

■ CNE Article

Barriers to Using Palliative Care: Insight Into African American Culture

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As the hospice care setting becomes more racially and ethnically diverse, attending to the different conditions and needs of various groups is essential to providing optimal care. African Americans make up only a small percentage of hospice users in the United States. This article highlights barriers associated with the underenrollment of African Americans into hospice and palliative care programs. A thorough analysis of the literature was conducted to define hospice and palliative care and assess circumstances that impact the use of hospice services by African Americans. Many African Americans are not choosing hospice care because of cultural issues or knowledge deficits, whether through lack of communication or low literacy. Healthcare providers can begin by familiarizing themselves with hospice organizations and developing and putting into practice strategies to communicate with and educate patients and families about hospice care in a culturally sensitive manner.

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Hospice is a concept of care designed to provide comfort and support to patients and their families when life-limiting illness no longer responds to cure-oriented treatments. The modern hospice movement dates back to the founding of L'Association des Dames du Calvaires for the care of the dying by Jeanne Garnier in Lyon, France, in 1842 (Hospice Foundation of America, 2012; O'Mahony et al., 2008; Yancu, Farmer, & Leahman, 2010). Modern palliative and end-of-life care was pioneered by Dame Cicely Saunders in the United Kingdom in 1967 and Florence Wald in the United States in 1974, and taken up by World Health Organization (WHO) in the mid-1980s (Macaden, 2011). With hospice care and palliative care sharing the same core values and philosophies, it was believed that adding palliative care to the name would better reflect the range of services and care offered. Palliative care broadens the principles of hospice care to those individuals who could benefit from receiving services offered through hospice earlier in the disease process (National Hospice and Palliative Care Organization [NHPCO], 2012).

Defined by WHO (2012), palliative care addresses many facets of care at the end of life, with the goal of improving the quality of life of patients and their families during this time. That is done by concentrating on not only physical pain, but the emotional, spiritual, and social well-being of the patient and their family, as well. To achieve quality of life among patients and their families,

interventions in areas such as education, drug availability, and, specifically, policy, must be addressed. Good policy affords the foundation for effective health care and facilitates the implementation of programs intended to provide care for all people in need, allowing equal access to affordable products and services such as medication and therapy (Macaden, 2011; WHO, 1996).

Hospice and palliative care medicine has been approved by the American Board of Medical Specialties as a subspecialty and is a fast-growing benefit of the Medicare program (Connor, 2008; Yancu et al., 2010). The Medicare hospice benefits, enacted by Congress in 1982, are the predominant source of payment for hospice care, with the percentage of payment being about 84% versus other sources (NHPCO, 2012). Eligibility for Medicare hospice benefits requires that the patient be formally diagnosed as having a terminal illness, has a life expectancy of six months or less, and agrees to discontinue curative treatment in favor of comfort care (Stein, 2004; Yancu et al., 2010).

Although hospice services have grown, with more than 1.5 million Americans receiving hospice services in 2010, African Americans continue to underuse these services (NHPCO, 2012; Yancu et al., 2010). In fact, according to the NHPCO (2012), African Americans make up less than 9% of hospice users in the United States. Despite the acknowledgment that palliative care is an approach that improves the quality of life of patients and their families, African Americans largely still are not

using the service—a difference that holds for both genders and across age groups (Yancu et al., 2010). Why African Americans are reluctant to use the service is unclear. The purpose of this article is to summarize the literature and present reasons for the underuse of hospice services by African Americans, including cultural issues, historical perspective, and matters related to knowledge deficit.

Cultural Issues

Family

Culture informs normal responses to health and illness, healing and care for loved ones, and coping with loss. Sociologists interpret cultural values as a blueprint for living (Iwamoto, 1994). In the African American culture, caring and being cared for by a family member are valued ways to express respect and dignity for loved ones, and they take precedence over independence (Iwamoto, 1994; Taxis, 2006; Yancu et al., 2010). African Americans place trust in their loved ones to make the best end-of-life decisions. Therefore, this population seems to use advanced directives less often and has less need for documents instructing families on end-of-life decision making (Yancu et al., 2010).

Spirituality and Religion

Spirituality also has a role in African Americans' use of hospice services. The use of hospice requires acceptance of death, which is a concept conflicting with the spiritual beliefs of many African Americans because acceptance often is equated with giving up. Some African Americans would rather pray for a miracle than accept that a disease is in its terminal stages (Yancu et al., 2010). For many African Americans, spiritual beliefs lead them to view death as a transition and not as a final state and to equate being right with God with a good death experience (Bullock, McGraw, Blank, & Bradley, 2005; Campbell & Ash, 2007; Dillon, Roscoe, & Jenkins, 2012). Ideally, many African Americans would rather be in a place where their traditions are embraced and not just tolerated, meaning the inclusion of time for prayer, Bible reading, spiritual counseling, and singing religious hymns as a part of end-of-life care (Dillon et al., 2012).

Historical Perspective

Although African Americans generally approach events and share experiences similar to the Caucasian population, the African American experience has historically been compounded by racism and discrimination (Yancu et al., 2010). The legacy of slavery, abuses in medical experimentation, economic and legal injustices, and racial profiling have caused many African Americans to distrust the healthcare system (Melhado & Bushy, 2011). In fact, several participants in a research study by Pullis (2011) verbalized not liking or not trusting doctors, and others commented on remembering the Tuskegee experiment, which was a clinical study conducted from 1932–1972 by the U.S. Public Health Service to study the progression of untreated syphilis in African American men. The participants thought they were receiving free health care from the U.S. government; they were never told they had syphilis, nor were they ever treated for it. When the

study started, no treatment existed for the disease, but when penicillin became a standard cure for syphilis, the medicine was withheld because the Tuskegee scientists wanted to continue to study how the disease spreads and kills. The experiment lasted until public health workers leaked the story to the media; by that time, however, dozens of the men had died, and many wives and children had been infected as well (Chadwick, 2002). Another example of mistrust in the literature was many African Americans voicing fears of receiving inferior care if they signed advanced directives (Kagawa-Singer & Blackhall, 2001; Yancu et al., 2010).

Ineffective outreach education about hospice in African American communities may contribute to the knowledge deficit and the underuse of hospice services.

Knowledge Issues

Lack of Information and Misconceptions

General lack of knowledge about hospice services may contribute to the underuse of hospice by African Americans. Research revealed that many African Americans lacked specific information that they described as important in making decisions about enrolling in hospice care, specifically the nature of hospice services, locations, payment, and the quality of hospice care (Dillon et al., 2012). In fact, one study participant revealed that misconceptions definitely exist in the African American community about what hospice is and does (Dillon et al., 2012). The study revealed that some African Americans assumed that hospice was only available if patients had adequate private insurance, and others expressed concern that hospice care would cause a financial burden on their families (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Dillon et al., 2012). Some African Americans assumed that hospice was a location, and were unwilling to move loved ones out of their homes. Ineffective outreach education about hospice in African American communities may contribute to the knowledge deficit and the underuse of hospice services (Melhado & Bushy, 2011).

Low Literacy

The National Adult Literacy Survey reported that about 48% of American adults lack the essential literacy skills to adequately comprehend and act on health information (Melhado & Bushy, 2011). Individuals with lower health literacy tend to favor more aggressive care instead of palliative care, regardless of race (Pullis, 2011). With that in mind, low literacy may impair patient and family understanding of disease, making it difficult to make decisions regarding end-of-life care. Evidence suggests that African Americans are among the groups with low health literacy and may have a decreased ability to understand and evaluate options available to them (Pullis, 2011).

Physician Communication

Studies have found that personal biases of physicians have an impact on quality of care and, therefore, affect their ability to discuss end-of-life issues with their patients. When speaking of end-of-life care, physicians may not initially take the patient's

or family's wishes into consideration and may be reluctant to discuss palliative care or hospice care because of their comfort level. That could be attributed, in part, to the physician relying on personal rules and philosophies when treating patients (Larochelle, Rodriguez, Arnold, & Barnato, 2009; Pullis, 2011). Some physicians find it difficult to discuss prognosis and may present it in an overly optimistic fashion or avoid having the discussion entirely (Pullis, 2011). Many healthcare providers also are inefficiently educated about hospice programs and palliative care. In fact, one study revealed that physicians reported inadequate formal education in the complexities involved in providing palliative care (Goepf et al., 2008). Patients rely on their healthcare providers for information about hospice, which can be problematic when physicians frequently fail to discuss hospice with African American patients and families, who often have little information about hospice to begin with (Dillon et al., 2012). Many physicians wait for families to initiate the conversation about end-of-life care. They often avoid discussing death and dying, but death has always been a universal human experience (Dillon et al., 2012; Pullis, 2011). Patients and their loved ones now have choices as death approaches. Actively participating in informed medical decision making requires patients and their loved ones to have the knowledge necessary to understand whether hospice care could meet their needs (Dillon et al., 2012).

Implications for Nursing and Patient Education

The inability to address social differences and acknowledge the need for culturally competent health care can have a major impact on African Americans (Betancourt, Green, & Carrillo, 2002). Being culturally competent is imperative. Providing culturally competent health care involves having diverse values, beliefs, and behaviors, and being able to employ those in a way that is sensitive to members of other cultures. This may include tailoring a plan of care specific to African Americans (Betancourt et al., 2002), which is particularly useful when considering increasing enrollment of African Americans into hospice programs.

Healthcare providers can begin by familiarizing themselves with the hospice organization prior to discussing the option of hospice with patients and families. That could involve incorporating the use of an interdisciplinary team including a hospice liaison. The liaison could educate healthcare providers on different characteristics of the hospice organization, which could provide a constructive link to initiating dialogue about hospice.

When discussing hospice with African American patients and families, the healthcare provider could begin by inquiring

about their perception of hospice in an attempt to clear any misconceptions about the program. For example, some patients and families believe hospice care is only appropriate in the last hours of life (Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2010). Those fallacies must be challenged to improve enrollment in hospice care programs.

Hospice leaders advise finding out how the patient and family register the severity of the illness as a baseline to initiating conversation about hospice (Vig et al., 2010). Using that approach could potentially foster conversation that allows the healthcare provider to identify patient and family needs. Tailoring a description of hospice to meet the expressed needs of the clients is the next step (Vig et al., 2010). With that measure, the healthcare practitioner could emphasize what hospice does in a culturally sensitive way, such as that hospice care could be delivered at home if necessary, that telephone assistance is always available to patients and caregivers, and that hospice pays for most medical equipment (Vig et al., 2010). Doing so might alleviate some of misconceptions associated with hospice by African Americans.

Hospice organization leaders also recommend explaining to patients and families that they can receive services longer than six months as long as they continue to meet hospice eligibility criteria. In addition, suggesting that they try hospice care for three months while emphasizing that they can unenroll at any time and still access hospice care if needed in the future might be beneficial (Vig et al., 2010). Conversing with and educating African Americans about hospice care could afford a sense of trust and lead to an increase in the use of hospice services.

Other Interventions

NHPCO recommended that hospice organizations change the standard and establish trusting relationships with the underserved communities, including these communities in the hospice design and promotion (Reese, 2011). The challenge is not to change the African American culture, but to tailor hospice programs with measures that are culturally relevant to the people served (Reese, 2011). Cultural tailoring of interventions involves any combination of information or change in strategies intended to reach one specific person or group based on unique characteristics, related to an outcome of interest, and derived from an individualized assessment (Dillon et al., 2012).

Such change could begin with developing a connection with African Americans through community outreach strategies that focus on the role of family, spiritual considerations, and ensuring that necessary knowledge about the hospice program is delivered. That could come in the form of designing culturally appropriate messages for African Americans with family care being valued, given that caring for or being cared for by a family member is a way to show respect and dignity for many African Americans (Yancu et al., 2010). Those messages should describe the role of family in hospice and stress the physical, emotional, and spiritual support provided to the family (Dillon et al., 2012). Highlighting the inclusion of a chaplain in the interdisciplinary team could prove to be an effective strategy in increasing hospice usage by African Americans because the tailoring of spiritual support for patients and families has been described as being a primary component of hospice care in the United States by NHPCO (Dillon et al., 2012).

Exploration on the Go

A hospice in the Washington, DC, area found a large disparity between African Americans and Caucasians seeking hospice services. To access a video about the study, open a barcode scanner on your smartphone, take a photo of the code, and your phone will link automatically. Or, visit <http://wj.la/ftsmmR>.



Implications for Practice

- ▶ Reaching out to hospice leaders and building trust with leaders in the African American community may improve knowledge deficits and misconceptions about hospice in this population and increase its enrollment into hospice programs.
- ▶ The incorporation of end-of-life options in the plan of care and not delaying referrals to hospice may improve quality of life for patients at the end of their lives.
- ▶ Acknowledging cultural differences and tailoring individual care plans to ensure cultural sensitivity may improve trust among African Americans with doctors and the healthcare system, increasing use of hospice services when recommended.

Building trusting relationships with leaders of community and social centers, including church pastors, local politicians, and educators in the African American community, also could improve hospice enrollment by African Americans (Carrion, Park, & Lee, 2012). Another medium is the provision of culturally specific literature in neighborhood gathering spaces, beauty and barber shops, and religious institutions (Carrion et al., 2012). The Medicare Payment Advisory Committee (2012) reported that the majority of recipients of hospice care benefits were White, so increasing relations between diverse communities and hospice is crucial. The incorporation of more culturally competent actions into hospice programs could be the vehicle that fosters positive results in terms of hospice use by the African American community.

A need for reliable and consistent cultural education of physicians, advanced practice nurses, and other healthcare providers also is essential. The lack of cultural competence on the part of healthcare professionals may further oppress culturally diverse groups that have already faced biased behavior within the larger society (Reese, 2011). Physicians and nurse practitioners have primary control over the treatment plan of their patients, bear the responsibility of deciding whether hospice is appropriate, and should eloquently recommend it when necessary (Pullis, 2011). Healthcare providers should be able to successfully communicate the need for hospice care. Research by Goepp et al. (2008) revealed that physician participants noted priority being given to speed and volume of patient care, factors that seem to be in direct conflict with values associated with palliative care.

Conclusion

Through examining current literature, one might conclude that even efforts successful in increasing the chances that African Americans have adequate and culturally appropriate information about hospice care might fail, as not all will use these services. Research revealed that African Americans have strong reliance on religious values and may be more apt to choose aggressive treatment versus enrolling in hospice care (Dillon et al., 2012). On many occasions, hospice care has the potential to improve the quality of life for patients at the end of life and comes with many other benefits, as well. Without proper information about end-of-life options, African American patients and their families are not making informed decisions.

Although death often is referred to as the great equalizer, the care that individuals receive as they near the end of life serves as another example of the alarming health disparities experienced by African Americans (Dillon et al., 2012). Healthcare providers must inform patients of their readiness for hospice care and include the knowledge and expertise of a culturally sensitive interdisciplinary team that can make the transition meaningful for the patient and family.

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References

- Betancourt, J.R., Green, A.R., & Carrillo, J.E. (2002). *Cultural competence in healthcare: Emerging frameworks and practical approaches*. Retrieved from http://www.commonwealthfund.org/usr_doc/betancourt_culturalcompetence_576.pdf
- Born, W., Greiner, K.A., Sylvia, E., Butler, J., & Ahluwalia, J.S. (2004). Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *Journal of Palliative Medicine*, 7, 247-255. doi:10.1089/109662104773709369
- Bullock, K., McGraw, S.A., Blank, K., & Bradley, E.H. (2005). What matters to older African Americans facing end-of-life decisions? A focus group study. *Journal of Social Work in End-of-Life and Palliative Care*, 1(3), 3-19. doi:10.1300/J457v01n03_02
- Campbell, C., & Ash, C. (2007). Keeping faith. *Journal of Hospice and Palliative Nursing*, 9, 31-41. doi:10.1097/00129191-200701000-00008
- Carrion, I.V., Park, N.S., & Lee, B.S. (2012). Hospice use among African Americans, Asians, Hispanics, and Whites: Implications for practice. *American Journal of Hospice and Palliative Care*, 29, 116-121. doi:10.1177/1049909111410559
- Chadwick, A. (2002). Remembering Tuskegee: Syphilis study still provokes disbelief, sadness. Retrieved from <http://www.npr.org/programs/morning/features/2002/jul/tuskegee/>
- Connor, S.R. (2008). Development of hospice and palliative care in the United States. *Omega*, 56(1), 89-99.
- Dillon, P.J., Roscoe, L.A., & Jenkins, J.J. (2012). African Americans and decisions about hospice care: Implications for health message design. *Howard Journal of Communications*, 23, 175-193. doi:10.1080/10646175.2012.667724
- Goepp, J.G., Meykler, S., Mooney, N.E., Lyon, C., Raso, R., & Juliard, K. (2008). Provider insights about palliative care barriers and facilitators: Results of a rapid ethnographic assessment. *American Journal of Hospice and Palliative Care*, 25, 309-314. doi:10.1177/1049909108319265
- Hospice Foundation of America. (2012). What is hospice? Retrieved from <http://www.hospicefoundation.org/whatis hospice>
- Iwamoto, R. (1994). Cultural influences on quality of life. *Quality of Life: A Nursing Challenge*, 3(4), 68-73.
- Kagawa-Singer, M., & Blackhall, L.J. (2001). Negotiating cross-cultural issues at the end of life: "You got to go where he lives." *JAMA*, 286, 2993-3001. doi:10.1001/jama.286.23.2993
- Larochelle, M.R., Rodriguez, K.L., Arnold, R.M., & Barnato, A.E. (2009). Hospital staff attributions of the causes of physician variation in end-of-life treatment intensity. *Palliative Medicine*, 23, 460-470. doi:10.1177/0269216309103664
- Macaden, S.C. (2011). Moving toward a national policy on palliative and end of life care. *Indian Journal of Palliative Care*, 17(Suppl.), S42-S44. doi:10.4103/0973-1075.76242

Medicare Payment Advisory Committee. (2012). *Report to the Congress: Medicare payment policy*. Retrieved from http://www.medpac.gov/documents/Mar12_EntireReport.pdf

Melhado, L., & Bushy, A. (2011). Exploring uncertainty in advance care planning in African Americans: Does low health literacy influence decision making preference at end of life. *American Journal of Hospice and Palliative Care, 28*, 495-500. doi:10.1177/1049909110398005

National Hospice and Palliative Care Organization. (2012). *NHPCO facts and figures: Hospice care in America*. Retrieved from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2011_Facts_Figures.pdf

O'Mahony, S., McHenry, J., Snow, D., Cassin, C., Schumacher, D., & Selwyn, P.A. (2008). A review of barriers to utilization of the Medicare hospice benefits in urban populations and strategies for enhanced access. *Journal of Urban Health, 85*, 281-290. doi:10.1007/s11524-008-9258-y

Pullis, B. (2011). Perceptions of hospice care among African Americans. *Journal of Hospice and Palliative Nursing, 13*, 281-287. doi:10.1097/NJH.0b013e31821adb18

Reese, D.J. (2011). Proposal for a university-community-hospice partnership to address organizational barriers to cultural competence. *American Journal of Hospice and Palliative Care, 28*(1), 22-26. doi:10.1177/1049909110370744

Stein, G.L. (2004). Improving our care at life's end: Making a difference. *Health and Social Work, 29*(1), 77-79. doi:10.1093/hsw/29.1.77

Taxis, J.C. (2006). Attitudes, values, and questions of African Americans regarding participation in hospice programs. *Journal of*

Hospice and Palliative Nursing, 8, 77-85. doi:10.1097/00129191-200603000-00011

Vig, E.K., Starks, H., Taylor, J.S., Hopley, E.K., & Fryer-Edwards, K. (2010). Why don't patients enroll in hospice? Can we do anything about it? *Journal of General Internal Medicine, 25*, 1009-1019. doi:10.1007/s11606-010-1423-9

World Health Organization. (1996). *Cancer pain relief* (2nd ed.). Geneva, Switzerland: Author.

World Health Organization. (2012). WHO definition of palliative care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>

Yancu, C.N., Farmer, D.F., & Leahman, D. (2010). Barriers to hospice use and palliative care services use by African American adults. *American Journal of Hospice and Palliative Care, 27*, 248-253. doi:10.1177/1049909109349942

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