

CASE AND COMMENTARY

According to Which Health Outcomes Measures Should Palliative Psychiatric Prognosis, Progress, and Success Be Defined?

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Abstract

This commentary on a case considers moral reasons to adopt a palliative approach to the care of some psychiatric patients. A conceptual framework is proposed for determining who is an appropriate candidate for palliative psychiatry. The article then argues that rigorously defined patient- and family-centered outcomes should guide how successes in palliative psychiatry are measured.

Case

MG is a 50-year-old patient with coronary artery disease, advanced heart failure, tobacco use disorder, and persistent, unremitting schizophrenia who experienced several inpatient psychiatric stays over the last decade. Dr A is a psychiatrist who has become familiar with a pattern that has repeated during that time: (1) MG stops taking whatever antipsychotic medication MG is prescribed at the time, (2) MG loses ability to perform activities of daily living, (3) MG behaves erratically, and (4) MG is transported by law enforcement personnel to the organization's emergency department or a regional jail. MG's networks of resources and support erode during each cycle, making recovery diminishingly likely with each inpatient admission. Dr A wonders whether a palliative approach for MG is appropriate and what that would look like.

Commentary

Physicians' twin responsibilities are to cure disease and relieve suffering. While these objectives are often complementary, in MG's case—and in most cases of serious, incurable illness—these goals may be misaligned. Indeed, a single-minded **focus on curing disease** or extending life when those objectives are no longer achievable can obscure patients' true goals of care and unwittingly contribute to further suffering. Palliative care addresses this tension by helping patients achieve the best possible quality of life, and its application to psychiatry could enable a reimagining of the clinical approach to severe, persistent mental illness. Because palliative psychiatry is a nascent field, however, it is critical to define what high-quality, palliative psychiatric care looks like and under what circumstances a palliative model might prove particularly beneficial.

This article explores the moral grounds for adopting a palliative approach and proposes a conceptual framework to determine who is an appropriate candidate for palliative

psychiatry. It then argues that rigorously defined patient- and family-centered outcomes should serve as the basis of future efforts to measure success in palliative psychiatry.

Who Is Palliative Psychiatry for?

Palliative care was historically developed in the context of end-of-life cancer care and is increasingly offered to patients with a wide range of serious, progressive somatic diseases.^{1,2} Despite the relative novelty of palliative psychiatric care, psychiatrists commonly encounter clinical scenarios in which disease has become so severe, disabling, or life-threatening as to foreclose the possibility of any meaningful remission. In their review of palliative psychiatry, Strand et al identify a few such scenarios, including treatment-refractory schizophrenia, persistent anorexia nervosa, and chronic suicidality in borderline personality disorder.³ While there is continued debate about how best to define severity in psychiatric disorders, existing diagnostic systems tend to categorize **mental illness severity** according to symptoms' frequency and intensity; their responsiveness to treatment; and their impacts on independence, social functioning, and quality of life.⁴ In MG's case, the emphasis on curative treatment with antipsychotics has led to a predictable and self-reinforcing cycle of disengagement from care, clinical deterioration, and subsequent stabilization in acute care settings. MG's social support networks have eroded, probably due to despair and a sense of helplessness. Finally, it is worth noting that MG's medical comorbidities and schizophrenia may be mutually reinforcing. Psychiatric illness can make it more difficult for clinicians to assess somatic concerns and optimally manage chronic disease—indeed, most premature mortality in patients with mental illness is attributable to excess deaths from general medical conditions (eg, cardiovascular disease) rather than to external causes (eg, suicide).⁵ Conversely, medical comorbidities can complicate the treatment of mental illness by making the use of psychiatric treatments risky or untenable. (In this case, MG's preexisting heart disease might serve as a contraindication to treatment with the antipsychotic clozapine due to its risk of myocarditis.⁶)

Given these observations, is MG an appropriate candidate for palliative psychiatry? One way to answer this question is to return to the foundational principles of medical ethics. The principle of beneficence holds that physicians have a positive duty to seek the benefit and well-being of their patients. In this case, Dr A notices that her therapeutic approach is failing to meaningfully modify the course of MG's illness. While useful for acute stabilization, MG's visits to the emergency department and local jail are unlikely to positively alter his clinical trajectory. These settings experience high throughput, are poorly equipped to address mental health needs, and are likely to privilege standardized procedures guided by disposition concerns over personalized, patient-centered approaches. The sister principle—nonmaleficence—enjoins physicians to do no harm. Its practical application in this case would be for Dr A to carefully weigh the expected benefits of psychiatric interventions against their potential harms. For instance, clozapine—the drug of choice in resistant schizophrenia—carries a low but life-threatening risk of neutropenia,⁷ and regular monitoring of blood counts might prove challenging in this scenario. Dr A might also take account of the **potential harms** posed by MG's repeated encounters with law enforcement personnel, who do not have the resources or training to effectively de-escalate psychiatric crises.⁸

Applied to MG's case, these ethical principles should compel Dr A to shift toward a palliative approach aimed at achieving the best possible quality of life, guiding the patient and surrogate decision makers in establishing goals of care, and promoting the

patient's ability to cope with advanced mental illness. Although the choice to initiate palliative care in patients with poor psychiatric prognosis should be individualized, clinicians and patients need empirical evidence and clinical guidelines to guide decision making. Several experts have advocated for the use of clinical staging models akin to those used in oncology and cardiology to stratify patients with poor psychiatric prognosis.^{3,9} In constructing these staging models, psychiatry should look to develop and validate a comprehensive set of prognostic indicators that take into account the biopsychosocial impacts of mental illness. For instance, in addition to considering whether psychiatric illness is severe, progressive, and refractory to evidence-based treatments, clinicians might evaluate its impacts on independent functioning and ability to perform activities of daily living. Recognizing that loneliness exacerbates poor mental health outcomes,¹⁰ clinicians might also map patients' relationships or use validated questionnaires (eg, the UCLA Loneliness Scale¹¹) to examine the degree to which psychiatric illness is negatively affecting their social networks. Validating the prognostic value of these indicators is critical for their acceptance and use in clinical settings and might shed light on whether candidacy for palliative psychiatry is best determined using disease-specific models or cross-diagnostic criteria.^{12,13}

What Should Palliative Psychiatry Look Like?

Because palliative psychiatry proposes a patient-centered approach to care, definitions of progress and success should take as a starting point patients' own descriptions of what goals and outcomes they most value. Surveys administered to patients at the end of life have consistently revealed their most important priorities to be relief from bothersome symptoms, guidance in navigating medical decision making, support in dealing with the emotional and practical aspects of their disease, and assurances that caregivers' needs are being addressed.^{14,15} While these surveys were administered in the context of somatic disease (eg, patients on dialysis), studies exploring the impacts of serious mental illness on patients and their caregivers have identified some similar themes, including the need for acceptance, self-compassion, caregiver empowerment, and supportive relationships.^{16,17,18} Taken together, these findings can begin to inform which goals and interventions should be prioritized in psychiatric palliative care so as to best address the social, spiritual, practical, and psychological needs of patients.

Because these needs touch on such varied dimensions of illness and suffering, palliative psychiatry is best conceptualized as a multidisciplinary endeavor characterized by specialized, validated interventions and clinicians' meaningful and consistent engagement with the patient's social supports. Just as modern palliative cancer care traces its roots to the nurse-led hospice movement,² so palliative psychiatry should adapt existing models of care. Specifically, Strand et al propose that a palliative approach to the care of patients with resistant schizophrenia might include social skills training, cognitive behavioral therapy, or novel therapies such as AVATAR,³ the latter of which helps patients cope with and gain control over paranoid auditory hallucinations via a dialogue with a digital representation of their imagined persecutor.^{19,20} Beyond addressing symptoms such as hallucinations, palliative psychiatry could work to adapt the patient's social environment to enhance accommodation of mental illness and ease burdens on caregivers. Family-based interventions for psychosis have been found to be effective in reducing relapse, improving functioning, and empowering caregivers to engage more effectively with their affected relative.²¹ Finally, palliative psychiatry should promote the development of low-barrier, integrated care delivery models aimed at flexibly and creatively managing medical comorbidities in patients with serious psychiatric illness.²²

As with any medical intervention, palliative psychiatric care should be subjected to rigorous assessments. For instance, a study evaluating a palliative psychiatry intervention might choose as its primary endpoints the following outcomes: longitudinal assessments of health-related quality of life as captured by validated instruments (eg, the RAND 36-Item Short Form Survey Instrument)^{23,24}; self-reported measures of fear, anxiety, or discomfort (eg, the Subjective Units of Distress Scale, or SUDS)²⁵; rates of emergency department visits and hospital readmissions; and caregiver well-being and self-efficacy.

Conclusion

High-quality palliative care should be regarded as an ethical obligation when patients with mental illness no longer benefit from a purely curative therapeutic approach. The decision to initiate palliative care should be individualized and informed by a comprehensive understanding of how mental illness affects the patient's independence and relationships. Palliative psychiatric interventions should be rigorously assessed for their ability to improve patients' quality of life, reduce harms associated with mental illness, and promote caregivers' ability to understand and accommodate mental illness.

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