

Editorial

Palliative Care in African American Communities

LaVera Crawley, MD

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"Everybody wants to go to heaven, but nobody wants to die. [For African Americans,] it's not so much the act of dying itself, but the things that are surrounding death: injustice, poverty, mistreatment and evil... We won't be stopped by those things—it's our 'somehow theology.' Some how, some way, we will get through this."

Presbyterian Minister, Oakland California

African American patients, health care professionals, and community organizations can offer perspectives on death and dying that have for the most part been absent in the mainstream discourse on palliative and end-of-life care.¹ In this issue of *Innovations*, we hope to bring the unique voice of African Americans to the table of palliative and end-of-life care and to broaden the dialogue on improving care for all segments of society.

The opening epigraph points to issues essential to an understanding of a stance toward end-of-life care held by some African Americans. Death, in the black community, has often been associated with various forms of institutional and individual injustice. High mortality from cancer, cardiovascular disease, AIDS, homicide, and other disease states and illnesses reflect societal disparities that affect African Americans disproportionately. Access to and utilization of hospice and other end-of-life services has been limited for many African Americans and other minorities. The reasons are not altogether clear. Accepting a comfortable death may be seen as a misplaced priority, given the continuing legacy of racism and discrimination that is part and parcel of the black experience in America.

The epigraph also suggests two values important in the black community. The first is religious faith, which plays an important role in the life and death of African Americans. The black church and other institutions representing spiritual traditions have provided great support, comfort, and direction to individuals and families facing death. In this issue we include a personal reflection by Rosemary Ashford on her work with the Balm of Gilead program. Her work exemplifies the role of faith and the church in providing care for the dying and the bereaved.

The second value suggested by the quote—particularly salient when an individual faces death—is the notion of struggle. What may appear to those outside of the community as unnecessary suffering during the dying process, might be perceived within the community as an expected part of life's continual struggle. In the African American community, such personal struggle takes on an air of

dignity and nobility, which resonates with broader social and political struggles to insure equality or correct injustice.

The Enigma of Inequities

Heart disease is the number one killer for Blacks.² Yet, in 1999, a controversial study published in the *New England Journal of Medicine* made headlines when it suggested that discrimination against blacks by health professionals might contribute to cardiovascular mortality.³ Investigators found that physicians were less likely to recommend cardiac catheterization for blacks and females than for white males with identical complaints of chest pain. Although this study was criticized for its statistical modeling,^{4,5} similar findings have been documented in other studies.^{6,7,8}

Similarly, treatment for lung cancer, the second most common cause of death for African Americans, was found to differ according to race and ethnicity.^{9,10} In an analysis of eight years of data from cancer registries linked to Medicare information, investigators found that lower survival for blacks from stage 1 lung cancer may in part be due to lower referral rates for potentially curative surgical procedures as compared to whites.¹¹

Pain management is another area for minorities where suffering is greater than that experienced by whites. In nursing homes,¹² emergency departments,¹³⁻¹⁶ and cancer centers,^{17,18} pain severity was found more likely to be underestimated and effective analgesia less likely to be prescribed for blacks and Hispanics as compared to whites. Pharmacies also show patterns of discrimination. A study conducted in New York City found that pharmacies in predominantly nonwhite neighborhoods did not adequately stock opioids based on fears of addiction, medication abuse, and theft—fears unsubstantiated by comparative police data on actual thefts and other crimes across neighborhoods.¹⁹

These studies highlight what is commonly experienced by many black patients: that medical care for minorities, the poor, and the elderly is different, and in some cases, less optimal, than care available for whites. Herein lies a key to understanding resistance on the part of some African Americans toward palliative and end-of-life care. As a group, blacks have been shown to prefer lifesaving interventions even when such therapies could be deemed as physiologically or medically futile.^{20,21} This preference evokes an image of "going down fighting"—the "somehow theology" mentioned in the opening epigraph. It may make sense to resist the notion of a "good death" when prior access to basic preventive services and treatment was limited due, in part, to institutional racism.

The Strength of Traditions

There is an ancient myth of African origin that holds death as an illusory state.²² The tale is told among different African ethnic groups that a messenger was once sent by God to deliver a message to humans on Earth. The message was that, after that great sleep, we do not actually die but, rather, pass on to some other realm. This was an essential truth for humans to embrace; yet, God's choice of a messenger to deliver this important message was questionable. En route, the courier was convinced by a trickster to delay the news. Some traditions hold that this trickster offered to deliver the news in the courier's place. Others say that by distracting God's messenger, the trickster was able to reach the humans first. Regardless of the form of the subterfuge, the result was that a false emissary arrived before God's true messenger did. The false messenger spread the news among humanity that death was not an illusion, but rather, a final state. Unfortunately, the later appearance

of the true messenger only served to confuse the masses. The tale attempts to explain why, although we are to believe in our immortality, death is still a great mystery.

Moral aspects of this tale are seen in values and perspectives held by some African Americans. We speak of someone who has died as having "passed on," suggesting that their death was not their final state. The title of a recent conference held at Duke University's Institute for Care at the End of Life, *Crossing Over Jordan: African Americans and Care at the End of Life*, spoke to this notion of the immortal soul carrying on its journey of life after death. Certain funeral customs, including the placement of personal items in caskets, may represent vestiges of traditional practices that recognize and provide for the needs of the deceased in their journey to the next life. In this issue, Dr. Ronald Barrett, Professor of Psychology at Loyola Marymount University, furthers this idea of the immortality of the self by providing a description of the variety of funeral and bereavement practices among diverse groups of persons of African descent in the Americas.

The belief in the immortality of some essential aspect of the self has immediate relevance to the clinician, ethicist, or others involved in the care of the dying African American patient, as well. Most specifically, there exists a problem of language. Regardless of the use of qualifiers, (we often speak of compassionate or quality care when referring to palliative and hospice services), the notion of the finality of death is reflected in much of our language. Our field defines its domain as that point leading to the *end of life*. As such, we must ask ourselves if our language and behaviors place us in the inadvertent role of the false messenger when we conceptualize or discuss death within the context of African Americans patients and families. While it may be impractical to eliminate altogether the phrase, "end of life," from our discourse, we should become more sensitive to the larger meanings that such terms can convey.

The Paradox of Barriers

Although it is important to identify those barriers that influence access to and utilization of palliative care services for African Americans and other minority groups, it is equally important to understand how those barriers were constructed in the first place and what forces maintain them. The notion of trust is a good example. As a concept, trust has been unsystematically applied in discussions of provider/health care and minority patient relationships. It is useful to think of trust as either dispositional—that is, a part of a person's inherent disposition—or situational—in response to a specific incident.

Medical and ethics literature on health disparities often identify an undifferentiated notion of trust as an important influence on the attitudes and behaviors of African American patients toward palliative care.²³⁻²⁵ Unfortunately, statements about trust in this literature are usually in the form of commentaries and not based on trials that have directly measured trust as a variable. These comments tend to suggest that minority mistrust may be dispositional or culturally or historically based, existing *a priori* to any specific medical encounter the patient may be in at the moment.

While social injustices (historical and contemporary) may contribute to dispositional mistrust, there is another domain to be considered. Situational trust develops in response to real-time experiences—to actual situations that prove to be either trustworthy or not. Limiting our understanding of trust to dispositional rather than situational domains, that is, those outside of a local institutional context, may discourage health care providers from looking within their own practice environments as the source of untrustworthiness.²⁶ Some physicians do hold negative biases toward African Americans²⁷ and their behaviors toward their black patients, however subtle, can be

felt. Mistrust is a barrier to care but the onus of responsibility for change does not rest on minority patients, alone. The trustworthiness of those who work in this field could be enhanced if, in the course of offering compassionate and quality palliative care, health care providers contribute to the efforts to identify and eliminate discriminatory practices in their own environments.

What may look like a barrier from the vantage point of a health care giver may be a protective strategy or a source of comfort and security when viewed from a different angle. As discussed earlier, included among the barriers among minorities to end-of-life care is a resistance to accepting death in light of continued disparities and inequities in the prevention and treatment of life-threatening diseases. Because of the pervasiveness of these documented race-based inequities, perhaps the African American community should continue to question palliative and hospice services as a priority in the health care agenda. This is a controversial idea, but one that is important to consider.

For African Americans, good palliative care needs to be part of a larger continuum of equitable care that includes prevention practices and risk assessment, diagnosis, and appropriate evidence-based curative treatment. Efforts to increase utilization of hospice and other palliative care services will fail if they do not address the larger societal issues faced by minorities. Community-based interventions—ones that have their origins *within* the community and therefore reflect these larger concerns—are more likely to be successful. The Harlem Palliative Care Network, the featured innovation in this issue, is an example of a community initiative that serves to improve care offered to seriously ill and dying patients.

Do the issues discussed here and illustrated by the opening epigraph suggest collusion with practices and behaviors that perpetuate a denial of death? I hope not. Neither do I wish to fuel the debate between the role of patient or group preference versus institutional or systemic factors as contributing to barriers to effective care for dying patients and the families that care for them. It will not serve to create or perpetuate either/or dichotomies, especially in this case where African American preferences may, themselves, arise in response to institutional practices. What I wish to raise here is that, like death itself, the issues involved in understanding African American perspectives of death and dying are rich and complex.

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