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 patients 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.3,4 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.5

Successful end-of-life care relies on trusting relationships between physicians and patients.3,6 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.7,8 Extra effort is needed to build trust with minority patients in interracial settings.9-12 Research shows that building trust depends on the physician’s communication skills and knowledge about the patient.9 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, FAAP, at daniel.dierfeldt@louisville.edu. Reprints are not available from the authors.

Author disclosure: No relevant financial affiliations.

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References