

Palliative Psychiatry

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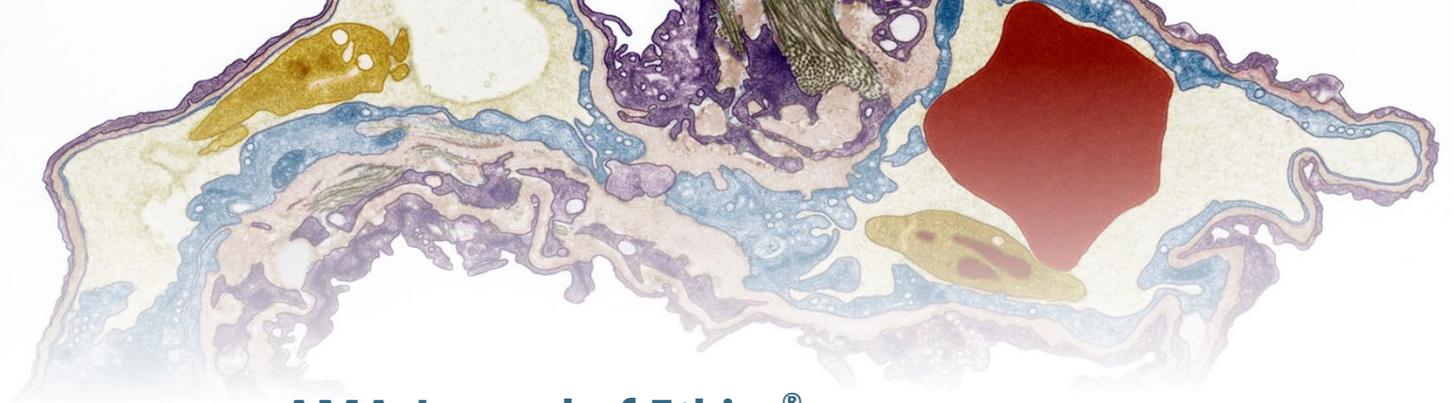
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FROM THE EDITOR

Palliative Approaches to Psychiatry

Michelle Raji, MD

While psychiatry, like other **specialties**, has played explicit roles in palliative care of patients with life-threatening illnesses such as heart failure or cancer, palliative care has not traditionally been viewed as a legitimate approach to helping patients with life-threatening, treatment-resistant mental illnesses.¹ By some estimates, at least a fifth of patients with psychiatric disorders experience treatment resistance,² most commonly defined as an inadequate reduction in symptom severity.³ Palliative approaches to psychiatry can be controversial because they concede an uncomfortable truth: pursuing curative pharmacotherapy of some **mental illnesses**, such as severe persistent schizophrenia, depression, or **anorexia nervosa**, might do more harm than good. For the 20% to 50% of patients with schizophrenia who experience treatment resistance,⁴ exposure to further antipsychotics might be intolerable⁵ or inconsistent with their goals.⁶ In major depression, rates of remission after successive medication trials decrease exponentially, often resulting in polypharmacy.⁷

Rather than cycling through more interventions with marginal utility, responding with care to the needs of these patients requires prioritizing symptom management and quality of life, reducing harm from aggressive interventions, and minimizing use of physical and chemical force. This issue of the *AMA Journal of Ethics* explores palliative psychiatry as one response to pharmacological **futility**, renewing attention on patients whose illnesses and symptoms challenge our faith in health care as a life-affirming source of hope. This issue also demonstrates how inquiry into palliative psychiatry—at the patient, health system, social, and policy levels—can reinvigorate core philosophy of medicine investigations into what health care is for.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Does It Matter Whether a Psychiatric Intervention Is “Palliative”?

Brent M. Kious, MD, PhD and Ryan H. Nelson, PhD

Abstract

Palliative interventions are intended to alleviate suffering and improve quality, not quantity, of life and are not intended to cure illness. In psychiatry, uncertainty about which interventions count as palliative stems from the fact that psychiatry generally prioritizes symptom management irrespective of diagnosis or specific pathophysiology of illness. This commentary on a case considers how distinctions between palliative and other psychiatric interventions might not be all that helpful in resolving clinical and ethical questions about which interventions are—and when they are—appropriate.

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Case

CC is a 40-year-old patient who has experienced multiple shifts in diagnoses over 10 years among mood disorders, substance use disorders, and personality disorders. CC is currently recovering from a 6-year addiction to cocaine and has been involuntarily admitted several times during the last 8 years for self-harm. After just over 1 year of reliable symptom control with an antidepressant, electroconvulsive therapy, and psychotherapy, CC is again experiencing passive suicidal ideation and worsening depression. Dr P worries that CC might attempt suicide or relapse into drug use and wonders whether a new US Food and Drug Administration (FDA)-approved drug for depression and suicidal ideation would help. This drug rapidly reduces suicidal ideation in a matter of hours in some cases, but evidence does not yet reliably indicate how long suicidal ideation is reduced after treatment or whether suicidal ideation reduction is attributable to dissociation and euphoria, for which the drug has become known since it started being used recreationally.

Commentary

Cases like this one frequently confront psychiatrists and other mental health professionals. They raise important questions about how these practitioners should address severely treatment-refractory symptoms. The case also raises a difficult question about whether an intervention that carries a **risk of addiction**—since the proposed intervention produces euphoria, which is associated with dependence⁴—should be used in order to achieve other benefits, such as the reduction of suicidal

ideation. As we see it, the central dilemma of the case is this: Should Dr P give CC the new FDA-approved treatment, given the possibility that it will reduce her suicidal ideation, despite the risk that she could become addicted to it?

It is tempting to suppose that this question can be answered by applying the concept of palliative psychiatry. Would giving the new medication to CC be a palliative intervention? And, if so, is CC the sort of patient for whom palliative interventions would be appropriate? There is some merit to this approach to reframing our thinking, but we do well to remember that asking whether palliative interventions are appropriate for patients endorses a false dichotomy. After briefly reviewing attempts to define palliative psychiatry, we argue that distinguishing features of palliative psychiatry remain unclear. Irrespective of **whether a new medication should be considered palliative** for CC, what Dr P should do depends mainly on whether the medication promotes CC's best interest and whether it offers greater expected net benefit than alternative interventions. In other words, whether it is properly called *palliative* requires investigation.

Defining Palliative Psychiatry

According to the World Health Organization (WHO), palliative interventions are focused on alleviating suffering and improving quality of life.² In theory, a palliative approach could be taken to any kind of illness, including mental illness.

The concept of palliative psychiatry was originally described by Berk and colleagues in 2012.³ They noted that persons with severe mental illness often receive aggressive treatment, show little response to treatment, and have high levels of disability; they suggested that adopting a palliative approach could benefit such persons by reducing rehospitalization and side effects of medications. Levitt and Buchman subsequently suggested that palliative interventions should be considered whenever other treatments for a psychiatric illness seem "futile,"⁴ meaning (in this context) that they are unlikely to produce significant changes in symptoms and that the patient will still likely see her quality of life as unacceptable. Separately, Trachsel and colleagues suggested that palliative interventions are a way to avoid **futile care**.⁵ They offered a definition of futility similar to Levitt and Buchman's and implied that palliative psychiatry should be construed as involving unconventional treatments, such as psychiatric "long-term residential care for patients with clozapine-resistant schizophrenia," avoidance of involuntary refeeding for severe enduring anorexia nervosa, and palliative sedation for treatment-refractory depression coupled with a life-threatening somatic illness.

More recently, Westermair and colleagues defined palliative psychiatry in the narrow sense as the "provision of end-of-life care for persons dying from a mental illness" and palliative psychiatry in the broad sense as involving "all approaches aiming at improving quality of life by means other than reduction of ... symptoms, namely harm reduction and relief of suffering."⁶ They give as examples of broad palliative care supervised injectable heroin for treatment-refractory opioid use disorder and the Community Outreach Partnership Program for anorexia nervosa, which involves "letting go of curative goals of care ... that are in all likelihood unattainable" and instead focusing on "relief of suffering and improvement of quality of life."

When Is a Psychiatric Treatment Palliative?

Despite these attempts to define palliative psychiatry, it is uncertain whether the new medication that Dr P is considering for CC counts as palliative in any interesting sense. According to the WHO definition of palliative care, for it to do so, it would have to focus

not on curing the underlying illness but primarily on reducing suffering or improving quality of life. We would also add a third consideration: for the distinction between palliative and non-palliative psychiatric interventions to be ethically relevant, it must be the case that most ordinary psychiatric treatments do not already count as palliative according to the WHO definition. The problem is that ordinary psychiatric care looks palliative in that sense.

Consider the first condition—whether a treatment is focused on curing an illness. Many psychiatric treatments are not curative in the sense that they do not eliminate or normalize some underlying disease process. Psychiatric illnesses often have high relapse rates despite treatment, and many require lifelong treatment to reduce the risk of relapse.^{7,8,9,10} Based on these facts, it can be inferred that many psychiatric treatments are not focused on a cure in the sense of eliminating or normalizing a disease process. One might think, however, that “curative” interventions need not eliminate a disease process but only target its pathophysiology. Nevertheless, many ordinary psychiatric treatments do not seem to address disease processes even in this weaker sense. Indeed, many psychiatric treatments have mechanisms that are still incompletely characterized and are plied against conditions with poorly defined causes.^{11,12,13,14} Do ordinary antidepressants like fluoxetine really “cure” major depressive disorder (MDD), in the sense of correcting some biological difference that is causative of (or at least contributory to) that condition, or do they simply cause changes in brain states that make the symptoms of MDD less bad? Surprisingly, the answer to this question is not known.¹⁵ Other treatments, such as benzodiazepines administered for generalized anxiety disorder, might also be regarded as simply alleviating a symptom without specifically “curing” any illness, since benzodiazepines reduce anxiety whether or not one has generalized anxiety disorder.¹⁶

Related to the second condition—whether a treatment is focused on reducing suffering or improving quality of life—mental illnesses are typically defined in terms of symptoms, as evidenced by diagnostic criteria laid out in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*.¹⁷ Thus, to “treat” a mental illness successfully is necessarily to alleviate the symptoms defining it, much like “treating” pain often means alleviating the pain with an analgesic without addressing the cause of the pain. It follows that most psychiatric treatments are aimed at improving symptoms—thereby reducing suffering and improving quality of life—and can plausibly be classified as palliative based on the WHO definition.

But if there is no set of psychiatric interventions that are uniquely palliative, then palliative psychiatry is just the same as ordinary psychiatry. This is probably why Westermair and colleagues define palliative psychiatry in the broad sense as involving “all approaches aiming at improving quality of life by means *other than reduction of ... symptoms*” (emphases added).⁶ But this definition, although intended to capture palliative psychiatry broadly, is still too narrow, since relief of difficult symptoms is often an essential part of relieving suffering and improving quality of life. The inseparability of symptom relief and palliative care goals is also true of general palliative care, wherein palliative treatment for metastatic prostate cancer, for example, should involve alleviating the pain that is a symptom of the cancer.¹⁸ Likewise, using sedation to alleviate the anxiety of a person with severe treatment-refractory panic disorder¹⁹ would seem to be palliative, even though treatment is focused on improving a troublesome symptom.

Does It Matter Whether a Treatment Is Palliative?

Although it remains deeply unclear how to distinguish specifically *palliative* psychiatric interventions from ordinary psychiatric interventions, this distinction is neither clinically nor ethically necessary. Lindblad and colleagues have argued that a definition of palliative *psychiatry* adds little to conventional conceptions of palliative care and is not necessary for goals-of-care discussions for patients with severe persistent psychiatric illness.²⁰ Critical treatment decisions like CC's should, as with any treatment decision, be determined primarily by a comparison of the risks and benefits of the treatment with its alternatives. Thus, we argue, *whether or not the new treatment is palliative*, it should be offered to CC only if the expected net benefit (defined as the expected benefit minus the expected harm) of this new intervention is better than any alternatives. Conversely, if the new treatment's expected net benefit is less than some alternative, then CC should not be offered it, *whether or not it is palliative*.

We noted earlier that it has been argued that whether a patient's symptoms are extremely treatment refractory—so that ordinary treatments start to seem “futile”—might determine whether a palliative approach is necessary.^{4,5} But, on our view, the degree to which a patient's symptoms are treatment refractory matters only because it is a guide to whether the risk-benefit ratio of unconventional treatments (eg, opioids to treat mood or anxiety, continuous sedation to treat refractory distress, or even withdrawing guideline-approved interventions such as clozapine in treatment-refractory schizophrenia) is likely to be favorable compared to alternatives. If someone's condition is very treatment refractory, the relative expected net benefit of a novel treatment might be great enough that it is worth trying, even if the risks are great.

We concede that use of the term *palliative psychiatry* to denote more (or less) intensive, unconventional treatments for patients with extremely treatment-refractory conditions could have a sort of hermeneutic benefit even if it is not conceptually justified. It could help psychiatrists, patients, family members, insurers, hospital administrators, and others recognize a set of clinical possibilities that are otherwise hidden. It could help psychiatrists who are caring for such patients redirect their attention from treating illness as the primary method for improving those patients' lives to simply trying to improve patients' lives per se. Publicly distinguishing between palliative and non-palliative approaches in psychiatry might make it easier to countenance potentially helpful interventions that usually seem inappropriate because, for instance, they are not even ostensibly aimed at treating an illness or they aim at improving quality of life even at the cost of some unwanted side effect, such as addiction.

Conclusion

Ultimately, then, what matters when it comes to recommending an intervention is whether, for the patient, the expected net benefits of that intervention are greater than the expected net benefits of other interventions. Perhaps all psychiatric interventions are palliative. Perhaps none of them are. But whether we should offer a particular treatment, provided other moral constraints are satisfied, depends primarily on whether it stands to benefit the patient most, on balance, relative to the other things we could do to help the patient. The main value in the concept of palliative psychiatry is in helping us see that.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Long-Term Psychotherapy Address Ethical Questions During the Palliative Care of a Patient With Serious and Persistent Mental Illness?

Constance E. George, MD, MA

Abstract

This commentary on a case considers the course of a palliative approach to care of a patient with a serious and persistent mental illness. Supposing a psychiatrist and patient mutually agree that the patient's chronic refractory illness should be palliatively managed with long-term psychotherapy, the next step is to forecast possible ethical questions that can arise during the course of such care and to share decision making about how to respond to those questions.

Case

AA is a 55-year-old combat veteran of the Iraq War with chronic posttraumatic stress disorder (PTSD) exemplified at this time by profound feelings of isolation, intrusive memories of combat, anxiety, depression, and frequent nightmares. AA is divorced, lives alone, and is alienated from children. AA is unable to sustain intimate relationships and avoids the public, as it triggers violent memories; AA is homebound much of the time. AA rarely sees a primary care physician and avoids health care settings, which also trigger painful memories and anxiety.

Over years of treatment, trauma-focused interventions—such as cognitive behavioral therapy and eye movement desensitization and reprocessing—have not proved beneficial. Medications are intermittently helpful with symptoms but have not resulted in remission. AA has a long-term relationship with a psychiatrist, Dr P, and they meet weekly. Dr P no longer focuses on medications or codified therapy for PTSD but does implement medications to relieve problematic symptoms when indicated. AA often reflects on how painful experiences in the present trigger memories of combat trauma, which in turn increase anxiety and depression. AA and Dr P agree that AA's treatment is palliative.

Commentary

Palliative care is a treatment course developed for patients with life-threatening illness that focuses on **quality of life** rather than remission or cure of disease. The World Health Organization defines palliative care as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated

with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.”¹ It is often described as a team approach, enlisting professionals, caregivers, and patients.

Although psychiatrists are often members of palliative care teams in the general medical setting, primary psychiatric illnesses are not traditionally in the purview of palliative care.² This division of labor may be attributable to several issues, but one of the most relevant is a general disregard for the association between general medical illness and psychiatric illness and the hesitation on the part of the medical community to acknowledge that psychiatric illness may be terminal over the long run in a subgroup of psychiatric patients.^{3,4} Indeed, those suffering from mental health disorders, particularly severe and persistent mental illness (SPMI), die younger than members of the general population.⁵ There are measurable differences in years of life lost between people with and without mental disorders for both natural and unnatural causes.^{5,6}

Defining psychiatric illness as life-threatening is also hindered by the lack of biological markers to aid diagnosis, as psychiatric illness is clinically defined by a cluster of symptoms rather than quantifiable biomarkers.⁷ Of note, reliance on symptomatology is not unique to psychiatry; for many life-threatening illnesses that have long existed in neurology, such as Alzheimer’s disease, only recently have reliable biomarkers been identified, and they remain dependent on a constellation of symptoms for accurate diagnosis. Acknowledging psychiatric illness as the primary life-threatening illness in the implementation of a palliative care plan elevates it to its appropriate level of severity. In so doing, clinicians have impetus to explore effective palliative psychiatric care through multiple options that relieve suffering.

A Case for Palliative Psychiatry

Presently, the goals of psychopharmacology and psychotherapy are recovery and remission.⁸ Indeed, psychiatric patients do improve, recover, and live hopeful, satisfying, and productive lives per their own and their clinicians’ assessments.⁹ However, there exist subgroups of people with SPMI who do not recover from their illness or experience symptom remission. Such subgroups include those with therapy-refractory mood disorders, **severe chronic schizophrenia**, therapy-refractive anorexia nervosa, or treatment-refractory PTSD.^{4,10} These are life-threatening illnesses that negatively impact quality of life. Individuals with these illnesses may experience social distress in the form of homelessness, loss of employment, food insecurity, isolation, poor self-care, poor access to medical care, or physical deterioration. They may also experience symptoms of psychological distress: loneliness, despair, nightmares, flashbacks, unrelenting suicidal ideation, and compromised ability to concentrate or read. Moreover, hopelessness accompanies multiple failed medical and psychotherapeutic interventions employed to achieve remission.^{11,12}

This failure of treatment focused on recovery or remission for people with SPMI, along with the significant negative impact of the condition on their quality of life, indicates the appropriateness of palliative care for such patients as a primary intervention and the easing of their suffering as a primary goal. Manuel Trachsel at the University of Zurich and colleagues have written extensively on palliative psychiatry in the last decade and provide the following definition:

Palliative psychiatry (PP) is an approach that improves the quality of life of patients and their families in facing the problems associated with life-threatening severe persistent mental illness (SPMI) through the prevention and relief of suffering by means of a timely assessment and treatment of associated physical, mental, social, and spiritual needs. PP focuses on harm reduction and on avoidance of burdensome psychiatric interventions with questionable impact.⁴

Applicable palliative care interventions in psychiatry range from psychopharmacological, psychotherapeutic, and medical and social interventions involving caretakers, practitioners—and, when available—family members. One such intervention argued for here is long-term psychotherapy.

Long-Term Psychotherapy as Palliative Care

Long-term psychotherapy has proven effective in the treatment of chronic mental illness.¹³ The long-term relationship between the patient and psychiatrist is a locus of predictability and trust for the patient.¹⁴ The relationship itself serves as a safe harbor for the patient to discuss concerns regarding the present and future. Patients themselves have noted the value of a psychiatrist who remains a steadfast presence even when treatments don't achieve the desired positive effect.¹⁴ In this way, the demoralization a patient might otherwise experience from multiple failed treatments is ameliorated and hope is sustained.^{14,15,16} It is within this therapeutic alliance that the patient may find access to resources both practical and existential, provision of support, and collaboration in exploring ideas and meaning.^{14,17}

Patient and psychiatrist can discuss the prognosis and address the patient's feelings of loss and despair as well as what to hope for. In the context of palliation of psychiatric symptoms, hope can expand in definition from hope for a full recovery, with all its inherent benefits, to hope for a day without the burden of suicidal thoughts or hope for a week without a flashback. Psychiatrist and patient can also collaborate on advance care planning, both psychiatric and medical.⁴ The psychiatrist can document the patient's capacity to make thoughtful, informed decisions with an eye not only to advance care planning but also to attestation of the patient's stable capacity over time. This documentation can help other medical professionals or surrogate decision makers in the future should the need arise.

In addition, the psychiatrist is uniquely positioned to administer medications when necessary as well as psychotherapeutic interventions to address symptoms that affect the patient's life on a week-to-week basis, thereby palliating distress and pain. The psychiatrist may also serve as a liaison between the patient and the general medical community, again helping the patient gain access to care needed to relieve physical concerns outside the purview of psychiatry.⁴ All these interventions—providing medications, acting as a liaison, remaining a safe harbor even when treatments fail—work together to improve a patient's quality of life.¹⁴ The relationship itself is one of the most effective means of improving quality of life for patients undergoing long-term therapy.¹⁸ Patients in long-term relationships with psychiatrists often remark on the benefit of the relationship to their quality of life based on the compassion, involvement, and expertise of said physicians.¹⁹

Ethics and Long-Term Therapy as Palliative Care

Although palliative psychiatric care is focused on buttressing patient autonomy and the delivery of beneficent care by a treating psychiatrist, ethical issues can arise. Patients can and will, for example, discuss their desire to die. In such cases, psychiatrists must balance their desire to offer the patient a safe place to discuss suicidal thoughts and

state law pertaining to psychiatrists' obligations regarding suicidal patients. Psychiatrists may find themselves in a situation wherein they are legally obligated to inform the state of an impending suicide.²⁰ For this reason, at the time the patient is reflecting on decisions regarding sharing in therapy, the psychiatrist is under an ethical obligation to inform the patient of their obligation to the state. This disclosure might make the patient less inclined to discuss their inner conflicts regarding life and death, which are likely crucial issues for the patient. However, the therapeutic alliance can ameliorate this ethical dilemma. Given a strong level of trust developed over time, the psychiatrist can help the patient make realistic choices regarding life and death in the absence of an imminent plan. For example, the psychiatrist and patient might have open and frank discussions pertaining to the patient's distress in contemplating suicide or the realities of certain types of suicide vs romanticized notions of ending one's life. They can collaborate on specific palliations of such distressing thoughts, including the use of medications. New medications, such as psilocybin, have proved helpful in palliation of hopelessness, depression, and demoralization in patients with life-threatening illness and will soon be available in the psychiatric arsenal.²¹ By incorporating medication, long-term psychotherapy can palliate psychic pain when suicidal thoughts are present.

The emergence of psychosis is another concern in which the psychiatrist's ethical obligations to others and to the state intersect. A patient may wish to stop all psychotropics; however, if the patient presents a danger to others due to symptoms such as paranoia, the psychiatrist has an obligation to protect the public and thereby to continue a medication that reduces paranoid symptoms regardless of patient choice.²⁰ A long-term relationship can weather temporary paternalism and loss of autonomy as the patient leans on years of a beneficent relationship and trust in the psychiatrist's judgment during episodes of decompensation.²²

There is also an ethical conflict in naming long-term therapy as *palliative*. Does this designation imply giving up? It is true that when caregivers give up on patients, patients give up on themselves.^{15,23} However, palliative care never branded itself as hospice care, as it is not focused on care before dying; rather, it is focused on improving quality of life when curative treatments remain elusive in life-threatening illness. Futility in psychotropic management focused on cure or remission is not equated with futility of *treatment*—to ameliorate pain and suffering in the absence of a cure remains an act of beneficence.^{15,24} It is incumbent on the psychiatrist to educate the patient on the difference between treatment aimed at cure or symptom remission and treatment aimed at relief of suffering and to collaborate on the choice. Equally pertinent is the fluidity of palliative care. Palliative care can change course in both psychiatric and medical illness.²⁵ When a new treatment arises, a psychiatrist is uniquely positioned to implement that treatment should the patient be both interested and willing. Such treatments include emerging treatments focused on remission and cure, resulting in a possible exit from the palliative care paradigm. Again, it is incumbent on the psychiatrist to educate the patient on the fluidity of choice over time based on medical advances.

Conclusions

If the mental health community resolves to implement palliative care and long-term psychotherapy as a part of that treatment, practical issues present a formidable structural barrier.

Finding a treating psychiatrist in general and finding one who accepts insurance can be difficult in and of itself, let alone for long-term treatment.^{26,27,28} And for those under care

at present, an insurance change can translate into a loss of coverage and loss of clinician.

Psychiatric care is also not well subsidized publicly. Community mental health care is unlikely to be equipped to provide palliative psychiatric care to those who need it. Multidisciplinary teams to implement palliative care in psychiatry do not exist, with the result that willing clinicians are overburdened—stretching boundaries to help patients where other help does not exist—and knowing that the loss of any single clinician can prove emotionally catastrophic to the patient.

Implementation of adequate palliative care in psychiatry is necessary for compassionate care of both patient and practitioner. In this way, those with SMPI are not left behind and demoralized. Long-term psychotherapy is an essential tool of palliative care for such patients, as a trusting, dependable relationship with a practitioner is integral to improving quality of life. In the future, should long-term psychotherapy and proper medication management—along with social work care, medical care, and, if available, family participation—be combined to provide **full-spectrum palliative care**, the improvement in quality of life for patients with SPMI will prove immeasurable.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

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

Reece Carter and Celia Mizelle

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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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

What Makes Palliative Mental Health Care Ethical Health Care?

Virginia A. Brown, PhD, MA and Ashley Trust, MD

Abstract

Treatment-resistant schizophrenia can create a high disease burden for some patients, making it challenging for all involved to navigate a good outcome. Such cases require physicians to regard symptom eradication and treatment success as the same. This commentary on a case considers a palliative psychiatry approach grounded in the well-being of patients and inclusion of all stakeholders in decision-making processes.

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Do good and avoid evil is the primum principium of all ethics.

Edmund Pellegrino¹

Case

Mr M is a 45-year-old man with schizophrenia, type 2 diabetes requiring insulin, and hypertension, who is admitted to the psychiatric hospital for the second time in 10 months after he poured flammable liquid on himself in an attempt to burn his body. Prior to admission, the patient believed worms were crawling out of his skin and thought burning himself would be curative. His positive symptoms include somatic delusions and auditory hallucinations, and his negative symptoms include flat affect, avolition, and complete social withdrawal.

Mr M's psychiatric illness started in high school and has become progressively worse, resulting in 15 psychiatric hospitalizations throughout his lifetime. He's tried both first- and second-generation antipsychotic oral medications and long-acting injectables with minimal effect and has had no additional benefit from electroconvulsive therapy. He previously tried clozapine, which decreased delusion intensity but was stopped because he was sedated and had some falls due to postural hypotension. This high disease burden has resulted in his father becoming his guardian for health care, among other matters.

The treating team retrials clozapine and sees cessation of self-injurious behavior, yet optimal therapeutic levels have not been attained, and Mr M's delusions persist. This situation prompts the team to continue to aim for a therapeutic dose. Regrettably, while titrating the dose, Mr M experienced a fall during his father's visit. This event triggered a

meeting with Mr M's father and the care team to discuss his care and plans for potential discharge. During the meeting, Mr M's father explained that, due to this incident and side effects from a prior clozapine trial, he would not give consent to continue increasing the dosage of clozapine, stating: "We are done here. I've been down this road before, and I don't want him to be hurt anymore. You doctors just need to hear me, we're done, he's coming home."

Despite the team's efforts to convince Mr M's father that the fall was in no way indicative of the need to stop treatment with clozapine and that continuing to titrate, albeit slowly, was within the standard of care, Mr M's father remained emphatic: *he was done*. The meeting ended with no agreed-upon plan of care. The clinical team members, distressed by this impasse, decided to call an ethics consultation, stating that they did not see a way forward to resolve this situation and wondering if Mr M's father truly understood the gravity of Mr M's position.

Commentary

In this case, the treating team and Mr M's father, the legally appointed guardian, are at an impasse regarding how to continue care. The team members remain distressed over their inability to convince the father, who protests that he does not want his son "to be hurt anymore," to continue a trial of clozapine and see this incident as a failure to have their expertise as clinicians accepted.

Analysis of this case centers on the tension between the respect for autonomy—in this case, the autonomy of the father on behalf of the son—and the clinical team's duty to promote a good outcome, or beneficence. Regrettably, neither party knows with certainty what Mr M would want for himself, and thus a **best interests standard** will guide the deliberation. Maximizing benefit while minimizing harm demands that both the treating team and the proxy decision maker assess the risks and benefits of the proposed plans and identify a plan that yields the highest utility, thereby shifting the focus toward quality of life.² Yet, while each of the parties recognizes this obligation to all involved, their proposed actions appear incongruent. How ought we to proceed?

Beneficence

In this case, we begin by asking what is the father's and the treating team's *prima facie* duty in creating a plan of care for Mr M when his desires are not known. The application of the best interests standard has extensive support.³ This standard "requires acceptable and reasonable choices grounded in a web of established duties" to incompetent as well as incapacitated persons.³ The team's and Mr M's father's duties and obligations to Mr M can be addressed through application of the best interests standard.

Kopelman identifies 3 considerations when applying the best interests standard.³ Firstly, what are the interested parties' *prima facie* duties related to weighing the benefits and burdens of the proposed decision? Secondly, is the recommendation "good enough" in the sense that a reasonable and informed person would arrive at a similar conclusion? And, lastly, does the recommendation reflect both the moral and the legal duties we owe to someone who is no longer able to self-advocate? Approaching this case with these considerations in mind serves to guide ethical decision making.

Clozapine, while indicated for treatment-resistant schizophrenia,⁴ might reduce Mr M's quality of life by leaving him overly sedated and in need of ambulatory assistance, but

discharging him home without consensus regarding treatment goals is equally problematic. Is clozapine, with its attendant side effects, conducive to the quality of life that clinicians want for their patients even if it is an evidence-based solution? While this case is complicated, its resolution requires a shift in clinical thinking from equating symptom remission with quality of life to ensuring the well-being of Mr M and the inclusion of all stakeholders in the decision-making process about his care. The shift to a person-centered approach focuses on engagement of the family, patient, and treatment team in the decision-making process about a care plan that is collaboratively achieved; centered on both physical and emotional well-being as well as on family preferences, values, and cultural traditions; and shared in a timely and transparent manner.⁵

Analysis

The issues and points of conflict in this case center on collaboratively identifying the *good* while avoiding harm. Traditionally, in clinical encounters, “the physician ... offers to heal, help, care for, or comfort a sick person.”¹ Moreover, such acts represent the embodiment of “[t]he well being of the patient ... the *good* end of medicine and of the physician’s art and action” (emphasis added).¹ However, it becomes difficult to reconcile the “cure”—in this case, symptom remission—with the good end of medicine, since symptom remission may not be possible. Simply put, for the physician, the clinical team, and the father, to discover the **moral ends** of medicine is to discover that while “[c]ure may be futile ... care is never futile.”¹ On this view, considering palliative care is the ethically optimal approach.

In Mr M’s case, shifting to palliative psychiatry represents ethically appropriate action for his discharge. While explicit guidelines regarding the shift to palliative psychiatry are lacking, the focus on prioritizing quality of life is central to good patient care. While palliative psychiatry is a relatively new approach to care, it does not imply giving up on caring altogether; rather, it reflects a shift in the goals of care,¹ one that I argue embodies the good. As to the moral and legal duties the stakeholders share, “the good must be the focal point and the end of any theory or professional action claiming to be morally justifiable.”¹ The moral end, in this case, is to reduce Mr M’s pain and suffering by taking an ethically permissible action (one that does not violate the law) and, as Strand et al note:

Explicitly switching to a palliative treatment route—with continued pharmacological maintenance treatment in reasonable doses in combination with an increased focus on symptom management and quality of life interventions—could potentially instill hope, increase autonomy, and improve overall outcomes for patients with treatment-refractory schizophrenia or other chronically disabling psychotic disorders.⁴

Assuming that the treating team, Mr M’s father, and the ethics consultant are all in agreement that Mr M can be discharged with palliative psychiatry, the optimal balance of pharmacological, **psychotherapy**, and psychosocial rehabilitation could include continued monitoring of clozapine as well as other interventions, such as acceptance commitment therapy (ie, an evidence-based cognitive behavioral therapy that utilizes acceptance and mindful-based strategies) and social skills training.⁴

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Is There a Case for Palliative Care Addiction Psychiatry?

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Abstract

This commentary on a case suggests how palliative care psychiatry can facilitate compassionate resolution of ethical conflicts in end-of-life care decision making with persons with substance use disorders.

The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ available through the AMA Ed Hub™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Case

Mr R is a 52-year-old man with methamphetamine-associated cardiomyopathy (MACM) admitted to an acute medicine service for failure to thrive for the second time in 6 months. Mr R has a 3-decade history of methamphetamine use in various forms, including injection.¹ Mr R has received evidence-based therapy, including outpatient and residential treatment. His longest period of sobriety (7 months) was 9 years ago when he participated in a contingency management program.² Advanced MACM was diagnosed about a year ago when his ejection fraction was less than 40%. Three months before his diagnosis, Mr R had stopped using methamphetamine because he did not have the stamina to obtain and prepare the drug. Mr R lives alone in an apartment; home health services personnel visit him several times a week. His ex-wife, S, is designated as Mr R's durable power of attorney for health care and has been assisting him with meals and transportation. S reports that Mr R eats little during meals before he becomes exhausted. Mr R has lost 10 pounds since his last inpatient admission.

Dr C, a cardiology consultant, documents Mr R's increasing adherence to his medication regimen, notes that medical care options are maximized, and recommends a palliative care consultation. Dr W, an addiction psychiatrist and palliative care physician, follows up, meets Mr R, and confirms Mr R's classic symptoms of advanced heart failure: fatigue, apathy, anhedonia, and anorexia. Dr W notes Mr R's passive thoughts of being better off dead and his frustration with not being able to do anything but sleep. For previously diagnosed depression, sertraline and bupropion provided little benefit, and Mr R was unable to tolerate venlafaxine due to worsening hypertension. Dr W notes that Mr R has no active suicidal ideation, intention, or plan and attributes Mr R's current depression to his heart failure experiences. Dr W informs Mr R and S that he meets criteria for hospice care and recommends a care plan focused on promoting Mr R's

quality of life and end-of-life goals, including interacting with his ex-wife, playing with his dog, and listening to music.

Mr R expresses interest in trying low-dose methylphenidate to improve his appetite, energy level, and overall well-being while in the hospital. The attending hospitalist, Dr H, and the clinical pharmacist on the team, Dr B, decline to follow Dr W's recommendation, however, and express both clinical and ethical concerns about prescribing methylphenidate for a patient whose end-stage cardiac disease is partially due to methamphetamine use. S also expresses fear that, given Mr R's history, he will not be able to control his use of the methylphenidate.

Members of the care team, S, and Mr R consider how to best respond to Mr R's needs.

Commentary

An analysis of National Survey on Drug Use and Health statistics on nonelderly adults found that, from 2015 to 2019, methamphetamine use among US adults increased 43%; frequent use increased 66%, and overdose deaths from psychostimulants, excluding cocaine, increased 180%.³ These and other data indicate that, alongside the far more publicized opioid crisis, America is also suffering from a stimulant epidemic. After overdoses, MACM is the second leading cause of death among individuals using methamphetamine.⁴ Veterans like Mr R are increasingly diagnosed with the condition.⁵ Patients with MACM tend to be younger, present later, and have more severe disease than patients with other types of heart failure.⁶ However, despite the more advanced stage of their cardiomyopathy, these patients' abstinence from methamphetamine and adherence to cardiac medications can improve their prognosis.⁷ Unfortunately for Mr R, his cessation of methamphetamine and recent adherence to medical management came too late to significantly reverse his cardiac damage.

Consultation-liaison psychiatrists have long used psychostimulants like methylphenidate and dextroamphetamine to treat depression, fatigue, and apathy in the medically ill.⁸ The evidence that these drugs are effective for **treatment of fatigue** in patients with cancer is insufficient for them to be recommended for treating cancer-related fatigue⁹; for treatment of depression, the evidence of efficacy is equivocal.¹⁰ Side effects include induction of mania or psychosis, agitation, anger, and—most pertinent for Mr R's case—increase in blood pressure and pulse rate with potential exacerbation of heart failure.¹¹ When effective, psychostimulants can stimulate appetite and improve mood.¹² One major advantage of using them in palliative care is their rapid onset of action; clinical benefits or adverse effects can both be detected in a matter of days as opposed to the weeks it may take for antidepressants to become effective.¹³

Ethical Analysis and Recommendations

Palliative care psychiatrists have helped to identify, analyze, and propose ethically justifiable approaches related to end-of-life treatment for patients with severe and persistent mental illness.^{14,15} Similar attention has not yet been directed to addiction and the ethical issues that arise in cases like that of Mr R, although it is sorely needed.¹⁶ There is a small but growing body of hospice and palliative medicine literature that considers ethical aspects of opioid prescribing for patients with a diagnosis or history of opioid use disorder, such as stereotyping,¹⁷ that may be applicable to Mr R's case. Physicians like Dr W, who recommend psychostimulants for palliation in patients with methamphetamine use disorder, are likely to encounter the same knowledge deficits, fears of liability, and unconscious bias toward addiction as practitioners trying to palliate

symptoms of life-limiting illness in persons with opioid use disorder. To overcome these barriers, Dr W can underscore to the treatment team that Mr R is experiencing 2 end-stage disease processes: MACM and amphetamine use disorder. Mr R's life expectancy from their combined burden is limited, and Dr W has determined that Mr R meets hospice criteria. The focus of the treatment team should now shift to promoting Mr R's goals of care, enhancing his quality of life, and improving his comfort.¹⁸ Dr W thinks that a trial of methylphenidate would seem to offer at least a reasonable chance of obtaining these aims. Drs H and B have legitimate concerns about the risks involved in prescribing methylphenidate to Mr R. Based on their response to Dr W's suggestion and the literature, their concerns would seem to reflect 4 obligations stemming from core ethical principles, such as nonmaleficence, respect for autonomy, and justice.¹⁹ Dr W will need to satisfactorily address each of these to obtain the multidisciplinary support needed to implement his recommendation.

The first concern is that the prescription of methylphenidate will result in Mr R being unable to manage his use of the drug safely and responsibly. Dr W can advise S and the treatment team that several clinical trials of methylphenidate to treat methamphetamine use disorder have shown that methylphenidate might decrease cravings for methamphetamine.^{20,21,22} Similar to the use of buprenorphine and methadone to treat opioid use disorder, prescribed psychostimulants like methylphenidate may have less potential for abuse and reduce overall harm and thus enable Mr R to control his use of the drug. These trials show that Dr W is not recommending just the same substance Mr R was addicted to, as the treatment team assumes.

The second ethical concern is that even low-dose stimulants could worsen Mr R's MACM and hence do more harm. Dr W could discuss this uncertainty with S and Mr R during the informed consent discussion. He may also be able to leverage research suggesting that the etiology of MACM is more complex and multidetermined than the treatment team believes—that is, that methamphetamine use is not the sole cause of MACM²³—in discussion with other members of the treatment team. These data may enable the treatment team to respond with what philosopher Hanna Pickard has referred to as a stance of “responsibility without blame.” Pickard explains this view as it relates to caring for patients like Mr R: “Hence the clinical task with such patients is not to deny their agency and rescue them from blame by pathologizing their behavior, but to work with them and help them to develop their sense of agency and responsibility to support and empower them to make different choices.”²⁴

Third, there are understandable prudential fears in this case. Dr W, perhaps with the assistance of an ethics consultation, can emphasize that good documentation of a sound informed consent discussion with Mr R and his ex-wife is the best defense not only to any legal challenge but also to any risk management challenge, such as Mr R becoming addicted to the medication or the drug worsening his heart failure. The ethics consultant might remind the treatment team that the use of methylphenidate for Mr R is a prime example of harm reduction: an efficacious and established public health approach to substance use disorders.²⁰

Fourth, and more difficult to elicit and address, research suggests that the treatment team may be **stigmatizing** Mr R as a person with a substance use disorder.⁷ Dr W can empathically help his colleagues to see that stigma and health disparities also shaped Mr R's sad situation and that prescribing a trial of methylphenidate is a small act of

social justice.²⁵ Even offering the medication to Mr R conveys a level of respect for his dignity and trust in him as a moral agent that he may seldom have received from the health care system and that can, independently of the medication, have a healing impact on the remainder of his life.

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CASE AND COMMENTARY

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

Nicolas Trad

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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Editor's Note

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MEDICAL EDUCATION: PEER-REVIEWED ARTICLE

Moral Intuitions About Futility as Prompts for Evaluating Goals in Mental Health Care

Anna L. Westermair, MD and Manuel Trachsel, MD, PhD

Abstract

Mental health professionals' moral intuitions about futility should prompt reevaluation of goals of care and care plans. Mostly, it will suffice to improve the care plan and/or slightly adjust the goal of care (eg, lower expectations), which is standard practice. Sometimes, however, all care plans that seek to reduce core symptoms (ie, that pursue a curative goal) are most likely futile and thus should not be imposed. Here, it may be in the patient's best interest to change the goal of care toward palliation (ie, harm reduction, relief of suffering, and best possible quality of life). Thus, futility can function as a moral counterweight to the duty to treat, helping mental health professionals find the right balance between over- and undertreatment.

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Moral Intuitions

- *I wouldn't want this for myself.*
- *Treatment is making my patient suffer horribly.*
- *There is no good option here.*
- *No matter what I do, I don't think my patient is going to get better.*
- *I have no choice but to use coercion.*
- *I feel that we're only making matters worse.*
- *I wouldn't be surprised if my patient died this year.*

Thoughts like these and associated feelings of unease, helplessness, and being stuck are not uncommon among mental health professionals, especially those caring for persons living with severe and persistent mental illness (SPMI).^{4,2} Typically, these concerns are dismissed or attributed to burnout, lack of training or experience, or unprofessional pessimism. Instead, this article explores these concerns as moral intuitions with the potential to improve care for persons living with SPMI.

Moral intuitions are thoughts that incline one toward a certain moral response (eg, *We should not continue this patient's current treatment*) and arise without conscious effort.

These inclinations are accompanied by a metacognitive feeling of (un)certainty: if all of the morally relevant information favors the same response, a sense of certainty drives the mental health professional to spontaneous action, often without their being aware of the underlying ethical dimension. If, however, the available information engenders competing responses (eg, to continue or curtail a burdensome treatment), an inclination may be accompanied or even eclipsed by a feeling of uncertainty. This is true of the moral intuitions and thoughts listed in the opening paragraph: the patient's ill health and endangerment demand intervention, but, for some reason, this seems pointless or useless—in short, *futile*.

According to Cecchini,³ the resulting feeling of uncertainty about the appropriate moral response serves to prompt the mental health professional to engage in conscious reflection. However, while there is empirical evidence that mental health professionals make futility judgments in their clinical work,^{1,2,4} there are hardly any scientific contributions, practice recommendations, or tools to support reflection.⁵ As a first step toward bridging this gap, the present article offers some guidance for reflecting on instances of possible futility in mental health care.

Futility

According to one common definition,⁶ *physiological futility* refers to instances in which a given treatment cannot possibly achieve the intended physiological effect. More often, in cases of *quantitative futility*, a treatment might have the intended effect, but the chances of success are unacceptably low. In cases of *qualitative futility*, a goal of care may be attainable with an acceptable level of probability, but attainment would fail to provide significant benefit to the patient, or any treatment benefits would be outweighed by the associated burdens (for clinical examples, see the Table, columns 1-3).

Table. Examples of Futility and Goals in Mental Health Care

Case summary	Standard goal(s)/core care plan	Type of possible futility in pursuing standard goal(s)	Possible palliative goal(s) of care/core care plan
<p>Having lived with schizophrenia for more than 20 years, a man feels obliged to fast and walk incessantly to atone for humanity's sins. As last-resort treatment attempts (including clozapine and ECT) fail to alleviate his delusions, involuntary tube feeding is the only means of preventing starvation. This requires hospitalization and restraint for much of the time, as he repeatedly tears out PEG tubes. The patient is miserable, suffering from delusions, unable to engage in meaningful activities, and experiencing multiple somatic complications that include pneumonia and empyema.⁷ (For a similar case concerning a woman with delusional disorder, see Bassirpour et al.⁸)</p>	<p>Keeping patient alive (eg, by tube feeding)</p>	<p><i>Qualitative futility.</i> While coerced feeding achieves a prima facie worthwhile goal (keeping the patient alive), it may not benefit the patient, as his subjective QOL under treatment is unacceptably low, and improvement is very unlikely (see quantitative futility below).^a</p>	<p>Maximize QOL by prevention and relief of suffering (by forgoing coercion, initiating home palliative care, and accepting a high risk of a lethal outcome)</p>
	<p>Remission (or at least reduction) of delusions by antipsychotic medication and ECT</p>	<p><i>Quantitative futility.</i> The probability is exceedingly low that further treatment will reduce the patient's delusions to a point at which he can live more independently (w/o artificial feeding) and achieve a subjectively acceptable QOL.</p>	
<p>A 52-year-old man with autism spectrum disorder habitually picks up and eats cigarette butts from the floor of his residential care facility. Although he never shows any signs of nicotine poisoning, the team feels obliged to eliminate any risk. After several failed attempts to treat this behavioral symptom, only coercion (short physical restraint to force the cigarette butt out of his hand) can prevent ingestion. Each instance of coercion destabilizes the patient for several days, initiating destructive cycles of aggressive behavior and further coercion.⁹</p>	<p>Preventing nicotine poisoning (ie, harm reduction) by removing cigarette butts</p>	<p><i>Qualitative futility.</i> Although the intervention achieves a prima facie worthwhile goal (reducing the risk of nicotine poisoning), this benefit may be outweighed by the intervention's high burden (repeated coercion, increased psychological suffering, lower quality of relationships with staff members).</p>	<p>Maximize QOL by prevention of suffering (by forgoing coercion and accepting some risk of nicotine poisoning).^b</p>
<p>A 42-year-old man with schizophrenia presents with catatonia, characterized by high levels of rigidity, tension, and mutism. For more than a year, he receives intensive care involving guideline-conforming pharmacological treatment (antipsychotics and benzodiazepines) as well as nonpharmacological treatments for catatonia (ECT, tDCS) without any perceptible clinical benefit.¹⁰ (For a similar case, see Trachsel et al,¹¹ and for similar cases in the context of affective disorders, see Levitt et al¹² and Tuerlings et al.¹³)</p>	<p>Keeping patient alive by means of intensive care and treatment of somatic complications of immobility</p>	<p><i>Qualitative futility.</i> Intensive care achieves a prima facie worthwhile goal (keeping the patient alive), but this may not be of benefit to the patient, as his QOL in intensive care is likely to be unacceptably low, and the chances of improvement are slim (see quantitative futility below).^a</p>	<p>Relieve suffering by forgoing life-sustaining measures and initiating end-of-life care</p>
	<p>Remission (or at least reduction) of catatonic symptoms by medication and brain stimulation</p>	<p><i>Quantitative futility.</i> After a year of competent treatment, the probability is exceedingly low that further treatment will reduce the patient's catatonic symptoms. Future research may identify irreversible histopathological changes in the brains of persons with treatment-resistant catatonia, rendering further treatment <i>physiologically futile</i>.</p>	

<p>Now in his 50s, a man with opioid use disorder had become dependent on oxycodone when an accident in his 20s left him with chronic pain. After transitioning to injecting heroin in his 30s, the patient also began to inject stimulants. He dropped out of methadone treatment several times, as cravings led to ongoing street heroin use. It was not possible to switch him to buprenorphine/naloxone treatment because he was unable to tolerate the withdrawal required for induction. Two attempts at residential treatment resulted in only temporary abstinence.¹⁴</p>	<p><i>Short-term goal.</i> Replacement of heroin by long-lasting oral opioids (requiring the patient to learn to tolerate residual cravings and to manage w/o the euphoric effect of heroin)</p> <p><i>Long-term goal.</i> Reduction of dependence by gradually reducing dosage</p>	<p><i>Quantitative futility.</i> The probability of retaining the patient in a further attempt at oral opioid replacement therapy is exceedingly low.</p> <p><i>Qualitative futility.</i> As the patient is unlikely to benefit from further oral opioid replacement therapy, the expected benefits may be outweighed by the burdens of another unsuccessful attempt, such as a sense of failure and despair.¹⁵</p>	<p>Maximize QOL by means of HAT,¹⁶ which provides the euphoric effect of heroin, relieves suffering in the form of craving and withdrawal, and reduces harms from use of street heroin.^c</p>
<p>A 30-year-old woman with past diagnoses of ADHD, PTSD, major depressive disorder, and GAD had suffered from anorexia nervosa since the age of 13. She had received more than 20 long-term inpatient or residential treatments for her eating disorder, including appetite-stimulating medication and repeated tube feeding—in some instances achieving full weight restoration. However, the patient could never sustain gained weight and sometimes even lost weight during treatment. She is now presenting with a BMI of less than 10, as well as hypoglycemia, bradycardia, and elevated liver enzymes. She refuses tube feeding and accepts only enough dextrose infusions to maintain consciousness. Two independent psychiatrists found that she had not retained decision-making capacity regarding her nutritional intake.¹⁷ (For similar cases, see Dyer,¹⁸ Dyer,¹⁹ Lopez et al,²⁰ O’Neill,²¹ Trachsel et al,²² Weber et al,²³ Yager.²⁴)</p>	<p>Keeping patient alive by means of tube feeding and cardiopulmonary resuscitation as needed</p> <p>Weight restoration (initially by means of tube feeding)</p>	<p><i>Qualitative futility.</i> If successful, cardiopulmonary resuscitation would probably result in chronic pain from rib fractures that are unlikely to heal because of cachexia, leading to a life of unacceptable quality (as judged by the patient’s sister, who has power of attorney).</p> <p><i>Quantitative futility.</i> Given the chronicity of the patient’s anorexia and her long-standing lack of motivation to recover, the probability of weight restoration without coercion is exceedingly low.</p> <p><i>Qualitative futility.</i> The benefits of at least partial weight restoration by coerced tube feeding may be outweighed by the suffering this would engender, especially as any weight gain is unlikely to be sustained after discharge.</p>	<p>Prevent suffering by forgoing coerced tube feeding and cardiopulmonary resuscitation, and relieve suffering by initiating end-of-life care</p>

Abbreviations: ADHD, attention deficit hyperactivity disorder; BMI, body mass index; ECT, electroconvulsive therapy; GAD, generalized anxiety disorder; HAT, heroin-assisted treatment; PEG, percutaneous endoscopic gastrostomy; PTSD, posttraumatic stress disorder; QOL, quality of life; tDCS, transcranial direct-current stimulation.

^a Of note, these statements are based on the normative premise that life is not an absolute value, ie, that being alive is not unconditionally good.

^b This case illustrates that (1) while palliative psychiatry includes harm reduction, it goes beyond it²⁵ and (2) palliative psychiatry, like palliative care for somatic diseases, is not exclusively concerned with end-of-life care.²⁶

^c As many patients exhibit improved psychosocial functioning under HAT, and some even transition to oral opioid replacement therapy, HAT illustrates that palliative goals of care can often be pursued in parallel with rehabilitative goals and may even serve as a starting point for the pursuit of curative goals.²⁶

^d In some cases, forgoing coercion and initiating end-of-life care seems to enable the patient to develop an autonomous desire for treatment aiming at weight restoration.²⁷ Accepting the futility of coerced refeeding may therefore (somewhat paradoxically) improve the patient’s prognosis, health, and life expectancy.

Qualitative and quantitative futility share 3 ethically relevant characteristics: normativity, context independence, and specificity. First, futility is not simply an empirical issue but is inherently normative²⁸—that is, it is based on values and not on facts alone (normativity). Judgments of quantitative futility require a cut-off value for the chance of success (between “low but just about acceptable” and “unacceptably low”), and this is itself a value-based decision. Qualitative futility is even more normatively driven because the benefit a person might derive from a given treatment is both highly personal and value based, as are the burdens that one may be willing to accept in pursuit of successful treatment. In the context of intensive care, the concept of futility has been heavily criticized for this normativity and discredited as a tool for paternalistic physicians to assert their own value-based judgments over patient wishes in withdrawing or withholding treatment.²⁸ However, the mental health context is fundamentally different; in the most challenging situations, mental health professionals must decide whether to force treatment on an incompetent patient against their stated wishes or accede to their request to withdraw or withhold treatment. In many cases, patients have no valid advance directive²⁹ and no close relationships, which means that there is no one to convey their autonomous wishes, preferences, and values.³⁰ Here, substituted judgment is unfeasible, leaving mental health professionals (as well as judges, professional guardians, and others, depending on jurisdiction) with no choice but to make decisions according to the **best interest standard**.³¹ It follows that, in some cases, the duty to make value-based decisions for individuals with SPMI on the basis of minimal information about their autonomous wishes and personal values is inescapable.

Second, futility is independent of the macro context (eg, the respective health care system and jurisdiction) in the sense that it pertains to ideal circumstances (context independence). While pragmatic considerations (such as reimbursement schemes or laws on coercion) are important in devising good care plans, they are unrelated to futility. Care plans can be implementable and promising (eg, not futile), implementable but futile, promising but not implementable, and both futile and not implementable. Futility may allow for a nonmaleficence-based justification for withholding or withdrawing an intervention, from which follows the ethical obligation to offer or develop different interventions. Lack of implementability, perhaps due to lack of resources, may allow for a justice-based justification for withholding or withdrawing an intervention, from which follows the ethical obligation to develop just allocation schemes that ensure equitable access to health care. The importance of differentiating between futility and lack of implementability has been widely discussed in the context of ventilator allocation during the COVID-19 pandemic.³²

Third, futility always pertains to a specific intervention, aiming at a specific goal of care, for a specific patient, at a specific moment in time.^{33,34} Of note, this specificity of futility is in stark contrast to mental health professionals’ often all-encompassing intuition about futility (eg, *Nothing at all can be done anymore!*). In addition, patient-related specificity includes, among other things, the ability of the patient to show the minimum cooperation required for the intervention to take effect.⁵ Care plans can become futile when mental health issues make it impossible for the patient to adhere to them (eg, when overwhelming fears of contamination prevent a patient from acting on her autonomous decision to take medication for her obsessive-compulsive disorder). Competent refusals of care plans, on the contrary, do not constitute cases of futility. The crucial difference is between not being able to cooperate with treatment and (autonomously) not wanting to do so.

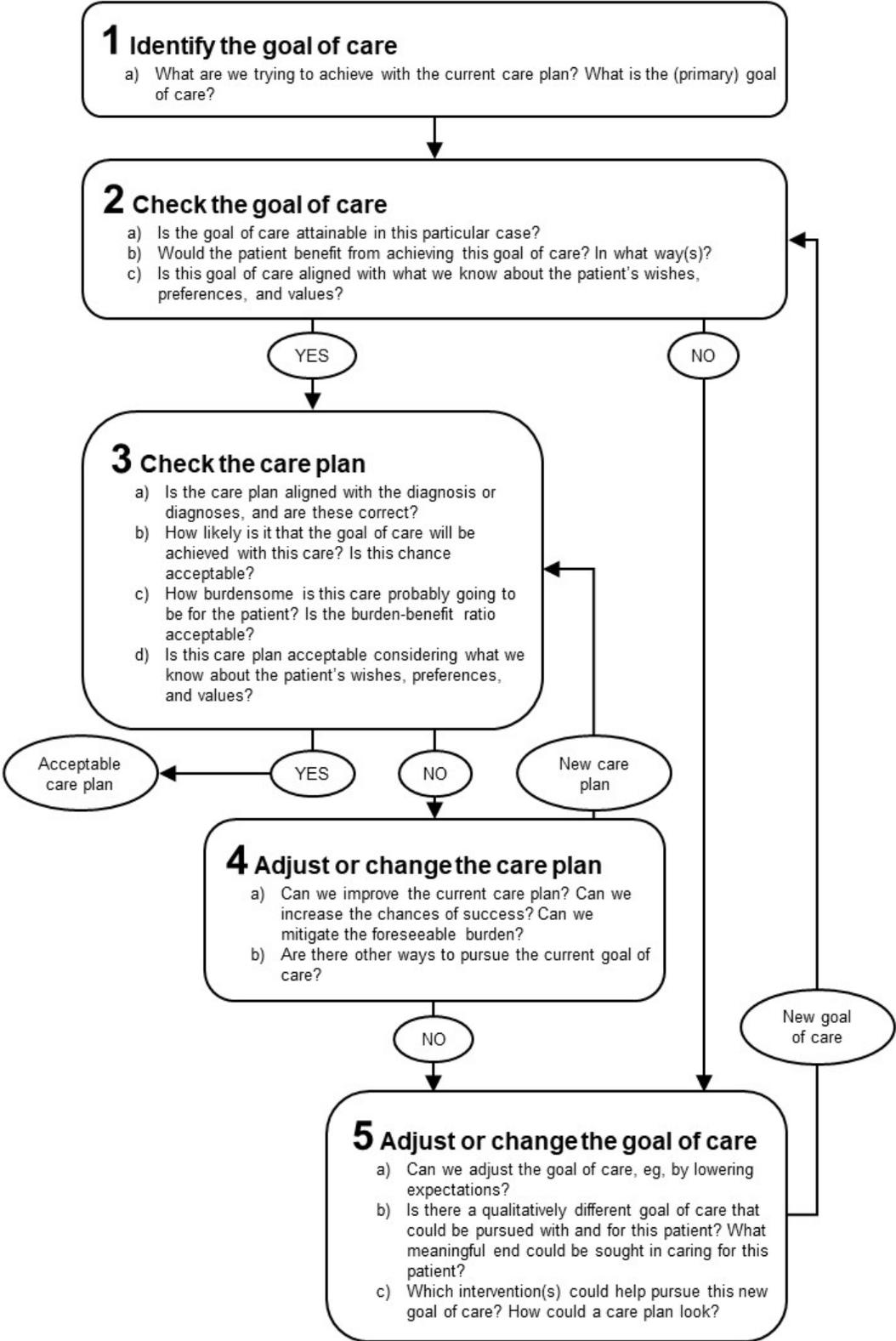
Importantly, specificity opens up possibilities for coping with futility: to identify non-futile care plans, the original care plan can be improved and/or the goal of care can be changed. Other possible courses of action—turning to another patient or waiting for the chances of achieving the original goal of care to improve—could alleviate the professional’s futility-related distress but cannot answer the ethical question of how best to care for a given patient in the present moment. Therefore, those options are not pursued here.

Reflecting on Possible Futility

The flowchart in the Figure, which supports reflection on instances of possible futility, should ideally be used with colleagues, a supervisor, and/or a clinical ethicist. As goals in mental health care are often implicit, vague, or unclear, deliberation should start with clearly and explicitly formulating the current goal of care (step 1). The goal of care and the associated care plan should then be checked for futility (steps 2 and 3). If any of the questions cannot be answered affirmatively, pursuit of the current goal of care with the current care plan is likely currently futile for the patient in question and therefore inappropriate. In such cases, deliberation should focus on adjusting or changing the care plan (step 4) or the goal(s) of care (step 5). Given the high specificity of futility, such changes can help to sidestep the anticipated futility of the original goal of care or care plan.

While this flowchart was developed for reflection on care based on the best interest standard, it may also prove useful for preparing for shared decision making with competent patients or substitute decision makers. After elaborating different goals of care and associated care plans, the mental health professional should discuss all options with the patient or their substitute decision maker, clearly differentiating between professional knowledge and expertise (eg, estimated chances that a given care plan will achieve a given goal) and value judgments (eg, whether the burdens associated with a given care plan make this a chance worth taking). Finding alternative acceptable care plans with this flowchart may also be useful when the care plan that is deemed optimal by the mental health professional is (1) refused by a competent patient or substitute decision maker or (2) not implementable, keeping in mind that these scenarios do not constitute instances of futility and that they necessitate a different ethical justification for deviating from standards of care.

Figure. Flowchart for Reflection on Possible Futility in Mental Health Care



Reflection on possible futility can produce 1 of 3 broad outcomes: *pseudo-futility*, *irrelevant futility*, or *futility of standard care*.

Pseudo-futility. First, careful reflection may reveal that, contrary to a moral intuition or initial thought, the care plan is not futile for the case in question (all questions in steps 2 and 3 of the Figure are answered affirmatively). This pseudo-futility or subjective uncertainty about how best to care for the patient in question can originate from a lack of professional expertise or training (eg, regarding the probability or usual timing of a response to a specific intervention), the professional's state of mind (eg, habitual pessimism, burnout), or the professional's moral values (eg, who deserves treatment and which treatment is worthwhile). For example, procedures such as repeat heart surgery for endocarditis caused by intravenous drug use or removal of foreign bodies in the context of repetitive ingestion are sometimes refused on grounds of futility because there is a high risk of recidivism. However, the goal of care (to cure the endocarditis or remove the foreign object) is readily achieved, with benefits for the patient related to quality (and often also duration) of life. These scenarios may provoke debate about quality of care, resource allocation, and stigmatization, but they do not constitute instances of futility.^{35,36} However, even in cases of pseudo-futility, reflection on the possibility of futility is likely to prove more useful than outright rejection of the concept. In particular, guided reflection can improve mental health professionals' awareness of their personal values and of the morally relevant features of clinical situations and increase their knowledge of relevant ethical concepts such as the fact-value distinction.³⁷ These outcomes of reflection can mitigate the impact of intuitions surrounding instances of pseudo-futility on patient care. Future research should explore the "differential diagnosis" of futility to help mental health professionals identify instances of pseudo-futility more readily.

Irrelevant futility. Second, in cases of ethically irrelevant futility, professionals correctly conclude that (1) the care plan in question has an unacceptably low chance of achieving its goals or entails an unacceptably low benefit-burden ratio, rendering the care plan futile. However, (2) this shortcoming is easily rectified by optimizing the care plan (eg, switching the antipsychotic medication to clozapine; step 4 in the Figure) or slightly adjusting the goal of care (eg, lowering weight gain expectations from a pound to a half pound per week; step 5a in the Figure). The clinical literature is replete with tips, strategies, and recommendations of this kind, often associated with keywords like "nonresponder" or "treatment-resistant." A glaring example of ethically irrelevant futility is treatment based on wrong diagnoses (eg, monotherapy with antipsychotics for auditory flashbacks in borderline personality disorder misdiagnosed as demeaning voices in schizophrenia). While it may pose a *clinical* challenge to correctly diagnose a specific patient, this scenario does not pose an *ethical* challenge, as there is an unambiguously better care plan within standard care. Whether or not we categorize such instances as futility as opposed to suboptimal, incompetent, or inappropriate care is irrelevant from an ethical point of view, as optimizing the care plan is ethically mandated in any case. Nevertheless, explicit reflection on instances of (ethically) irrelevant futility is (clinically) relevant, as it can improve patient care and provide learning opportunities for mental health professionals.

Futility of standard care. Third, questions of futility become ethically relevant when they concern all standard care plans or standard goals of care for a given patient (futility of standard care; for examples, see Table, columns 2-3). Needless to say, mental health professionals should exert extreme caution here. Until guidelines on this issue are

published, we suggest consulting at least 2 independent experts on the patient's condition. Should their advice yield an acceptable care plan, the matter would be identified as pseudo- or irrelevant futility. Otherwise, it may be reasonable to conclude that there is no care plan that would offer an acceptable chance of success and benefit-burden ratio, even for a scaled-down version of the original goal of care. To address the ensuing ethical challenge of being obligated to provide care in the face of probable futility of standard care, we propose a qualitative shift in the goal(s) of care (see the Figure, steps 5b and 5c).

Goals of Mental Health Care

By default, the goals of mental health care are **curative** in the sense that they focus on the alleviation of core symptoms of mental disorders—that is, diagnostic criteria such as delusions, catatonic symptoms, inability to control substance use, and restrictive eating (see Table, column 2).^{15,38} Although mental health care often addresses symptoms rather than causes and achieves only partial symptom reduction rather than complete remission, as long as the focus is on reducing core symptoms, the goals of care remain *curative*.³⁸ Qualitatively different are rehabilitative and palliative goals of care. The overarching *rehabilitative goal* in mental health care is to improve the psychosocial functioning of persons living with SPMI—in other words, the development of “the emotional, social and intellectual skills needed to live, learn and work in the community with the least amount of professional support.”³⁹ This means, for example, that “symptom control does not necessarily have the highest priority, as some side effects of pharmacological treatment can weaken a person's ability to perform his or her social roles, and impair vocational rehabilitation.”³⁹

Given that, in some cases, even the pursuit of rehabilitative goals of care is likely futile, some have advocated the implementation of palliative approaches to mental health care (ie, palliative psychiatry).^{15,26,40,41} The overarching *palliative goal* in mental health care is to maximize quality of life through harm reduction and relief of suffering.²⁶ While curative psychiatry also seeks to improve quality of life, these approaches differ in 2 respects. First, in terms of strategies applied, curative psychiatry strives to improve quality of life through *reduction of core symptoms*, while palliative psychiatry aims to reduce harms and relieve suffering by *working around core symptoms* of the SPMI.²⁶ For example, **anorexia nervosa** often reduces quality of life because underweight-related fatigue limits the social activities the patient can partake in. A curative approach would aim at increasing weight and thus tackle a core symptom of anorexia nervosa, which—if successful—is likely to *indirectly* enable the patient to be more active, thereby improving her quality of life. A palliative approach would *directly* aim at improving quality of life by, for example, arranging weekly home visits by an experienced mental health nurse to alleviate loneliness without pushing for weight gain. The second difference relates to time frames: while curative psychiatry seeks to improve the patient's *future* quality of life—sometimes accepting an undesired but foreseen reduction of current quality of life by side effects or coercive measures—palliative psychiatry prioritizes *current* quality of life. For example, abstinence-oriented treatment for opioid use disorder prioritizes the hope of a better quality of life after successful treatment over current quality of life, which is reduced by withdrawal and craving, while heroin-assisted treatment prioritizes current quality of life, which is improved by relief of craving and induction of euphoria (see Table, line 5 for a clinical example).

While palliative goals of care often can (and should) be integrated with rehabilitative and curative goals,²⁶ sometimes mental health professionals must prioritize one goal over

the others (eg, when having to decide whether to impose burdensome treatment of doubtful effectiveness in the face of acute endangerment of a patient whose autonomous wishes and values are unknown). In such challenging situations, futility can act as a moral counterweight to the duty to treat, helping mental health professionals find the right balance between over- and undertreatment. In instances of futility of curative and rehabilitative care plans, the palliative goal of preventing suffering may justifiably be prioritized over any other goal, sometimes even over the minimal goal of keeping the patient alive.

In conclusion, futility of standard care calls for not imposing the care plan(s) in question, but it does not relieve mental health professionals of the general obligation to provide care. To fulfill this obligation of providing care in the face of futility of standard care, mental health care as a discipline needs to develop, evaluate, and provide alternative approaches to standard care, such as palliative psychiatry.

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STATE OF THE ART AND SCIENCE: PEER-REVIEWED ARTICLE

A Life-Affirming Palliative Care Model for Severe and Enduring Anorexia Nervosa

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Abstract

Some individuals with severe and enduring anorexia nervosa experience dramatically degraded quality of life in the face of refractory illness and compulsory treatment. We propose a palliative care (PC) model for this group of patients that aims to support their unique goals of care, improve social-professional function, reduce physical suffering, and honor the whole person. Far from representing a pre-hospice model, a PC model for those with severe and enduring anorexia nervosa instead provides an alternative to current practices in hopes of meaningfully improving quality of life and outcomes.

Severe and Enduring Anorexia Nervosa

Among patients with anorexia nervosa (AN), a well-recognized subset with severe and enduring anorexia nervosa (SE-AN), comprising approximately 20% of patients with AN, suffer from disease states refractory to classic treatment modalities and have high disease-specific mortality risk.^{1,2,3} Many of these patients experience multiple comorbidities and poor quality of life.⁴ Some die of complications of their illness.^{5,6} Consequently, experts have suggested (and debated) the appropriateness of palliative care (PC) for patients with SE-AN.^{7,8,9} To date, however, discussions on defining PC models for these patients have been limited. Trachsel and colleagues eloquently described this deficit of PC models for psychiatric disease as the “loud silence.”¹⁰ Based on a literature review and our clinical experiences, we address this silence by proposing a clinical framework for a **palliative approach to care** of patients with SE-AN.

A Narrow Approach to PC for SE-AN

As its primary aim, PC prioritizes quality of life and the prevention and relief of suffering. No longer relegated to end-of-life care, PC has become an important upstream intervention for highly burdensome illnesses and can be applied alongside curative-intent therapies. The mainstay of PC is an interdisciplinary, whole-person therapeutic assessment and care plan that emphasizes physical, social, emotional, spiritual, and relational health. PC elevates the therapeutic alliance, compassionate witnessing, and quality of life as a care constellation. When aptly applied, PC improves quality of life, caregiver burden, and end-of-life care outcomes and decreases acute care utilization and care costs.^{11,12}

Multiple reports on SE-AN demonstrate that palliative approaches can reduce suffering, increase independence, and improve quality of life.^{1,7,13,14,15,16,17,18} Several authors have attempted to identify which SE-AN patients would benefit from PC approaches. Lopez et al suggested criteria such as lack of sustained treatment response, physical and psychological decline, and an inexorable course.⁷ Relatedly, but focusing on patients specifically receiving end-of-life care, Gaudiani et al and Yager et al recently proposed the following criteria for terminal AN: (1) a diagnosis of AN; (2) age 30 or older; (3) prior persistent engagement in high-quality, multidisciplinary eating disorder care; and (4) consistent, clear expression on the part of the patient (or surrogate) that they understand further treatment to be futile, choose to stop trying to prolong life, and accept that death will be the natural outcome.^{18,19} These criteria are well-reasoned steps for identifying a target population that might benefit from PC, but inherent to these criteria is a terminal prognosis, with the expectation that PC will ease suffering in the dying process. We suggest instead that a successful PC model can be extricated from end-of-life care and applied to the SE-AN population regardless of prognostic outlook.

Broadly speaking, we imagine a new application of PC for those with SE-AN, including those who meet the criteria of Lopez et al and of Gaudiani et al and Yager et al. Historically, this group of patients has been marginalized by outpatient practitioners who feel uneasy acquiescing to disease progression. A PC model, by contrast, warmly embraces the lived experience of these brave individuals regardless of their past or future therapeutic outcomes. By honoring the therapeutic alliance, this model seeks to improve quality of life and, potentially, survival. Toward this end, practitioners would benefit from the delineation of a PC model distinct from curative, **disease-modifying**, function-centered, and harm-reduction approaches.^{10,18,20}

A New Model of PC for SE-AN

An evolving consensus in the literature suggests that a PC model for AN is ethically appropriate for patients whose disease has been recalcitrant to curative and harm reduction approaches.^{1,7,13,14,15,16,17,18} Wonderlich et al note common themes in palliative approaches to SE-AN, including team engagement, emphasis on quality of life, and avoidance of physically harmful and compulsory treatments.¹⁷ Consistent with these themes, Williams et al have developed a program focused on multidisciplinary, goal-focused, psychosocial care with pre-negotiated and patient-centered triggers for medical and psychiatric care.¹⁵

Our proposed model has 4 key structural components: establishment of goal-concordant care, coordination of an interdisciplinary team, a focus on suffering mitigation, and—for a small subset of individuals—preparation for dying. This PC approach supports disease recovery, clinical equilibrium, or a peaceful dying process as equally acceptable as long as the outcome is aligned with the patient's goals.

Establishing goal concordance. A PC approach is founded on goal concordance between a patient and her treating team. Insofar as identity, core values, and aspirations of joy and tolerance of suffering vary significantly among individuals, a PC approach elicits these foundational perspectives from the patient and shapes the care plan care in accordance with them. To establish a therapeutic program, a goals-of-care (GOC) conversation is a critical first step. The PC team asks the patient—not the medical team—to determine how medical care can serve her. GOC are mutable and are revisited over the course of patients' experience of illness as their disease changes. For example, the GOC at the outset of PC may be to maintain and strengthen social relationships. As

the disease progresses, GOC may shift toward excellent symptom control and maintenance of autonomy. If the disease progresses toward increased debility and limited life expectancy, so, too, may goals shift toward legacy preservation, spiritual wholeness, and a peaceful death. The PC team works to adapt medical care to these goals as they change, providing compassionate and nonjudgmental support throughout the disease course. Key to goal concordance is non-compulsory care, with patients' own perspectives guiding the care plan insofar as patients retain decision-making capacity. It is recognized, however, that neuropsychiatric changes related to severe caloric restriction may alter a patient's capacity for making care decisions, and, in some cases, a thorough clinical assessment of capacity may be necessary. However, it is our clinical experience that though some patients vacillate in their intentions, most patients persist in their intention to forego further treatment at higher levels of care while continuing to seek a life that brings them joy and connection. For vacillating patients, ongoing discussions and motivational assessments are in order, and palliative plans should not be instituted until greater clarity and consistency of purpose is achieved. It should be noted that receiving PC does not close the door to future full recovery-oriented care or goals. Patients may willingly undertake a higher level of care and pursue a fuller recovery at any time, although those interventions are not compulsorily enacted.

Interdisciplinary cooperation. Our PC model for SE-AN requires multiple practitioners with varied expertise. The medical team consists of an eating disorder specialist, a PC practitioner, and interdisciplinary team members, who may include spiritual care practitioners, dietitians, psychologists, and registered nurse care managers. The team communicates consistently to discuss the care plan and adjust interventions to meet changing goals.

Within the medical team, PC specialists and eating disorder specialists play key roles. PC specialists support and help clarify patients' goals in alignment with their changing state of illness and manage symptoms to enable meaningful improvements in quality of life to be achieved. If a patient declines to the point of requiring end-of-life care, PC specialists may assume primary responsibility for overall medical care. Eating disorder specialists help guide therapeutic programs that allow patients to maintain their goals. If a patient's goals focus on maintaining function (eg, being able to work or having enough energy to exercise), a nutrition plan to maintain those goals is established. If a patient's goals focus more on relief of suffering, non-interventionist, supportive, and therapeutic witness programs are established. We emphasize that a PC model for SE-AN entails a collaborative therapeutic effort among PC and eating disorder specialists and that medical care of these individuals is a shared responsibility.

A wide range of interdisciplinary team members is critical for our model. Existential and spiritual care practitioners work with patients to find sources of purpose and meaning. Mental health practitioners help patients deal with depression, family and social dynamics, and feelings of negative self-worth.²¹ Nurse care managers coordinate team resources and communicate care plans across institutions and care settings.¹⁵ Dietitians help patients reorient their food choices with an eye to taste, pleasure, satisfaction, and desired energy. The interdisciplinary team provides frequent-touch, nonjudgmental relationships, thereby helping to maintain and grow the therapeutic alliance.

Other resources, where available, might include creative therapy practitioners, physical therapists, and integrative practitioners. The practicalities of implementing

interdisciplinary care by groups of busy and geographically dispersed practitioners can be challenging. Fortunately, treatment plan coordination and clinical cohesion can be achieved through regular video conferencing among team members.

Mitigating suffering. Relief of suffering is often critical for patients living with SE-AN.²² A PC approach seeks to both diminish current suffering and avoid future sources of suffering, including repeated exposure to retraumatizing violations of autonomy and bodily integrity.^{17,23} Current curative and harm-reduction models often consider the tolerability of interventions to be less important than life extension or symptomatic improvement. PC models invert this hierarchy by privileging the acceptability of interventions over their effects on disease trajectory. In cases in which benefits of acceptable interventions outweigh risks, medication management may address pain, anxiety, nausea, depression, and constipation. Simultaneously, intolerable compulsory interventions are avoided and replaced by compassionate witnessing and therapeutic alliance. Yager notes that “high degrees of interpersonal attunement, empathic holding, and nonjudgmental positive regard” can reduce patients’ existential fear and provide affirmation and validation.²²

Death and dying. If a patient’s goals align with achieving a peaceful death from progression of their disease, the PC team helps develop an end-of-life care plan. Elements of a “good death,” defined by patients and their loved ones, may include maintenance of dignity, legacy preservation, sharing love and forgiveness, and relief from pain and fear.²⁴ In SE-AN, dying may be complicated by unresolved intrapsychic conflicts, interpersonal disputes, requests for forgiveness, regrets, and other emotionally difficult communications. In these instances, the mental health specialist, together with other team members who are closest to the patient and family members, can help achieve emotional repair. As a patient’s illness progresses to terminal decline, hospice services may provide wrap-around comprehensive support for the **dying process**. In this model, death as a natural outcome in terminal illness is positively and deliberately incorporated in the care plan rather than being shunned or avoided. After the patient’s death, care turns towards providing bereavement support to surviving loved ones.

Conclusion

A PC model for the care of individuals with SE-AN does not presently exist, but it should. Our model provides a pragmatic, responsive solution to calls by experienced clinicians and patients themselves to serve those with SE-AN better and differently in hopes of improving their quality of life, as it represents a new care option alongside the harm-reduction and full recovery models. Our PC model for those with SE-AN must be understood as separate from a hospice model—in other words, not limited to the pre-hospice stage—but rather as a novel and positive support system. When patients feel this is the kind of care that best fits their values and they demonstrate clear and verifiable decision-making capacity, a PC approach should be considered.

While proposing core components of a PC approach for patients with SE-AN, we respectfully note that passionate, intelligent, and ethically robust debate exists concerning acceptance of life-limiting trajectories for some SE-AN patients.^{1,18,20,25,26} Practitioners must be cautious about using the imprecise label of **terminality**, however. Using a definition of “terminal anorexia” as justification for truncating or otherwise denying disease-focused care when a patient desires it is unequivocally unethical. A PC model can be applied when the patient and her care team feel it would align with dignity and person-focused care and when curative or harm-reduction models have been

harmful or exhausted. In this way, our model does not discourage a patient from seeking curative-intent or harm reducing care, nor would it deny her the opportunity if such care aligns with her goals. We therefore contend that a palliative paradigm can exist alongside, rather than in opposition to, curative-intent and harm reduction modalities. In circumstances when conflicts arise between harm-reduction recommendations for compulsory care and palliative recommendations for autonomy preservation, revisiting a GOC conversation can help clarify and unify treatment intent.

Our hope is that acceptance of this model will lead to cross-pollination of eating disorder expertise in the PC community and PC expertise in the eating disorder community. We anticipate that the majority of PC care would take place in the outpatient setting, but it is intriguing to imagine PC-focused residential eating disorder programs that would foster voluntary admissions for respite care. These programs might involve a short admission for supportive care on terms the patient sets, such as arresting eating disorder behaviors such that they are easier to resist following discharge; getting social support from peers; and receiving more intensive support during a challenging time in life. A similar model for patients with AN has proven quite effective.²⁷

Future investigations should enroll selected patients in pilot studies to assess relevant outcomes. Measures of model viability might include subjective suffering analyses, quality-of-life indices, and time toxicity, a metric assessing the burden of health care interactions for a defined population.²⁸ We hope that such data will further support the formal establishment of PC as a life-affirming, compassionate, novel, and positive treatment paradigm for patients with SE-AN.

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What Should Clinicians Know About Palliative Psychopharmacology?

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Abstract

The nature and scope of palliative psychiatry and associated ethical implications are debated in the literature. This article examines conceptual limitations of extant accounts of palliative psychiatry, with a focus on psychopharmacological practice, and suggests that modifiable and unmodifiable psychiatric illnesses exist on a spectrum along which broader or narrower palliative psychiatric care approaches can be outlined. The article also discusses how these approaches intersect with questions about whether and to what extent psychiatric medications have symptom-reducing or disease-modifying effects. The discussion leads to the conclusion that clinicians are ethically obliged to distinguish among and clearly formulate goals of care in a dynamic and ongoing process of shared decision making with patients.

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Introduction

Palliative approaches in psychiatry have received increasing attention in recent years. Although existing work has attempted to define the boundaries of what constitutes palliative psychiatry,^{1,2} many conceptual issues and their ethical implications remain in need of further clarification. In this article, I examine the conceptual limitations of existing accounts of palliative psychiatry, focusing on the practice of psychopharmacology, and address these limitations by emphasizing modifiable and unmodifiable aspects of the illness in relation to other distinctions. I also discuss how this approach intersects with ongoing debates about whether psychiatric medications have symptom-reducing or **disease-modifying effects**.

When Is Psychopharmacology Palliative?

Although palliative medicine was initially focused on end-of-life care, it is currently conceptualized as relevant to all chronic, serious, or life-threatening medical conditions, and it can be offered concurrently with curative treatments. The World Health Organization defines palliative care as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early

identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.”³ Palliative psychiatry applies the principles of palliative care to serious and persistent mental illness. Unlike many chronic conditions in general medicine, the etiology and pathophysiological mechanisms of various psychiatric conditions remain poorly understood, and our ability to modify the mechanisms directly involved in pathophysiology remains limited. The boundary between routine psychiatric care and palliative psychiatric care has accordingly proven to be more elusive than that between palliative and general medicine.

This demarcation problem brings uncertainty to the practice of palliative psychopharmacology, with attendant ethical consequences. If we present palliative treatment as curative, we generate an erroneous idea that the etiological causes or the causal mechanisms of the distressing and impairing states are being addressed. By the same token, adopting a palliative approach prematurely or inconsistently—for instance, by opting for symptomatic pharmacological relief without addressing modifiable psychosocial factors that causally contribute to the persistence and severity of the psychiatric illness or by failing to recognize that one has shifted from a curative to a palliative approach—is ethically significant, since doing so may result in an inadvertent narrowing of the focus of clinical care, with suboptimal outcomes. How, then, to conceptualize the relationship between psychiatry and palliative care?

Broad and Narrow Applications

On the relationship between psychiatry and palliative care, Trachsel et al have noted that “several clinical approaches in contemporary psychiatry can already be considered palliative, as they aim at reducing symptoms and suffering from mental illness rather than seeking to achieve disease remission or disease modification.”¹ Balon et al have gone further in raising the possibility of characterizing psychiatry *itself* as a form of palliative care: “in many aspects, psychiatry itself is a form of palliative care because psychiatric treatments are frequently not curative.”⁴ Other proponents of palliative psychiatry, however, have recognized that this suggestion is too expansive² because it blurs the distinctive ways in which palliative care **prioritizes quality of life** and harm reduction strategies over other clinical goals in the management of chronic, serious, or life-threatening conditions and have proposed that the term *palliative psychiatry* be used to describe care of those only with severe and persistent mental illness (SPMI). Rather than characterize psychiatry itself as a form of palliative care, Westermair et al have elaborated on narrow and broad notions of palliative psychiatry: “palliative psychiatry *in a narrow sense* refers to the provision of end-of-life care for persons dying from a mental illness. An example is hospice care for persons dying from anorexia nervosa.... [P]alliative psychiatry *in a broad sense* refers to all approaches aiming at improving quality of life by means other than reduction of SPMI symptoms, namely harm reduction and relief of suffering.”² My interest here is in psychopharmacology in palliative contexts, so I will not focus on other interventions, such as various modalities of psychotherapy, which have an essential role to play in palliative psychiatry in the broad sense.

We can extract 2 sorts of views about palliative psychopharmacology implicit in the quotations above: one view, exemplified by Trachsel et al and Balon et al, focuses on whether medications are symptom reducing or disease modifying and, to the extent that psychiatric medications are symptom reducing, maintains that they are potentially palliative (provided they are used in the appropriate clinical context). According to the other view, exemplified by Westermair et al, medications are curative if used with the

goal of symptom reduction and palliative if the goal is not symptom reduction but improved quality of life. As I will explain, both approaches encounter significant limitations.

Disease Modification and Symptom Reduction

There are different paths to improving quality of life. Some involve modifying the central pathophysiology of the illness, some involve symptom reduction without disease modification, and some involve neither symptom reduction nor disease modification. It has been argued that psychiatric medications, for the most part, are symptom reducing (akin to analgesics and antipyretics) and not disease modifying.⁵

Ghaemi, a notable proponent of the distinction in psychiatry between symptom-reducing and disease-modifying interventions, defines disease modification partly biologically and partly clinically.⁵ Biological disease modification involves altering the pathophysiology of the disease process. Lipid-lowering drugs and antihypertensive drugs in cardiovascular illness are examples. Clinical disease modification involves improvement in the course of illness and mortality. Examples include reduced risk of future myocardial infarctions and malignant recurrences. Ghaemi argues that most psychiatric medications do not satisfy either criterion and that medication classes such as antidepressants and antipsychotics, while effective in reducing symptoms, do not modify the etiology or the long-term course of the illness.⁵

Ghaemi, building on earlier work with Selker,⁶ calls for evidence of disease modification to meet a certain threshold.⁵ For instance, this would require that reduction of future episodes of illness be demonstrated in randomized trial designs other than “randomized discontinuation” trials,⁶ that evidence for modification of long-term course should not come only from observational studies, and that evidence for neuroprotection should involve a range of neuroprotective markers and be shown in vivo in humans. There is evidence that antidepressants do reduce risk of future relapse of depression⁷ and enhance neuroplasticity and neurogenesis,⁸ that early treatment of psychosis modifies long-term course,⁹ and that antipsychotics lower mortality,⁹ but this body of evidence doesn’t meet the criteria laid out by Ghaemi.⁵ In other words, there is evidence suggestive of disease modification, but the scientific debate on this issue extends to what threshold of evidence is sufficient for us to accept that disease modification is taking place. There are additional considerations, such as the hypothesized “kindling” phenomenon in mood disorders, according to which each episode of a mood disorder reinforces brain pathways that render the individual more susceptible to a future episode. It is hypothesized that early treatment may modify this progression.¹⁰ While I do consider neuroscientific hypotheses and observational evidence in support of disease modification to be important and relevant, it is not my intention to settle the matter here in either direction; we only have to note that uncertainty about the evidence complicates labeling an intervention as disease modifying or symptom reducing. In particular, if we link the palliative status of psychopharmacological treatment to whether or not it is disease modifying, we’d have to acknowledge that there is a lack of scientific consensus on the matter, precluding us from saying with certainty whether the intervention is palliative or not. This circumstance prompts us to consider other standards by which psychiatric treatments may be judged to be palliative.

As noted, a superficial impression is that palliative psychopharmacology involves the use of symptomatic agents while a curative approach involves disease-modifying agents, but this distinction is misleading. The curative-palliative distinction is orthogonal to the

symptomatic-disease-modifying distinction, and medications used for palliative purposes may be either symptomatic or disease modifying, depending on the context in which and the purpose for which palliative care is being offered. For instance, chemotherapy targets malignant cells directly and is disease modifying, but **palliative chemotherapy** is often used to improve symptoms or quality of life in advance-stage cancers.

Symptom Reduction as Curative

Some authors, such as Westermair et al,² have distinguished curative psychiatry from palliative psychiatry by characterizing symptom reduction as a curative goal in psychiatry: “whereas curative psychiatry strives at improving quality of life by way of symptom reduction or even complete remission, palliative psychiatry aims at relieving suffering and thus improving quality of life *directly* by working around irremediable SPMI symptoms.”² This characterization of the goal of symptom reduction as curative in psychiatry is problematic, since it doesn’t hold for palliative medicine generally, as improving quality of life via targeting symptoms (such as pain or shortness of breath) is a recognizably palliative goal.¹¹

Modifiable vs Unmodifiable Aspects of Illness

In my view, the relevant distinction in palliative psychopharmacology is not etiology vs symptoms or symptoms vs quality of life, but rather *modifiable vs unmodifiable* aspects of illness in relation to quality of life—aspects that may be either etiological mechanisms or symptoms. My use of the term *unmodifiable* is also intended to describe situations in which we have decided not to modify an aspect of the illness in the interest of prioritizing quality of life. The essence of palliative care, I suggest, is when we are forced to *work around* an aspect of the illness to enhance quality of life. This aspect will be different in different situations. In prototypical instances of terminal illness in palliative medicine, the aspect that must be worked around is the inevitability of death from illness progression. In conditions such as advanced chronic obstructive pulmonary disease, it is the unalterable nature of pathophysiological changes in the lungs; symptoms have to be improved by working around the damaged lung tissue. In palliative psychiatry as envisioned by Westermair et al,² it is the persistent symptoms of SPMI, such as chronic hallucinations or persistent functional disability that respond inadequately to antipsychotic treatment.

The notion of “unmodifiable” presented here has similarities to the notion of “futility,” which has been applied to palliative psychiatry by Levitt and Buchman.¹² Invoking futility implies that the nature of the situation is such that available interventions will almost certainly have no benefit, either because of the terminal nature of the condition or because treatment resistance has made the dynamic risk-benefit ratio unfavorable. The notion of unmodifiable complements the notion of futility and is not in conflict with it; it is a broader notion that highlights that aspects of an illness may be unmodifiable even in the absence of futility (eg, cognitive impairment in first-episode schizophrenia), just as aspects of even a terminal illness are modifiable palliatively (eg, reducing acute anxiety or panic with benzodiazepines).

I elaborate on the notions of modifiable and unmodifiable in the Table by applying them to various aspects of psychiatry and palliative care.

Table. The Spectrum of Palliative Psychiatry

Type of Care	Description	Modifiable aspects of illness	Unmodifiable aspects of illness
Psychiatric care in palliative medicine	Care of patients facing terminal medical problems and experiencing psychiatric distress that is targeted by psychiatric medications.	Psychiatric symptoms, such as depression and anxiety, experienced by patients with advanced or terminal medical illness	Progression of advanced or terminal medical illness
Palliative psychiatry (narrow)	Psychiatric care focused on improving symptoms and quality of life in patients experiencing terminal psychiatric conditions (eg, advanced dementia or advanced anorexia)	Symptoms such as pain, fatigue, anxiety, depression, hallucinations, and agitation that can be addressed with psychotropics.	Progression of terminal psychiatric illness and eventual illness-related death
Palliative psychiatry (broad)	Psychiatric care that is focused on improving quality of life, despite persistent or unremitting psychiatric symptoms.	Symptoms such as anxiety, agitation, sleep, or low mood that may remain responsive to treatment in SPMI	Chronic and persistent psychiatric symptoms, such as thought disorganization or cognitive impairment in chronic schizophrenia, and associated disability
Palliative psychiatry (very broad)	All psychiatric care that is not disease modifying and that focuses on symptom improvement and improving quality of life	Symptoms	Etiology or pathophysiology of the psychiatric disorder (often poorly understood or unknown)

Abbreviation: SPMI, severe and persistent mental illness.

A Palliative Spectrum

We can make further fine-grain distinctions as well. For instance, the severity of symptoms may be modifiable but not their persistence (for instance, hallucinations may become less intense or less frequent but otherwise continue to be experienced); acute episodes may be modifiable but not their recurrence (for instance, for some patients, antidepressant medications may alleviate an active episode of depression but may not successfully prevent future episodes). These examples serve to illuminate the dimensionality of palliative goals and their overlap with curative goals. What distinguishes any particular instance of care as palliative is an emphasis on quality of life and an acceptance of the unmodifiable aspects of an illness. The unmodifiable aspects of an illness are also not predetermined. The traditional instances of palliative care are recognizable with reference to treatment contexts wherein the unmodifiable aspects are obvious and stable—as in advanced or terminal physical illness—but as the application of palliative approaches extends to other treatment settings, what is characteristic of palliative care may be less obvious. Conversely, unmodifiability does not necessarily imply that the care provided is automatically palliative. Where exactly we draw the line on this spectrum between modifiable and unmodifiable aspects of illness—

the threshold at which the characterization of our clinical approach begins to shift from curative to palliative—is a pragmatic matter.

Broader or narrower notions of “palliative” offer correspondingly different advantages and disadvantages. Very broad notions (eg, that routine psychiatric care itself is a form of palliative care) may be unhelpfully broad compared to narrower notions that keep the focus on improving symptoms and quality of life in cases of treatment resistance, SPMI, or futility. Consider the use of intravenous ketamine (or intranasal esketamine)¹³ to treat severe and persistent depression that has proven refractory to standard treatments. If the goal is remission or significant alleviation of depressive symptoms, this intervention will not typically qualify as palliative. However, consider other possible outcomes of treatment: ketamine temporarily relieves depression but the depression inevitably returns (unmodified recurrent course); ketamine reduces depression severity but the depression persists otherwise (unmodified chronicity and persistence); or the depression is unaltered but the psychoactive experiences (eg, euphoria, dissociation) make depression more tolerable for the patient (unmodified symptoms). If treatment is continued in the case of such outcomes, these goals can reasonably be considered palliative. Whether ketamine treatment increases or decreases quality of life and by what pathway can't be determined in advance for a particular individual. Similar considerations can also apply to other psychotropics, such as antidepressants for which it is possible that different individuals experience benefit via different pathways.¹⁴ A consequence of this view is that clinicians have an ethical imperative to distinguish among and clearly formulate goals of care in a dynamic and ongoing process of shared decision making with patients.

Palliative Psychopharmacology

The importance of how psychiatric treatment is conceptualized by patients was recently illustrated by the “chemical imbalance” debate in the public.¹⁵ Many individuals in the public who erroneously thought that depression is caused by a serotonergic deficiency and that antidepressants are normalizing serotonin levels were upset to learn that this explanation was fallacious.¹⁶ At least some of the causes of severe, persistent depression are contextual and relational and not addressed by pharmacological treatment. If a pharmacological treatment is being employed palliatively, both the clinician and the patient need to be aware of that. Understanding that treatment is palliative is an issue that pertains not only to informed consent and nonmaleficence, but also to hermeneutic justice. Gaining more clarity on what their treatment seeks to modify and what it leaves unmodified will help patients better understand the nature of their psychiatric care and will ensure that clinicians do not ignore potentially modifiable causes.

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