

Study by Former DC Commissioner of Mental Health Finds Hospice Care Benefits Black Families

Research By Howard, Harvard Alumnus Into African Americans' Views on End-of-Life Care Raises Issues of Religion, Race and Class

A year-long study of how African Americans make decisions about end-of-life care reveals strong support for hospice care and indicates intriguing areas of future research that would benefit African Americans' health. All findings are based on interviews conducted in 2003 with the primary caregivers of African Americans who died in the care of Montgomery Hospice, based in Rockville, Maryland, between January 1, 2000 and June 30, 2002. The study's author is available for media interviews.

Challenging Conventional Wisdom

In several respects, the report's findings do not support common beliefs about how African Americans make medical decisions about end-of-life care. For example, the study did not support the prevalent view among healthcare professionals that African Americans tend to wait until death is imminent to engage hospice service. The median length of stay in hospice of patients in the study was twice that of all Montgomery Hospice patients. This difference suggests that African Americans in the study were more likely, not less, to engage hospice service early in an illness.

Two questions raised by the research affect end-of-life care for African Americans in that they concern fundamental questions of spirituality and racial equality:

1) What's Faith Got to Do With It? - Caregivers in the study reported that spirituality was important to themselves and to patients. Both groups were frequent churchgoers and were often involved in other religious pursuits. However, religious concerns did not influence the decision to engage hospice services and pastors were rarely consulted while the issue was under consideration. This finding may be at odds with theories that African Americans are less inclined to accept hospice care and engage in other end-of-life planning because of their religious beliefs. More study would be helpful.

2) Do Economics & Education Outweigh Race? - The majority of interviewees reported that race played no role in their assessments of patients' medical care and in the decision to engage hospice services. However, study participants had relatively high incomes and educational levels: 83% had more than high school education. The author notes that it would be interesting to research whether lower-income African Americans feel differently about race as a factor in assessing their medical care, as well as their perceptions of how much control they have in choosing medical providers.

African Americans & Hospice Care

For reasons that researchers have never clearly identified, African Americans are underrepresented as hospice patients. By not accessing the "comfort care" of hospice, terminally ill African Americans may be more likely to suffer physically, emotionally and spiritually in their final weeks or months.

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In the study, 92% of caregivers said hospice services met or exceeded their expectations and 96% said they would recommend hospice services to other African Americans.

The study showed particular benefits of hospice care to patients' families. Half the caregivers reported that their experience with hospice had reduced their own anxieties about death by, in effect, showing them that dedicated professionals could care for them and their loved ones should they become terminally ill.

The availability of Montgomery Hospice's inpatient care facility, Casey House, seemed particularly beneficial to families in which caregivers work full-time in middle or low-paying jobs. The percentage of patients using Casey House exclusively or in combination with home care (46%) significantly exceeded that of the general Montgomery Hospice population (roughly one third). Eighty-three percent of those who used Casey House exclusively and 80% of those who used a combination of home care and Casey House said their expectations for care were exceeded. One-hundred percent of those who used Casey House exclusively worked full-time.

Who Conducted the Study and How

Among other positions held in his long career in counseling and public health, psychologist and chaplain Robert A. Washington was DC Commissioner of Mental Health from 1987 until 1992. He received his Ph.D. in Clinical Psychology and Public Practice from Harvard University in 1974. He studied at the Howard University School of Divinity and became an ordained minister in the United Church of Christ in 2003. A DC resident, Dr. Washington has cared for terminally ill patients and their families as a full-time Montgomery Hospice chaplain and bereavement counselor since July 2001.

Dr. Washington's study, which was funded by the Carpenter Foundation, consisted of in-person or phone interviews with the 24 primary caregivers of 24 African Americans who died between January 1, 2000 and June 30, 2002 while receiving care from Montgomery Hospice. The sample represents almost one-quarter of African Americans cared for by Montgomery Hospice during those 30 months.

All caregivers interviewed were African American. All interviews took place in 2003 and consisted of identical questions about demographics, faith and impressions of hospice care's impact on the patient and family.

Montgomery Hospice & African Americans

Studies such as Dr. Washington's and educational partnerships with black churches help ensure that Montgomery Hospice meets its mission of caring for all Montgomery County residents who need care. From 2000 through 2002, Montgomery Hospice tripled its percentage of African American patients to mirror the approximate overall death rate of African Americans due to illness in the county.

Montgomery Hospice is independent, nonprofit, and cares for patients regardless of their ability to pay. Every year, more than 1,000 Montgomery County residents and their families get the help they need through Montgomery Hospice's *Hospice at Home* service, *Casey House* inpatient facility, and affiliated physician practice, *Palliative Medicine Consultants*.

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