



How to Address Racial Disparities in End of Life Care

Lillian Mehran, End of Life Choices New York

Nearly everyone needs health care at some point in their lives, but access to care and quality of care varies widely. Scholars who study such variations find pronounced disparities along racial lines, compounded by various other inequalities such as those by income, education, gender, immigration status, insurance coverage, and patterns of clinician bias. Usually, more than one factor contributes to disparities in health care access and quality — which, in turn, lead to significant differences in health.

At the end of life, these long-standing health care disparities continue. Compared to their white counterparts, African Americans and Latinos are less likely to: receive adequate pain management, receive hospice care, and receive information about end-of-life options. African Americans and Latinos are also less likely to have advance directives, such as a living will, or have designated health proxies.

Research on Racial Disparities in End of Life Care

Research suggests several reasons for these disparities. However, one key factor is how well, and how often, healthcare providers and patients discuss end-of-life care. Miscommunication and lack of communication are often associated with care that is poorer in quality and less likely to align with patient preferences. Communication issues can themselves be grounded in the lack of a common spoken language, implicit bias, differences in culture, and the structure of medical visits (which are often short and therefore more likely to focus on present or urgent needs). Additionally, many healthcare providers have not received training on how to have end-of-life discussions with patients, and may feel uncomfortable or unprepared to discuss the topic.

What Policymakers, Healthcare Providers, and Advocates Can Do

Although there are no “quick fixes” to address racial disparities in end of life care, there are important steps that can be taken by policymakers and advocates:

- **Enact laws that require healthcare providers offer to discuss end-of-life rights and options with terminally-ill patients.** New York State’s Palliative Care Information Act and Palliative Care Access Act are examples of this approach. As policymakers and advocates work together to spread such laws and ensure compliance, efforts should be made to identify and address barriers to implementation.
- **Use resources provided by Medicare and other forms of insurance.** End-of-life advance planning discussions with patients, family members, and surrogates are currently billable under Medicare, including both 30-minute independent visits and “add-on” 30-minute discussions. Officials and advocates should consider developing state-level policies that require similar discussions be covered by Medicaid and private insurance.

- **Train healthcare providers.** To ensure that end-of-life discussions are successful — that the patient's wishes are identified and honored — healthcare providers must receive training on how to have these conversations. Training should include reviews of all end-of-life options and patient rights, discussion of ways to identify patient and family wishes (including when the provider and patient may be from different cultural backgrounds), and information about how caregivers and providers can advocate for and implement patient wishes. Trainings for end-of-life care conversations may depend on institutional reforms. Healthcare providers should consider requesting their institutions hold continuing education workshops focusing on end-of-life care. Some states' laws already allocate funding for end-of-life training for healthcare providers and medical students, so providers in those states may consider applying for such funding. Providers in other states can consider working with policymakers to pass similar funding provisions.
- **Educate the public.** Community organizations and patient advocates can mount awareness campaigns about advance care planning, options, and rights to help people facilitate desired end-of-life care. Public workshops and presentations could focus on palliative care, hospice, advance directives, health proxies, speaking with healthcare providers, and other rights and options. Whenever possible, public events should be held in existing community spaces such as libraries, community centers, health centers, and faith institutions, and should be conducted in the language(s) most commonly spoken in the area. Online content and written material may help also spread awareness. Additionally, "train the trainer" programs can help sustain public education and outreach, by ensuring that a range of community leaders become well-versed in end-of-life issues and resources.

Racial disparities in end-of-life care are well-documented, and efforts must be made to address them. Collaborations among policymakers, patients, advocacy groups, and health care providers can ensure that patients are more likely to receive the end-of-life that aligns with their wishes.