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Listening and learning: the need for a compassionate and patient-centered approach for longstanding AN

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Abstract

A 2022 paper proposing preliminary clinical characteristics of adults with anorexia nervosa who might be supported in compassionate end-of-life care generated public dissent in the peer-reviewed literature and the media as well as private expressions of support. Several years of listening and learning by the lead author resulted in a greater understanding of personal, clinical, and scholarly concerns that arose as a result of this article. In this piece, the lead author expressly disavows the concept and phrase of "terminal anorexia nervosa." This essay attempts to acknowledge the original article's inadequacies, aims to bring clarity and specificity to the issue, and calls for ongoing discussions and collaboration to improve treatment for our complex and vulnerable patients.

In 2022, I co-authored a small case series proposing clinical characteristics of adults with anorexia nervosa (AN) who might qualify for access to compassionate end-of-life care [1, 2]. In this short essay, I hope to validate voices of criticism and concern, stand by my advocacy to improve care plans for the exceptionally rare patient who merits support rather than abandonment at the end of life, and encourage a continued dialogue in the field about improving treatment for those with longstanding eating disorders.

After the publication of the 2022 article, some eating disorder treatment professionals, families, and individuals affected by eating disorders expressed dismay, fear, and serious concerns about it. They emphasized the complexity of evaluating decision-making capacity when malnutrition and core eating disorder symptoms impact self-assessment, even while other faculties remain clear. They highlighted the risk of misusing the article to justify cessation of treatment, allowing death when treatment options had not been exhausted. And they challenged the establishment of end-of-life protocols given varied access to effective treatment. I took these criticisms very seriously.

After the article's publication, others reached out to express their agreement with and gratitude for the article. They cited a puzzling hesitancy in the eating disorder field—visible in clinical practice and in the scarcity of literature written on end-of-life care—to plan for the support of individuals who, despite best prolonged efforts, do not survive. They emphasized that this lack of acceptance can cause a clinical team to discontinue care, believing this to be the correct legal and ethical choice, which can leave patients to die alone and unsupported. I also heard from patients who, after decades-long struggles, were granted permission to choose a palliative or even hospice pathway and discovered that this very autonomy allowed them to choose recovery. In contrast to the wave of critical publications and social media posts, these stories of encouragement and hope were communicated privately,

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presumably to avoid public condemnation. I share both perspectives to highlight that there are indeed multiple viewpoints that deserve to be heard, learned from, and honored. One philosophy cannot speak for all lived experience.

As a result of the variety of responses to the 2022 article, I spent the next three years vowing to reevaluate my own understanding of this complex topic, meeting in person and virtually with critics and supporters. I co-hosted a day-long meeting with direct stakeholders on this topic—clinicians, families, and those with lived experience, a group that collectively held widely divergent views—to explore both our differences and our areas of shared belief. It turned out there were many of the latter. I believe the participants, including myself, emerged with a more vibrant understanding of the "other side's" life experiences and perspectives, while being unified on our passion for the improvements that are clearly needed in the medical and psychiatric care of those with longstanding AN. This is a designation that emerged over the last few years as preferable to "severe and enduring AN," although future clarification of terminology will be beneficial.

The participants identified three specific areas of agreement:

- One, a desire to understand the role of palliative care when people who have experienced many rounds of treatment become medically and/or psychiatrically unstable yet decline or cannot access a higher level of care.
- Two, that every effort should be made to avoid abandonment of patients when they struggle to engage with recovery work despite increasing medical risk.
- And three, that more thoughtful discussions and research are needed about the unique challenges of assessing decision-making capacity in those with longstanding AN.

I do not regret the care I provided to the wonderful patients I described in the article, nor do their families who loved them best and walked a lifetime alongside them. I do, however, regret several procedural and structural inadequacies in my writing that contributed to distress and significant concerns. I wrote the article as a piece of representative support for the exceptionally rare individual with longstanding AN who, as best an experienced treatment team can tell in the absence of field consensus on this topic, qualifies for compassionate and expert end-of-life care. I hoped that families, clinicians, and hospice providers would benefit from the stories and considerations as they explored this sensitive topic, and that the paper would provide a starting place for better conceptualization, research, and clinical care.

However, I failed to circulate it as widely as I should have prior to publication. Had I done this, I would have revised it to address the important critiques as much as possible, given philosophical differences. In March 2023 at the International Conference on Eating Disorders, on my clinic's social media accounts, and now in this article, I fully disavow the concept of and phrase "terminal anorexia nervosa." I was wrong to have used it.

I also regret that, despite my sincere efforts, the detailed storytelling in the article alongside the proposed characteristics failed to encapsulate the exquisite specificity of the patient population who might be considered for end-of-life care. I was not clear enough. When I verbally describe the actual clinical practices I used for the patients in the paper, I have often heard, "Oh, this feels very different from the article and makes more sense to me." The short format of this piece does not lend itself sufficiently to the complexity of the topic, but I still hope to clarify and correct the record for many reasons. Among them, the language of the original paper led some to believe they would qualify for end-of-life care when they most definitely would not.

To clarify my core treatment philosophy, every individual with an eating disorder, of every age, severity, and chronicity, who wishes to receive treatment should receive it. Those who are ambivalent, as is common, deserve strengths-oriented, enthusiastic, and determined care to help them progress toward a future free of the eating disorder. This may take months or decades, and it is worth every effort. Those who have tried treatment many times and continue to struggle have not failed. Rather, the available treatment system, at any level of care, may have failed them. We clinicians and researchers must continue to strive for better options and access, including and perhaps especially for people with longstanding illness. My role as an internist who specializes in eating disorders is to identify and ameliorate medical issues to improve recovery rates and save lives and help others do the same. Too often, medical issues are still overlooked and undertreated. The field has begun to grapple with barriers to recovery across social, psychiatric, neurodiversity, medical, and neurocognitive fronts. These efforts are exciting and relevant and will surely continue to benefit patients.

For individuals who feel too traumatized to return to higher levels of care, feel it has not been helpful, or cannot access it for financial or other reasons, outpatient care must become more welcoming, knowledgeable, persistent, and effective, treating the whole person inclusive of medical and psychiatric complexity. I firmly believe that, when accessible, it is appropriate to require younger patients and those who have not yet received extensive high-quality, expert eating disorder treatment to accept the level of care that optimizes their recovery outcomes. As a field, we also must get better at patient-centered harm reduction, so that our clients feel successful and hopeful through achievement of more granular progress. Insisting on one abstinence-only or swiftly-paced version of recovery can alienate many and paradoxically stall recovery work.

For adults who have already received as much care in an inpatient or residential setting as they can tolerate, the clinical team message ideally would change from, “Try again or we will stop seeing you” to, “While honoring ethics and informed consent, we are ready to encourage creative care (including modalities like ketamine, psilocybin, neurostimulation, stellate ganglion block, and others that show great promise but as yet lack a full evidence-base for those with eating disorders). One or several of these might help you find recovery momentum toward a safer harm-reduction goal while honoring your values.” This still leaves space for drawing firm clinical boundaries, which may include establishing patient-specific medical and psychiatric parameters below which the patient agrees to admit to a higher level of care. An adult patient with decision-making capacity who is engaged in a harm-reduction model must be encouraged with warmth, hope, and respect to reduce morbidity and mortality.

All this said, some people are not able to commit to life-sustaining treatment of any type. We want this not to be true, but it is true. Despite a preponderance of academic papers whose first sentence cites the high mortality rates of AN [3], the field has struggled to reckon with this reality. Vitally, the decision to stop life-sustaining treatment cannot and never should be made *for* a patient by a provider or system. Many can, in fact, live within this context and condition for many years, a testament to the body’s resiliency. These patients deserve compassion, emphasis on quality of life, and active harm-reducing care to the extent possible—through what has been called a “life-affirming palliative approach” [4]. Willingness to reengage treatment certainly does occur.

A very small subset of qualifying adults will, however, consistently refuse treatment and progress inexorably toward death due to the chronic medical effects of malnutrition. Those with likely fatal trajectories merit multiple meetings with the treatment team and family that emphasize the deadly risk and consider whether acceptable alternatives exist. All potentially helpful complementary treatments should be offered. Many promising newer modalities exist but are not yet commonly used or readily available, and others are on the horizon.

Decision-making capacity, not yet clearly established for those with longstanding AN especially when it comes to end-of-life care decisions, must be considered throughout this process. Experts in decision-making capacity should conduct competency assessments, although a lack of expertise in AN might allow a psychiatrist or psychologist who is not well versed in eating disorders to miss specific evidence of incapacitation. Until the field settles this question through research and clinical experience, it seems reasonable to rely on these professionals in addition to the established clinical team and patients’ loved ones. When the professionals and family collectively agree that the individual still possesses the fundamental capability to understand treatment risks, benefits, and alternatives, articulating consistent desires for their care that are aligned with long-held values, we must respect the patient’s autonomy. This is then balanced alongside beneficence, non-maleficence, and justice in determining next steps. When a person lacks decision-making capacity, involuntary treatment can be life-saving and enable the individual to regain capacity.

Clinical support as patients progress down a path toward death centers around relational connections, spirituality, and the integration of grief. At any time during this process, patients can and do choose to reengage life-sustaining treatment, and the team should unreservedly support this. When physical decline worsens toward risk of imminent death unless the patient chooses to return to a higher level of care, and activities of daily living become impaired, home hospice services can be engaged for family support and symptom amelioration. Even at this point, survival is very possible through admission to expert inpatient medical care and provision of closely monitored nutritional support. However, if the patient persists in declining such care, then comfort and dignity must be emphasized and the whole family system supported in anticipation of death within weeks or months. Only at this advanced juncture might I identify that someone has anorexia nervosa likely to result in death. My reflections should not ever be interpreted as a rationale for prematurely withdrawing care. Instead, they invite careful, collaborative consideration for rare and complex cases within a well-supported, person-centered framework.

In conclusion, I humbly acknowledge the personal, clinical, and scholarly concerns our original article raised; I am also grateful that many found it helpful. The vast majority of patients with eating disorders recover, and recovery rates can and must further improve. There is an overall consensus in the field that we must do better in our clinical care of those with longstanding AN, and that intention, rigorous discussions, deliberate changes in clinical practice, and research can make a vital difference. Similarly, we can better serve the very rare population of patients at the end of their lives and their families, who can feel banished from peer support due to the implication that they “failed” because of their loved one’s death. In light of my lifelong professional commitment to improving medical care for those with eating disorders so that they thrive and recover, I hope this essay brings some clarity and specificity to the topic.

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References

1. Gaudiani JL, Bogetz A, Yager J. Terminal anorexia nervosa: three cases and proposed clinical characteristics. J Eat Disord. 2022;10(1):23. https://doi.org/10.1186/s40337-022-00548-3. PMID: 35168671; PMCID: PMC8845309.
2. Gaudiani J, Touyz S, Obituary. Joel Yager, BS, MD, (1941-2024). J Eat Disord. 2025;13:34. https://doi.org/10.1186/s40337-025-01220-2
3. Attia E, Walsh BT, Eating Disorders A, Review. JAMA. 2025;333(14):1242-1252. https://doi.org/10.1001/jama.2025.0132. PMID: 40048192.
4. Treem J, Yager J, Gaudiani JL. A Life-Affirming Palliative Care Model for Severe and Enduring Anorexia Nervosa. AMA J Ethics. 2023;25(9):E703-709. https://doi.org/10.1001/amajethics.2023.703. PMID: 37695873.

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