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Barriers to Hospice Use and Palliative Care Services Use by African American Adults

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This study explored the reasons for low levels of hospice participation by African Americans. *Methods*: Data about attitudes toward dying and death, advanced directives, and barriers to using hospice services were collected from 314 adults attending 11 diversely populated churches in North Carolina. *Results*: Almost all participants indicated (91%) willingness to use hospice, particularly if the hospice team were diverse (77%). Most are without a living will (72%) or health care power of attorney (81%); approximately half (54%) have shared final care wishes. *Discussion*: Despite evidence of a willingness to use hospice, African Americans were unlikely to complete advanced directives or share final care wishes. However, many were more likely to use hospice if the care team were diverse suggesting the importance of culture.

Keywords: End-of-life care planning; cultural values

Introduction

Hospice is a singular concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments.[1] The goal is to improve the quality of a patient's last days[2] by addressing the biopsychosocial symptoms of a disease. A special emphasis is placed on pain control and offering comfort and dignity using a team-oriented group of specially trained professionals, volunteers, and family members. Hospice's focus on palliative rather than curative care helps patients manage physical, spiritual, social, and practical issues and assists families through bereavement for a year following the death of a family member.[3]

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Hospice: A Philosophy of Care

Although scholars believe that the concept of compassionate care is deeply rooted in human history, the modern hospice movement dates back to the founding of L'Association des Dames du Calvaire for the care of the dying by Jeanne Garnier in Lyon, France, in 1842.[3] Hospice and palliative care medicine has been approved as a subspecialty by the American Board of Medical Specialties and is today the fastest growing Medicare benefit program.[4] Eligibility for the Medicare hospice benefit requires that patients must be formally diagnosed as having a terminal illness with a life expectancy of 6 months or less and agree to discontinue curative treatment in favor of comfort care.[5]

Hospice has grown dramatically in the last 30 years. In 2005, more than 1.2 million Americans received hospice care at more than 4000 hospice sites around the country.[4] In spite of its growth, 2 service-related factors remain a challenge for providers. The first is that those who enroll do so late in their illnesses, often in the last week of life.[6] More significantly for this study, its use among nonwhite minorities has not increased substantially in recent years; there is some indication that it has declined.[7]

Only about 8% of hospice patients are African American.[2,7-10] This difference holds for both men and women and across age groups.[11]

Theoretical Framework: Palliative Care, Advanced Directives, and African American Cultural Beliefs and Practices

Current research shows that African Americans are significantly less likely to complete advanced directives and more likely to express concerns about hospice care.[12] If hospice care is dedicated to improving quality of life for all patients at the end of life it is reasonable to ask why African Americans are less likely to use palliative care services than terminally ill white patients. The premise underlying the current study is that the hospice philosophy represents core values of the dominant white culture: independence, individual rights, acknowledgement of death, focus on quality of life, and fear of receiving too much care at the end of life.[9] This philosophy is inconsistent with non–Anglo-American values,[13] in particular African American cultural attitudes about planning for end of life, preferences for life-prolonging treatments regardless of prognosis, and attitudes toward dying.

Culture informs normal responses to health and illness, healing and care for loved ones, and coping with loss.[13] Sociologists interpret cultural values as a blueprint or design for living. In African American culture, caring for and being cared for by a family member is a valued way to express respect and dignity for loved ones and takes precedence over independence.[7] Decision-making styles also vary. In contrast to the hospice focus on the individual's right to make end-of-life decisions, African Americans place trust in families to make the best end-of-life care decisions.[9,7] Historically, the extended family structure typical of the African American community has provided members with an invaluable resource pool for coping with social adversity and the crises associated with serious illness and death.[14] Thus, there is less use of advance directives and less perceived need for documents instructing the family on end-of-life decision making.[7,9,15-18] In fact, many African Americans fear they would receive inferior care if such documents were signed.[9]

Use of hospice requires that both the patient and the family acknowledge impending death, a concept that often runs counter to African American spiritual beliefs. God is benevolent and has miraculous powers and only he can make life and death decisions.[9,10,19] Some would rather pray for a miracle than accept terminality, which may be viewed as a breach of faith. A reluctance to plan for death echoes a belief that death is accepted as a welcome friend and will come when it is God's will.[8,10]

The hospice focus on quality rather than quantity of life also differs from the common African American belief in longevity and the redemptive nature of suffering.[7-10,17,19] Although studies show that patient preference for life-sustaining treatment over palliative care may be a common cultural barrier to hospice admission, the ethic of struggle over surrender may be more important than quality of life among African Americans.[7,9,10,19] Moreover, hospice is often equated with giving up.[7,20] This focus on fighting for survival may be a culturally adaptive response to 2 centuries of adversity and is often coupled with a desire for aggressive treatment,[7,9,12,19] less likelihood of agreeing to withdrawal of life support,[7] the belief that longevity is intrinsically good,[17,19] and emphasis on living and prolonging life.[7] This is counter to the mainstream, predominantly white fear of too much care at the end of life.

Institutional Reasons for Low Use of Hospice by African Americans

In addition to cultural and spiritual differences in attitudes toward end of life, there are a number of institutionalized barriers to hospice use by African Americans. Importantly, although African Americans share many of the same stressful circumstances as the white population, for example, inflation, unemployment, natural disasters, and illness, the African American experience has historically been compounded by racism and discrimination.[14] Use of hospice requires ultimate trust[20] and African Americans have a long and often justified mistrust of the medical system.[3,7,8,10,16,17,19] The requirement of a physician's certification of a terminal illness with a prognosis of 6 months or less is problematic for a number of reasons. Patients and families may refuse to acknowledge that the patient is dying[21,20] and either do not request or refuse to accept such information from a physician. Many African Americans are socioeconomically impoverished and lack a regular primary care physician to make a trusted diagnosis.[3,7,10] Adding to socioeconomic differences, many physicians are reluctant to discuss their patients'

end-of-life care preferences and may wait for families to initiate the conversation.[6] Differential treatment within the health care system leads to less physician explanation of medical conditions, test results, treatment options, shared decision making,[9,19,22,23] and lack of discussion and recommendation of hospice.[3,8,24]

Another barrier, common to the general public and particularly pertinent to African Americans, is lack of knowledge about access to hospice care and lack of understanding of the mechanics of hospice services.[7,8,16,19,20] A reluctance to go outside the network of family and friends for help with care for a loved one[19] is compounded by an unwillingness to have health care workers in one's home,[7] particularly if those workers are primarily white. Additionally, a lack of racial/ethnic diversity among most hospice teams[3,7,19] and perceived lack of cultural sensitivity[3] are also contributing factors. Finally, there are fears about cost and reimbursement issues.[3,8,10]

Purpose of the Study

The purpose of this study is 2-fold: (1) to assess the use of hospice by African Americans in the piedmont area of North Carolina and (2) to ascertain the reasons why African Americans in this area would or would not use hospice themselves or for the care of a loved one with a terminal illness.

Methods

Selection and Description of Participants

This study used a cross-sectional, quantitative design. The study was a collaborative effort between Hospice and Palliative CareCenter (HPCC), a hospice that serves 13 counties in North Carolina, and Leadership Winston-Salem, a civic organization with the mission of educating, connecting, and energizing leaders to serve and improve the community.

Surveys were completed by 314 male and female adults, 18 years old and older, at 11 predominantly African American churches in Forsyth County, NC, between October 2006 and May 2007.

Data Collection and Measures

Participants completed a 32-item questionnaire that included demographic information and questions that assessed attitudes about dying and death, advance directives, and willingness and barriers to using hospice services. Demographic information included age, gender, race/ethnicity, marital status, education, work status, household income, self-rated health, and having health insurance.

Attitudes about dying and death included participants' level of comfort in talking about their own deaths or the death of someone close to them, planning their own funerals, and making care decisions for a loved one. Advanced directive questions focused on participants' level of understanding and prior completion of the following documents: living will, health care power of attorney, durable power of attorney, and last will and testament.

Willingness to use hospice services was assessed through questions such as "If you were very sick and your doctor recommended hospice care for you, would you agree to that?" and "Where would you prefer your end-of-life care?" with hospice listed among the possible responses. Participants were also asked whether they would be more likely to use hospice services if they could be certain that their care team would be ethnically and racially diverse. Barriers to hospice use were ascertained through yes/no questions covering the following areas: cost of services, knowing how to contact hospice, knowing what hospice does, thinking hospice means giving up hope, and likelihood of physician recommending hospice.

Data Analysis

Data were analyzed through univariate and bivariate techniques using the statistical package for the social sciences (SPSS).[25] Univariate descriptive analyses were performed on all variables using means and ranges, numbers, and percentages. Bivariate analyses using cross-tabs and Cramer V measured the strength of the relationships among independent variables and reasons given for reluctance to use hospice care. χ^2 estimated statistical significance. An α level of .05 was set to prioritize the strongest relationships.

Results

Descriptive Results

Participants were predominantly older (200, 64%, 50+), female (210, 67%), married or partnered (176, 56%), and in good/excellent health (275, 89%) with a range of educational and work statuses

Table 1. Descriptive Characteristics of Sample (N = 314)

Variable	n (%)
Age (years)	
18-30	20 (6.4)
31-50	93 (29.7)
51-75	181 (57.8)
75+	19 (6.1)
Gender	
Male	93 (30.7)
Female	210 (66.9)
Education	
High school or less	109 (36.1)
Associate degree	40 (13.2)
College degree	79 (26.2)
Professional/graduate degree	73 (24.2)
Marital status	
Married/partnered	176 (56.1)
Separated	10 (3.2)
Divorced	48 (15.3)
Widowed	29 (9.2)
Never married	51 (16.2)
Annual household income	
<US$20 000	43 (14.5)
US$20 001-US$50 000	121 (40.9)
>US$50 000	132 (44.6)
Employment status	
Full time	162 (53.6)
Part time	17 (10.9)
Retired	90 (29.8)
Unemployed	17 (5.6)
Self-rated health	
Good/excellent	275 (89.3)
Fair/poor	33 (10.7)

(Table 1). More than a third (109, 36%) had a high school education or less; half (152) had a college or graduate degree. Slightly more than half (162, 53%) were employed full time and nearly a third (90, 30%) were retired. Nearly half (132, 45%) had an annual household income of US$50 000 or more; only a few (43, 15%) had annual household incomes <US$20 000.

Research Findings

Very few of the participants in this study reported having a living will (29, 32% of men and 55, 26% of women) or health care power of attorney (18, 20% men and 38, 18% women; Table 2). Older adults were more likely than younger adults to have a living will (64, 32% of 50+, 22, 20% <50) and health care power of attorney (46, 23% of 50+, 13, 12% <50). More men and women, younger and older adults, had a last will and testament (115, 37%) than a living will (84, 27%) or health care power of attorney (56, 18%).

More women (138, 82%) than men (51, 66%) stated that they would be willing to use hospice if the team were diverse (Table 3). Most would use hospice if recommended by their physician (177, 93% female, 71, 87% male) particularly those who were more educated. The vast majority, especially those younger than 50, believed that hospice provides the same care for all racial groups (85, 96% <50, 147, 87% 50+). Those with lower levels of education (45, 48%) were more likely to believe African Americans use hospice as frequently as whites.

Barriers to hospice use included a preference for taking care of loved ones at home and the belief that hospice means giving up hope. Among individuals who reported barriers, a higher percentage of those who want to keep loved ones at home were in excellent/good health (n = 54, 96.4% vs 75, 85.2%; $P = .03$). A higher percentage of those who felt that hospice would not be too costly had annual incomes >US$20 000 (n = 91; 86.7%, US$20 000 plus/year vs 28, 71.8%; $P = .04$). Additionally, a higher percentage of those who believe that hospice is not too expensive were older than 50 (71, 67.6%, vs 20, 46.5%, 50+; $P = .01$). Although women were nearly twice as likely as men to equate hospice use with giving up hope, the difference did not reach significance (Table 4).

Discussion

The results support lack of knowledge and cultural differences in attitudes toward dying as primary barriers to hospice use by African Americans. Many were reluctant to use hospice because they preferred to care for their loved ones at home indicating a lack of knowledge about hospice services, confirming what has been found in other studies.[7,8,16,19,20]

Cultural values of not accepting a terminal diagnosis and reluctance to plan for death were also evident. Many believed that hospice meant giving up hope. Analogous to what was found in the literature,[7,9,15-18] most had not shared final care wishes or completed advance directives despite endorsing a willingness to use hospice services.

Lack of trust does not appear to be a major barrier to hospice use; most believe that hospice provides equal care to all racial groups. However,

Table 2. Persons With End-of-Life Care Directives in Place

Variable		Has a Last Will and Testament	Has a Living Will	Has Appointed a Health Care Proxy
Gender	Male	37 (40.2)	29 (31.5)	18 (19.6)
	Female	73 (34.9)	55 (26.3)	38 (18.2)
Age group	Adult	30 (26.5)	22 (19.5)	13 (11.5)
	Older adult	85 (42.9)[c]	64 (32.3)[c]	46 (23.2)[c]
Marital status	Not partnered	45 (32.6)	34 (24.6)	22 (15.9)
	Partnered	70 (40.2)	52 (29.9)	37 (21.3)
Education	12 years or less	32 (29.6)	21 (19.4)[d]	17 (15.7)
	2- to 4-year college	42 (35.6)	38 (32.2)	21 (17.8)
	Professional/graduate school	37 (50.7)[c]	25 (34.2)	20 (27.4)
Work status	Not working	49 (45.8)	35 (32.7)	25 (23.4)
	Employed	65 (33.7)[b]	45 (23.3)[b]	30 (15.5)[a]
Health status	Fair/poor	8 (25.0)	10 (31.2)	6 (18.8)
	Excellent/good	107 (39.1)[d]	76 (27.7)	53 (19.3)

a. $P < .1$ (1-tail test).
b. $P < .05$ (1-tail test).
c. $P < .01$ (1-tail test).
d. $P < .05$ (2-tail test).

Table 3. Hospice and Palliative Services Consideration by Basic Descriptive Characteristics

Variable		Believes That African Americans Use Hospice as Often as Whites	Believes Same Care Received Across Racial Groups	Would Use If Care Delivery Teams Were More Diverse	Has Shared End-of-Life Wishes With Another	Would Use Hospice if Recommended by Physician
Gender	Male	31 (37.8)	72 (88.9)	51 (66.2)	50 (54.9)	71 (86.6)
	Female	66 (36.9)	151 (89.9)	138 (82.1)[c]	110 (53.4)	177 (92.7)[a]
Age group	Adult	38 (29.6)	85 (95.5)	66 (73.3)	56 (50.0)	91 (89.2)
	Older adult	64 (36.8)	147 (87.0)[b]	130 (79.3)	110 (56.1)	167 (91.8)
Marital status	Not partnered	51 (43.6)	94 (86.2)	87 (78.4)	74 (53.6)	115 (92.0)
	Partnered	51 (33.3)[a]	138 (92.6)[a]	109 (76.2)	92 (54.1)	143 (89.9)
Education	12 years or less	45 (48.4)	84 (89.4)	68 (80.0)	54 (50.0)	83 (83.8)[d]
	2- to 4-year college	36 (35.6)	87 (90.6)	77 (77.8)	61 (51.7)	100 (93.5)
	Professional/graduate school	15 (23.4)[e]	52 (91.2)	41 (69.5)	45 (61.6)	63 (95.5)
Work status	Not working	30 (32.6)	82 (88.2)	68 (80.0)	62 (59.6)	86 (87.8)
	Employed	68 (40.5)	143 (91.7)	120 (74.5)	99 (51.3)	161 (92.5)
Health status	Fair/poor	9 (37.5)	25 (92.6)	24 (88.9)	23 (69.7)	26 (89.7)
	Excellent/good	90 (37.3)	89.4 (203	169 (75.8)	142 (52.0)[b]	226 (90.8)

a. $P < .1$ (1-tail test).
b. $P < .05$ (1-tail test).
c. $P < .01$ (1-tail test).
d. $P < .05$ (2-tail test).
e. $P < .01$ (2-tail test).

as other studies have found, a perceived lack of diversity among hospice workers is problematic[3,7,19]; many would use hospice services if the care team were diverse suggesting that culture and possibly mistrust of the health care system influence the decision to use hospice.

The results of this study should be viewed with several limitations in mind. First, the small sample size may limit the ability to uncover some relationships. However, this limitation is to a degree offset by this study's focus on the attitudes, beliefs, preferences, and practices of a nonpatient population

Table 4. Main Reasons Given for Reluctance to Use Hospice Care in Order of Importance

Variable		Take Care of Loved One at Home, N = 149 (47.5)		Hospice Means Giving up Hope, N = 148 (47.1)		Hospice is Too Expensive N = 148 (47.1)	
		No	Yes	No	Yes	No	Yes
Gender	Male	26 (30.2)	21(37.5)	29 (30.9)	18 (37.5)	34 (34.0)	13 (31.9)
	Female	60 (69.8)	35 (62.5)	65 (69.1)	30 (62.5)	66 (66.0)	29 (69.0)
Age group	Adult	30 (33.0)	27 (47.4)	37 (37.4)	20 (40.8)	34 (32.4)	23 (53.5)
	Older adult	61 (67.0)	30 (52.6)	62 (62.6)	29 (59.2)	71 (67.6)	20 (46.5)
						CV = .197	
						P = .014	
Marital status	Not partnered	42 (46.2)	24 (42.1)	47 (47.5)	19 (38.8)	45 (42.9)	21 (48.8)
	Partnered	49 (53.8)	33 (57.9)	52 (52.5)	30 (61.2)	60 (57.1)	22 (51.2)
Education	12 years or less	38 (43.2)	22 (40.0)	37 (38.9)	23 (47.9)	40 (39.6)	20 (47.6)
	Some college	50 (56.)	33 (60.0)	58 (61.1)	25 (52.1)	61 (60.4)	22 (52.4)
Income	<US$20 000/year	17 (19.3)	8 (14.3)	16 (16.5)	9 (19.1)	14 (13.3)	11 (28.2)
	US$20 000 or more/year	71 (80.7)	48 (85.7)	81 (83.5)	38 (80.9)	91 (86.7)	28 (71.8)
						CV = .174	
						P = .036	
Work status	Not working	30 (34.1)	21 (36.8)	36 (36.7)	15 (31.9)	40 (38.8)	11 (26.2)
	Employed	58 (65.9)	36 (63.2)	62 (63.3)	32 (38.1)	63 (61.2)	31 (73.8)
Health status	Fair/poor	13 (14.8)	2 (3.6)	9 (9.4)	6 (12.5)	11 (10.7)	4 (9.8)
	Excellent/good	75 (85.2)	54 (96.4)	87 (90.6)	42 (87.5)	92 (89.3)	37 (90.2)
		CV = .179					
		P = .026					

Abbreviation: CV = Cramer V.

rarely seen in larger clinical studies. A second and important limitation is that this study involved a single, church-based population limited to a relatively small geographic area. Generalizability to a broader population of African Americans should be viewed with extreme caution. Nonetheless, this sample is heterogeneous with respect to several important factors, including age and socioeconomic status. Finally, these data are the product of secondary analysis. Questions that could lead to ambiguity in sample response were interpreted conservatively; for example, in the question "Has anyone in your family ever used hospice service?" the word service could be interpreted in multiple ways.

Although palliative care itself is well established, effective service delivery models designed to reach increasingly ethnically diverse populations is still lacking.[12] Future research should include a more in-depth, qualitative exploration of culture-specific attitudes and concerns about end-of-life care, preferences, and planning; the resultant knowledge should be used to develop a culturally sensitive, evidence-based, educational training tool for health care professionals, hospice teams, and family caregivers to broaden knowledge and understanding of cultural beliefs and attitudes surrounding end-of-life care. Among African Americans specifically, the evidence provided by this and other studies, for example, Johnson et al,[12] suggests that such qualitative data would be an invaluable tool to extend palliative care's outreach to this population.

This study contributes to our understanding of the cultural concerns of male and female, younger and older African American adults, about hospice and some of the barriers to its use. This information is valuable to hospices as they seek to reach a broader racial/ethnic population of clients. It suggests that more community education on the purposes and practices of hospices, particularly among the African American community, and that a willingness to respect and honor a broader range of attitudes and beliefs about dying and death will enhance the ability of hospices to serve nonwhite constituents.

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