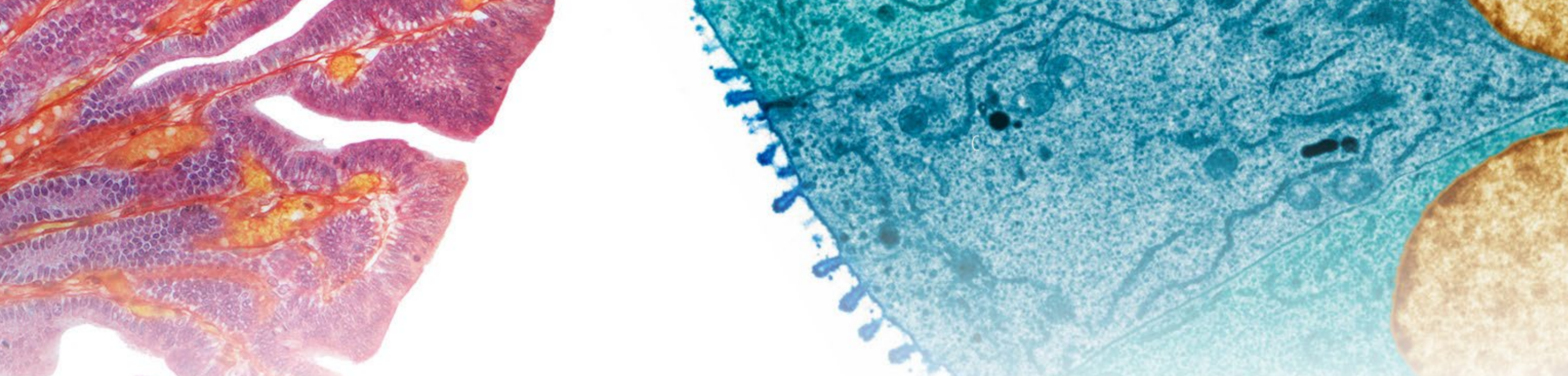

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STATE OF THE ART AND SCIENCE: PEER-REVIEWED ARTICLE

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, dieticians, 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] Dieticians 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.

References

1. Westmoreland P, Krantz MJ, Mehler PS. Medical complications of anorexia nervosa and bulimia. *Am J Med.* 2016;129(1):30-37.
2. Broomfield C, Stedal K, Touyz S, Rhodes P. Labeling and defining severe and enduring anorexia nervosa: a systematic review and critical analysis. *Int J Eat Disord*. 2017;50(6):611-623.
3. Touyz S, Hay P. Severe and enduring anorexia nervosa (SE-AN): in search of a new paradigm. *J Eat Disord.* 2015;3(1):26.
4. Yager J. Managing patients with severe and enduring anorexia nervosa: when is enough, enough? *J Nerv Ment Dis.* 2020;208(4):277-282.
5. Zipfel S, Löwe B, Reas DL, Deter HC, Herzog W. Long-term prognosis in anorexia nervosa: lessons from a 21-year follow-up study. *Lancet*. 2000;355(9205):721-722.
6. Franko DL, Keshaviah A, Eddy KT, et al. A longitudinal investigation of mortality in anorexia nervosa and bulimia nervosa. *Am J Psychiatry*. 2013;170(8):917-925.
7. Lopez A, Yager J, Feinstein RE. Medical futility and psychiatry: palliative care and hospice care as a last resort in the treatment of refractory anorexia nervosa. *Int J Eat Disord*. 2010;43(4):372-377.
8. Trachsel M, Irwin SA, Biller-Andorno N, Hoff P, Riese F. Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks. *BMC Psychiatry*. 2016;16(1):260.
9. Westmoreland P, Parks L, Lohse K, Mehler P. Severe and enduring anorexia nervosa and futility: a time for every purpose? *Psychiatr Clin North Am*. 2021;44(4):603-611.

10. Trachsel M, Hodel MA, Irwin SA, Hoff P, Biller-Andorno N, Riese F. Acceptability of palliative care approaches for patients with severe and persistent mental illness: a survey of psychiatrists in Switzerland. *BMC Psychiatry*. 2019;19(1):111.
11. Kavalieratos D, Corbelli J, Zhang D, et al. Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. *JAMA*. 2016;316(20):2104-2114.
12. Dalal S, Bruera E. End-of-life care matters: palliative cancer care results in better care and lower costs. *Oncologist*. 2017;22(4):361-368.
13. O'Neill J, Crowther T, Sampson G. A case study: anorexia nervosa. Palliative care of terminal psychiatric disease. *Am J Hosp Palliat Care*. 1994;11(6):36-38.
14. Russon L, Alison D. Does palliative care have a role in treatment of anorexia nervosa? Palliative care does not mean giving up. *BMJ*. 1998;317(7152):196-197.
15. Williams KD, Dobney T, Geller J. Setting the eating disorder aside: an alternative model of care. *Eur Eat Disord Rev*. 2010;18(2):90-96.
16. Trachsel M, Wild V, Biller-Andorno N, Krones T. Compulsory treatment in chronic anorexia nervosa by all means? Searching for a middle ground between a curative and a palliative approach. *Am J Bioeth*. 2015;15(7):55-56.
17. Wonderlich S, Mitchell JE, Crosby RD, et al. Minimizing and treating chronicity in the eating disorders: a clinical overview. *Int J Eat Disord*. 2012;45(4):467-475.
18. Gaudiani JL, Bogetz A, Yager J. Terminal anorexia nervosa: three cases and proposed clinical characteristics. *J Eat Disord*. 2022;10(1):23.
19. Yager J, Gaudiani JL, Treem J. Eating disorders and palliative care specialists require definitional consensus and clinical guidance regarding terminal anorexia nervosa: addressing concerns and moving forward. *J Eat Disord.* 2022;10(1):135.
20. Westermair AL, Buchman DZ, Levitt S, Trachsel M. Palliative psychiatry for severe and enduring anorexia nervosa includes but goes beyond harm reduction. *Am J Bioeth.* 2021;21(7):60-62.
21. Steinhausen HC. The outcome of anorexia nervosa in the 20th century. *Am J Psychiatry*. 2002;159(8):1284-1293.
22. Yager J. Working with patients with severe and enduring eating disorders who refuse further treatment. *Eat Disord Rev*. 2021;32(5):1-3.
23. Westermair AL, Buchman DZ, Levitt S, Perrar KM, Trachsel M. Palliative psychiatry in a narrow and in a broad sense: a concept clarification. *Aust N Z J Psychiatry*. 2022;56(12):1535-1541.
24. Shneidman E. Criteria for a good death. *Suicide Life Threat Behav*. 2007;37(3):245-247.
25. Geppert CM. Futility in chronic anorexia nervosa: a concept whose time has not yet come. *Am J Bioeth*. 2015;15(7):34-43.
26. Levitt S, Buchman DZ. Applying futility in psychiatry: a concept whose time has come. *J Med Ethics*. 2021;47:e60.
27. Strand M, Bulik CM, von Hausswolff-Juhlin Y, Gustafsson SA. Self-admission to inpatient treatment for patients with anorexia nervosa: the patient's perspective. *Int J Eat Disord*. 2017;50(4):398-405.
28. Gupta A, Eisenhauer EA, Booth CM. The time toxicity of cancer treatment. *J Clin Oncol*. 2022;40(15):1611-1615.

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