Journal of Eating Disorders

CORRESPONDENCE Open Access

# First, do no harm: the proposed definition of "terminal anorexia" is fraught with danger for vulnerable individuals

Megan Riddle[1], Anne Marie O'Melia[2] and Maryrose Bauschka[3,4*]

**Abstract**

A recent article in the Journal of Eating Disorders (10:23, 2022) proposed criteria for "terminal anorexia" with a cited goal of improving access to end-of-life care (Gaudiani et al. in J Eat Disord 10(1):23, 2022). The authors presented three cases in which patients received end-of-life care, including the prescription of medical assistance in dying (MAID), also known as physician-assisted suicide (PAS). The proposed criteria lack the evidence base for adoption and do not acknowledge the compelling evidence that exists surrounding possible prolonged timelines to recovery for some individuals and the nuances of assessing capacity in this population.

**Keywords:** Anorexia nervosa, Terminal anorexia, Medical assistance in dying, Capacity, Physician-assisted suicide, Severe and enduring anorexia nervosa, Severe and enduring eating disorders

## Main text

Primum non nocere. In an effort to avoid harm to the loved ones of the individuals involved, this commentary will not discuss specifics of the cases presented in Gaudiani and colleagues' article, "Terminal anorexia: three cases and proposed clinical characteristics". We appreciate the authors' initiation of a discussion as to how to best support individuals who suffer profoundly from anorexia nervosa (AN) and its effects over a prolonged period of time, as this conversation is much needed in the field. However, the proposed clinical criteria for "terminal" anorexia nervosa are overly broad. These criteria are specified as (1) a diagnosis of anorexia nervosa, (2) age 30 or older, (3) prior engagement in high-quality and multidisciplinary eating disorder treatment and (4) capacity to choose death as an outcome of their illness. We highlight the risks posed to individuals with anorexia nervosa by labeling patients as "terminal" without a basis in evidence.

### Potential pitfalls of the first three proposed criteria

The field has long called for a unified definition of severe and enduring anorexia nervosa (SEAN) and a variety of markers related to chronicity and severity have been proposed [1, 2]. We wholeheartedly agree that the field needs to determine characteristics and risk factors that may predict lack of recovery in anorexia nervosa, however, we would argue that this article does not offer evidence-based criteria for what is described as "terminal anorexia." While age over 30 has been proposed elsewhere as a marker of increased risk of the development of chronic illness [3], studies have suggested that recovery can occur, even well after two decades of struggling with an eating disorder [4]. In addition, attempts to stratify risk of long-term illness based on clinical characteristics have been of limited utility; while we may be able to predict at a population level who is at increased risk of developing SEAN, we lack the ability to predict whether a specific individual

*Correspondence: maryrose.bauschka@ucdenver.edu

[3] Department of Psychiatry, University of Utah School of Medicine, Salt Lake City, UT 84108, USA
Full list of author information is available at the end of the article

© The Author(s) 2022. **Open Access** This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by/4.0/. The Creative Commons Public Domain Dedication waiver (http://creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated in a credit line to the data.

will develop enduring illness or be able to make steps towards recovery [5, 6]. Thus, labeling these patients as terminal robs them of the opportunity for treatment that could improve their quality of life. Also, while the vast majority of individuals who develop anorexia nervosa do so at ages younger than 30, there are cases that present later in life or persons who do not seek or who may be unable to access treatment until they are in their 30 s or later [7]. This then risks the label of "terminal" in the context of either a short duration of illness and/or simply not enough time spent in treatment to engender true brain changes towards recovery. From clinical experience, many patients require several treatment episodes spanning many years, or even decades, to gain traction in recovery [4]. Additionally, the various barriers that can arise to accessing high-quality care including cost and insurance barriers, limited or no local resources, and personal hardships that may be posed by taking time away from their daily life may change over time for an individual [8]. Recovery from anorexia nervosa can and does occur after the age of 30 and thus setting an arbitrary age criteria without an evidence base may limit patients' ability to receive the care they need.

## Criteria 4 and the challenge of capacity assessments in anorexia nervosa

Additionally, the article fails to fully acknowledge the challenges of assessing capacity specific to patients with anorexia nervosa. Patients with anorexia nervosa are often adept at listing back the risks, benefits and alternatives to the proposed treatment, and expressing their choice, but fail to appreciate how the information applies to them [3, 9]. Cognitions and behaviors secondary to anorexia nervosa are ego-syntonic, which adds to the challenge, and there is qualitative work to suggest that values regarding life and death differ between healthy individuals and those struggling with anorexia nervosa [10, 11]. There also is no acknowledgement of the impact of malnutrition on the brain [12], and how the eating disorder itself can usurp a patient's autonomy [13], which would also be crucial to account for in a capacity evaluation. Rather, this article describes the use of local psychiatrists to assess capacity—who may or may not have expertise in this area [14, 15]—while negating the importance the role of ethics committees in the care and clinical decision-making of such complex patients. It will be crucial to identify reliable methods for determining capacity in this population, particularly with respect to end-of-life care decisions, through research and input from stakeholders including individuals with the lived experience of an eating disorder, their loved ones, and treating providers.

## The lack of objective data to define terminality

Central to medical assistance in dying (MAID), also known as physician-assisted suicide (PAS), is a terminal diagnosis. While receiving nutrition is immensely distressing to an individual with an eating disorder, it is critical to note that malnutrition is not a terminal illness and nearly all of the resulting medical complications can be reversed with nourishment [16]. The authors themselves note that, "there are no explicit physiologic markers or measurables (weight, degree of weight loss, presence of or degree of organ failure, vital signs) which delineate someone with terminal AN " and that "the human body can be exceptionally resilient even with terminal malnutrition." In the setting of no identified physiologic markers or measurables, or data, how can one predict whether or not an individual with anorexia nervosa has a less than six-month prognosis, and without this objective data is "terminal" the appropriate descriptor?

## The need to expand resources and expertise beyond higher levels of care

This paper does highlight the lack of resources and guidance available to patients with severe and enduring illness. While eating disorder treatment centers frequently have expertise in the management of these patients, ranging from a focus on recovery to shifting towards harm reduction and palliative care, individuals with anorexia nervosa may not have access to the same level of expertise in their community when they return home. We, as specialists in this complex and paradoxical illness, need to increase support for our colleagues in the long-term management of these patients.

## Conclusions

We again thank the authors of the article under comment for prompting a much-needed discussion about how to identify and best support individuals with anorexia nervosa who ultimately may be less likely to recover from their illness. It is true that some patients may find continued treatment more distressing than making the decision to die from their illness, and the eating disorder field needs to acknowledge and identify ways to address this lived experience. Patients with chronic psychiatric illness in general are a highly vulnerable population, and feelings of helplessness and discouragement are inherent in the battle for recovery; it is common for patients to repeatedly "fail" treatment before making progress towards recovery. Since this article was published, we have already had patients approach us to ask if we feel their case is "terminal." If providers do not hold the hope for

these patients when they can't do so for themselves, use evidence to guide our recommendations, and acknowledge our own limits in knowing what the future holds for them, what will become of these vulnerable individuals?

**Abbreviations**
SEAN: Severe and enduring anorexia nervosa; MAID: Medical assistance in dying; PAS: Physician-assisted suicide.

**Acknowledgements**
None.

**Author contributions**
MR and MB participated in the literature search, writing, editing and approval of the final manuscript. AO participated in the outlining and editing, and provided approval of the final manuscript. All authors read and approved the final manuscript.

**Funding**
No funding was received for this manuscript.

**Availability of data and materials**
Not applicable.

## Declarations

**Ethics approval and consent to participate**
Not applicable.

**Consent for publication**
Not applicable.

**Competing interests**
The authors report no competing interests.

**Author details**
[1]Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle, WA 98195, USA. [2]Department of Psychiatry, University of Utah School of Medicine, Salt Lake City, UT 84108, USA. [3]Department of Psychiatry, University of Utah School of Medicine, Salt Lake City, UT 84108, USA. [4]Department of Psychiatry, University of Colorado School of Medicine, 13001 E 17th Pl, Aurora, CO 80045, USA.

Received: 7 June 2022 Accepted: 10 June 2022
Published online: 16 June 2022

**References**

1. Gaudiani JL, Bogetz A, Yager J. Terminal anorexia nervosa: three cases and proposed clinical characteristics. J Eat Disord. 2022;10(1):23.
2. Westmoreland P, Parks L, Lohse K, Mehler P. Severe and enduring anorexia nervosa and futility: a time for every purpose? Psychiatr Clin N Am. 2021;44(4):603–11.
3. Westmoreland P. Tipping the scales: ethical and legal dilemmas in managing severe eating disorders: American Psychiatric Association Publishing; 2020.
4. Eddy KT, Tabri N, Thomas JJ, Murray HB, Keshaviah A, Hastings E, et al. Recovery from anorexia nervosa and bulimia nervosa at 22-year follow-up. J Clin Psychiatry. 2017;78(2):184–9.
5. Franko DL, Tabri N, Keshaviah A, Murray HB, Herzog DB, Thomas JJ, et al. Predictors of long-term recovery in anorexia nervosa and bulimia nervosa: data from a 22-year longitudinal study. J Psychiatry Res. 2018;96:183–8.
6. Wildes JE, Forbush KT, Hagan KE, Marcus MD, Attia E, Gianini LM, et al. Characterizing severe and enduring anorexia nervosa: an empirical approach. Int J Eat Disord. 2017;50(4):389–97.
7. Jenkins ZM, Chait LM, Cistullo L, Castle DJ. A comparison of eating disorder symptomatology, psychological distress and psychosocial function between early, typical and later onset anorexia nervosa. J Eat Disord. 2020;8(1):56.
8. Thompson C, Park S. Barriers to access and utilization of eating disorder treatment among women. Arch Womens Ment Health. 2016;19(5):753–60.
9. van Elburg A, Danner UN, Sternheim LC, Lammers M, Elzakkers I. Mental capacity, decision-making and emotion dysregulation in severe enduring anorexia nervosa. Front Psychiatry. 2021;12:545317.
10. Elzakkers IF, Danner UN, Hoek HW, van Elburg AA. Mental capacity to consent to treatment in anorexia nervosa: explorative study. BJPsych Open. 2016;2(2):147–53.
11. Tan JO, Hope T, Stewart A. Anorexia nervosa and personal identity: the accounts of patients and their parents. Int J Law Psychiatry. 2003;26(5):533–48.
12. Keys A, Brozek J, Henshel A, Mickelson O, Taylor HL. The biology of human starvation, vols. 1–2. Minneapolis: University of Minnesota Press; 1950.
13. Hope T, Tan J, Stewart A, McMillan J. Agency, ambivalence and authenticity: the many ways in which anorexia nervosa can affect autonomy. Int J Law Context. 2013;9(1):20–36.
14. Mahr F, Farahmand P, Bixler EO, Domen RE, Moser EM, Nadeem T, et al. A national survey of eating disorder training. Int J Eat Disord. 2015;48(4):443–5.
15. Jones WR, Saeidi S, Morgan JF. Knowledge and attitudes of psychiatrists towards eating disorders. Eur Eat Disord Rev J Eat Disord Assoc. 2013;21(1):84–8.
16. Westmoreland P, Krantz MJ, Mehler PS. Medical complications of anorexia nervosa and bulimia. Am J Med. 2016;129(1):30–7.

## Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

**Ready to submit your research? Choose BMC and benefit from:**

- fast, convenient online submission
- thorough peer review by experienced researchers in your field
- rapid publication on acceptance
- support for research data, including large and complex data types
- gold Open Access which fosters wider collaboration and increased citations
- maximum visibility for your research: over 100M website views per year

**At BMC, research is always in progress.**

**Learn more** biomedcentral.com/submissions