

VIEWPOINT

A “Good Death” for All: The Need to Teach Racially Sensitive End-of-Life Care

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As first-year medical students during the COVID-19 pandemic, we hear about death every day. In between zoom classes on asthma and diabetes, we also learn about racial and ethnic disparities in mortality for these same diseases—inequities that have been further amplified by the COVID-19 pandemic. While learning about *death* is an expected part of medical school training, when we hear stories from our preceptors about the difficult conversations they have had with patients and families making urgent end-of-life care decisions, we worry that we are not learning as much about *dying*. As we train during a pandemic that has disproportionately affected people of color, we also know that Hispanic patients are less likely to complete advance directives that express their end-of-life care wishes,¹ and Black, Native American, and Asian patients are less likely to die in hospice facilities.² Just as the HIV epidemic transformed the medical training of many of our preceptors, we hope that the COVID-19 pandemic will similarly change the way we approach death and dying, especially for our most vulnerable patients. Given the disparities we see in how our patients experience illness in life, how can we ensure that the care we provide does not also lead to differences in how our patients die? How should our medical school curriculum prepare us to provide our patients with equitable and culturally humble care not only during the prime of their lives, but also during their final days?

While end-of-life care training is integrated as a longitudinal theme across all four years of our Harvard Medical School curriculum, like most other US medical schools, our medical training will not include a required palliative care clerkship.³ Since the Liaison Committee on Medical Education (LCME) only requires a vague, “baseline level” of end-of-life training, it is unsurprising that our third-year colleagues at our medical school reported rarely or never caring for dying patients in their core clerkships, and if

they did, teams did not formally debrief or reflect on these experiences.⁴ These data are representative of a national inadequacy of end-of-life training during medical school. Although our home institution has advanced practical and emotional student preparation for difficult conversations, including at the end-of-life, and elevated patient and family preferences, the lack of LCME-mandated end-of-life exposure has pushed this education into the “hidden curriculum.” We are left to absorb passively our preceptors’ bedside approach toward patients at the end of their lives, as well as our preceptors’ perceptions and potential biases about what entails a good death. While the finding of racial and ethnic differences in end-of-life care experiences is not new with the COVID-19 pandemic, it raises the question of whether these differences represent inequities that need attention or preferences that should be respected. In turn, we worry that an unstructured, informal approach to end-of-life education, without exploring explicitly distinct patient values, will underprepare us to respect the nuanced and complex cultural and racial dynamics which may inform end-of-life care preferences. As our COVID-19 medical school class begins our in-person training in the coming months, how can we hope to avoid falling prey to paternalistic assumptions about end-of-life care when we are not formally exposed to and trained in it?

We have been inspired by medical schools, including our own, that have found ways to exceed required competencies and prepare their students for culturally humble end-of-life conversations. We second calls from our colleagues around the USA to standardize this education and expand LCME-mandated end-of-life care education in medical school.⁵ Some medical schools have opted to surpass LCME standards and include a geriatric and/or palliative care clerkship or home visit component to emphasize the importance of and varying approaches to end-of-life care. Others have included courses which facilitate interviews with bereaved family members to allow medical students to consider whether families of diverse backgrounds received the care they desired at their family member’s death. Medical schools must ensure they have adequate representation of culturally diverse backgrounds in courses which address end-of-life care. Academic medical centers that train medical students must prioritize cultural humility and diversity on care teams. They must also educate medical students about the value of racially and culturally

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concordant care informed by community outreach (e.g., to church groups) to improve the quality of end-of-life care.^{6,7} These conversations will remind medical students about our obligation to the bereaved as well as their family members.

But end-of-life care education must also be prepared to acknowledge racial differences in care preferences as well as pre-existing inequities. Medical student training in cultural humility is not enough to address the social, political, and economic systems that have created institutions which foster justified mistrust in our patients throughout and at the end of their lives. When insufficient focus has been paid to living well, a renewed focus on dying well rings hollow. Comprehensive care for minority groups throughout their lifespan requires a renewed commitment to improving the quality of their care at the end of their lives.

Racial differences in end-of-life care may represent a disparity to be remedied, a cultural preference to be heeded, or a mistrust to be healed. While robust research is lacking in this area, we acknowledge that disparities in end-of-life care plague most minority groups, including Latinx, Native Americans, Asians, and sexual and gender minorities. Here, we discuss how improving undergraduate medical education can expand end-of-life care training and thus improve care for all. As we become an integral part of the medical system, we hope to join ongoing work towards building trust by measuring quality of end-of-life care not based on *equality*, with all patients receiving the same care, but *equity*, in which we listen to patients' preferences and provide them care which meets their specific needs and respects their values. Providing the highest standard of care to our patients will require a medical education which acknowledges these complexities and exposes the work yet to be accomplished. Deeper exposure to culturally humble end-of-life care during medical school may also encourage students to consider a career in palliative care and fill an urgent need for diverse providers. During a year in which death has been rampant, especially among minority communities, we ask the LCME to elevate end-of-life care

education and these difficult conversations from the “hidden curriculum” to a core competency. Only then can medical students across the country take our first steps towards providing a “good death” for all patients we serve.

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REFERENCES

1. **Portanova J, Ailshire J, Perez C, Rahman A, Enguidanos S.** Ethnic Differences in Advance Directive Completion and Care Preferences: What Has Changed in a Decade? *J Am Geriatr Soc.* 2017;65(6):1352-1357. <https://doi.org/10.1111/jgs.14800>.
2. **Cross SH, Kaufman BG, Quest TE, Warrach HJ.** National Trends in Hospice Facility Deaths in the United States, 2003-2017. *J Pain Symptom Manage.* 2021;61(2):350-357. <https://doi.org/10.1016/j.jpainsymman.2020.08.026>.
3. **Head BA, Schapmire TJ, Earnshaw L, Chenault J, Pfeifer M, Sawning S, Shaw MA.** Improving medical graduates' training in palliative care: advancing education and practice. *Adv Med Educ Pract.* 2016;7:99-113. <https://doi.org/10.2147/AMEP.S94550>.
4. **Smith GM, Schaefer KG.** Missed opportunities to train medical students in generalist palliative care during core clerkships. *J Palliat Med.* 2008;11(19):1200-1202.
5. **Bair H, Horak PW.** A Call to Address Mortality in the Medical School Curriculum. *J Palliat Med.* 2021;24(2):170. <https://doi.org/10.1089/jpm.2020.0591>.
6. **Cicoello, K., & Anandarajah, G.** (2019). Multiple Stakeholders' Perspectives Regarding Barriers to Hospice Enrollment in Diverse Patient Populations: A Qualitative Study. *Journal of Pain and Symptom Management*, 57(5), 869-879. <https://doi.org/10.1016/j.jpainsymman.2019.02.012>
7. **Hughes, M. C., & Vernon, E.** (2020). “We Are Here to Assist All Individuals Who Need Hospice Services”: Hospices' Perspectives on Improving Access and Inclusion for Racial/Ethnic Minorities. *Gerontology and Geriatric Medicine*, 6, 233372142092041. <https://doi.org/10.1177/2333721420920414>

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