

FROM THE EDITOR

Ethical Dimensions of Caring Well for Dying Patients

Ilana Stol, MD

Dying is a uniquely individual yet deeply shared and universal experience; it profoundly impacts perceptions of culture, personhood, and identity. For many Americans, it is also an experience widely discrepant from the one they want and envision for themselves and their loved ones.¹ Over the past decade, there has been growing awareness of the incongruence between the way Americans say they want to die and how they actually do.¹ But while most would agree that this reality is not the ideal that clinicians or patients strive for, what is less agreed upon is what the roles of clinicians and patients should be in defining what actually constitutes dying and good care of dying people. What do patients and clinicians need to know about dying and care at the end of life? What barriers exist to accessing and employing this knowledge in the face of difficult decisions?

To best answer these questions, it is useful to examine the social structures and supports already in place for end-of-life care and to understand how they are being utilized. To begin with, hospital palliative care programs are expanding rapidly in order to meet the physical and emotional needs of patients with serious or terminal illness.² Robust evidence now exists demonstrating that early palliative care improves the dying experience for both patients and families while generally reducing health care costs and potentially prolonging survival.^{3,4} Despite these facts, there is significant variation in physician practice in the care of patients at the end of life and a general consensus that palliative and hospice care are underutilized by physicians.⁵ Underlying these facts is an intricate network of social, political, and cultural factors that have real consequences for dying patients and their families. In order to provide the highest quality end-of-life care, clinicians have to both recognize and reconcile the complex patient and physician factors influencing the dying experience. This issue of the *AMA Journal of Ethics* aims to explore each of these factors and their critical implications for care at the end of life.

The ethics cases in this issue examine a number of important themes crucial to discussion of care for the dying patient. Alexander Craig and Elizabeth Dzung examine the potential roles and ethical limits of physicians in facilitating patients' control over their own death experience through a clinical case of a patient with amyotrophic lateral sclerosis (ALS) who asks for assistance in ending his life. In doing so, they provide a framework for exploring the ethical implications of active [physician aid in dying](#) in cases in which the nature of patients' terminal condition renders them unable to exercise the

right granted to them in states that have passed death with dignity laws. In the case of a [patient who refuses tracheostomy](#) as part of a planned perioperative intubation, Katherine Gentry and Aaron Wightman examine the moral quandary of an anesthesiologist who wishes to respect the patient's autonomy but fears deviating from the standard of care and being culpable should the patient die. Shyoko Honiden and Jennifer Possick navigate end-of-life decision making in situations in which [physicians don't agree](#) on whether to pursue comfort-only care for a complex patient in the intensive care unit. The authors argue that shared decision making allows for physician variation but that clinical momentum—the escalation of aggressive care at the end of life—might lead clinicians to pursue care that puts them in conflict with patients' wishes and agreed-upon treatment plans. In the fourth case, James L. Bernat and Nathaniel M. Robbins examine the medical definitions of death and their impact on the [organ donor dying experience](#) in the case of organ donation in a young woman whose heart stopped in the operating room. The authors highlight the variation in definitions of donor death among hospitals in cases of organ donation and how physicians justify their roles in the dying process of living donors for the benefit of preserving the transplanted organ for the recipient.

In our current health care climate, it is becoming more and more self evident that clinicians must think critically about systemic implementation of effective communication concerning patients' prognosis and end-of-life care. Carin van Zyl and Dawn M. Gross discuss the significance and inherent challenges of recent legislation under which Medicare now provides [reimbursement for advance care planning](#).⁶ The authors deliberate on the fact that, unlike other reimbursable interventions such as medical procedures, formalizing standards and measuring outcomes for advance care planning conversations is both ethically challenging and fundamental to the competent delivery of patient-centered end-of-life care. Bryan A. Sisk and Jennifer W. Mack define the [purpose and process of prognostic communication](#) and argue that while most interventions aimed at improving prognostic communication have been focused on the process, more work needs to be done to address the purpose of such communication. Providing an example of the importance of diagnostic communication, Sabhyta Sabharwal, Jason W. Mitchell, and Victoria Y. Fan discuss the need for [policies mandating serostatus disclosure to adolescents](#) who, when they become adults, will be required by law to disclose their positive serostatus to needle-sharing or sex partners.

Two articles address ways in which training and education in end-of-life communication can deepen physician comfort with and effectiveness in engaging in difficult conversations. Mark Pfeifer and Barbara A. Head provide an overview of [evidence-based communication skills](#) necessary for meaningful end-of-life conversations as well as a discussion of established frameworks for developing clinician competency in these skills. Indrany Datta-Barua and Joshua Hauser discuss [similarities between psychiatry and palliative care](#) and how certain skills and approaches key to the practice of psychiatry can

be applied and incorporated in the practice of palliative care.

In further exploring the events leading up to death, 3 articles examine the impact of medical interventions on the dying process. Peter T. Hetzler III and Lydia S. Dugdale discuss the modern [transformation of death](#) as a natural process into one that must be intervened upon or “medicalized.” Helen Stanton Chapple examines clinical momentum through the lens of ritual, reimbursement patterns, and actor network theory and considers how dying patients are underserved when this happens. And, in the [podcast](#), Chapple discusses how hospital clinicians can allow patients and their families to take the lead in the dying process, and Caitlin Doughty discusses what clinicians can do to help families begin a grieving process in the immediate aftermath of a death.

Two other articles focus on personal experiences of providing care to highlight the importance of individual perspectives on illness and death. One article discusses unique and underexplored needs of veterans at the end of life. Tracy Shamas and Sarah Gillespie-Heyman emphasize the impact of military culture, war, and posttraumatic stress disorder on [veterans’ end-of-life care](#) and discuss their own experiences in individualizing their approach to care for veterans with challenging needs. From a patient perspective, Nora W. Wong explores the seemingly paradoxical [role of compassion](#) in the lack of, or late, palliative care referral by physicians and discusses how this potential barrier can be overcome through improved communication.

Individual perspectives take a visible form in 4 artistic contributions. In his graphic narrative, Nathan A. Gray explores the irony and implications of [“compassionate” dialysis](#) provided to immigrants without health insurance. Two images provide different perspectives on resuscitation. While Tracy A. Brader portrays a [team effort resuscitation attempt](#), Munir H. Buhaya portrays the solitariness of an [unrepresented patient](#) for whom a physician completes a do-not-resuscitate order. And Cheyanne Silver portrays the hope of [physicians struggling](#) with dashed career expectations and disappointment.

The diverse array of clinicians, scholars, and trainees who have contributed to this month’s issue of the *AMA Journal of Ethics* focus our attention on many challenges facing end-of-life care and implore us to regularly include these issues in our conversations with patients. In order to care well for dying patients and their families, it is necessary to understand how prognosis, culture, policy, and training all shape a physician’s capacity to provide exceptional care for those navigating an experience that is, without exception, shared by all.

References

1. Gruneir A, Mor V, Weitzen S, Truchil R, Teno J, Roy J. Where people die: a multilevel approach to understanding influences on site of death in America. *Med Care Res Rev.* 2007;64(4):351-378.
2. Dumanovsky T, Augustin R, Rogers M, Lettang K, Meier DE, Morrison RS. The growth of palliative care in US hospitals: a status report. *J Palliat Med.* 2016;19(1):8-15.
3. Smith S, Brick A, O'Hara C, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med.* 2015;28(2):130-150.
4. Temel JS, Greer HA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med.* 2010;363(8):733-742.
5. Finestone AJ, Inderwies G. Death and dying in the US: the barriers to the benefits of palliative and hospice care. *Clin Interv Aging.* 2008;3(3):595-599.
6. Centers for Medicare and Medicaid Services, US Department of Health and Human Services. Advance care planning. <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf>. Published August 2016. Accessed March 2018.

Ilana Stol, MD is a hospice and palliative medicine fellow at the University of Pittsburgh. She recently completed an internal medicine residency and geriatric medicine fellowship at the Yale School of Medicine. Her clinical and research interests include the intersection of geriatrics and palliative medicine, medical care for older adults with intellectual disability, and complex medical decision making in geriatric patients with multiple comorbidities.

Citation

AMA J Ethics. 2018;20(8):E678-682.

DOI

10.1001/amajethics.2018.678.

Acknowledgements

I would like to thank Dr. Mark Siegel for his guidance, support, and mentorship both during this project and throughout my entire residency.

Conflict of Interest Disclosure

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

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.