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Palliative psychiatry: research, clinical, and educational priorities

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Background: Palliative psychiatry has been proposed as a new clinical construct within mental health care and aims to improve quality of life (QoL) for individuals experiencing severe and persistent mental illness (SPMI). To date, explorations of palliative psychiatry have been largely theoretical, and more work is needed to develop its approaches into tangible clinical practice.

Methods: In this paper, we synthesize existing literature with discussions held at a one-day knowledge user meeting titled “A Community of Practice for Palliative Psychiatry” to generate priorities for research, clinical practice, and education that will help advance the development of palliative psychiatry.

Results: Palliative psychiatry will benefit from research that is co-produced by people with lived experience (PWLE) of mental illness, that clarifies contested concepts within mental health care and wider medicine, and that adapts existing interventions that have the potential to improve the QoL of individuals experiencing SPMI into the mental health care context. Specific methods and tools might be developed for use in clinical spaces taking a palliative psychiatry approach. More work must be done to understand the populations that might benefit from palliative psychiatry, and to mitigate mental health care providers' (MHCPs') anxieties about using these approaches in their work. As palliative psychiatry is developed, current MHCPs, trainees, individuals experiencing SPMI, and their loved ones will all require education about and orientation to this novel approach within mental health care.

Conclusions: There are several priorities in research, clinical practice, and education that can help advance the development of palliative psychiatry. All future work must be considered through a human rights-based, anti-oppressive lens. Research projects, clinical models, and educational initiatives should all be developed in

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co-production with PWLE to mitigate the epistemic injustices common in mental health care.

Keywords: Palliative psychiatry; mental health ethics; severe and persistent mental illness (SPMI)

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Introduction

Background

Although palliative care has traditionally been understood to apply to end-of-life care for physical medical conditions, there is an emerging consensus that palliative care is “*the active holistic care of individuals across all ages with serious health-related suffering*” (1). This changing understanding of palliation raises questions for mental health care, particularly for people diagnosed with severe and persistent mental illness (SPMI). SPMI refers to the serious nature, and the enduring functional impairment and disability associated with certain mental, behavioural, and emotional diagnoses (e.g., schizophrenia, anorexia nervosa) (1,2). Recent surveys among physicians and nurses in Switzerland have found that participants endorse some cases of SPMI as terminal illnesses (3-5). There is growing recognition among clinicians and scholars that ongoing ‘aggressive’ treatment

in some cases of SPMI may not provide meaningful benefit to the person in terms of symptom remission and quality of life (QoL), and may even be harmful (6-8). Going beyond care provided at end-of-life, palliative psychiatry has been described as an approach centred on the QoL concerns of patients and their families in circumstances of SPMI where there is a likelihood of significant morbidity or mortality (9).

High-quality palliative care has been associated with improvement in both quantity and QoL in persons with physical illnesses (10,11). Unlike people experiencing somatic disorders, individuals experiencing SPMI are typically offered interventions that continue to focus on reducing core SPMI symptoms (12). Palliative psychiatry has been proposed as a new clinical construct that promotes QoL for individuals living with SPMI. It is a departure from other mental health care models in its explicit focus on improvement of QoL, rather than functional outcomes or core symptom reduction.

A historical overview of palliative psychiatry

The literature describing and debating concepts of palliative psychiatry is recent. In 2010, Lopez, Yager, and Feinstein tacitly introduced the idea of palliative approaches as a clinical model of care in their discussion of criteria for declaring futility in the treatment of severe and enduring anorexia nervosa (13). In 2016, palliative psychiatry was proposed as a distinct model of palliative care for psychiatry (9). Palliative psychiatry as a clinical construct was based on the World Health Organization’s (WHO’s) model of palliative care, which describes maintaining QoL through preventing and relieving physical, psychosocial, and spiritual suffering (14). As is central to pre-existing palliative care models, Trachsel *et al.* argued that the aim of palliative psychiatry is to reduce suffering for people experiencing SPMI by preventing harm due to overly aggressive care. The concept of ‘futility’ was central to their proposition; that is, the assertion that there are certain cases of SPMI for which further treatments will not achieve the

Highlight box

Key findings

- Palliative psychiatry is an emerging person-centred, relational approach to working with individuals experiencing severe and persistent mental illness (SPMI) that focuses on improving quality of life (QoL).

What is known and what is new?

- Palliative psychiatry approaches aim to reduce suffering as a means of improving QoL. These approaches are in their infancy of being developed into clinical practice.
- Research, clinical, and educational programs that are co-produced with people with lived experience (PWLE) are necessary to advance the development of palliative psychiatry as a clinical construct.

What is the implication, and what should change now?

- Palliative psychiatry must be developed through a rights-based, anti-oppressive lens if it is to achieve its goal of providing approaches to improve QoL for individuals experiencing SPMI.
- Future research, clinical, and educational projects require interdisciplinary approaches, centring the perspectives of PWLE.

desired outcome (9). It should be noted here that we will use palliative psychiatry as the term to describe approaches to psychiatric care which prioritize the reduction of suffering (rather than—although this may include—symptom control). While we are reductionistic in language, we mean to be broad in execution: if this work can lead to more person-centred compassionate mental health care we hope all health care providers working with individuals experiencing SPMI will feel comfortable with these approaches.

The academic literature on palliative psychiatry includes attempts to clarify how it might differ from or complement other care approaches such as harm reduction, rehabilitation, and personal recovery (7,9,12,15,16), and why it is important to make such a distinction (17,18). Some authors have expressed concern that conceiving of palliative psychiatry as a distinct model of care could inadvertently worsen access to patient-centred care for individuals experiencing SPMI by diverting human resources into a new, but limited, care pathway (6). However, there is also evidence that mental health care providers (MHCPs) would accept palliative psychiatry as something to offer their patients (3-5). A recent publication outlining a palliative approach to mental health care found that individuals who were cared for through this service experienced a reduction in aggression, self-harm, and acute hospitalizations, while also benefiting from deprescribing and an increased sense of belonging in community (19).

Lack of conceptual clarity around controversial concepts such as ‘futility’ and ‘terminal illness’ in mental health care (6,7,20-22), and even the definition of ‘SPMI’, have been identified as barriers to the continued development of palliative psychiatry approaches (23). There has recently been debate regarding the ethical acceptability of mental disorders as sole underlying conditions eligible for medical assistance in dying (MAiD) (24-27). Palliative psychiatry has been positioned as a possible alternative to MAiD in offering relief of suffering (28,29), yet much of the literature has made pointed efforts to avoid addressing the question of MAiD for mental illness (7,9). Questions remain about how palliative psychiatry may or may not integrate with MAiD for individuals experiencing SPMI. Many authors have acknowledged that a major barrier to the acceptance of palliative psychiatry is the criticism that it may amount to or result in abandonment of already structurally vulnerable individuals (9,30). Though proponents of palliative psychiatry have highlighted that it is intended as a highly patient-centred model of care that holds the therapeutic relationship as primary (7,9,15,29), the absence of tangible

clinical models that demonstrate how this theory is put into practice makes it difficult to provide examples of how structural vulnerabilities are accounted for and addressed. Unanswered questions surrounding palliative psychiatry echo many broader unanswered questions within healthcare, including important epistemological and ontological questions about symptom remission and cure, what constitutes terminal illness, and what types of interventions (e.g., MAiD) fit within the larger project of biomedicine.

Rationale and knowledge, conceptual, and practice gaps

To date, there are no accepted clinical models of palliative care for individuals experiencing SPMI. Multiple knowledge, conceptual, and practice gaps result in barriers to practice of palliative psychiatry [e.g., issues of clinicians’ medicolegal responsibilities such as managing risk and accepted standards of practice (31); the contested notion of mental illness as terminal illness (32); a culture of practice amongst MHCP (refers to interprofessional healthcare workers including psychiatrists, nurses, social workers, occupational therapists, community mental health workers, and peer support workers) that symptom remission is to be pursued above all (7,31), and that death directly related to symptoms of the mental disorder is overwhelming viewed as an adverse—never a natural—outcome (3)]. There is increasing acknowledgment of the contribution of social and structural determinants of health in influencing the construct, onset, and prognosis of mental illness (7,15,16). The multidimensional influences on a course of a mental illness present a significant challenge to structuring clinical models of palliative psychiatry, as symptoms of mental disorders can seem bound to factors that health care providers have little influence over. Yet, the acceptance of the concept of “treatment resistant” illness and the strong evidence supporting a shifting risk-benefit ratio with repeated trials of biological treatments, hospitalization, and psychotherapy underlie the need for novel approaches to care in psychiatric practice (7).

Objective

In this paper, drawing upon both the literature and our work at a one-day knowledge exchange meeting called “A Community of Practice for Palliative Psychiatry”, we provide our recommended priorities for research, clinical practice, and education to further develop palliative psychiatry as a clinical construct.

Table 1 Primary background of meeting participants

Participant primary background [†]	Number
MHCPs	
Psychiatrist	5
Social worker	1
Nurse	1
Student	1
Palliative care provider	
Physician	2
Nurse	1
Bioethicist	
Bioethicist	4
Student	1
Mental health advocate	2
Person with lived experience	3
Total	20

[†], many participants brought multiple lived and learned perspectives to the discussion. For example, some participants had both bioethics and psychiatry content expertise, and others had a healthcare profession background in addition to mental health lived experience. MHCPs, mental health care providers.

Methods

On March 2, 2023, an international group of experts including MHCPs, palliative care providers, bioethicists, mental health service users, and advocates gathered for a hybrid in-person/virtual meeting at the University of Toronto to discuss the research, clinical, and educational priorities required to grapple with these questions and discuss future directions for developing a community of practice for palliative psychiatry (see *Table 1* for a breakdown of the participants). Participants were selected based on their established expertise in the field of palliative care for individuals experiencing SPMI, as determined by the event organizers, S.L., a psychiatrist, and D.Z.B., a bioethicist. There was representation of participants from three countries, with most participants residing in Canada (across three provinces). Established expertise was assessed based on the concept of ‘expert by experience’, presence in the academic literature on this topic, and by knowledge of participants’ work through the organizers’ professional networks. The organizers tried to strike a balance between including diverse perspectives for discussion and keeping

the meeting group small enough to promote engagement.

The meeting was funded by the Canadian Institutes for Health Research (CIHR), and facilitated by S.L. and D.Z.B. *Table 2* provides a detailed outline of the meeting agenda, including plenary and small group discussion topics. Detailed notes were taken throughout the day by S.L., D.Z.B., and a research student (L.P.). Following the meeting, S.L. synthesized the content of the day’s discussion with existing literature and disseminated the findings and conclusions for feedback to the wider group of authors. The authors on this paper are individuals who attended the meeting, indicated that they wished to be contacted about future projects, and then participated in the development of the manuscript. Here, we present a summary of our discussion, followed by recommendations for those who wish to engage with this work.

Discussion

Research priorities for palliative psychiatry

People with lived experience (PWLE)-centred research in palliative psychiatry

The group discussed that the largest gap in the palliative psychiatry literature is the absence of perspectives on this clinical construct from PWLE [we have opted to use the term ‘PWLE’ here given that it is the most widely accepted term because it does not assign a valence to the types of experiences the individual may have had within the mental health system (33)] of receiving mental health care. The literature consistently suggests that including PWLE in research is an essential next step in the development of palliative psychiatry models (3,19,29). This recommendation is congruent with guidance that the inclusion of PWLE in mental health service research is an ethical priority and part of a rights-based anti-oppressive practice (33). A rights-based approach values equality and non-discrimination, participation and inclusion, and transparency and accountability (34). It is consistent with anti-oppressive practices in mental health care which encourages MHCPs to reflect on their own privileges and acknowledge the densely woven patterns of systematic disadvantage that shape the lives of the people with whom they work (35). People living with SPMI can be considered to be part of a population that tends to face intersecting patterns of systematic disadvantage (35). Such consideration of persons with SPMI as an oppressed social group obliges society, health care organizations and MHCPs to pay

Table 2 Meeting agenda

Time	Outline	Goals
09:00–09:20	Land acknowledgment and introductions	Orientation of attendees, including discussion of ‘ground rules’ and outlining key objectives for the day
09:20–09:50	Plenary lecture	Overview of palliative psychiatry
09:50–10:20	Plenary lecture	A rights-based perspective to developing palliative psychiatry approaches
10:20–10:35	Discussion of key objectives for the day	Meeting organizers presented stakeholder and content expert input to help guide the discussion
10:35–10:45	Health break (with project team members available for check-ins for those who need)	
10:45–11:45	Break out group—Session 1	Discussion of how a community of practice can support clinical skill building in palliative psychiatry in predetermined small groups
11:45–12:15	Debrief of Session 1	Large group debrief of small group ideas facilitated by meeting organizers
12:15–13:00	Health break (with project team members available for check-ins for those who need)	
13:00–14:00	Break out group—Session 2	Discussion of how a community of practice can support research and educational goals for palliative psychiatry in predetermined small groups
14:00–14:30	Debrief of Session 2	Large group debrief of small group ideas facilitated by meeting organizers
14:30–14:45	Health break (with project team members available for check-ins for those who need)	
14:45–16:15	Synthesis of community of practice opportunities, needs, and challenges	Large group discussion facilitated by meeting organizers
16:15–17:00	Summary and future planning	Discussion of developing community of practice infrastructure and potential working groups that can support ongoing work to advance projects pertaining to palliative psychiatry

particular attention to the needs and interests of members of this diverse social group and to facilitate their meaningful inclusion in health policy making that directly affects them.

Some meeting attendees suggested that given the potential risks associated with palliative psychiatry—including abandonment, perpetuating structural vulnerabilities and stigmatization, and repeating the historical lack of inclusion of PWLE in developing healthcare models—it seems especially important that this clinical construct is only further developed and co-produced [while co-production remains contested in that it does not fully challenge traditional hierarchies in knowledge production (36), it is also a research practice that specifically attends to sharing power, inclusion of different perspectives and skills, valuing the knowledge of all individuals working on the project, reciprocity in knowledge creation, and building trust to maintain relationships (37); this ethos is important

to bring forward into palliative psychiatry research] with PWLE. We discussed how one cannot justify the ethical development of a palliative psychiatry model without the meaningful involvement of PWLE as both researchers and participants given the centrality of QoL to this type of care and the importance of having that defined by those persons positioned to receive, rather than provide, the service. Meaningful involvement will include ensuring that PWLE hold leadership positions within research teams, including a wide range of PWLE (with a focus on involving PWLE who have traditionally been marginalized from research roles), and attending to processes whereby involvement of PWLE can challenge and disrupt biomedical models of mental illness (38).

We discussed several challenges that have been highlighted in involving PWLE in palliative psychiatry research. For instance, individuals who live with SPMI often

face multiple structural vulnerabilities that can make ethics review boards hesitant about their involvement as research participants. The idea that certain individuals are ‘too vulnerable’ has recently come under scrutiny (39) and there is growing recognition that researchers ought to facilitate the inclusion of oppressed social groups in research that directly affects them (40). Without the inclusion of diverse voices (including those who have been most radically marginalized) researchers sustain epistemic injustices like ‘elite capture’, where normative understandings of mental wellness determine the appropriateness to participate in knowledge production (41). Members of the group identified how research practices such as person-oriented research, community-based participatory research, co-design, or user-driven designed research may all provide methods to promote the inclusion of PWLE of SPMI in palliative psychiatry research. Studies examining palliative care provision and end-of-life decision making for persons experiencing SPMI and serious medical conditions are concrete examples of how inclusion of PWLE and SPMI is possible (42–45).

Conceptual clarification

Futility has been described as an indicator of when to introduce palliative psychiatry in clinical contexts (7,29,46). Unique features in psychiatric illness and practice challenge the direct application of concepts of futility from somatic medicine to the treatment of mental disorders (47). The group reflected on how it is necessary to understand the normative underpinnings to the concept of futility in mental health care (a concept that remains debated in other areas of medicine), as well as the empirical and values-based processes for making these types of determinations. Currently, it seems that persons experiencing SPMI require an ‘extreme nonresponse’ or to ‘fail treatment’ before it is acceptable for a clinician to make a futility determination, and this is often done on an ad-hoc basis without due process (48). Furthermore, the group noted how it is difficult to make futility determinations in clinical care without addressing how structural and systemic inequalities such as poverty and access to care could be affecting treatment response (49). We identified that an examination of how structural inequalities contribute to judgments of futility is a necessary line of inquiry, and one that should actively be grounded in PWLE perspectives about the concept. This line of inquiry may even illuminate that futility may be neither necessary nor sufficient to the use of palliative psychiatry as a clinical construct.

The goal of palliative psychiatry approaches is to improve QoL, a concept complicated by being inherently situated in individual value judgements. Individuals who experience SPMI have identified that the loss of autonomy is an omnipresent existential threat and that personal development (including learning to accept their symptoms) is important to QoL (43,50). The group discussed how these realities should inform further critical examination of QoL for individuals experiencing SPMI. Better understanding of concepts of QoL will advance the development of palliative psychiatry as it would guide conversations required in this clinical space to ensure the work achieves its aims. There was general agreement that processes should be developed that ensure that QoL is determined by individuals experiencing SPMI themselves.

Mental health care has a long tradition of engaging individuals who could participate in analytic psychotherapies in deep explorations of suffering. However, the biomedical model that dominates care for most individuals experiencing SPMI does not promote this same curiosity in understanding how symptoms of SPMI might translate into individual suffering (51,52). Suffering has been conceptualized as an affliction in which not only the body, but also the self, is threatened (53), and has been linked to a reduction in QoL among individuals experiencing SPMI (54). This definition offers a good starting point for further examination of how threats to the self are manifested in the presence of SPMI and how the mental health care system can play a role in alleviating this suffering, both through healthcare-based interventions and through acknowledging (and where possible addressing) the intersecting social determinants of health. Research in this field must be creatively designed to acknowledge the diversity of individual human experience given that suffering is both a collective experience and an intensely personal one. The group discussed how explorations into suffering would offer opportunities to recognize the experiential authority of PWLE and use experiential knowledge to challenge biomedical understandings of mental distress (55). This research might also explore non-verbal expressions of suffering that can be examined by the individual experiencing SPMI, their loved ones, and their clinical teams to come to an intersubjective understanding of their experience. Increased MHCP attunement to suffering might lead to new understandings of how to palliate a mental illness (when solicited and desired).

Mapping and translating pre-existing palliative supports

Mental health care provision is often understood as

Table 3 Examples of palliative psychiatry skills with their opportunities and challenges

Skill	Opportunities	Challenges
Communicating diagnosis and prognosis	Development of staging models	Lack of biomarkers in diagnosis of mental disorders Inherent uncertainty in the course of mental disorders due to impact of SDoH, treatment accessibility, etc.
Advance care planning	Developing structured tools to facilitate individuals experiencing SPMI providing advance directives Adapting pre-existing palliative care tools to support shared decision-making and care planning (e.g., Serious Illness Conversation Guide) Educating MHCPs around GoC discussions to increase their comfort in engaging in these discussions in the clinical setting	Understanding how capacity evaluations for treatment fit within these discussions Adapting GoC discussions to work with individuals who live with internal ambiguity about engaging in health-harming behaviours (e.g., certain types of substance use, self-injurious behaviours, suicide attempts)
Responding to caregiver needs	Promotes caregiver engagement in SPMI care Consistent with WHO model for palliative care	Preserving and protecting confidentiality for the person experiencing SPMI Identifying who might serve as a caregiver for the person experiencing SPMI as they may live within a community that values non-traditional relationships
Deprescribing	Reduce the iatrogenic harms associated with treatment for SPMI	Current lack of evidence-based and clinical guidelines to support deprescribing practices

SDoH, social determinants of health; SPMI, severe and persistent mental illness; GoC, goals of care; MHCPs, mental health care providers; WHO, World Health Organization.

encompassing only those formal MHCPs who work within typical health care settings. Many individuals with SPMI receive informal mental health care through other social supports (e.g., housing workers), personal caregivers (e.g., loved ones), and their peers. Members of the group highlighted that it is likely that palliative interventions are already occurring across these other supports without being labelled as such (e.g., discussions with peers about health care directives). It is important that palliative psychiatry researchers identify and evaluate these approaches in the context of current palliative psychiatry programs. Research into the translation of effective strategies in palliative medicine to palliative psychiatry should also be pursued, much like how advance care planning is gaining traction within mental health care. Psychiatric advance directives—legal documents that allow an individual to direct their future mental health care treatment (56)—have been identified by PWLE as a tool that can improve their care (57). Some studies examining end-of-life preferences for individuals experiencing SPMI might also be adapted to the palliative psychiatry context, such as Foti's "Do It Your Way" study that used case studies to elicit preferences from individuals experiencing SPMI to support decision-making capacity and

maintenance of autonomy (42). Inquiring into pre-existing palliative care tools and practices should also examine the barriers to adoption in palliative psychiatry models, such that challenges can be overcome in an iterative fashion.

Priorities in clinical practice

Methods and tools of palliative psychiatry

Palliative psychiatry can be considered a philosophy of care within mental health practice, with an associated set of strategies and skills (see *Table 3* for a discussion of specific palliative psychiatry skills). It is widely agreed that palliative psychiatry is necessarily a patient-centred and individualized model of care (3,30). We discussed how palliative psychiatry requires an interdisciplinary approach given that this model of care is typically enacted in situations of high clinical complexity (29). Palliative psychiatry approaches will benefit from collaborative practices where MHCPs, individuals experiencing SPMI, and their families and/or substitute decision makers are all able to discuss their viewpoints to come to shared understandings and generate creative approaches towards directions of care.

One justification for palliative psychiatry includes

mitigating the risk of overly aggressive (and often coercive) treatment for persons who experience SPMI, which reflects the customary practice of MHCPs to continue with treatments for which there is little to no evidence (3). As we develop practices of palliative psychiatry, the group described that it is important to consider how evidence-based approaches might be established, or where the very notion of ‘evidence-based practice’ might be problematized given the practical mission of palliative psychiatry to reduce suffering (58). This tension is represented in the Oyster Care model of palliative psychiatry which emphasizes flexibility so that patient needs remain central over institutional or professional concerns. For example, while one person might benefit from an adaptive environment, another’s suffering might be reduced by decreasing unwanted side effects through lowering the dosage of otherwise evidence-based medications. ‘Treatment’ takes on a broad definition in this model and practitioners take pride in developing creative and practical interventions that only aim to address symptoms or issues that are causing suffering (19). Palliative psychiatry offers opportunities for MHCPs to interrogate the medicalized approach to caring for individuals experiencing SPMI and challenge its focus on symptoms that lend themselves to description and discrete intervention over concentrating on other aspects of individuals’ lives.

Given the uncertainties in prognosis inherent to mental disorders (8), the influence of social and structural determinants of health on SPMI conditions, and the possibility of novel treatments for these disorders, it is important that practitioners of palliative psychiatry feel comfortable moving between and working simultaneously in different mental health care models. Palliative psychiatry might be pursued alongside other mental health care models such as Open Dialogue (where listening and engaging social networks is emphasized) (59), Trieste’s “open door-no restraint” system (where mental health care is provided by a network of community services) (60), or Soteria Houses (which use a demedicalized therapeutic milieu, rather than antipsychotics, to treat psychosis) (61). The Bow Tie Model of palliative care (which describes how palliative care and curative medicine can be employed simultaneously) offers a way to conceptualize how palliative psychiatry might be introduced while other models of mental health care continue to be pursued (62). The value of naming a palliative psychiatry approach at any stage of care is to help place a focus on QoL—as defined by the person experiencing SPMI—as a priority in planning a course of care.

Identifying target populations

When first introduced, the aim of palliative psychiatry was to offer an alternate model of care to individuals experiencing SPMI who had multiple comorbidities and higher-than-average mortality rates (9). These terms carry significant ambiguity, such that it remains unclear for whom palliative psychiatry approaches are most relevant or applicable. Some case reports and case vignettes have attempted to provide concrete examples of situations where palliative psychiatry might be implemented (30,48). It is also essential to understand how people who experience SPMI might think about palliative psychiatry, and whether this type of approach is desired. The group discussed how these voices should be engaged in co-constructing the clinical eligibility criteria that are often required by the institutions within which MHCPs work.

Living with SPMI has clearly been identified as one of the core features of an individual who might benefit from palliative psychiatry. This criterion suggests that diagnosis might serve as one potential entry point into this model of care. If so, it behooves MHCPs to take the WHO’s recommendation that palliative care only be deployed once attention has been paid to providing an ‘impeccable diagnosis’ (19,63). Confidence in diagnosis is especially necessary, though complicated, in formulating the symptoms of mental disorders (64). Much has been written on the fuzzy-boundary concepts of psychiatric classification (65), including how the *Diagnostic and Statistical Manual of Mental Disorders* is an imperfect and even problematic tool (66). While diagnosis should not be the sole criterion for access, it can potentially serve as a signpost for engaging with palliative psychiatry. The introduction of staging models may further support the link between diagnosis and appropriateness of palliative psychiatry (8). However, psychiatric staging models have been criticized on the grounds that people experiencing mental illness often do not have access to all guideline-based treatments (e.g., psychotherapies) making it difficult to use staging in a clinically predictive manner with respect to initiating palliative psychiatry approaches (67). Moreover, risks of associating specific diagnoses with the use of palliative psychiatry include the implication that certain diagnoses carry more suffering than others, which may be harmful and invalidating to individuals’ experiences. Certain diagnoses, such as borderline personality disorder, carry immense stigma that result in a dearth of care for individuals labelled with this diagnosis (68). For these reasons, the group discussed how we should be cautious

in using diagnostic categories as criteria for eligibility for palliative psychiatry as it may inadvertently worsen access to other QoL promoting treatments.

Those at risk for overly aggressive treatment is similarly a vague, but tacitly proposed, criterion for the types of individuals who might benefit from palliative psychiatry. An intervention may be considered 'overly aggressive' if it exists outside of guideline or evidence-based medicine or there is reason to suspect that it may cause more harm than benefit. No population has been empirically proven as being at risk for overly aggressive treatment, though it has been repeatedly suggested that individuals experiencing SPMI belong to this group (6,8,9,69). Structural vulnerabilities complicate the idea of overly aggressive treatment. For example, an individual might be receiving multiple psychotropic medications to reduce their risk of unsafe behaviour and control their behaviour related to psychosis (thereby mitigating their risk of hospitalization), while also having the experience of being unable to work and generate an income. Poverty, in turn, leads to situations of underhousing or homelessness resulting in these individuals lacking spaces that helps them feel physically and psychologically secure such that they might not require as much medication or be labelled treatment-resistant. Structural vulnerabilities may also contribute to a lack of access to more conventionally understood evidence-based treatments (e.g., psychotherapy) that could prevent the overuse of psychotropic medications or coercive treatment practices. It is difficult to distinguish those who are at risk for 'overly aggressive treatment' from those who are at risk of 'undertreatment', and the group discussed how it is possible that individuals experiencing SPMI might be at risk of both simultaneously. This speaks to an overarching tension in palliative psychiatry between not doing 'too much' while also not abandoning individuals experiencing SPMI by doing 'too little'. It is essential to critically question these concepts as pathways are developed between treatment-as-usual to palliative psychiatry models. The group agreed that it is imperative that PWLE be included in discussions around eligibility to provide their expertise around experiences of different 'levels' of treatment and what they would have found helpful or validating in those instances of care.

Addressing MHCPs' professional anxieties in exploring palliative psychiatry

We discussed how MHCPs may struggle with several anxieties if they undertake a practice of palliative psychiatry.

MHCPs might feel distressed about limited access to care-as-usual for some people with SPMI that has therefore affected the trajectory of their illness such that palliative psychiatry is now being considered. Access to intensive mental health and socioeconomic supports can also be limited, though they have had proven impacts on mental health outcomes (70,71). It is also worth considering if MHCP engagement with palliative psychiatry might improve access to care for people experiencing SPMI. Working closely with individuals with treatment-resistant mental disorders is associated with increased health care provider burnout and high rates of staffing turnover (8,72). MHCPs have described a permanent sense of powerlessness in the face of treatment-resistant symptoms and contributing structural discrimination and stigma (19,73). In contrast, MHCPs working within one clinical model of palliative psychiatry described that they had increased job satisfaction, decreased burnout, and felt validated by the work (19). The introduction of clinical models for palliative psychiatry might re-energize MHCPs to start engaging more with individuals experiencing SPMI such that there is greater availability of services.

MHCPs might also experience moral distress as they navigate building strong and trusting therapeutic relationships that are essential to the practice of palliative psychiatry. Dominant practices within mental health care have created a culture where symptom reduction or remission is highly valued, even if MHCPs should consider how such symptoms might be beneficial to or have a neutral impact on the person experiencing them (19,74). It is important to incorporate tools and cognitive models into developing practices of palliative psychiatry that will help MHCPs process the possibility that symptoms associated with SPMI might bother health care workers or other caregivers more than those experiencing the symptoms themselves. Caregiver distress might be contained by formulating how symptoms might be benefiting the person, or contextualizing symptoms within the life histories of those experiencing them (19).

Moral distress can arise when MHCPs are tasked with managing risk (e.g., suicide, self-harm) in situations where there are no novel or effective treatments available for the individual in question (31). The very concept of risk has been criticized as a tool for controlling individuals and populations by translating hypothetical events with poor predictability into real restrictions (75). Some authors argue that the psychiatric project's focus on risk undermines the ability of MHCPs to work collaboratively with patients to

understand what is important to their personhood (76,77), a skill we believe is central to the practice of palliative psychiatry. Repeated risk assessments are not without their own risk, including potentially excessive restrictive and coercive interventions (76,78). Members of the group pointed out how mental health service users have experienced considerable harm historically and currently at the hands of the mental health system, and these experiences can create barriers to building relationships with MHCPs.

Several strategies have been proposed as alternatives to dominant paradigms of risk assessment. “Positive risk-taking” refers to collaborative assessments between the individual experiencing symptoms and their MHCP where risk is jointly conceptualized and formulated and decision-making is done in partnership with the goal of improving the QoL for the individual who is ‘at risk’ (19,78). This approach might include MHCPs working with the identified ‘at risk’ individual to formulate their behaviours and mutually determine a threshold for more invasive interventions. Other authors argue that if the broader ethos of mental health care centred on fostering trust it might be possible to manage risk and meet needs through relationship building (77). Both approaches are salient to the practice of palliative psychiatry. Fostering the service user-provider relationship is similarly central to palliative psychiatry, by harnessing the trust that develops through strong relationships, and this might help mitigate the challenges of coercion and patient decision-making capacity that MHCPs face when engaging with palliative approaches to care. Positive risk-taking fits within palliative psychiatry as a relational model of care and might be a way to start understanding risk management within palliative psychiatry approaches.

Educational priorities to advance palliative psychiatry

We discussed how building capacity and dissemination of methods and models of palliative psychiatry will be important to furthering its acceptance and use in mental health care. The overarching questions of this educational mission are:

- ❖ Who should be the targets of education?
- ❖ What are the goals of the education?
- ❖ Who is designing the curriculum?

These questions are complicated by the lingering issue of whether palliative psychiatry should be considered a ‘subspecialty’ of mental health care, or a subset of ‘generalist’

skills to support work with individuals experiencing SPMI.

Current practitioners

Providing current MHCPs with professional development opportunities (such as through conference workshops or ‘upskilling’ courses) in palliative psychiatry would help disseminate these models more widely and provide opportunities for palliative psychiatry practitioners and researchers to receive critical feedback from clinicians with extensive clinical experience. Training experienced MHCPs with techniques and tools in palliative psychiatry might decrease barriers to access given more widespread familiarity with the model. Given that palliative psychiatry proposes new ways of approaching issues like futility, risk, and coercion, education initiatives might benefit from promoting a reflexive stance towards these topics to help overcome the commitment of experienced MHCPs to existing approaches (which have often been informed by specific interpretations of how to mitigate the risk of malpractice).

Learners

Providing mental health care learners with education about palliative psychiatry would likely be a fertile endeavour for broader dissemination of these ideas and models. There have been multiple recommendations for cross-disciplinary training and education between palliative care and mental health care trainees (29,79), and these educational activities might serve as a gateway to introduce palliative psychiatry to trainees. It would be important to attend to methods to cultivate the necessary moral and intellectual virtues (e.g., trustworthiness, clinical courage) necessary in the work of palliative psychiatry (15,29,80). Trainee education in palliative psychiatry would require moving beyond teaching content (such as skills or algorithms in care) to providing spaces to reflect on process, including how to become more comfortable with uncertainty and complexity in clinical decision-making. Medical education prioritizes outcomes over process, teaching students to be uncomfortable with uncertainty and fearful of making mistakes (81). Palliative psychiatry requires MHCPs to take an unassuming and inquisitive approach to the care of individuals experiencing SPMI. It challenges MHCPs to reconceptualize tenets fundamental to their work (e.g., the avoidance of risk) and thus increase their ability to navigate discomfort in clinical work and professional identity is an asset in this practice. Involving PWLE in curriculum planning and teaching would support trainee dexterity with complexity

and uncertainty (82). Palliative psychiatry curricula would benefit from being co-productions between medical educators and PWLE, following educational guidelines for doing so in a safe and epistemically just manner (82,83).

Individuals experiencing SPMI and their caregivers

The group identified how service user and family-facing education is an important aspect of a palliative psychiatry curriculum. Models of palliative psychiatry must also be introduced to individuals experiencing SPMI and their caregivers to increase a sense of preparedness of what to expect should it be raised in a clinical encounter. In keeping with the ‘Bow-Tie’ approach to palliative care, education about palliative psychiatry approaches could be offered early in the individual’s clinical course to increase the likelihood that they will be able to appreciate concepts in palliative psychiatry and state their preferences about their care and QoL. It will be essential to address the stigma associated with the term “palliative care” in order to reassure individuals experiencing SPMI and their loved ones that this model does not amount to the abandonment feared by its critics and that the person may not be at the end-of-life (30,84).

Education around palliative psychiatry might also create opportunities for new types of discussions between individuals experiencing SPMI and their MHCPs. For example, creating new spaces could allow opportunities for stakeholders to discuss death and existential anxieties without meeting a coercive response or having the conversation dismissed as outside the purview of mental health care. MHCPs interested in palliative psychiatry models can work with community organizations to meet people where they are at to introduce these approaches and create partnerships that facilitate ongoing discussion and education about this practice. Palliative psychiatry education could also occur within clinical encounters through accessible user-facing materials, and in public discussion or debate. Ideally, service user and family facing education would be led and implemented by PWLE.

Limitations

In this paper we have described research, clinical, and educational priorities to advance palliative psychiatry as a clinical construct that can benefit individuals experiencing SPMI. Our suggestions are based on a synthesis of existing literature and discussions held between attendees at our one-day meeting. We recognize that there are significant limitations to this work. The ongoing conceptual confusion

around palliative psychiatry meant that our assembled group, despite our collective lived and content expertise, had to spend a significant amount of meeting time ensuring we were all discussing the same idea when referencing palliative psychiatry. The meeting ended with an incomplete consensus definition of palliative psychiatry with some of our group suggesting that given the legitimacy of overlaps between palliative psychiatry approaches and other established models of care, and a desire to not have MHCPs choose one over the other when both could possibly provide benefit(s), it may be more pragmatic to describe palliative psychiatry as a person-centred, relational psychiatric care approach rather than as a new subspecialty or distinct model of care. Since our meeting in March 2023, there have been important contributions to the literature describe why it is clinically and ethically relevant to name palliative psychiatry explicitly (17,18). This ongoing debate likely influenced the nature of discussion and conclusions, and we recognize that our conclusions may shift as consensus emerges regarding underlying assumptions about palliative psychiatry.

Moreover, although we had international representation from Switzerland and the United States, the meeting participants were largely familiar with the Canadian context for mental health services which is diverse in and of itself. There are likely specific regional considerations that we have overlooked when describing palliative psychiatry as part of broader mental health systems and attempting to provide recommendations for such. While mental health service users were involved in the meeting planning and discussions, we cannot claim that this manuscript is a work of co-production. Our group had to navigate tensions in creating an agenda and coming to agreement about some of the fundamental assumptions that underlie this work. We learned first-hand that a single day is insufficient to build the trust and relationships necessary to have some of those honest conversations. We also struggled to overcome some of the limitations in creative engagement of PWLE when producing work within the confines of academic journal timelines and work schedules. Finally, we recognize that we are presenting idealized versions of this clinical concept without reconciling how this approach might fit within current funding and resource limitations of different contexts.

Conclusions

Palliative psychiatry might offer a different clinical model, or at least another conceptual approach towards mental health care, that can be employed to enhance person-

centred care for individuals experiencing SPMI. Palliative psychiatry cannot and should not be used to legitimize, apologize, or condone the iatrogenic harms that have been associated with dominant models of mental health care, nor should it be used to restrict access for people experiencing SPMI to treatment aiming at clinical remission. This manuscript represents the first attempt to collate and state explicitly what is needed to transform palliative psychiatry models from theoretical to clinical constructs. Most importantly, when advancing work in palliative psychiatry, researchers, clinicians, and educators should consider:

- ❖ Palliative psychiatry must be rooted in rights-based, anti-oppressive approaches to care for persons experiencing SPMI.
- ❖ That research projects, clinical pathways, and educational endeavours must be co-produced with PWLE and aim to mitigate the epistemic injustices often perpetuated in mental health care services, research, and education.

The research priorities to advance palliative psychiatry should include:

- ❖ Interdisciplinary, conceptual, empirical, and critical examination of multiple values-based concepts are required to further the work of palliative psychiatry.

The clinical priorities to advance palliative psychiatry should include:

- ❖ Developing an armamentarium of tools and techniques in mental health care that specifically respond to QoL concerns and centre the therapeutic relationship.
- ❖ Re-evaluating the medicolegal responsibilities around risk and standard of care in many jurisdictions, which will require institutional support around reconceptualizing risk to ensure that individuals experiencing SPMI have access to palliative psychiatry approaches when appropriate.

The educational priorities to advance palliative psychiatry should include:

- ❖ The development of thoughtful educational programs that attend to both content and process will be important both for MHCP trainees and as continuing professional development for those already in practice. MHCPs' increased comfort with palliative psychiatry should be directly linked to encouraging them to provide more access to QoL-promoting care for individuals experiencing SPMI.

- ❖ Efforts must be made to engage and educate individuals experiencing SPMI and their caregivers about experiences of death and dying with mental illness and to help reduce stigma around the idea of 'palliation'.

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