is an appropriate method for assessing face and content validity [17, 18]. Through purposive and snowball sampling, twelve professionals and two academics experienced in working with people experiencing SPMI through the Oyster Care model, as well as one next of kin were recruited. Twelve of them had not participated in the initial research phase and the professionals had various backgrounds. Data collection took place between October 2022 and March 2023. Through an iterative process, the expert panel assessed the indicators for clarity using a dichotomous answer option of 'clear' or 'not clear', and the relevance of the indicator to the concept of Oyster Care was asked using a 5-point Likert scale. The first and third Delphi rounds were organized through the completion of an anonymous, digital questionnaire and the experts had the opportunity to explain their quantitative answers in a qualitative manner. The second Delphi round was conducted via a digital live meeting. The Item-Content Validity Index (I-CVI) was calculated to measure the extent to which experts reached consensus [19, 20]. Fifteen experts participated in the first round, while twelve participated in both the second and the third round. The threshold for consensus on the clarity and relevance of an indicator was set at 86.67%, slightly higher than the conventional 80%, due to the experts' consistently positive scoring on the complete questionnaire in Delphi round one. Indicators that scored 86.67% or higher were retained. Those scoring between 66.67% and 86.67% were individually reviewed by the researchers, with decisions on these indicators discussed during the second Delphi round and communicated to the experts via email for further input. This feedback process included the experts who did not continue in subsequent rounds. Indicators scoring below 66.66% were removed from the monitor.

In the *first Delphi round*, experts were asked to evaluate 192 quality indicators. Some of the indicators that met the cut-off threshold of $\geq 86.67\%$ were presented in the second round for further discussion based on qualitative feedback from participants. This feedback suggested the removal or revision of entire sub-themes to which these indicators belonged. Indicators with a cut-off of 66.67% to 86.67% were either rejected, e.g. overlapping content, or adjusted based on participant feedback. New indicators were introduced based on qualitative feedback to fill gaps in the original set. In the *second Delphi round*, participants discussed, revised and introduced indicators, as well as relocating indicators under (sub)themes as (sub)thematic renaming. For example, the sub-theme 'physical complaints' was renamed to 'physical health' to include items related lifestyle. After the second round, indicators were revised based on expert input and new indicators were drafted, all assessed in the *third Delphi round*.

Surveying management perspectives on the structure of Oyster Care teams: The study also explored a potential ninth theme "team structure" for which insufficient data was collected in the initial research phase. The aim was to address the following question: What is an ideal structure of an Oyster Care team? To investigate this, the researchers surveyed six head nurses from various Oyster Care teams within the participating facilities via e-mail. The survey focused on the current and desired number of Full-Time Equivalents across different disciplines, educational backgrounds, contract hours and other related team structure factors. These insights led to the development of fifteen new indicators, which were presented to the experts for evaluation in the third Delphi round. However, no consensus was reached and qualitative feedback from the experts revealed too much variation, due to various needs in different care settings. Consequently, it was decided not to retain these indicators.

Phase 3: Developing a Minimal Set as a Practical Monitoring Tool

Following the Delphi study, approximately 160 indicators emerged as clearly described and relevant to Oyster Care. However, feedback from Delphi experts and other stakeholders indicated that this extensive set needed further refinement and narrowing to ensure its feasibility for practical implementation [21]. Consequently, the decision was made to downsize the set of indicators to make it more manageable for use in practice. This marked the third and final phase of the study, focusing on selecting the most important indicators for delivering high-quality Oyster Care. To develop this minimal set of quality indicators, experts in each of the eight themes were consulted based on their specialized knowledge. For instance, a general practitioner and nurse reviewed somatic care, a psychiatrist and psychologist assessed psychological care and a head nurse and manager evaluated the care process. Each theme was reviewed by at least two experts who had participated in earlier phases of the study. Additionally, indicators were reorganized within sub-themes to establish a more chronological order. The choices were then cross-checked with the research group, incorporating scores and qualitative feedback from the first and second phases. Simultaneously, one of the founders of the Oyster Care model was asked to independently select the most important indicators for all themes. The selections made by the experts, a founder of the Oyster Care model and the research group were found to be consistent with one another.

Enduring collaboration between the research team and expert consultants: During the two-year study, regular consultations were held with the research team, consisting of individuals with expertise in various research methodologies and the development of quality indicators, palliative care approaches and end-of-life care, ethical considerations within care provision, and founders of the Oyster Care model. Additional expertise was enlisted on an ad hoc basis, including ART and FACT researchers with expertise in quality management. Moreover, amidst exploration of effective care modalities for people experiencing SPMI there arose a dialogue across borders. In Belgium, healthcare workers are embracing practices from Dutch partners about prioritising the integration of people experiencing SPMI into society. At the same time, Dutch partners undertake a similar effort by exploring Belgian perspectives on delivering high-quality care within institutional settings to their own practices. This cross-border exchange of ideas and practices highlights the dynamic interplay between community-based initiatives and the infrastructure of institutional support systems.

Ethical Considerations

The study adhered to the Declaration of Helsinki and European General Data Protection Regulation rules, and was approved by the Medical Ethics Committee of the Vrije Universiteit Brussel (VUB) (approval no. EC-2021-322). All participants were asked to sign an informed consent form ensuring their anonymity and confidentiality

Results

An iterative process of various methods in order to 1) develop a quality framework 2) develop and validate operational indicators for the care model and 3) develop a practical tool for monitoring the quality of Oyster Care led to the development of 78 indicators of high-quality Oyster Care. See Figure 1 for a flowchart detailing the research phases and key results. The 78 indicators were grouped into 24 sub-themes each consisting of three to five indicators, which were in turn organized under eight overarching themes. The eight themes are: 1. The care process, 2. The somatic pillar, 3. The psychological pillar, 4. The social pillar, 5. The existential pillar, 6. End-of-life care, 7. Team vision, culture and development and 8. The living environment. The corresponding scale-level content validity index for these indicators shows 97% for clarity, meaning 97% of the items were found easy to understand, and 93% for relevance, meaning 93% of the items were found relevant for the construct Oyster Care. The complete monitor can be found in Appendix 1. A description of each theme's content is provided below.

During *the care process*, the focus is on promoting the well-being and quality of life of the care user. To this end, the care user, next of kin and the team work together to develop a care plan that responds to the care user's unique needs and values, and a care process marked by trial-and-error and the continual adaptation of care and treatment plans. For this, team has an important role in interpreting verbal and nonverbal cues to understand and respect the care user's deeper desires, using the life story as a valuable guide. To provide personalized care and adapt the intensity of care to the changing needs of the care user, a balance between preparedness and flexibility is needed. Predefined strategies for care intensification help ensure a coordinated responsiveness, while pragmatism and adaptability are essential because standard protocols are not always appropriate. The care process consists of four themes: the acquaintance, the personal support plan, the support discussion, the upscaling and downscaling of care intensity.

In the *physical pillar*, physical symptoms are detected early and assessed holistically, taking into account somatic, psychological, social and existential factors. When lifestyle choices are harmful to health, the team discusses the underlying needs of the unhealthy behavior and formulates an approach to mediate. In addition, the team focuses on restoring contact with the body, and medication policy balances between symptom relief and minimizing side effects. An indicator related to healthcare users having a voice in meal choice was considered less important by the experts. However, it was retained because this insight emerged as highly significant in qualitative interviews with people experiencing SPMI. For many, it served as a motivation to get out of bed, participate in cooking activities (due to the ability to choose what they ate, aligning with their preferences), or to venture outside as outings often concluded with a visit to a bistro (which in turn contributed to feeling connected to the broader community). The physical pillar comprises: physical health, the eating environment, contact with the body and medication policy.

The care relationship is a cornerstone of the *psychological pillar* and serves as the foundation for further interventions, such as exploring, understanding and effectively treating psychiatric and psychological symptoms and behaviors. Understanding the care user's personal history and unique communication style facilitates this process, and the team explores creative ways to address these symptoms, intervening only when the care user or their environment are truly affected. Therapy and activities aim to create the right conditions for connection, relieve suffering and improve feelings of well-being by providing a measured amount of stimulation. The team recognizes early signs of overstimulation and creates an emotionally safe and structured environment by "closing the shell" to offer security. As the need for care decreases and the behavior and decisions of the care user become less harmful, "the shell reopens". For example, a care user with chronic suicidal ideation and frequent impulsive suicide attempts experienced heightened emotional distress following the sudden death of his uncle. To ensure his safety, particularly given his impulsivity, the care team, in consultation with the care user, implemented a plan requiring him to travel only with accompaniment to reduce the risk of a suicide attempt. As his grief subsided and his social network provided strong support, the team gradually allowed him more autonomy, permitting occasional solo outings under structured agreements. Moving forward, the team will continue to evaluate his progress and cautiously grant him increasing independence as his emotional

stability improves. This approach addresses the dynamic nature of autonomy, which is influenced by the care user's often fluctuating levels of decision-making capacity. Four themes cover the psychological pillar, namely: the care relationship, therapy and activities, coping with symptoms and dealing with crisis and coercive measures.

Within *the social pillar*, the team identifies people important to the care user from the past and investigates why contact with them was lost or broken. Together with the care user, they consider whether restoring these relationships makes sense and/or look for ways to maintain the meaning of these relationships without direct contact. In addition, the team supports care users in nurturing existing relationships and building reciprocal ties, providing the network with practical and emotional support. A tailored, predictable structure of activities and interactions supports care users in leading an active and as independent life as possible. Hereby participating together in daily social life and regular contact with volunteers helps to feel connected to the outside world. In addition, the team tackles institutionalization and stigma to help care users integrate into society and take on roles beyond those of a care user. The social pillar is structured around three central themes: family and next of kin, activation, and social participation and inclusion.

Shedding light on the existential dimensions associated with experiencing SPMI *the existential pillar* is described. To foster a sense of connection, meaning and identity, the team (re)recognizes and understands in the care user feelings of hopeless existential suffering and grief arising from the loss of life dreams, relationships, health and self-worth. They provide an external structure within which care users can (re)discover values important to them, experience meaning in their daily functioning and reconnect with themselves, others, nature and the transcendent. These elements are covered in the theme 'Connection, meaning and identity'. In addition, the team recognizes and responds to care users' spiritual and religious needs by creating an open and respectful environment for such questions. They collaborate with experts to ensure that care users' spiritual and religious concerns are addressed. This focus on the journey towards reclaiming their humanity and sense of self is captured in the theme 'Spirituality, worldview and religion'.

Due to the prolonged stay of people experiencing SPMI in Oyster Care units, these facilities are equipped to accommodate the possibility of reaching the end stage of life. High quality *end-of-life care* for care users in the last phase of life requires a careful and coordinated team approach so that efforts can be made to maintain and/or improve quality of life, quality of care and autonomy. To implement this, the theme of end-of-life care outlines indicators that can be divided into three subthemes, namely advance care planning, end-of-life care and post-death care. Decisions regarding end-of-life care hinge upon regular discussions held with the person and next of kin regarding their needs and preferences. Providing palliative care requires a lot from a team. Ethical consultation can help increase a team's ability to provide care and assist in end-of-life decisions. The team should have the opportunity to employ additional staff for one-on-one care when needed. Continual training in palliative care and the addition of a specialist or collaboration with a palliative home care service improve the quality of care.

The team vision, culture and development theme focuses on the importance of a shared mission and values within a healthcare team, the importance of a positive team culture and how continuous growth and collaboration improve the quality of care. A number of key competencies are essential for an Oyster care team, these include demonstrating flexibility and creativity, being respectful and understanding of each other and of care users, and having sufficient professional knowledge. Providing Oyster Care can place significant demands on caregivers, therefore it is essential to create an environment of resilience, self-care and mutual support. The seventh domain is divided into three subthemes, namely attitude; professionalization, innovation and quality of care; and leadership.

The eighth and final theme *the living environment* focuses on creating appropriate living and housing space and designing infrastructure that meets the needs of care users, next of kin and the care team. This theme first addresses the opportunities and challenges inherent in communal living, where the coexistence of diverse personalities and individuals with severe illnesses can

present some difficulties. To mitigate these challenges, the infrastructure must meet several specific requirements: it should be age-appropriate and provide structure, feature small living units and smaller living groups, offer single rooms, and include multipurpose rooms and low-stimulation rooms. Additionally, a pleasant garden and other supportive environmental features are essential to create a therapeutic and accommodating living environment. The living environment has one subtheme: living space and environment.

The analyses showed a lack of definitive answers as to how an Oyster Care team should be structured because of the different needs in different care settings. This could have constituted a potential ninth theme in the study. However, the findings underscored the crucial need for sufficient staff, especially for responding promptly to peaks in intensity of care, depending on the non-stable condition of this population, and providing one-on-one support. The importance of therapists from various professional backgrounds was also stressed. This inclusiveness ensures that every care user can access and participate in therapies and activities that appeal to them personally. Moreover, the presence of psychiatrists and psychologists was considered essential for understanding symptoms, including through the lens of the person's life story that may explain coping mechanisms. Collaboration with general practitioners and sufficient hours for social workers and existential care professionals were also considered necessary to meet users' somatic, social and existential needs, enabling holistic care delivery. This need is exacerbated by the various ethical and existential dilemmas and needs (e.g., dynamics around giving autonomy and providing structure; or dealing with various loss experiences) present in this population.

Each theme within the monitoring tool begins with a description of the quality framework developed during the first phase of the research. This introduction focuses on outlining the care needs and challenges encountered by people experiencing SPMI, their next of kin and healthcare professionals in relation to that theme. Additionally, it provides theoretical context for the indicators, ensuring a comprehensive understanding of the framework's foundation. Subsequently, each theme is further divided into two to four sub-themes, which represent specific aspects of that theme. For each sub-theme, a detailed rationale of how high-quality Oyster Care can be delivered in response to stakeholders' care needs is provided. This rationale is complemented by a list of validated and selected indicators that are considered essential for ensuring high-quality Oyster Care. In addition, clear guidelines are provided for interpreting and measuring these indicators so that they can be applied accurately and effectively in practice. Best practices collected throughout the study are also covered in each sub-theme. Although these practices were not directly translated into formal indicators or not selected during the final validation phase, they are presented as further examples for improving the practical implementation of quality care, beyond the framework of the validated indicators. At the conclusion of each subtheme, teams are presented with a 4-point Likert scale to evaluate their level of implementation for that specific subtheme. This scale ranges from 'not visible' to 'in development,' 'embedded,' and 'pearl', the latter drawing on the shell metaphor. 'Pearl' can also be interpreted as 'exemplary' or representing excellence in implementation. The subtheme is scored as a whole, with the associated indicators offering an indication of the extent to which that subtheme has been implemented within their Oyster Care practice. For illustration, see Table 2.

Table 2: Theme 2. Physical pillar includes subtheme 5. Physical health, which encompasses three indicators

Subtheme 5. Physical health				
Not visible	In development	Embedded	Pearl	Comments
The team timely assesses the care user's physical (pain) symptoms to understand and, if necessary, treat them The team acts as a liaison between the care user and practitioner, providing support to the care user during a medical examination if needed The team encourages care users to adopt a healthy lifestyle, provides tailored advice and support, and mediates when lifestyle choices are detrimental to health				

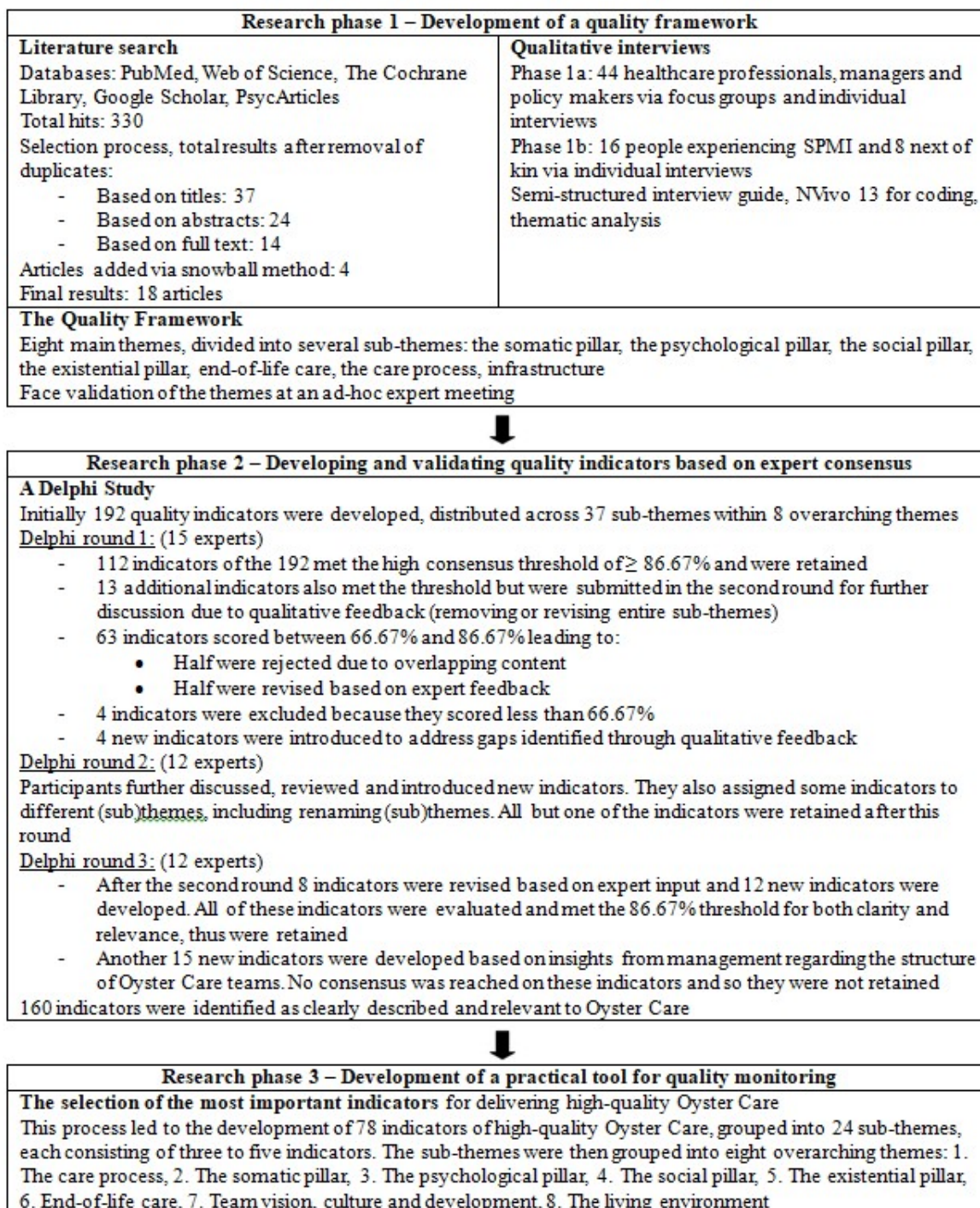


Figure 1: A flowchart detailing the research phases and key results

Discussion

In this study, a quality framework for Oyster Care was developed through a comprehensive literature review and qualitative research involving various stakeholders of the care model. These insights were translated into measurable indicators of high-quality Oyster Care and validated through a Delphi procedure. Following this, the most significant indicators important for high-quality Oyster Care were selected, resulting in a practical monitor comprising 78 indicators across 8 themes. The resulting practice monitor is designed for use in Flemish psychiatric hospitals and psychiatric nursing homes, as a tool to aid and assess the implementation of the Oyster Care model. By evaluating their practices, teams have the opportunity to gain objective in-

sights into their own performance and identify areas for improvement.

In line with the Oyster Care model and an expanding body of evidence, the researchers emphasized the importance of inclusivity and meaningful engagement with people experiencing SPMI in both research endeavors and healthcare development [22,23,24]. A strength of this study lies in the extensive interviews conducted with people experiencing SPMI. The interviews were conducted in accordance with established standards, albeit with a deliberate embrace of non-conventional approaches while advocating an attitude of critical, ethical reflection to reach the most vulnerable people within this population. However, over the course of the study, a critical stance toward the role of gatekeepers remained imperative, especially given the tendency to overprotect these individuals. The researchers ensured that the selection of participants was not biased in favour of those who were most articulate or had positive experiences of treatment and care. Despite using a qualitative research methodology, efforts were made to include a diverse range of voices and certainly those of the hardest-to-reach. This was facilitated by gatekeepers who were highly committed to addressing the needs of this population—with all its subgroups—and their recognition of the potential positive impact that inclusion in research could have on practical outcomes [25]. The researchers were able to interview only a limited number of next of kin, which reflects the reality that people experiencing SPMI often have a limited social network [6,10]. This limitation highlights not only the challenges posed by the individual's condition but also issues within the mental healthcare system, such as the insufficient involvement of next of kin in treatment decisions. This is unfortunate, as the family member who participated in the second phase of the study provided valuable insights that differed from those of the professional experts. Their perspectives offered important nuances that the experts had not considered, enriching the overall understanding of the care experience and, consequently, what should constitute high-quality Oyster Care for them. This highlights the importance of collaboration between the care user, their network, and professionals, aligning with the principle of "nothing about them, without them."

The absence of people experiencing SPMI—despite efforts to include them—and the underrepresentation of next of kin in the expert panel might have had an impact on the consensus scores during the second phase of the study. It could be argued that incorporating indicators scoring less than 80% might compromise the validity of the research and should be approached with extreme caution. Nonetheless, these lower scoring indicators emerged as highly important during discussions with those not present in the expert panel. Nonetheless, these lower-scoring indicators emerged as highly important during discussions with those not present in the expert panel. For example, while the experts rated 'involvement in meal choices' as only moderately relevant, it was a recurring theme in conversations with people experiencing SPMI. Similarly, family meetings that provided opportunities for peer contact among family members were rated lower by the expert panel, yet in discussions with families, these meetings were highlighted as having significant added value. This discrepancy may be a result of the underrepresentation of these stakeholders in the panel, again highlighting the need for continued dialogue with them, both in care provision and in the development of policy and research, rather than making decisions on their behalf. The inclusion of lower-scoring indicators was therefore a deliberate decision to mitigate potential bias.

One of the essential resources is sufficient staffing to implement Oyster Care as it is intended, which relies on providing one-on-one care when needed, adjusting care intensity to the care user's needs, conducting activities in small groups and delivering personalized care that meets the complex needs of the individual [8]. This need is further intensified by the ethical and existential dilemmas and needs present in this population, such as balancing autonomy with structure and addressing various loss experiences, as well as providing end-of-life care and managing its associated challenges [26,27]. Although this study provides some insights, future research will be required to determine the optimal team structure for implementing Oyster Care interventions effectively in practice, assisting policymakers in allocating resources efficiently and ensuring the delivery of high-quality care.

In the development of a practical monitoring tool, the third phase of the study focused on reducing the number of indicators to

retain only the most crucial ones for delivering Oyster Care. Although an additional Delphi round could have been conducted to finalize these selections, the experts were already heavily burdened by extensive questionnaires and had put significant effort into providing qualitative responses for each indicator. To maintain their engagement and avoid overburdening them, it was decided to select the most important items within each theme with the experts related to that theme. These choices were reviewed with all experts from the second phase of the study, and no substantial objections were received. This strategy aimed to balance the need for expert input with the practical constraints of their involvement, ensuring that their feedback remained an integral part of the entire Oyster Care development process.

Under the influence of discussions with FACT and ART partners, the scoring system prioritizes highlighting strengths within an assessment rather than merely checking off items [13]. In this approach, the individual indicators for each theme represent a substantial portion of the score but function more as a qualitative interpretation rather than a rigid evaluation. This allows for an emphasis on best practices while ensuring that less successful elements do not dominate the overall assessment. Consequently, the evaluation process becomes more nuanced, offering recommendations that are better aligned with the specific needs of each team. It is essential that the components of a theme are evaluated in context, rather than as isolated metrics to be averaged, to ensure a more comprehensive and meaningful analysis of practice effectiveness. This encourages innovation and creativity and empowers teams to explore what strategies work best in supporting and caring for people with SPMI within an offered quality framework that underscores Oyster Care's core principles.

Furthermore, quality indicators can be adapted and refined to align them with the (evolving) needs of the target population, the social context, available societal resources and new insights into factors that influence healthcare outcomes [28]. It is recommended to carefully document what changes – to adapt indicators to their specific context – are made to facilitate measurement of their impact on outcomes. This need for contextual flexibility also partly explains why no definitive answer could be drawn about the team structure required to implement Oyster Care. Different settings, such as psychiatric hospitals versus psychiatric nursing homes, and varying case mixes require different resources and approaches. In future studies, efforts will be made to translate and adapt the indicators for use in other care contexts, including general nursing homes and outpatient psychiatric teams.

Understanding and effectively implementing interventions necessitates a thorough analysis of their core components and accurate monitoring of their delivery. This monitoring ensures compliance with care protocols and verifies that the target population is being reached, thereby enabling rigorous research on intervention effectiveness. However, many key elements of Oyster Care remain unclear, complicating the development of a precise measurement tool [12,16]. A planned pilot study will capture the experiences of end-users – professionals who utilize the monitor – and to evaluate the implementation process of Oyster Care using the monitor. This would assist in refining the process based on their feedback and experiences, given the complexity and variability inherent in Oyster Care ensuring consistent implementation is challenging. The pilot study will be conducted from April 2024 to April 2025 in four mental health facilities. The primary aim of this study is to evaluate and optimize the implementation of Oyster Care through a comprehensive approach, including validating the monitor – to ensure that detailed measurements are feasible – developing review protocols and implementing coach-led improvement processes. In parallel, another study will be conducted to assess the effects of Oyster Care on health outcomes. These measurements can provide insight into health changes, inform treatment decisions and are crucial for evaluating cost-effectiveness and improving resource allocation [29].

Conclusion

A practice monitor was developed and validated for Oyster Care in this study, addressing three main objectives: creating a quality framework, formulating and validating operational indicators, and developing a practical monitoring tool. The tool provides

a structured mechanism for teams to implement the care model as intended, engage in continuous reflection and improvement of their practices, and rigorously evaluate care outcomes.

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Authors' Contributions

CVH, LM, KL, ID, YV and KC contributed to the study conception and design. CVH and LB conducted the data collection and data analysis with input from all authors. All authors contributed to the content of this article, derived from discussions held in various meetings. KC and LM supervised the project and provided guidance throughout the study. CVH wrote the first draft of the manuscript. CVH, LM, KL, KC, AL, LB and YV critically revised the manuscript. All authors approved the final version.

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References

1. Mistiaen P, Cornelis J, Detollenaere J, Devriese S, Farfan-Portet MI, Ricour C (2019) Organisation of mental health care for adults in Belgium. Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE), KCE Reports 318.
2. James SL, Abate D, Abate KH, Abay SM, Abbafati C, et al. (2018) 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. *The Lancet*, 392: 1789–1858.
3. Oakley P, Kisely S, Baxter A, Harris M, Desoe J, et al. (2018) Increased mortality among people with schizophrenia and other non-affective psychotic disorders in the community: A systematic review and meta-analysis. *Journal of Psychiatric Research*, 102: 245–53.
4. Plana-Ripoll O, Musliner KL, Dalsgaard S, Momen NC, Weyer N, et al. (2020) Nature and prevalence of combinations of mental disorders and their association with excess mortality in a populationbased cohort study. *World Psychiatry*, 19: 339-49.
5. Trachsel M, Irwin SA, Biller-Andorno N, Hoff P, Riese F (2016) Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks. *BMC Psychiatry*, 16: 260.
6. Woods A, Willison K, Kington C, Gavin A (2008) Palliative Care for People with Severe Persistent Mental Illness: A Review of the Literature. *The Canadian Journal of Psychiatry*, 53: 725-36.
7. Zumstein N, Riese F (2020) Defining Severe and Persistent Mental Illness-A Pragmatic Utility Concept Analysis. *Frontiers in Psychiatry*, 11: 648.
8. Decorte I, Verfaillie F, Moureau L, Meynendonckx S, Van Ballaer K, et al. (2020) Oyster Care: An Innovative Palliative Approach towards SPMI Patients. *Frontiers in Psychiatry*, 11: 509.
9. Levitt S, Buchman DZ (2020) Applying futility in psychiatry: a concept whose time has come. *Journal of Medical Ethics*, 47: e60.
10. Moonen C, Lemiengre J, Gastmans C (2016) Dealing With Existential Suffering of Patients with Severe Persistent Mental Illness: Experiences of Psychiatric Nurses in Flanders (Belgium). *Archives of Psychiatric Nursing*, 30: 219-25.
11. Gloeckler S, Trachsel M (2021) Nurses' views on palliative care for those diagnosed with severe persistent mental illness: A Pilot Survey Study in Switzerland. *Journal of psychiatric and mental health nursing*, 29: 67-74.
12. Bond GR, Becker DR, Drake RE (2011) Measurement of fidelity of implementation of evidence-based practices: Case example of the IPS Fidelity Scale. *Clinical psychology: science and practice*, 18: 126-41.
13. Westen KH, van Vugt MD, Bähler M, Delespaul PH, Kroon H (2019) De ontwikkeling van de vernieuwde Flexibele ACT-schaal: F-ACT-s 2017. *Tijdschrift voor psychiatrie*, 61: 97-103.
14. Zomer LJC, Voskes Y, van Weeghel J, Widdershoven GAM, van Mierlo TFMM, et al. (2020) The Active Recovery Triad Model: A New Approach in Dutch Long-Term Mental Health Care. *Frontiers in Psychiatry*, 11: 592228.
15. Johnson RB, Onwuegbuzie AJ, Turner, L (2007) Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*, 1: 112-133.

16. Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3: 77-101.
17. Mowbray CT, Holter MC, Teague GB, Bybee D (2003) Fidelity criteria: Development, measurement, and validation. *American journal of evaluation*, 24: 315-40.
18. Taherdoost H (2016) Validity and reliability of the research instrument; how to test the validation of a questionnaire/survey in a research. *International Journal of Academic Research in Management*, 5: 28-36.
19. Polit DF, Beck CT (2021a) *Nursing Research: Generating and Assessing Evidence for Nursing Practice* (eleventh edition). Philadelphia, United States: Wolters Kluwer.
20. Yusoff MSB (2019) ABC of content validation and content validity index calculation. *Education in Medicine Journal*, 11: 49–54.
21. Leemans K, Deliens L, Van den Block L, Vander Stichele R, Francke AL, Cohen (2017) Systematic Quality Monitoring For Specialized Palliative Care Services: Development of a Minimal Set of Quality Indicators for Palliative Care Study (QPAC). *The American journal of hospice & palliative care* 34: 532-546.
22. Carlsson IM, Blomqvist M, Jormfeldt H (2017) 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. *International Journal of Qualitative Studies on Health and Well-Being*, 12: 1368323.
23. Dempsey L, Dowling M, Larkin P, Murphy K (2016) Sensitive Interviewing in Qualitative Research. *Research in Nursing & Health*, 39: 480-90.
24. Kars MC, van Thiel GJ, van der Graaf R, Moors M, de Graeff A, van Delden JJ (2016) A systematic review of reasons for gatekeeping in palliative care research. *Palliative Medicine* 30: 533–48.
25. Van Hoe C, Moureau L, Verhofstadt M (2023) How to engage people experiencing severe and persistent mental illness in qualitative research: a descriptive and reflexive analysis. *International Journal of Qualitative Studies on Health and Well-being*, 19: 2408817.
26. Liégeois A, Moureau L (2023) Aspects éthiques des soins crustatifs. *Revue d'éthique et de Theologie Morale*, 318: 67-87.
27. Moureau L, Verhofstadt M, Liégeois A (2023) Mapping the ethical aspects in end-of-life care for persons with a severe and persistent mental illness: A scoping review of the literature. *Frontiers in Psychiatry*, 14: 1094038.
28. Durlak JA, DuPre EP (2008) Implementation matters: A review of research on the influence of implementation on program outcomes and the factors affecting implementation. *American journal of community psychology*, 41: 372-350.
29. Agency for Healthcare Research and Quality (2015) *Relationship Between Use of Quality Measures and Improved Outcomes in Serious Mental Illness*. AHRQ Publication No. 15-EHC003-EF. Relationship Between Use of Quality Measures and Improved Outcomes in Serious Mental Illness (ahrq.gov)

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