AMA Journal of Ethics®
April 2021, Volume 23, Number 4: E298-304

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Compassion Be Expressed as a Primary Clinical and Ethical Value in Anorexia Nervosa Intervention?

Melissa Lavoie, MD and Angela S. Guarda, MD

Abstract

Use of force in the care of patients with severe anorexia nervosa is controversial but can be justified when the disorder becomes life-threatening. This commentary examines the role of force in compassionate care of an adolescent patient hospitalized with extreme anorexia nervosa and suggests strategies for reaching consensus, minimizing harm, and maximizing the chance of a therapeutic outcome when forced intervention is a compassionate thing to do.

To claim one AMA PRA Category 1 Credit™ *for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming* AMA PRA Category 1 Credit™ *are available through the* AMA Ed Hub™.

Case

VV is a 17-year-old who has been hospitalized 5 times in the past year due to severe anorexia nervosa. Each admission was preceded by several weeks of dietary restriction, including fasting behavior, with VV often consuming as little as 200 calories per day. VV is admitted to the pediatric unit for medical stabilization and has refused to eat in the hospital over the past few days. She says she is hunger striking to protest how she was treated during prior hospitalizations and would eat if at home with her family. Her body mass index is 13 and her appearance cachectic.

VV's parents are desperate to convince VV to eat. Their worries grow as VV becomes weaker and develops electrolyte abnormalities, worsening bradycardia, and hypotension. VV's parents and clinical team recognize that VV's life is at risk and that chemical force, physical force, or both may be needed to treat VV.VV's physician recommends nasogastric tube placement due to her continued food refusal in order to initiate the refeeding process and to stabilize her medically. However, VV is refusing this intervention. VV's refusal—combined with her history of agitation, self-injury, and aggression—make placement of the tube and enteral feedings challenging. VV's parents have asked that tube feeding be implemented as soon as possible; however, they also request that VV be "put to sleep" rather than physically restrained for tube placement.

Despite agreement that forced tube feeding is necessary in the short-term to save VV's life, VV's mother and one of VV's nurses, GG, disagree about whether doing so is compassionate and respectful of VV's right to self-determination. During a team meeting with VV's parents, VV's mother says, "VV is a teenager. We're her parents, and it's our decision. VV has been and still is too ill to consent or even assent."

GG responds, "I see your point, but you have to consider long-term consequences for VV, too, and what it's like for us to have to force-feed her. The World Medical Association considers force feeding a human rights violation,[1] possibly even torture. I don't see that as a compassionate thing to keep doing to VV."

VV's mother adds, "Compassion is important, obviously. VV is our child. It is not, however, the primary value when compared to saving VV's life."

Everyone at the team meeting wonders how to respond and proceed.

Commentary

Anorexia nervosa is characterized by morbid eating restraint despite escalating negative consequences of starvation and has one of the highest mortality rates among psychiatric conditions.[2] Ambivalence towards interventions aimed at weight restoration is a hallmark of the disorder and contributes to high levels of perceived coercion in hospitalized patients, as most enter care under pressure from others.[3] Forced clinical interventions are ethically and clinically justified only when a patient's decision-making capacity regarding appropriate treatment is impaired, when the risk of death or serious morbidity is high, and when the likelihood of benefit outweighs the risk of harm.

VV's treatment refusal despite her medical instability presents her clinical team with a conflict between the ethical principles of respect for a patient's autonomy and beneficence. In this commentary, we explore clinical and ethical justifications for the use of force in the treatment of anorexia nervosa. We discuss the limitations and risks of nasogastric tube feeding compared to other effective, less coercive behavioral treatments for anorexia nervosa and suggest strategies for a coordinated team-based approach that may include the compassionate use of force while prioritizing the establishment of a collaborative therapeutic relationship among VV, her family, and her treatment team.

Autonomy and Right to Self-Determination in Anorexia Nervosa

VV insists that she is on a hunger strike to protest prior perceived medical maltreatment while her nurse worries that force-feeding VV represents a human rights violation. Unlike a hunger striker, whose refusal to eat is based on a political goal that, once achieved, would render continued food refusal unnecessary, VV has readily relapsed following multiple past admissions and is unlikely to eat at home. Her decision-making ability is impaired in that she lacks the capacity to appreciate both the severity of her condition and her likelihood of benefit from treatment.[4] It is not uncommon for patients with anorexia nervosa to recognize the need for others with the same condition to be treated against their will but not their own,[5] and many involuntarily hospitalized patients retrospectively acknowledge that they needed hospitalization but were unable to make a reasoned choice to enter treatment while acutely ill and malnourished.[6,7,8] Recovery from anorexia nervosa is often a protracted process that can take years; however, the majority of those affected will recover, with recovery possible even in the most severe and chronic cases.[9] While ill, however, individuals with anorexia nervosa may express a

sense of hopelessness, and it is important that clinicians not accept as fact patients' statements about the futility of treatment.

Different Views About Necessity of Force

VV's medical team believes that some kind of force (physical or chemical) is necessary to save VV's life, although they differ on the form this intervention should take. VV is refusing meals and is medically unstable as a result of her state of severe malnutrition. To be successful, any coercive intervention must help reverse her starved state, restore her decision-making capacity, minimize harm, be as compassionate as possible, and be likely to benefit her in the long-term.

VV's mother wants the team to place a nasogastric tube under general anesthesia, presumably believing this will be less traumatic for VV than placement during a physical hold, with or without medication. Aside from the risk of anesthesia, waking up with a tube in place may be more traumatic for VV than having the tube placed while awake, and if VV removes her tube, she may require multiple reinsertions. A Danish register-based study identified repeat nasogastric tube insertion as common in involuntary hospitalizations for anorexia nervosa.[10] Multiple reinsertions could increase risk for psychological and physical trauma, especially if VV actively resists them. Potential physical complications include nasopharyngeal trauma, tube misplacement, aspiration pneumonia, or esophageal perforation. Prolonged nasogastric tube feeding could decrease motivation to eat by mouth, result in tube dependency, and fail to assist VV in overcoming her fear of food.[11] VV's objection is not primarily to the mode of feeding (oral or nasogastric) but to feeding itself, which is not solved by tube placement under anesthesia, and VV may tamper with her tube feeds to avoid gaining weight.

Establishing Therapeutic Alliance

Clarifying VV's history. VV's case leaves us with unanswered questions regarding her treatment history. Although she has been hospitalized multiple times, many patients with anorexia nervosa obtain care in general medical or psychiatric wards where staff have minimal if any specialized training in eating disorders. Weight restoration is the strongest predictor of recovery from anorexia nervosa. Previously, on these other admissions, was VV's weight restored by discharge or was she just briefly medically stabilized and sent home? What follow-up care, if any, did she receive? The absence of a detailed treatment history has the potential to increase the risk that clinicians will opt for highly coercive interventions like involuntary nasogastric tube insertion, incorrectly assuming that the patient will be unresponsive to less invasive treatment approaches.

Building rapport. Compassionate and empathic listening, questioning, and reflection as part of history taking are important to establishing rapport with VV, as patients' perceived coercion concerning treatment has been linked to their feeling that they are not heard.[12] Collateral history collected from VV's parents and from review of outside records, where available, can help clarify the adequacy and quality of her prior hospitalizations and follow-up treatment. This information is crucial to helping the clinical team build a therapeutic alliance with VV, to instilling hope that she can get better, and to persuading her that the team is here to help her overcome her illness. A strong therapeutic alliance in patients with anorexia nervosa has been found to predict treatment completion and change in eating-related psychopathology, both at discharge and at 1-year follow-up.[13,14,15]

Evaluating Options

Ideally, the team should consider urgent transfer to a specialty behavioral program for the care of patients with eating disorders, especially if VV has not been treated in one before or has left treatment prematurely on past admissions. Expert eating disorders behavioral specialty programs can improve eating disorder symptomatology and weight-restore a majority of patients using a multidisciplinary approach that includes individual, group, and family-based treatments; supervised meals; and behavioral contingency management strategies.[16] When access to such a program is not possible or cannot be accomplished promptly, the team is faced with either winning VV's cooperation so that she starts eating meals or initiating tube feeding with the goal of transitioning VV to oral feeding as soon as possible. Signs that a patient might require urgent treatment to prevent life-threatening medical complications of malnutrition include a body mass index of less than 13, prolonged QT interval on electrocardiogram, severe hypoglycemia, or electrolyte abnormalities, especially hypokalemia or hypophosphatemia.[17] For patients who meet these criteria, at least in the short-term, forced nasogastric tube feeding might be lifesaving. In most cases, there is need for urgent rather than emergent intervention, and, in these cases, an ethics consult could help resolve disagreements among team members and help them reason through available options.

Unified Team-Based Approach

Achieving a shared understanding of the psychopathology of anorexia nervosa and the unique challenges of treatment resistance posed by this disorder is a priority for the clinical team. Discussion and education concerning the clinical, ethical, and legal rationale for involuntary treatment, including possible recourse to nasogastric tube feeds, should ideally take place before meeting with family members to facilitate clear and consistent messaging to VV and her family and to avoid the overt disagreement observed here within the clinical team in the family's presence.

Cases like VV's can generate strong emotional reactions in staff, trainees, and family members, which may undermine the therapeutic relationship. These reactions can include a sense of urgency to intervene to save VV's life at any cost, feelings of futility about her potential for recovery, frustration at her refusal to cooperate with medical recommendations, or overidentification with anorectic rationalizations for her treatment refusal. The treatment team should recognize and explore these responses to ensure that treatment decisions are rooted in the guiding values of compassion and good clinical care and not in these disparate emotions. Acknowledging these emotional experiences as common can help de-escalate conflict and reassure staff. Parents are often distressed and exhausted by repeated attempts to help their child combat her illness and are also likely to benefit from support and education. It might be preferable to meet separately with VV and with her parents to discuss treatment options and to answer their questions.

Preparing the Patient for What to Expect

If the patient's worsening medical status places her at imminent risk and the decision is taken to proceed with nasogastric tube feeding, it is important to prepare VV for the procedure. She should be reassured that the team will be as gentle as possible, that the expectation is that the tube feeding will only be temporary, and that the tube will be removed once she is taking in sufficient calories by mouth. Both the medical rationale for enteral feeding and the team's goal to help her overcome her illness and gain control over healthy eating should be stressed. Calmly presenting VV with the plan and explaining the steps involved in inserting the tube, who will be present, the importance

of her cooperating, and the possible need for a brief physical hold will help VV know what to expect. This message should be delivered empathically yet clearly, stressing the urgency of helping her body obtain the nourishment it needs. Providing her a choice to eat a meal at the last minute by having a tray ready as an alternative to tube placement often avoids the need for enteral feeds, as some patients report it is easier to eat when they feel they no longer have the option to postpone doing so.[5]

Compassion as a Primary Value

While nasogastric tube feeding may be ethically justified when a patient lacks capacity to make treatment decisions and faces life-threatening medical consequences, it is important to consider alternatives to enteral feeding that minimize the use of force or implement it in a more compassionate way. Successful treatment of anorexia nervosa hinges on persuading patients to gain weight and consume calorie-dense foods despite their aversion to doing so. Meal-based oral refeeding is safer and always preferable to enteral feeds. Specialized behavioral programs for eating disorders can weight-restore the vast majority of patients without the need for nasogastric feeding by utilizing behavioral expectations and contingencies to enhance patient motivation, compliance, and autonomy.[18] Access to these programs is limited, however, and few will accept involuntary adult patients. If VV's medical status or other limitations preclude her transfer to such a setting, short-term nasogastric tube feeding may be required to medically stabilize VV and initiate the refeeding process.

Compassion should always be a guiding value in the treatment of anorexia nervosa. In some cases of severe and life-threatening anorexia nervosa, however, compulsory treatment may be the compassionate choice, as patients' impaired capacity to freely choose recovery over illness can undermine their autonomy. Nonetheless, compulsory treatment should be undertaken with care and only when benefit is likely in order to minimize both futile interventions and risk of trauma. This decision requires careful assessment of the patient's past history and treatment outcomes, a unified team approach, a positive and caring therapeutic alliance, and dynamic reassessment of therapeutic progress.

References

1. World Medical Association. WMA Declaration of Malta on hunger strikers. Adopted November 1991. Revised October 2017. Accessed December 21, 2020. https://www.wma.net/policies-post/wma-declaration-of-malta-on-hunger-strikers/
2. Arcelus J, Mitchell AJ, Wales J, Nielsen S. Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. *Arch Gen Psychiatry*. 2011;68(7):724-731.
3. Guarda AS, Pinto AM, Coughlin JW, Hussain S, Haug NA, Heinberg LJ. Perceived coercion and change in perceived need for admission in patients hospitalized for eating disorders. *Am J Psychiatry*. 2007;164(1):108-114.
4. Elzakkers IFFM, Danner UN, Sternheim LC, McNeish D, Hoek HW, van Elburg AA. Mental capacity to consent to treatment and the association with outcome: a longitudinal study in patients with anorexia nervosa. *BJPsych Open*. 2017;3(3):147-153.
5. Tan JOA, Stewart A, Fitzpatrick R, Hope T. Attitudes of patients with anorexia nervosa to compulsory treatment and coercion. *Int J Law Psychiatry*. 2010;33(1):13-19.

6. Watson TL, Bowers WA, Andersen AE. Involuntary treatment of eating disorders. *Am J Psychiatry*. 2000;157(11):1806-1810.
7. Newton JT, Robinson PH, Hartley P. Treatment for eating disorders in the United Kingdom. Part II. Experiences of treatment: a survey of members of the Eating Disorders Association. *Eur Eat Disord Rev*. 1993;1(1):10-21.
8. Tiller J, Schmidt U, Treasure J. Compulsory treatment for anorexia nervosa: compassion or coercion? *Br J Psychiatry*. 1993;162:679-680.
9. Rigaud D, Tallonneau I, Brindisi MC, Vergès B. Prognosis in 41 severely malnourished anorexia nervosa patients. *Clin Nutr*. 2012;31(5):693-698.
10. Clausen L, Larsen JT, Bulik CM, Petersen L. A Danish register-based study on involuntary treatment in anorexia nervosa. *Int J Eat Disord*. 2018;51(11):1213-1222.
11. Krom H, de Winter JP, Kindermann A. Development, prevention, and treatment of feeding tube dependency. *Eur J Pediatr*. 2017;176(6):683-688.
12. Nicolini M, Vandenberghe J, Gastmans C. Substance use disorder and compulsory commitment to care: a care-ethical decision-making framework. *Scand J Caring Sci*. 2018;32(3):1237-1246.
13. Sly R, Morgan JF, Mountford VA, Lacey JH. Predicting premature termination of hospitalised treatment for anorexia nervosa: the roles of therapeutic alliance, motivation, and behaviour change. *Eat Behav*. 2013;14(2):119-123.
14. Marzola E, Albini E, Delsedime N, Fassino S, Abbate-Daga G. Therapeutic alliance in inpatients with severe anorexia nervosa. *Eur Eat Disord Rev*. 2019;27(6):671-681.
15. Stiles-Shields C, Touyz S, Hay P, et al. Therapeutic alliance in two treatments for adults with severe and enduring anorexia nervosa. *Int J Eat Disord*. 2013;46(8):783-789.
16. Attia E, Walsh BT. Behavioral management for anorexia nervosa. *N Engl J Med*. 2009;360(5):500-506.
17. National Collaborating Centre for Mental Health. *Eating Disorders: Core Interventions in the Treatment and Management of Anorexia Nervosa, Bulimia Nervosa and Related Eating Disorders*. British Psychological Society; 2004.
18. Ziser K, Resmark G, Giel KE, et al. The effectiveness of contingency management in the treatment of patients with anorexia nervosa: a systematic review. *Eur Eat Disord Rev*. 2018;26(5):379-393.

Melissa Lavoie, MD is a second-year resident in psychiatry at the Johns Hopkins University School of Medicine in Baltimore, Maryland, where she received her MD degree in 2019. She holds a BS degree in psychology from Yale University.

Angela S. Guarda, MD is the Stephen and Jean Robinson Associate Professor of Psychiatry and Behavioral Sciences at the Johns Hopkins School of Medicine and director of the Eating Disorders Program at Johns Hopkins Hospital in Baltimore, Maryland. Her clinical research interests include improving outcomes for intensive treatment of anorexia nervosa and overcoming ambivalence towards treatment. Her translational research has focused on pathophysiological mechanisms that might underlie anorexia nervosa and other eating disorders.

Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

Citation

AMA J Ethics. 2021;23(4):E298-304.

DOI

10.1001/amajethics.2021.298.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

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.

ISSN 2376-6980