

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Palliation Can Improve Care of Patients With Severe and Enduring Anorexia Nervosa

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Abstract

Palliative care refers to clinical interventions whose purpose is relief of suffering, not treatment of a patient's underlying illness. Palliation is widely used in the care of patients with serious physical illnesses, but its use in caring for patients with severe, persistent mental illnesses is controversial. This commentary on a case summarizes emerging themes in palliative psychiatry and explores its ethical feasibility in the care of patients with severe and enduring anorexia nervosa.

Case

Ms M is a 62-year-old woman admitted to the inpatient medical service for stabilization of electrolyte abnormalities in the setting of a long-standing diagnosis of anorexia nervosa (AN). During prior hospitalizations for this reason, she received involuntary nasogastric tube feeding. She has aged out of the hospital's inpatient interdisciplinary eating disorders service, and other inpatient programs in the state either have similar age restrictions or require residents to enter willingly. Ms M has undergone years of first-line therapies for AN, including psychotherapy and repeated weight restoration.¹

During this admission, she was assessed as lacking health care decisional capacity due to altered mental status. Ms M's sister, Ms J, became her surrogate decision maker. When the care team asked for Ms J's consent to place a nasogastric tube for refeeding purposes, she explained that Ms M recently stated she "no longer wants invasive interventions" and feels she is "living in a cycle of hospital visits which worsen her quality of life." Consequently, Ms J felt conflicted about giving consent for nasogastric tube placement and asked the care team about the possibility of palliative care for her sister.

Commentary

Clinical interventions are palliative when they are intended to relieve suffering, not to treat a patient's underlying, often terminal, disease.² Modern definitions of palliative care include interventions that aim to improve quality of life for patients experiencing "serious health-related suffering" but whose diagnosis is not terminal.^{2,3} Many professional organizations promote early, continuous assessment of palliative needs of patients with any serious illness and stress that palliative care can be delivered jointly

with curative care, not just after life-prolonging options have been exhausted.^{2,4,5} Although palliative care has historically focused on physical illnesses, a growing body of literature supports palliative approaches to caring for patients with severe, persistent mental illnesses. Current palliative psychiatry research focuses on harm reduction and improving quality of life for patients with certain conditions, such as treatment-refractory depression and severe and enduring AN (SE-AN).^{4,6} This commentary on a case summarizes emerging themes in palliative psychiatry and explores its ethical feasibility in the care of patients with SE-AN.

Severe and Enduring Anorexia Nervosa

Compared to other psychiatric illnesses, AN has a high mortality rate.^{4,7,8,9} Some individuals who live with AN for years develop SE-AN. While SE-AN is variably defined in the literature, illness duration and number of previously failed interventions are key in many definitions.^{10,11} One study noted that the most common illness duration required for a diagnosis of SE-AN was 7 years, but other diagnostic cutoffs range from as few as 3 years to more than 10.^{1,10} The types of intervention needed are similarly not well defined. Whereas treatment goals of AN include restoring a healthy body mass index and preventing relapse of maladaptive eating behaviors through psychotherapy,¹⁴ some patients with SE-AN require specialized care and adjustment of typical AN treatment goals.¹ However, what it means to “fail” at an intervention is unclear, so consensus on the number of failed interventions required for SE-AN diagnosis is lacking.¹⁰

Recently, criteria for the diagnosis of “terminal anorexia nervosa” were proposed to describe a subset of patients with SE-AN who feel further recovery-oriented treatment is futile, wish to stop trying to prolong their lives, and, in some cases, request aid in dying.¹² Some authors reject the use of the word *terminal*, advocating instead for palliative care that does not include the language of terminality or provision of aid in dying.^{8,13} Although palliative interventions can be delivered concurrently with disease-modifying therapy, notable discussions of the ethical challenges of palliative care for patients with SE-AN focus on patients who wish to discontinue recovery-oriented treatment and transition to an exclusively palliative approach.^{12,15}

Critiques of Palliative Approaches to SE-AN

One critique of exclusively palliative approaches to care of patients with SE-AN is that some patients recover after many years of curative intervention. One study found that 62.8% of treatment-seeking patients with AN fully recovered after 22 years—twice as many as recovered after only 9 years.¹⁶ Another study found similar results after 30 years of curative intervention.¹⁷ These data show that prolonged treatment can lead to remission of AN.

A second critique relates to informed consent. Because cognitive disturbance is a diagnostic criterion for AN, patients’ ability to consent to palliative care (possibly concurrent with curative treatment) has been called into question.^{18,19,20} Intact **decision-making capacity** requires patients to demonstrate that they (1) understand information about their illness, (2) appreciate the information as relevant to themselves, (3) reason using the relevant information, and (4) communicate a decision based on relevant information.^{18,19} In patients with AN, there is evidence that the primary factor driving diminished decision-making capacity is a patient’s lack of insight into their illness’ severity.^{18,19} Given the ego-syntonic nature of AN, some patients feel ambivalent about eating disorder (ED) treatment or actively resist it in part because they do not believe their condition is critical.^{7,18} There is also evidence that value judgments regarding life

and death are altered in some individuals with AN, further complicating assessment of patients' capacity to make treatment decisions.^{13,19}

Finally, a third critique is that since access to high-quality ED treatment in the United States is determined by financial and social factors, a subset of patients with AN may be funneled into palliative care and away from recovery-oriented treatment simply because they are unable to access the latter. Residential and outpatient ED programs, for example, do not accept all insurance, and some insurers do not cover treatment based on prior failed treatment responses, which inequitably affects individuals seeking care over many years.^{1,21} Furthermore, many behavioral or specialist programs target adolescent patients at early stages of illness, and there is little research—and fewer programs—focusing on needs of adults with SE-AN.^{1,7,21}

Benefits of Palliative Approaches to SE-AN

One benefit of a palliative approach to SE-AN is that suspension of therapies that are invasive and undesired upholds the maxims of nonmaleficence and respect for persons. Individuals with SE-AN are more likely to report “a revolving door pattern of admission and discharge”⁴ and a history of involuntary treatments that can be traumatizing, decrease quality of life, and increase the risk of future treatment refusal,^{1,7,22} especially if the instances of involuntary treatment are not separated by a return to good health.¹⁸ Additionally, extensive treatment over objection can increase the emotional dysregulation that characterizes AN, further worsening quality of life and exacerbating other symptoms.¹⁸ By minimizing involuntary invasive procedures like nasogastric tube feeding, physicians might prevent psychological complications—or even physical ones, such as tube dependency.⁷

Palliative approaches can validate patients' experiences and more fully enable their expression of autonomy. Indeed, some clinicians report that discussing palliative care options with their SE-AN patients can lead to renewed motivation to pursue disease-modifying, curative therapy, perhaps due to patients' greater sense of autonomy or insight into their disease's severity.^{4,8,15,22} Outlining palliative care treatment goals relies on strong patient-clinician relationships as well as the patients' own illness narratives. Close patient-clinician collaboration can promote clinicians' empathy and compassion, which have been identified as key guiding values in the treatment of AN.⁷ Given the lack of prognostic factors for recovery in SE-AN,^{8,13,22} collaboration and honest communication between clinicians and patients are essential to directing treatment. Advocates for palliative psychiatry point out that many goals and practices of palliative care and psychiatry are already aligned with these key clinical and ethical values.^{4,6,23}

Discussion

Regarding Ms M, there is ethical justification for considering a palliative psychiatry approach. She has undergone years of **psychotherapy** and inpatient stabilization with repeated involuntary interventions. Although studies have shown that almost two-thirds of patients with AN recover after 20 years of treatment,¹⁶ at least one-third of them do not. A statement Ms M made to her sister suggests that she no longer wishes to pursue recovery-oriented interventions, which needs to be considered in her care plan. In order for Ms M to participate in the goals-of-care discussion, the care team will need to place a nasogastric tube to try to restore her decision-making capacity. After her decision-making capacity is restored, a palliative approach could be introduced as an alternative to or conjointly with recovery-oriented treatment.

Palliative approaches can include completing medical orders for scope of treatment that forbid involuntary tube feeding, thereby shifting care goals from weight restoration to improving daily living and from a return to normal eating habits to dietary supplementation. Importantly, a decision to engage in palliative care need not be made immediately and need not be permanent; rather, a decision should consist of a series of discussions among Ms M, her sister, and her physicians. By creating a clinical environment that gives Ms M agency and holds her in positive regard, her team will increase the likelihood of providing interventions that are both compassionate and effective.

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