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Review Article

End-of-Life Care in Individuals With Serious Mental Illness



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Background: *Approximately 4.5% of the population live with serious mental illness (SMI), a term referring to mental health disorders that are chronic, impair function, and require ongoing treatment. People living with SMI are at risk of premature mortality relative to people without SMI. Chronic medical illnesses contribute significantly to mortality among individuals with SMI. The standard of care for individuals with serious medical illnesses includes palliative care. However, the provision of palliative care has not been operationalized for individuals with SMI. Objectives:* *To review existing data on end-of-life and palliative care for individuals with serious medical illness and comorbid serious mental illness. To operationalize the role of the consultation-liaison (C-L) psychiatrist in such care, with a particular eye towards redressing disparities. Methods:* *In this narrative review, we draw upon a review of the literature on end-of-life and palliative care provision for individuals with serious medical illness and comorbid serious medical*

illness. We also draw upon the experiences of the authors in formulating best practices for the care of such patients. Results: *Individuals with SMI are at risk of suboptimal end-of-life care. Patient, clinician, and system-level factors all contribute to disparities including decreased access to palliative care, uneven continued engagement with mental health services, and low rates of advance care planning. C-L psychiatrists can use their expertise at the intersection of medicine and psychiatry to address such disparities by (1) correcting mis-assumptions, (2) promoting advance care planning, (3) engaging long-term caregivers, (4) recognizing social needs, (5) ensuring ongoing access to psychiatric treatment, and (6) addressing suffering. Conclusions:* *There are significant disparities in the end-of-life care of individuals with SMI. C-L psychiatrists have expertise to ally with medical providers and redress these disparities.*

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Key words: palliative care, serious mental illness, end of life care, advance care planning, disparities, consultation-liaison psychiatry.

INTRODUCTION

The term “serious mental illness” (SMI) refers to psychiatric disorders that are chronic, require ongoing treatment, and have a significant impact on function, such as chronic psychotic disorders, bipolar affective disorder, and severe personality disorders.¹ Approximately 4.5% of the population lives with SMI.² Individuals with SMI die approximately 15–25 years earlier than those without mental illness and have an all-cause mortality 3.7-times higher than that of the general population.^{3–6}

The mortality gap among individuals with SMI has been the subject of extensive epidemiologic study. Although increased mortality among individuals with

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SMI is multifactorial, serious medical illnesses, most notably cardiovascular disease and cancer, contribute significantly to increased mortality. People with SMI experience standardized mortality ratios of 3.6 for cardiovascular disease, 2.4 for cancer, and 9.9 for chronic obstructive pulmonary disease.⁶ These disparities persist even when controlling for confounders such as socioeconomic status and comorbidities.⁷

The high burden of serious medical illness among individuals with SMI suggests a need for tailored palliative and end-of-life (EOL) care. Palliative care, a specialty of medicine dedicated to the holistic care of individuals with serious medical illnesses, has become part of the standard of serious illness care.⁸ The roles of palliative care include psychosocial-spiritual care, symptom management, and medical communication. However, most palliative care clinicians are not psychiatrists and may not have training in managing comorbid SMI. We submit that consultation-liaison (C-L) psychiatrists are well positioned at the interface of specialist medical services (oncology, cardiology), palliative medicine, and psychiatry, to fill this gap and improve the quality of EOL care for individuals with SMI.^{9,10}

In particular, the role of C-L psychiatrists in improving EOL care for individuals with SMI is more important now than ever. The COVID-19 pandemic has put unprecedented strains on palliative care delivery systems that require new models and tools, many of which may not be inclusive of or tailored toward individuals with SMI.^{11,12}

This article reviews current data on EOL care for individuals with SMI, with the goal of providing C-L psychiatrists necessary information to provide high-quality care to individuals with comorbid SMI and life-limiting medical illness. After a review of existing epidemiologic data on EOL care for individuals with SMI, we identify barriers to the provision of quality EOL care for such individuals and identify best practices in the role of the C-L psychiatrist to overcome such barriers. Finally, we discuss future opportunities in the field of C-L psychiatry for improving EOL care for individuals with SMI.

CURRENT PATTERNS OF EOL CARE FOR INDIVIDUALS WITH SMI: IDENTIFYING DISPARITIES

Utilization of and access to EOL services by individuals with SMI has been studied globally. Data from diverse

health systems demonstrate variations in EOL care for individuals with comorbid SMI. However, there are consistent differences in the quantity, quality, and nature of services accessed at the EOL between people with and without SMI.

Perhaps the most well-known investigation comparing utilization of EOL services by individuals with and without SMI is a 2012 study by Chochinov *et al.*¹³ Chochinov *et al.*¹³ used 12 years of provincial health data from Manitoba, Canada, comparing utilization of various health services among individuals with schizophrenia with matched controls. Individuals with schizophrenia were less than half as likely to receive specialty palliative care. Individuals with schizophrenia were about 30% less likely to be prescribed analgesia, possibly reflecting undertreatment or underreporting of pain; this discrepancy was even more pronounced among individuals with cancer. While terminally ill, individuals with schizophrenia also had significantly less access to their psychiatrists and were more likely to spend their last months in a nursing home. Population-level data from other health systems including Australia and New Zealand support Chochinov's finding that individuals with SMI are 2–4 times less likely than individuals without SMI to access palliative care services in the last months of life.^{14,15} Data from studies in Taiwan and France are somewhat more ambiguous: depending on the metrics used and the subgroups studied, palliative care utilization by medically ill patients with SMI could be seen to be either increased or decreased, or both.^{16,17}

Data from the United States are limited. A retrospective study of decedents from the University of Washington Health System showed that mental illness was associated with higher nursing home use and more emergency department (ED) visits at the EOL.¹⁸ However, these data were not specific to patients with SMI. Kelly Irwin *et al.*¹⁹ completed a retrospective study of 95 patients with breast cancer and schizophrenia in one health care system between 1995 and 2015. Only 38% of patients who died had a palliative care consultation, with all but one being inpatient, and only 44% had documented referral to hospice. In contrast, a small study in the Veteran Affairs system showed veterans with schizophrenia were significantly less likely to initiate chemotherapy but had comparable advance directives, opiate prescription, do-not-resuscitate/do-not-intubate orders, and hospice enrollment.²⁰

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To sum up so far, individuals with SMI have a heavy burden of serious medical illness and experience disparities in availability and kinds of EOL care. Such disparities include differences in access to palliative care and specialty medical care, differences in provision of both disease-modifying and life-extending treats in the EOL period, and differences in nursing home utilization and place of care. Such discrepancies may both lend themselves to and reflect suboptimal EOL care for individuals with SMI. Furthermore, there are almost no existing data on the clinical practice of EOL care for individuals with SMI; existing data focus on systems-level utilization and access and less so on clinical discrepancies in palliative care services such as analgesia.

BARRIERS TO CARE AND CONTRIBUTORS TO DISPARITY

Understanding the barriers to improving EOL care for individuals with SMI has been conceptualized as a tripart model which includes patient, health care, and societal factors (see [Table 1](#) for a review of barriers and potential interventions).²¹

Patient Factors

Multiple aspects of SMI make the provision of EOL care challenging. Patients with SMI may have poor insight into their health state and may struggle to communicate symptoms.^{22,23} This may be due to underlying psychiatric symptoms, poor health literacy, and neurobiological differences in pain and symptom response.^{24,25}

Underlying symptoms of SMI may include paranoia and hostility which can undermine the therapeutic alliance. Nurses identify this as one of the key barriers to providing quality care to patients with SMI.²⁶ Negative symptoms such as social withdrawal and apathy can also make forming a treatment alliance and establishing goals of care a difficult task, particularly for medical providers who may be unaccustomed to working with patients with mental illness.

It has been demonstrated repeatedly that many individuals with SMI are able to participate in conversations about their EOL preferences.^{27,28} According to more general studies of capacity, such as the MacArthur Treatment Competence Study, lack of ability to participate in treatment planning at the EOL is due to decision-making characteristics such as thought

disorganization, rather than diagnosis.²⁹ Studies have demonstrated that patients with SMI can use hypothetical scenarios to discuss EOL treatment preferences and that they feel positive about the opportunity to discuss EOL care.^{28,30,31} EOL care priorities identified by individuals with SMI are not appreciably different from those identified by individuals without SMI including companionship and symptom control.^{28,30} Similarly, views on EOL-specific topics such as palliative sedation and withdrawal of life support do not differ markedly between individuals with and without SMI, although patients with SMI may be less likely to agree with medical aid in dying.³⁰

Even with the interest and ability to engage in advance care planning, evidence suggests that individuals with SMI are unlikely to do so. Among adults in the community with SMI, about a quarter had conceptualized specific health care preferences, but only 2% had documented these preferences. Seventy-two percent of this cohort thought they should have a designated surrogate decision-maker and 62% specified an individual who might fill such a role, but only 18% had a documented proxy.³¹ Likewise, in nursing home settings, SMI was associated with a lower rate of advance care planning.³² In part, this may be due to a dearth of validated tools to enhance palliative care for individuals with SMI.²²

Health Care Factors

Before the development of a serious medical illness, patients with SMI may receive most of their care in the mental health setting. Given siloing of mental and physical health and the dearth of existing models of mental health and serious illness care codelivery, patients with new serious medical illness may be shifted from a predominantly psychiatric treatment frame to a medical one.^{9,33} Even if patients at the EOL are managed in a mental health setting, they may be subject to a different legal and regulatory context. For example, in the psychiatric setting, staff may worry about giving a patient too many pain medications and hastening the dying process or fear the legal ramifications of not performing resuscitation on a dying patient.³⁴

Psychiatrists may be uncomfortable with diagnosis and management of medical conditions and may have limited capacity to provide palliative care.¹⁰ Conversely, when patients with SMI enter a

TABLE 1. Barriers to Care and Potential Interventions

Barriers	C-L interventions
Patient factors	
Chronic psychotic symptoms	Ensure continuous psychiatric care, particularly by maintaining and adjusting psychiatric medication regimens as needed (e.g., monitoring drug interactions)
Cognitive sequelae of SMI	Encourage capacity assessments on a case-by-case basis to avoid the assumption that all patients with SMI lack decision-making capacity Assist specialist medical teams and palliative care providers in communicating medical information in a concrete and digestible manner tailored to an individual patient's cognitive and communicative abilities
Negative symptoms (social withdrawal, apathy, alogia)	Provide education to medical clinicians about negative symptoms Dispel incorrect assumptions about perceived disinterest Assist and "coach" patients in formulating questions and communicating effectively
Healthcare factors	
Siloed health care	Translate concerns between psychiatric and medical teams to facilitate communication between specialties and encourage adaptation of both psychiatric and medical care to the patient's needs
Lack of cross-specialty expertise	Provide cross-training between mental health clinicians and medical teams, e.g., by providing education to community mental health clinicians who may be less familiar with medical issues
Stigma against SMI	Help medical teams avoid pitfalls, such as the misattribution of physical symptoms to mental illness, to help patients with SMI receive timely and appropriate medical care
Sociocultural factors	
Lack of social resources	Integrate evaluation of social needs into medical care to adequately address concerns such as vulnerable housing and social isolation that may impede delivery of quality EOL care
Decreased access to health care proxies	Facilitate patient engagement in advance care planning and provide guidance for mental health and medical teams to participate in EOL care discussions

C-L = consultation-liaison; EOL = end of life; SMI = serious mental illness.

predominantly medical treatment setting, they may be cared for by clinicians with no experience with SMI. Medical specialists and even palliative medicine clinicians have limited or no required training in psychiatry as part of their certification requirements. As such, there may be significant discomfort caring for individuals with SMI. Presumptions of lack of capacity and inability to discuss challenging topics (e.g., advance care planning) may contribute to this lack of comfort.³⁵ Stigma against patients with SMI also contributes to misattribution of medical illness as a manifestation of mental illness.³⁶ In a qualitative study of palliative care and psychiatric nurses on EOL care for patients with SMI, both groups of nurses identified stigma as a barrier to providing quality EOL care.²⁶

Sociocultural Factors

Currently, EOL care is predicated on availability of social resources such as stable housing and social support.³⁵ Socioeconomically disadvantaged patients are generally underscreened for symptoms, regardless of mental illness.³⁷ In addition, individuals experiencing homelessness face unique barriers including worse

health overall, higher mortality, higher acute care utilization, and decreased care at the EOL.³⁸ Surrogate decision-making policies are usually predicated on individuals having substitute decision-makers in place. However, individuals with SMI are at high risk of social isolation, homelessness, and poverty. Patients with SMI and serious medical illness may find themselves without a treatment setting that can adequately address medical and social needs concurrently.^{26,36}

BEST PRACTICES: SUGGESTIONS FOR THE C-L PSYCHIATRIST

C-L psychiatrists are well suited to serve as champions for patients with SMI at the EOL. They have expertise in managing patients with complex comorbid medical and psychiatric issues clinically. But beyond this, they have a systems-level appreciation of the care of such patients. C-L training may include developing expertise in a range of palliative care skills and honing collaborations with specialty palliative care providers.¹⁰ In the following sections, we outline important roles that the C-L psychiatrist may find themselves filling in the EOL care of patients with SMI.

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Avoiding Assumptions

As previously discussed, most patients with SMI are capable of making treatment decisions.³⁹ The current standard of serious illness care is that patient be engaged in a model of shared decision-making, a paradigm of collaborative engagement between stakeholders including patients, clinicians, families, and other involved parties.⁴⁰ Even among patients with non-SMI diagnoses, there is evidence of an “engagement gap” in which patients and families may have a smaller decision-making role than desired in serious illness care.⁴⁰ This engagement gap may be more pronounced in individuals with SMI. However, models from forensic and mental health research suggest that individuals with SMI are more likely to be engaged in shared decision-making when they are perceived as being able to contribute to treatment planning.⁴¹ As liaisons between practitioners and systems of physical and mental health provision, C-L psychiatrists can help medical providers reframe their assumptions about the care of individuals with SMI. Such psychoeducation can occur in a didactic frame, but also through the process of informal teaching through clinical consultation.⁴²

Patients should be assessed for capacity to participate in EOL treatment planning on an individual basis, independent on their underlying diagnosis,⁴³ and patients should be assessed for decisional capacity on an individual basis.³⁹ In addition, clinicians should avoid the tendency toward diagnostic overshadowing: attributing physical symptoms to mental illness.⁴³

Planning Ahead

Patients with SMI who become seriously medically ill are at risk of having minimal advance care planning in place. Advance care planning, including identifying a health care proxy, is an important part of ensuring value-concordant care at the EOL. C-L psychiatrists can help address the advance care planning gap among individuals with SMI. Data from work done among people experiencing homelessness suggest that counselor-guided advance care planning may be helpful.⁴⁴ However, because psychiatrists and other mental health clinicians working in mental health settings may receive little training in palliative care, many may not be aware of the need or feel able to participate in advance care planning conversations with their patients.^{45,46} C-L psychiatrists are well positioned to serve

as teachers to less medicalized colleagues in community mental health.¹⁰ Such teaching should be aimed at empowering community mental health providers to invite their patients to engage in appropriate advance care planning discussions.

Engaging Long-Term Outpatient Clinicians

Patients with SMI often receive care in community-based mental health settings. Community-based care may not translate into medical settings. As a result, patients may lose out on contact with longstanding mental health providers as their physical capacity to continue engaging in ambulatory mental health services declines. In qualitative studies, this concern is prominent among individuals living with SMI, many of whom identify their clinic providers as *de facto* family.^{21,31,33}

By virtue of their position at the interface of medical and mental health, C-L psychiatrists can serve as advocates to involve long-term mental health providers in the EOL care of patients with SMI. Furthermore, C-L psychiatrists have training in “translating” the concerns of mental health teams and medical teams to facilitate communication and optimize care. Adaptations in the normal provision of care may be necessary to meet the needs of high-complexity patients, for instance, providing inpatient-level psychiatric care in medical settings for comorbid patients.

Recognizing Social Needs

People with SMI are at high risk of poverty, homelessness, and social isolation. These risks are amplified by the stressor of serious medical illness. Both clinicians caring for individuals with SMI and individuals with SMI cite social isolation, stigma, and other social factors have key concerns in EOL care.^{21,28}

Clinicians may feel distrustful of patients for whom receiving medical treatment is associated with “secondary gains” such as housing, food, or social contact. However, holistic EOL care includes attention to these needs. In patients experiencing homelessness, housing-based palliative care services are promising, for example, providing palliative care or hospice services in a shelter/supportive housing setting.⁴⁴ There is a question of whether this model could extend to the psychiatric care setting. For some patients undergoing treatment, a more flexible allowance of inpatient hospitalizations to facilitate treatment may be helpful, in

addition to assistance with transportation to and from treatment.⁴³

C-L psychiatrists can assist patients by ensuring that an inventory of social needs is a part of the medical assessment. In addition, C-L psychiatrists can leverage their comfort working in disparate systems to suggest solutions to dispositional challenges to meet the needs of both patients and clinicians—for example, by emphasizing to patients that inpatient hospice settings will meet housing, food, and social needs, rather than only focusing on medical care.

Ensuring Ongoing Psychiatric Care

Patients with comorbid SMI and serious medical illnesses are at risk for gaps in psychiatric care. This is especially true in the acute medical setting. C-L psychiatrists can offer patients ongoing subspecialty psychiatric care. C-L psychiatrists may be particularly helpful in ensuring that psychiatric drug regimens are maintained and updated in accordance with concurrent medical treatments, which may put the patient at risk for metabolic changes or drug interactions. C-L psychiatrists can also provide ongoing assessment of psychiatric comorbidities and risk given that the biopsychosocial stressor of serious medical illness may put patients at risk of psychiatric symptom flares, agitation, and/or suicidality. By ensuring continuous psychiatric care, C-L psychiatrists can give patients the best opportunity possible to fully participate in treatment while also widening disposition options.⁴⁷

Ensuring High Quality Care

Serious medical illness requires care across a range of settings from a wide variety of clinicians over the course of an illness. This includes specialty and subspecialty medical services and palliative care. As noted, individuals with SMI are at high risk of disparities care across their serious illness trajectory. These disparities may interpolate the care individuals with SMI get at every level: They are less likely to get referrals and receive differential, often inferior, treatment across both palliative and disease-modifying treatment frames.⁴⁷

Given the overwhelming evidence of widespread disparities and of disenfranchisement of individuals with SMI, C-L psychiatrists should serve as advocates for individuals with mental illness in the medical system. Such advocacy may be individually focused, as occurs when C-L psychiatrists suggest subspecialty

referrals or challenge assertions that a given patient is not appropriate for treatment. But it should also occur on the institutional and systemic level, as occurs when C-L psychiatrists collaborate with hospital administration to create policies that enhance engagement with care for individuals with SMI or design payment and accountability structures that are inclusive of individuals with comorbid SMI and serious medical illness.⁴⁸

Addressing Suffering

Complicated dispositional or psychosocial situations may challenge clinicians to “see the big picture.” For instance, clinical teams may become mired in questions of capacity that belie underlying clinical issues.⁴⁹ C-L psychiatrists can share a big picture perspective on a case aimed at reorienting a complicated patient’s care. To that end, it is important for psychiatrists involved in the care of patients with comorbid SMI and serious medical illness to use the alleviation of suffering in its many forms—a palliative care ethic—as a guiding principle in the care of such patients at the EOL.

CONCLUSION: C-L PSYCHIATRISTS AS LEADERS IN REDRESSING DISPARITIES

The involvement of C-L psychiatrists in individual cases fulfilling the roles described previously will improve the EOL care of individual patients with SMI. However, the disparities in care require more than individual clinical effort. The scholarly and administrative aspects of the subspecialty of C-L psychiatry have the potential to improve SMI/EOL care on a systemic level. Such improvements are contingent on C-L psychiatry leadership in the creation of model programs integrating palliative, specialty medical, and psychiatric care.⁵⁰ Such programs have begun to emerge in the field of psychooncology but must be disseminated more widely and applied cross-diagnostically. Inchoate models of integrated serious illness care and mental health care exist and may provide valuable insights into the care of this population.⁴⁸ However, new models will be contingent on workforce development, including increasing C-L psychiatry training in and comfort with palliative care.⁹ Although C-L psychiatrists may practice palliative care skills in their clinical work, training in palliative care for C-L psychiatrists remains uneven.¹⁰

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C-L psychiatrists can also advocate for the inclusion of patients with SMI in the arc of EOL care. Palliative care has grown rapidly in the United States and is constantly contending with new challenges and opportunities, for instance, responding to the COVID-19 pandemic, the discussion over medical assistance in dying, clinical trials in analgesia, and restructuring of palliative care delivery systems. Through academic, administrative, and policy efforts, C-L psychiatrists can ensure that people with SMI are factored into these changes.

In summary, patients with SMI and serious medical illness are subject to disparities of care at the EOL. Such disparities include differential access to advance care planning and palliative care services. These disparities may be reflected in lower rates of analgesia, loss of psychiatric services at the EOL, and high nursing home utilization. These disparities may emerge from

siloes in medical and mental health care. Data show that many patients with SMI can participate in EOL decision-making. C-L psychiatrists by virtue of their position at the interface of medicine and psychiatry and their familiarity with palliative care skills are ideally positioned to provide care to patients with SMI at the EOL. Going forward, the field of C-L psychiatry should take a leadership role in addressing care disparities by leveraging its administrative and academic resources to study and implement new models of integrated EOL care.

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