Published in final edited form as:

Gen Hosp Psychiatry. 2017 ; 44: 1–3. doi:10.1016/j.genhosppsy.2016.10.004.

A staggered edge: End-of-life care in patients with severe mental illness

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Approximately 6% of the population suffers from severe persistent mental illness (SPMI): mental illness that is chronic or recurrent, requires ongoing intensive psychiatric treatment, and significantly impairs functioning [1]. SPMI is associated with premature mortality across all age groups [1,2]. Despite common misassumptions that most individuals with SPMI die prematurely from violence and suicide, the majority of excess mortality is due to chronic diseases such as cancer, heart disease, chronic obstructive pulmonary disease, and dementia [3,4]. Excess mortality from chronic disease is multifactorial; increased substance use and its medical sequelae, decreased engagement with preventive health care, and poor access to medical care all contribute [4]. Patients with schizophrenia, for example, have a similar incidence of most cancers to the general population, but these patients have up to a two-fold risk of dying of their disease due to under-detection and under-treatment [4].

The standard of care for patients with chronic, potentially life-limiting illnesses includes timely access to palliative care. Palliative care is an interdisciplinary modality of care based on holistic alleviation of symptom burden and on psychosocial and spiritual support. Palliative care can be provided parallel to disease-oriented or curative treatments, or as the primary focus of care.

The benefits of palliative care span multiple domains including improvements in symptom burden, quality of life for patients and care-givers, mood and psychosocial status of patients, and, in some studies, improvements in survival and reductions in cost [5,6]. Such benefits are most notable with early provision of palliative care. Evidence suggests that early palliative care, often in conjunction with disease-oriented treatment, can profoundly affect the trajectory of illness by improving quality of life and mood, decreasing aggressive end-of-life interventions, and improving hospice utilization rates [7,8].

Despite the high chronic disease morbidity and mortality experienced by people with SPMI, data suggest that the provision of palliative care to these patients is poor. In a large cohort study of patients in the last six months of life, patients with schizophrenia were found to access palliative care at rates approximately half that of controls without schizophrenia [2]. Such lack of access to palliative care directly affects the management of end-of-life symptoms: patients with schizophrenia in the same study received significantly less opioid

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analgesia than did the control group. Additionally, patients with schizophrenia were approximately twice as likely to spend their final days in a nursing home, and, once admitted to a nursing home, spend an average of more than twice the number of days as other nursing home residents [2]. Finally, this cohort of patients not only experienced poor quality end-of-life care; their contact with their psychiatric providers also declined in the setting of terminal illness [2]. Palliative care disparities among the severely mentally ill are not limited to direct end-of-life care; a study comparing mentally ill and non-mentally ill nursing home residents in the United States found that mental illness was associated with a 24% odds reduction of a resident having any form of medical advanced directive [9].

The causes of inadequate end-of-life care among individuals with SPMI are complex. There are a number of assumptions made in the provision of palliative care that may inadvertently exclude individuals with mental illness. Care planning in the medical setting may be predicated on patients having basic resources that patients with severe mental illness often lack. Such resources include stable housing, available and engaged family support, and an intact provider-patient relationship. Many of the systems of care in place to provide good palliative care may be ill-equipped to provide holistic, high-quality care to mentally ill patients who are homeless, estranged from social support, and unable to form trusting alliances with new providers.

Additionally, patients with SPMI often experience disparities in care stemming directly from their mental illness. Non-psychiatric physicians and other providers feel inadequately trained regarding how to disclose and communicate pertinent medical information to patients with SPMI [10]. Further, providers may attribute medical or neuropsychiatric symptoms (such as new onset perceptual disturbances) to the premorbid psychiatric illness, a tendency that may be exacerbated in the setting of the clinical uncertainty that often complicates end-of-life care [11]. Conversely, mental health practitioners who feel more comfortable communicating with and caring for patients with SPMI may be less knowledgeable about palliative care than their medical colleagues, and thus mental health professionals may be less likely to introduce, suggest or discuss even basic palliative care interventions, such as advanced care planning [1].

Issues surrounding the assessment of capacity to make medical decisions, both real and perceived, are among the most challenging barriers to providing high quality palliative care to patients with SPMI. Medical providers often presume that those living with SPMI lack decision making capacity, despite the fact that high quality data demonstrate that individuals with chronic psychotic illnesses in remission are capable of participating in end of life decisions [10,12]. Although many patients living with chronic illnesses retain capacity to make medical decisions, such decisions may nonetheless be challenging due to amotivation, ambivalence and decision-making deficits that characterize certain chronic psychiatric disorders, such as schizophrenia [13,14]. Patients require practitioners with patience and experience to help them navigate complex decisions in spite of their deficits. Such needs may be a deterrent for non-psychiatrically trained physicians to engage patients with chronic mental illness in shared decision-making.

In the palliative care setting, providers rely on health care proxies to make decisions for patients who lack or lose capacity. Legal guardianship does not necessarily grant the privileges of a health care proxy, including withdrawal of life extending care [1]. Unfortunately, people with SPMI may not have the social support and necessary social-cognitive skills to create and invoke health care proxies to assist in medical decision-making [1].

In spite of these barriers, data suggest that people living with SPMI would benefit from increased access to palliative care. Beyond the implications of Chochinov et al.'s work suggesting that symptom management at the end of life is worse for people with SPMI, data also suggest that such patients have similar end-of-life preferences and concerns to persons without mental illness. In qualitative studies about end-of-life care, people with SPMI cited many concerns shared with people without mental illness: fear of physical pain, fear of dying alone, and hope for self-determination [12,15]. Among these cohorts, many patients with SPMI were interested in obtaining a health care proxy and participating in advanced care planning [16]. Advanced care planning is an important component of high quality palliative care, providing patients with the autonomy and dignity of directly communicating their preferences about treatment in the end stages of terminal illness.

Improving palliative care provision to people living with SPMI requires increased cross-disciplinary collaboration between psychiatry and palliative care. The lack of palliative care training for psychiatrists is well-recognized in the literature, both among palliative care and psychiatry providers [17,18]. Most of the literature advocating further training of psychiatrists in palliative care is focused on the treatment of psychiatric symptoms in patients with chronic or terminal medical illnesses, rather than on the care of terminally ill patients with pre-existing severe mental illness. However, data from psychiatric residents and from community mental health providers shows feasibility of and interest in further palliative care training [19,20]. Such training, beyond improving end-of-life care for patients with severe mental illness, also has the potential to improve the psychiatric care provided to patients with treatment-refractory mental illness; recent work by Trachsel et al. suggests that a palliative approach to treatment refractory psychiatric patients may improve symptomatic treatment and decrease the chance of either overly aggressive treatment or therapeutic neglect, thereby improving autonomy and outcomes for such patients [21].

Little has been written about training of palliative care providers in psychiatric assessment and management. The vast majority of palliative care clinicians are trained in internal and family medicine [22]. Non-psychiatrically-trained physicians providing palliative care may have little experience in communication strategies, capacity evaluations, and other challenges involved in caring for patients with SPMI. Such gaps could be mitigated by systematically training palliative care providers in caring for patients with severe mental illness and/or by integrating psychiatric consultation in the palliative care setting. Although challenging given the national shortage of psychiatrists, such initiatives may be feasible through the implementation of new technologies aimed at improving access, including telepsychiatry and electronic consultation, and interdisciplinary community-based care.

Community-based models are mainstays in both palliative and mental health care provision. Within both fields, such programs typically combine psychiatric/medical care, family engagement, and social services. In the knowledge of the authors, there are no programs specialized toward combined-palliative and psychiatric care for community dwelling, chronically ill patients with SPMI. Perhaps the closest proxy is the care provided by the Veteran's Administration, which offers a relatively integrated approach to care and which boasts positive end-of-life outcomes among its terminally ill patients with SPMI [23].

Building community programs to address the integrated care needs of chronically and/or terminally ill patients with SPMI represents an important strategy to improve the care such patients receive. Engagement of palliative care clinicians in community mental health settings would build naturally on the growing body of such programs already providing primary care. Such engagement would also give psychiatrically trained nurses, social workers, physicians, and staff opportunities to develop competency in caring for patients at the end of life. Conversely, greater engagement of psychiatrists in community palliative settings including hospice may improve the care such organizations can provide to their mentally ill clients and the competency of non-psychiatrically trained palliative care clinicians.

The upfront cost of such integrated programs may suggest that they are not practically feasible. However, because of their functional limitations, many patients with SPMI likely constitute high-need, high-cost patients, particularly when medically ill. Social cost for chronic mental illnesses such as schizophrenia is tremendously high [24]. Such patients require disproportionate resources for care, experience high levels of interactions with the health care system, and may receive worse quality care [25]. Community based, integrated care programs likely reduce the resource utilization and increase the quality of care provided to such patients [25,26]. Many of the general strategies employed to improve care to high-need, high-cost patients are germane to end-of-life patients with SPMI including a closely knit interdisciplinary approach; patient engagement in care; and specialized interventions targeted to specific subsections of the population. Structural changes to health care provision and reimbursement including the accountable care organization model, the Affordable Care Act's emphasis on integrated care, and the medical home model are all potential structural bases for deploying the model of palliative-psychiatric care we suggest. Among this high-resource use population, an integrated psychiatric-palliative care approach, though initially resource intensive, may prove to significantly curb costs while improving quality of care.

Palliative care for people with SPMI poses unique medical, psychiatric, and ethical challenges. Although end-of-life care for this population has not been robustly studied, existing data suggests significant disparities in end-of-life care for those living with severe mental illness. Given the high incidence of chronic medical conditions in patients living with SPMI, such disparities in care are unacceptable. Many of the factors leading to this disparity stem from inadequate interaction and inadequate collaboration between psychiatric and palliative care providers and from current care delivery systems that impede interdisciplinary care. Training opportunities at the intersection of palliative care and psychiatry, innovative integrated care delivery systems, and further research into the palliative care needs of those

with severe mental illness are all integral to improving access to and provision of comprehensive palliative care for individuals living with SPMI.

Acknowledgments

Funding

This research did not receive any grant funding from agencies in the public, commercial, or not-for-profit sectors. The authors report no conflicts of interest.

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