

Racially Associated Disparities in Hospice and Palliative Care Access: Acknowledging the Facts While Addressing the Opportunities to Improve

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IN FEBRUARY 2004 more than 500 individuals met in Atlanta for an historic conference, *The Last Miles of the Way Home*.¹ This landmark national conference supported by the Robert Wood Johnson Foundation through its Last Acts[®] campaign was the first of its kind giving voice to issues in end-of-life decision making and caregiving unique to African American patients, families, and communities. A major motivation to hold this meeting was to address the accumulating observations that racial and ethnic factors were important to determining disparities or differences in access to hospice and palliative care services, and the quality of care for those experiencing the services.² According to the Medicare Payment Advisory Commission in the year 2000, only 17% of Medicare decedents who used hospice were African American, compared to 23.8% who were white and 24.1 Hispanic. Although the use of hospice among Medicare decedents in all racial groups increased between the years 2000–2015, there is still nearly a 12-point difference between whites and African American hospice use.³ Current data from the National Hospice and Palliative Care Association (NHPCO) also documents persistent racial and ethnically based disparities in hospice use between blacks and whites, with at least 8.4% of all hospice patients identified as black or African American (with another 7.4% of patients identifying as “multiracial or other race”), compared to 80.9% white or Caucasian.⁴ This difference in hospice use is even more striking given that African Americans have excessive mortality from almost all causes of death, including hospice-appropriate illnesses.⁵

There is much evidence that palliative care improves the quality of life of seriously ill patients and families,⁶ in cost-effective ways.⁷ However the Institute of Medicine (now renamed The National Academy of Medicine) criteria for quality care requires evidence of equitable care—in addition to care that is safe, effective, timely, and patient-centered. Currently there is very little data relating to how equitable nonhospice palliative care services are. What little evidence there is suggests that there are minimal differences in access to inpatient palliative care services between racial groups,⁸ although one study reported a greater symptom burden and

persistence of cancer-related symptoms in African Americans and Hispanics, compared to whites cared for in an outpatient setting.⁹

Many factors account for disparities in hospice use, and in the differences between blacks and whites reported in the experience and outcomes of palliative care services more generally.¹⁰ Among the most important factors are (1) those based on influences of cultural beliefs and preferences¹¹—in particular values and beliefs that are strongly influenced by religious beliefs¹² that challenge the typical assumptions of advance care planning to limit medical interventions in terminally ill patients¹³ and (2) a preference for more “aggressive” care by African Americans when seriously ill—a preference that is greatly influenced by cultural and religious values and perspectives.¹⁴

There is a strong consensus in the hospice and palliative care community that advance care planning is a good thing because it allows a process for patients and families to consider their preferences and values that should guide care for them at the end of life. Although blacks show a higher preference than whites to die in hospital (as opposed to home), it is still true that a majority of African American Medicare beneficiaries still prefer to die at home.¹⁵ This preference for home care by the majority of African Americans Medicare beneficiaries should favor greater hospice use, and should be supported by written directives and instructions to health care surrogates, when they are available. Of note, a study by the California Healthcare Foundation noted that even though African Americans had less knowledge about advance care planning than other minority groups in California, they also had fewer negative attitudes about the concept than did other racial/ethnic groups in the study.¹⁶

African Americans are highly religious. A recent report from the Pew Research Foundation observed that “African Americans are markedly more religious on a variety of measures than the U.S. population as a whole, including level of affiliation with a religion, attendance at religious services, frequency of prayer, and religion’s importance in life. Compared with other racial and ethnic groups, African Americans are among the most likely to report a formal

religious affiliation, with fully 87% of African Americans describing themselves as belonging to one religious group or another.¹⁷ Religious-based concerns about the morality of advance care planning, and culturally based apprehensions about the motives of those promoting advance care planning, alarm many African Americans. For example, a survey of 205 African American patients at the Duke University Health System showed that “African Americans were more likely to express discomfort discussing death, want aggressive care at the end of life, have spiritual beliefs that conflict with the goals of palliative care, and distrust the health care system.”¹⁸ A systematic literature review also supports the observations concerning religious and spiritual views of African Americans that strongly endorse beliefs in miracles and the notion that only God can determine life and death.¹⁹

So, what is the way forward? A belief in fatalism and a desire to pursue aggressive medical care as a sign of faithfulness to Christian beliefs that honor preservation of life often drive medical decisions to delay hospice referral for many African American patients and families. However, it appears that these religious beliefs can be addressed by skillful medical teams in ways that can accommodate these spiritual views and lead to less aggressive hospital care at the end of life, even in patients who report strong support from religious communities. For example, Balboni et al. found that when spiritual support and end-of-life conversations were directed by medical teams to patients with advanced cancer who reported “a high degree of spiritual support from religious communities,” these patients had *greater odds* of receiving hospice care and *lower odds* of dying in an ICU when compared to similar patients who did not receive the medical team support.²⁰ This was the case, *in particular*, for racial/ethnic minority patients in their study.

These findings indicate that medical teams have an important role to play in helping strongly religious patients reframe the meaning of their spiritual beliefs in the context of their particular medical circumstances in ways that do not exclude care in hospice and palliative care settings. The positive influence of medical teams on end-of-life choices provide support for recommendations to modify hospice eligibility to enable so-called concurrent care models such as being studied in the Medicare Care Choices Model now being launched by The Centers for Medicare & Medicaid Services (CMS).²¹ The Medicare Care Choices Model is evaluating whether disease modifying treatments when combined with traditional hospice services will improve quality of life of patients with serious and terminal medical illness. Dissemination of concurrent care models should reduce disparities between whites and blacks in access to hospice and palliative care services, since they should address the strong preferences for continuation of medical treatments so often requested by African American—a factor that has been documented as an important factor in the persistence of this inequality.^{14,22}

Serious engagement with the religiously minded majority of African Americans to promote earlier referral to palliative care and hospice, longer lengths of stay, and fewer withdrawals from hospice care requires partnerships between community-based clergy, chaplains, and hospice personnel that provide ongoing conversations and education to engage deeply specific aspects of theology and religious belief. This

may be promoted by disseminating community-based support team models that partner spiritual leaders and peers of the patient with hospice and palliative care team providers focused on meeting the emotional and spiritual needs of African Americans with serious illness.²³ This will require commitments to ongoing and truly intraprofessional education of health care providers, chaplains, and community-based pastors to assure a common understanding of the medical issues faced by terminally ill African Americans and their theological interpretations of their life and illness experiences.

In addition to lack of information, misperceptions about the motives of providers and medical institutions advocating for advance care planning and greater hospice use is another factor driving disparities. This is supported by studies showing racial differences in knowledge about hospice care.²⁴ Thus use of nonconventional strategies for soliciting and preserving the patient’s voice, such as letter writing²⁵ and videotaping,²⁶ are simple tools that allow direct and nuanced communications between patients and doctors that cut across levels of health literacy, and should be used more commonly to facilitate communication with African Americans and other racial/ethnic minorities. Thoughtful, well-constructed education programs that provide practical information about what palliative and hospice services offer, that address misconceptions about the care provided, and that are delivered by trusted sources in the community with attention to social and spiritual needs of patients and families may be successful in increasing participation in advance care planning and earlier use of palliative and hospice care. If lower rates of hospice use and other disparities persist despite use of innovative communication and educational efforts, then at least one would have greater confidence that these decisions are based on a more informed knowledge base.

There is a wise saying: “Every man is in certain respects like all other men, like some other, and like no other man.”²⁷ Respecting and responding appropriately to these three aspects of a person’s identity poses a challenge to providing truly personalized quality palliative and hospice care—care that is safe, effective, patient-centered, timely, efficient, and equitable.²⁸ In addressing African American patients and families, these challenging goals can be accomplished by a commitment to acknowledging the pernicious effects of past and present racism, learning and respecting cultural and religious values, and expanding a commitment to continuous improvement in communication between providers and patients. Furthermore, there must be a commitment to strategic and creative engagement with community partners to delivery of truly comprehensive care that focuses on the well-being of persons throughout illness in body, mind, and spirit.

There is another wise saying, attributed to Thomas Jefferson, that goes, “Do you want to know who you are? Don’t ask. Act! Action will delineate and define you.”²⁹ This is great insight and good advice indeed for all in our hospice and palliative care community committed to provide the best care possible for all persons suffering with serious illness. We must not waver from the ongoing hard work of assuring equal access and the best possible outcomes for everyone who needs hospice and palliative care. This will be key in defining the great goals and purposes of our palliative care field.

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