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ASK THE EXPERT

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FEATURED EXPERT

An Interview with Joel Yager, MD

Professor Emeritus of Psychiatry, University of Colorado School of Medicine

Q. What are the specific challenges psychiatrists face when determining a patient's competence to make end-of-life decisions, particularly in the context of psychiatric disorders?

A: Decisions about competency are complex. First, clinicians have to decide on the criteria they'll use. Most currently rely on the four criteria established by Grisso and Appelbaum for competency to make treatment decisions, notably understanding, appreciation, reasoning, and expressing a choice (see reference in question 2). Some authorities suggest that these four criteria are insufficient and that clinicians should also make extra efforts to assure that patient are not making "serious prudential mistakes" (based on considerations of welfare) when they suffer from a condition that makes them more likely to make such a mistake. Clinicians always have to weight factors of respecting patients' autonomy with those of providing beneficent care.

Grisso T, Appelbaum PS, Hill-Fotouhi C. The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. Psychiatr Serv. 1997 Nov;48(11):1415-9. doi: 10.1176/ps.48.11.1415. PMID: 9355168.

Hawkins, J. 2024. Affect, values and problems assessing decision-making capacity. The American Journal of Bioethics 24 (8):71–82. doi:10.1080/15265161.2023.2224273.

Q: How do psychiatrists evaluate a patient's agency and decision-making capacity when they request medical aid in dying or withdrawal from conventional treatment?

A: They can use a formal instrument that came out of Grisso and Appelbaum's work, the MacCAT-T, or other detailed mental status examinations focused on capacity for clinical decision making.

Grisso T, Appelbaum PS, Hill-Fotouhi C. The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. Psychiatr Serv. 1997 Nov;48(11):1415-9. doi: 10.1176/ps.48.11.1415. PMID: 9355168.

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 May 22;79(4):17r11767. doi: 10.4088/JCP.17r11767. PMID: 29873952.

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Q: In what ways does having a psychiatric disorder complicate a patient's access to palliative and hospice care compared to patients without psychiatric diagnoses?

A: Studies show that patients with psychiatric disorders are less likely to access palliative and hospice care compared to others. A variety of factors may contribute, including patient characteristics (e.g. treatment reluctance, personality issues leading to avoidance, indecision, and paranoia about treatments in general), problems with access to health care in general (personnel, finances), and lack of access to health advocates or navigators in particular.

Butler H, O'Brien AJ. Access to specialist palliative care services by people with severe and persistent mental illness: A retrospective cohort study. Int J Ment Health Nurs. 2018;27(2):737-746.
Spilsbury K, Rosenwax L, Brameld K, Kelly B, Arendts G. Morbidity burden and community-based palliative care are associated with rates of hospital use by people with schizophrenia in the last year of life: A population-based matched cohort study. PLoS One. 2018;13(11):e0208220. Published 2018 Nov 29. doi:10.1371/journal.pone.0208220

Lavin K et al Effect of Psychiatric Illness on Acute Care Utilization at End of Life From Serious Medical Illness. J Pain Symptom Manage. 2017 Aug;54(2):176-185.

Chochinov HM, Martens PJ, Prior HJ, Kredentser MS. Comparative health care use patterns of people with schizophrenia near the end of life: a population-based study in Manitoba, Canada. Schizophr Res. 2012 Nov;141(2-3):241-6.

Q: Can you explain the ethical considerations involved when a psychiatrist encounters a patient with a psychiatric disorder who requests to hasten their death, and how does this differ from cases involving patients without such disorders?

A: Patients with psychiatric disorders are more vulnerable than others in certain ways. Their decision-making may be impaired by treatable psychiatric conditions (e.g. severe major depression), and they may be more vulnerable to thinking that others (e.g. family members) would be better off without them and might even want them to die or disappear. Clinicians have to carefully assess these vulnerabilities to make certain that patients' decision-making processes are not warped by these factors.

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 May 22;79(4):17r11767. doi: 10.4088/JCP.17r11767. PMID: 29873952.

Q: Do terminal psychiatric disorders exist? If so, are there any preliminary consensus definitions of terminal psychiatric conditions? What role do psychiatric providers have in shaping these conversations?

A: Terminal conditions exist when clinicians judge that patients appear to be on an inevitable, irreversible death trajectory, with the likelihood that the patient will die within six months. Although terminal condition in psychiatric disorders have been proposed, and the label appears from time to time in medical literature in relation to psychiatric disorders, the term "terminal anorexia nervosa" has raised considerable controversy. We used the term "terminal anorexia nervosa" to describe three patients who refused further care due to repeated failures of previous care, and for whom even involuntary force feeding seemed futile, at best offering short-term interventions that were unlikely to have any long-term positive benefit, while imposing harmful, traumatizing, stigmatizing and dehumanizing experiences.

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However, objection to the term “terminal” have been raised by clinicians and patients who believe that death can always be avoided through nutritional intervention, through involuntary means if necessary. They also fear that the term “terminal” can cause demoralization and perhaps contagion among vulnerable patients with severe and enduring anorexia nervosa. As a result, we have introduced (or reintroduced) the idea that some psychiatric disorders associated with foreshortened lives (in which patients may die “from” rather than simply “with” their psychiatric disorders may have “end stages”, for which we have provided tentative operational definitions.

Gaudiani, J. L., Bogetz, A., & Yager, J. (2022). Terminal anorexia nervosa: three cases and proposed clinical characteristics. Journal of Eating Disorders, 10(1), 23. https://doi.org/10.1186/s40337-022-00548-3

Yager J, Gaudiani JL, Treem J. Eating disorders and palliative care specialists require definitional consensus and clinical guidance regarding terminal anorexia nervosa: addressing concerns and moving forward. J Eat Disord. 2022 Sep 6;10(1):135. doi: 10.1186/s40337-022-00659-x. PMID: 36068601; PMCID: PMC9450436.

Guarda AS, Hanson A, Mehler P, Westmoreland P. Terminal anorexia nervosa is a dangerous term: it cannot, and should not, be defined. J Eat Disord. 2022 Jun 7;10(1):79. doi: 10.1186/s40337-022-00599-6. PMID: 35672780; PMCID: PMC9175496.

Yager J, Treem J, Strouse TB. Foreseeably Early Deaths in Patients With Psychiatric Disorders: Challenges in Caring for Patients Manifesting Likely Fatal Trajectories. J Nerv Ment Dis. 2024 Sep 1;212(9):471-478. doi: 10.1097/NMD.0000000000001789. PMID: 39207291.

Q: In many ways conversations about palliative care and terminal illness in psychiatry seem more controversial than the standards of care we follow when treating terminal illness in other areas of medicine, like oncology. In what ways is it different from managing patients with non-psychiatric terminal illnesses? What does the field need to do in order to advance these conversations, research and best practices?

A: Difficulties in initiating palliative include increased rates among patients with psychiatric disorders of alienation from families resulting in conflicted or distant relationships, homelessness, living in shelters or single room occupancies, imprisonment, stigmatization by healthcare workers and many others, and reduced access to health care services. For these reasons they are probably less likely to receive palliative care. These factors underscore the importance for the field of developing palliative care providers who are specially trained on issues that might be anticipated in caring for patients with psychiatric disorders and their families and for including non-specialists who are comfortable providing meaningful palliative care.

Treem J, Yager J, Gaudiani JL. A Life-Affirming Palliative Care Model for Severe and Enduring Anorexia Nervosa. AMA J Ethics. 2023 Sep 1;25(9):E703-709. doi: 10.1001/amajethics.2023.703. PMID: 37695873.

De Michelis, C., Gareri, P., & Castagna, A. (2020). Palliative care in psychiatric disorders: A new challenge? BMC Palliative Care, 19(1), 31. https://doi.org/10.1186/s12904-020-00556-5

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