American Clinicians Academy on Medical Aid in Dying www.ACAMAID.org

Aid in Dying Ethics Consultation Service

Summary of Consultation concerning a Patient with Anorexia Nervosa September 3, 2021

The mission of the Ethics Consultation Service of the American Clinicians Academy on Medical Aid in Dying is to provide support for clinicians involved in the practice of medical aid in dying. This support is primarily directed at addressing clinical ethics questions brought up by clinicians involved with patients considering medical aid in dying, as well as aid-in-dying issues that arise among hospice and palliative care agencies, healthcare organizations, grief and bereavement services, and requests from other ethics committees seeking aid from an ethics group with aid-in-dying expertise.

Case Summary

Female patient with anorexia nervosa requested aid in dying from her palliative care physician. She had participated in multiple inpatient and outpatient treatment programs for eating disorders over the past years without any sustained recovery. Her eating disorder physician, who participated in the consultation call, felt that, although the patient had not accepted or agreed to the "gold standard" treatment of full weight restoration to evaluate brain function, she was terminally ill. This physician as well as the consulting psychiatrist felt that the patient had decisional capacity. The patient was enrolled in hospice and lived with her family who supported her request to access aid in dying. The potential prescribing physician felt uncomfortable in prescribing for this patient and asked the ethical questions below be addressed.

Source of Consult Request

Palliative medicine physician who received the patient's request for aid in dying.

Ethical Questions

The requester identified the following four questions that were addressed by the Academy Consultation Team:

- 1. What is the role and evidence for medical aid in dying in cases of severe anorexia nervosa?
- 2. Should a patient be required to first exhaust all other potentially beneficial interventions and treatments offered by eating disorder specialists? Or can a patient refuse potentially beneficial interventions and then become eligible for aid in dying?
- 3. When is the illness irreversible and death inevitable for a patient with severe anorexia nervosa? When does the condition become a "terminal disease"?
- 4. Even if a patient meets the eligibility criteria specified in the aid-in-dying statute, if the physician does not feel comfortable prescribing for this patient but supports aid in dying in general, is declining and referring to another MD ethically defensible?

Ethical Questions and Issues Discussed

- 1. There have been no published cases on aid in dying for patients with anorexia nervosa describing the role or experience of aid in dying in such patients in this country.
- 2. Mandating that the patient exhaust all possible treatments before requesting aid in dying is not in keeping with other "terminal" illnesses. For example, we allow patients with end stage cancer to forgo chemotherapy or other potentially life-extending treatments and request medical aid in dying.
- 3. There is no consensus in the eating disorder literature regarding whether a patient who has severe enduring anorexia nervosa is "terminally" and "irreversibly" ill according to the definition in the State statute. The mortality rate for eating disorders is the highest of all psychiatric disorders (except substance use disorders); yet patients have recovered as far out as 22 years from a diagnosis of anorexia nervosa according to one study (Eddy KT). There are also no standard criteria for an "end stage" eating disorder and therefore it is difficult to define "terminal illness" for any one specific patient.

Outside Experts on Anorexia Nervosa

The Academy Consultation Team interviewed three physicians who have extensive experience in the treatment of anorexia nervosa and have published articles on the ethics of forgoing treatments, defining end-of-life cases, and recommending palliative care. The first physician found it ethically reasonable to support medical aid in dying for a patient who was clearly defined as "end stage" by her treating physician and was found to have decisional capacity by a qualified psychiatrist. The second physician felt that the patient did not meet the criteria of "irreversible" and "terminal" illness as the terminal nature of her clinical condition was her refusal to accept nutrition and not a terminal disease that she could not control. The third physician felt that in chronic, enduring, severe anorexia nervosa, some patients stand to benefit little from further treatments and have the right to refuse further involuntary treatments and should then be allowed and ethically supported to have a palliative plan of care, but stopped short of accepting aid in dying as an ethically appropriate option.

Ethics Consult Team Conclusions

- If the patient's eating disorder treating physician and evaluating psychiatrist agreed that she had a "terminal disease" and retained decision-making capacity, she would meet those requirements of the aid in dying statute in her jurisdiction.
- If the patient is found to meet the requirements of the aid-in-dying statute in her jurisdiction and the physician who received the request is not comfortable prescribing in this particular situation, it is both ethically and legally defensible for the physician to decline and to refer the patient to another physician.

The team had the same uncertainty and diversity of opinions about "irreversibly terminal" and "decisional capacity" as was reflected in the current literature on the treatment and outcomes of those suffering with chronic and severe anorexia nervosa.

Legal Disclaimer

The Ethics Consultation Service of the American Clinicians Academy on Medical Aid in Dying does not provide legal advice. Moreover, information in this consultation summary is provided for informational purposes only and is not legal advice. Transmission or receipt of information on the Academy website or listserv does not

create an attorney-client relationship and is not a substitute for obtaining legal advice from an attorney licensed to practice in your location.

Medical Disclaimer

Information in this consultation summary is not intended to be a substitute for professional medical advice, diagnosis, or treatment from treating, prescribing, and consulting clinicians or from mental health professionals.

Confidentiality Disclaimer

All consultations are confidential. Complete documentation is recorded and protected internally by the Ethics Consultation Service of the American Clinicians Academy on Medical Aid in Dying (the Academy). Opinions and options presented are by consensus of consultation service members and do not represent their associated institutions.

Short List of Reference/Resource Articles

Jackson JZ. A Case Note Regarding Force-Feeding of Anorexic Patients and the Right to Die. MDAdvisor, Fall 2017. pp. 20-25.

Westmoreland, P, Johnson C, Stafford M, et al: Involuntary Treatment of Patients with Life-Threatening Anorexia Nervosa. J Am Acad Psychiatry Law 2017; 45(4):419-425.

Eddy KT, et als. Recovery From Anorexia Nervosa and Bulimia Nervosa at 11-Year Follow-Up. J Clin Psychiatry, 2017 Feb: 78(2): 184-189.

Geppert CM. Futility in Chronic Anorexia Nervosa: A Concept Whose Time has Not Yet Come. Am J Bioethics 2015; 15(7): 34-43.

Yager J, Ganzini L, Nguyen DH, Rapp EK. Working with Decisionally Capable Patients Who Are Determined to End Their Own Lives. J Clin Psychiatry. 2018; 79(4): 17r11767.

Bianchi A, Stanley K, Sutandar K The Ethical Defensibility of Harm Reduction and Eating Disorders. Am J Bioethics. 2021; 21; 46-56. (with Peer Commentaries by Yager J; Kirby J, Geppert CMA, Rempala K et al; Westermaier AL et al, pp 57-70.

Patricia Westmoreland, M.D., Editor, <u>Tipping the Scales</u>; <u>Ethical and Legal Dilemmas in Managing Severe Eating Disorders</u>, Chapter 12 "Eating Disorders and Physician-Assisted Death" 181-195, American Psychiatric Association Publishing, 2021.