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# Regardless of inequities in care, terminal anorexia nervosa exists: a response to Sharpe et al.

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## Abstract

We are pleased that the concept of terminal anorexia nervosa is being considered in serious discussion. Our previous presentations were not intended to assess eating disorders care broadly, but solely to bring attention to the importance of end-of-life care issues for patients with anorexia nervosa. Regardless of differences in ability to access or utilize health care resources, inescapably, individuals contending with end-stage malnutrition due to anorexia nervosa who refuse further nutrition will progressively decline, and some will die as a result. Our description of these patients' last days and weeks as "terminal" and meriting thoughtful end-of-life care is consistent with how the term is used in other end-stage terminal conditions. We clearly acknowledged that precise definitions and guidelines for end-of-life care for these patients should be developed by the eating disorder and palliative care fields. Avoiding the phrase "terminal anorexia nervosa" will not make these phenomena disappear. We are sorry that some individuals are upset by this concept. Our intention is certainly not to demoralize by "triggering" fears of hopelessness or death. But these discussions will inevitably distress some people. Individuals who are adversely affected by considering these issues might well benefit from further explorations, clarifications, and discussions with their clinicians and others. Finally, we clearly applaud expanding treatment options and availability, and we strongly advocate for making every effort to provide every patient every possible option for treatment and recovery at every phase of their struggles.

**Keywords** Anorexia Nervosa, Terminal stage, Palliative care, Hospice care, End-of-life, Triggering

We were pleased to see the letter regarding terminal anorexia nervosa published in JED by Sharpe et al. since this indicates that this phenomenon is being considered and discussed in serious ways [2]. To further the discussion, several issues in the letter by Sharpe et al. merit response.

First, we fully acknowledge the presence of systems of oppression at work throughout every aspect of eating

disorder care and within society that harm both individuals and groups in pervasive ways. However, the scope of our article was not to assess the state of eating disorder care broadly. We would like to emphasize that the motivation for our articles [1, 3] was to bring attention to the importance of considering end-of-life care issues for patients with anorexia nervosa, not to stigmatize, or develop hierarchies, or privilege some patients over others.

The fact is that individuals contending with anorexia nervosa and end-stage malnutrition who refuse to alter their intake or level of care suffer days or weeks of progressive weakness and decline. During these experiences they may go through various types and intensities of physical and mental suffering. At the end they may have

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agonal breathing, and then stop breathing. Their hearts stop. They die. They terminate. The fact that we have described these patients' last days and weeks as "terminal" and meriting thoughtful end-of-life care is consistent with the use of the term in other end-stage terminal conditions. We clearly acknowledged that precise definition of the term remains to be developed and we invited the eating disorder and palliative care fields to systematically address these issues and develop consensus definitions and guidelines for these patients' end-of-life care.

Second, denying the existence or attempting to squelch or "cancel" use of the term "terminal anorexia nervosa" will not make the phenomena we are describing go away. Some patients with anorexia nervosa die as a result of their anorexia nervosa, whether or not they have access to or have experienced as much treatment as might be available. We are sorry that some individuals reading our paper have been upset by the concept that anorexia nervosa has a terminal stage. Terms and concepts published in scientific journals can be misunderstood, misinterpreted, and misrepresented, and they do not come with trigger warnings. We fully appreciate the need for authors to use appropriate lay terms and sensitive language in the clinical context. At the same time, all clinicians who work with this population know that the capacity for the anorexia nervosa "voice" to be triggered into ever-harsher, crueler demands and judgments is nearly infinite. If a casual comment on the street can do it, of course this discourse can too. Our intention is certainly not to cause distress, and individuals who are adversely affected by exposure to these terms might benefit from opportunities to further explore, clarify, and discuss their reactions to the issues raised by these concepts with their clinicians and others.

Finally, as we stressed in our initial article, we clearly applaud expanding treatment options and availability, and we strongly advocate for making every effort to provide every single patient every option for treatment and recovery at every phase of their struggles.

#### Author contributions

Dr. Yager prepared the first draft of the manuscript text. Drs. Gaudiani and Treem contributed text and editing to subsequent drafts. All authors approve of this submission.

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#### Declarations

#### Competing interests

The authors declare no competing interests.

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