

Editorials

Racial Disparities at the End of Life

Daniel Dierfeldt, DO, FAAFP; Kerstin Knopf, Dr rer nat, Lic Psych, FT, GC-C; and
Linda Jackson, MDiv, University of Louisville School of Medicine, Louisville, Kentucky

The COVID-19 pandemic has drawn greater attention to the continuing discrimination that racial minorities face within the medical system. Often these disparities are considered in the context of patients who are not actively dying. However, care delivered at the end of life is also susceptible to racial biases and inequities that greatly diminish the quality of life of our patients and their families during the dying process.

Black patients receive more aggressive and nonbeneficial medical care at the end of life. Black people diagnosed with terminal cancer have greater odds of intensive care unit and emergency department admissions, and those with lung cancer are also more likely to undergo mechanical ventilation.¹ Black patients with trauma are more likely to undergo highly invasive procedures and experience physician and systems-based biases compared with White patients with trauma.² When addressing end-of-life matters, physicians offer less information about a diagnosis, prognosis, and treatments to Black patients.^{1,2} Failure to share such information can lead to care that is discordant with patient values and late referrals to hospice or palliative care services.

Hospice use is lower among Black patients than White patients. Spiritual beliefs, cultural systems, and mistrust in the medical system help explain Black patients' preferences for life-sustaining treatments.^{3,4} Inadequate communication from physicians can cause patients to misunderstand hospice services, leading to inappropriate hospice referrals or hospice disenrollment. Difficulties accessing necessary resources may influence hospice use. Black patients are more likely to have difficulty accessing medications; their caregivers are less likely to receive home visits from care providers and aides, even when enrolled in hospice.³

Successful end-of-life care relies on trusting relationships between physicians and patients.^{5,6} Trust in physicians is associated with higher patient satisfaction, better perceived quality of care, enhanced treatment adherence, improved satisfaction, and higher quality of life with fewer symptoms.⁷⁻⁹ Extra effort is needed to build trust

with minority patients in interracial settings.¹⁰⁻¹² Research shows that building trust depends on the physician's communication skills and knowledge about the patient.⁸ Successful communication in end-of-life care includes the assessment of patients' values, beliefs, and preferences before life-altering decisions need to be made. Using two-way conversation and open-ended questions allows for combining the patient's preferences with the physician's medical knowledge. This technique facilitates collaborative decision-making, leading to better treatment adherence, health outcomes, and perceived quality of care.^{8,13-16} Transparency is another trust-building strategy, which includes providing timely and realistic prognostic information, setting realistic expectations about treatment outcomes, and disclosing clinical information.^{12,17}

Early family involvement in shared decision-making should be considered because racial minorities often favor including members of their support system in care planning.¹⁸⁻²² Engaging with the attitudes, values, and beliefs that operate within a family system and emphasizing strong family support lead to favorable health care outcomes.²³

Incorporating the patient's spirituality and community encourages empowering conversations, well-informed decision-making, and improved quality of life and end-of-life care. Spirituality and community provide deeply rooted connections that incorporate a patient's values and beliefs in the midst of distress triggered by serious illnesses. Spirituality can help to reframe hope and can bring a source of peace and strength. Community can reduce the effects of social isolation and loneliness. Black patients often rely on religious community support for medical decision-making.²⁴ Spiritual beliefs may influence care preferences, as evidenced by belief in divine intervention or miracles, that suffering is redemptive, and that God alone determines life and death.²⁵

Racial disparities at the end of life can be mitigated through improved communication,

relationship building, advance care planning, and community outreach. Information regarding diagnosis, treatment, and prognosis should be delivered to every patient in a timely, honest, and sensitive manner. Making advance care planning a standard for every adult patient would ensure that end-of-life wishes are known before a time of crisis. Establishing partnerships with faith and community leaders can build trust between physicians and Black patients. Following these recommendations can create an environment in which equitable care is provided to all at the end of life.

Address correspondence to Daniel Dierfeldt, DO, FAAFP, at daniel.dierfeldt@louisville.edu. Reprints are not available from the authors.

Author disclosure: No relevant financial affiliations.

The opinions and assertions contained herein are the private views of the authors and are not to be construed as official or as reflecting the views of the U.S. Air Force Medical Department, the U.S. National Guard Bureau, or the U.S. Air Force at large.

References

- Perry LM, Walsh LE, Horswell R, et al. Racial disparities in end-of-life care between black and white adults with metastatic cancer. *J Pain Symptom Manage*. 2021;61(2):342-349.e1.
- Hornor MA, Byrne JP, Engelhardt KE, et al. Examining racial disparities in the time to withdrawal of life-sustaining treatment in trauma. *J Trauma Acute Care Surg*. 2018;84(4):590-597.
- Rizzuto J, Aldridge MD. Racial disparities in hospice outcomes: a race or hospice-level effect? *J Am Geriatr Soc*. 2018;66(2):407-413.
- Ornstein KA, Roth DL, Huang J, et al. Evaluation of racial disparities in hospice use and end-of-life treatment intensity in the REGARDS cohort. *JAMA Netw Open*. 2020;3(8):e2014639.
- Luth EA, Prigerson HG. Unintended harm? Race, differences in the relationship between advance care planning and psychological distress at the end of life. *J Pain Symptom Manage*. 2018;56(5):752-759.
- Rousseau DM, Sitkin SB, Burt RS, et al. Not so different after all: all cross-discipline view of trust. *Acad Manage Rev*. 1998;23(3):393-404.
- Pearson SD, Raeke LH. Patients' trust in physicians: many theories, few measures, and little data. *J Gen Intern Med*. 2000;15(7):509-513.
- Chandra S, Mohammadnezhad M, Ward P. Trust and communication in a doctor-patient relationship: a literature review. *J Health Commun*. 2018;3(3):1-6.
- Birkhäuser J, Gaab J, Kossowsky J, et al. Trust in the health care professional and health outcome: a meta-analysis. *PLoS One*. 2017;12(2):e0170988.
- Alpers L-M. Distrust and patients in intercultural health-care: a qualitative interview study. *Nurs Ethics*. 2018;25(3):313-323.
- Matsumoto D, Hwang HS. Cooperation and competition in intercultural interactions. *Int J Intercult Relat*. 2011;35(5):677-685.
- Montgomery T, Berns JS, Braddock CH III. Transparency as a trust-building practice in physician relationships with patients. *JAMA*. 2020;324(23):2365-2366.
- Tongue JR, Epps HR, Forese LL. Communication skills for patient-centered care. *J Bone Joint Surg*. 2005;87A(3):652-658.
- HealthCare.gov. Patient Protection and Affordable Care Act. March 23, 2010. Accessed April 23, 2021. <https://www.govinfo.gov/content/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf>
- Swasey ML. Physician and patient communication: a grounded theory analysis of physician and patient weblogs. July 13, 2013. Accessed June 3, 2021. https://www.suu.edu/hss/comm/masters/capstone/thesis/swasey_thesis.pdf
- Sepucha KR, Belkora JK, Chang Y. Measuring decision quality: psychometric evaluation of a new instrument for breast cancer surgery. *BMC Med Inform Decis Mak*. 2012;12:51.
- Blumenthal D, Gustafsson L, Seervai S. Price transparency in health care is coming to the US—but will it matter? July 3, 2019. Accessed April 23, 2021. <https://hbr.org/2019/07/price-transparency-in-health-care-is-coming-to-the-u-s-but-will-it-matter>
- Kung FYH, Chao MM, Yao DJ, et al. Bridging racial divides: social constructionist (vs. essentialist) beliefs facilitate trust in intergroup contexts. *J Exp Soc Psychol*. 2018;74:121-134.
- Bornstein M, Sawyer J. Family systems. In: McCartney K, Phillips D, eds. *The Blackwell Handbook of Early Childhood Development*. Blackwell Publishing; 2006:381-398.
- Hawley ST, Morris AM. Cultural challenges to engaging patients in shared decision making. *Patient Educ Couns*. 2017;100(1):18-24.
- Centor RM. To be a great physician, you must understand the whole story. *MedGenMed*. 2007;9(1):59.
- Sabogal M, Marín G, Otero-Sabogal R, et al. Hispanic familism and acculturation: what changes and what doesn't? *Hispanic J Behav Sci*. 1987;9(4):397-412.
- Mazanec PM, Daly BJ, Townsend A. Hospice utilization and end-of-life care decision making of African Americans. *Am J Hosp Palliat Care*. 2010;27(8):560-566.
- Song M-K, Hanson LC. Relationships between psychosocial-spiritual well-being and end-of-life preferences and values in African American dialysis patients. *J Pain Symptom Manage*. 2009;38(3):372-380.
- Johnson KS, Elbert-Avila KI, Tulsy JA. The influence of spiritual beliefs and practices on the treatment preferences of African Americans: a review of the literature. *J Am Geriatr Soc*. 2005;53(4):711-719. ■