Helping African Americans of Faith Embrace End-of-Life Discussions

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GROWING UP in Memphis, Tennessee, as the daughter of African Methodist Episcopal Church pastors, I spent some Sunday afternoons visiting our sick-and-shut-in members, taking communion to families who were unable to attend service, and patiently waiting for my parents to tend to the needs of church members in crisis. The impact that this upbringing had on me was not lost during my pursuit of a career in medicine. I witnessed the comfort and counsel that my parents provided to the congregation; and I, too, aspired to provide similar comfort and counsel to my patients.

During my neurology training, I cared for and diagnosed numerous patients with devastating neurological diseases, assisted patients and families with navigating chronic and progressive illnesses, and often participated in difficult conversations with them about the declining clinical course and the ultimate realization that death was on the horizon. After completing residency, I embarked upon a palliative medicine fellowship with a plan to establish a career as a neuro-palliative medicine physician.

While leading family conferences and impromptu bedside discussions, it became evident to me that addressing end-of-life issues was a more sensitive undertaking among African Americans than among other racial and ethnic groups. As a physician, but moreso as an African American woman, inherently I understood why. The underlying issues were complex and delicate, and unlikely to be resolved in a single clinical encounter. A longstanding history of African Americans' mistrust of the health care system—which was perpetuated by covert, persistent racism in our society—led to skepticism regarding the type of care that would be provided if “comfort measures” were to be requested. Uncertainty in the diagnosis and in the prognosis contributed further to their hesitancy to accept the stated, poor outcome; and a core belief and faith in God's ability to heal and to perform miracles offered them hope that appeared contradictory to the medical team's opinion.

Researchers have demonstrated that advance care planning is substantially less common in African Americans than in Caucasians, and that African Americans are more likely than Caucasians to choose life-sustaining treatment at the end of life—even if the burden of treatment outweighs the potential, limited benefits.^{1,2} The underlying etiologies of these dif-

ferences in care at the end of life are multifactorial. Primary barriers indeed include greater mistrust of the health care system, as well as lower knowledge about advance care planning, greater valuation of communal decision making over individual autonomy, and specific spiritual beliefs in African Americans compared to other groups.^{1,2}

Informed by the knowledge of these known barriers and recognizing that the church is a critical social and value-conveying nexus within the African American community, I assembled a team of community and academic partners, and designed a study that aims to develop and pilot an advance care planning guideline for elderly, churchgoing African Americans in Los Angeles, California. This community-partnered participatory research project engages pastors and church leaders and trains them in effective techniques to facilitate discussions on advance care planning options within their congregations. Faith-based health collaborations have demonstrated promise within the health prevention realm, and have also been used for advance care planning efforts in other areas of the country.^{3–5}

Our hope is that by engaging pastors—who are trusted leaders within the community—we can bend the curve toward better understanding and acceptance of the need for early discussions regarding goals and preferences at the end of life, in a community that has been understandably hesitant to embrace this topic. With guidelines specifically tailored to the faith community, we are aiming to provide a culturally appropriate and spiritually sensitive method to address this topic in a manner that will be acceptable to the population that we are trying to reach. These are people I know well in my life roles as a neurologist, palliative medicine physician, health services researcher, pastors' daughter, and African American woman.

References

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