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Are there Racial Differences in Attitudes Toward Hospice Care? A Study of Hospice-Eligible Patients at the Visiting Nurse Service of New York

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Research on African American and white attitudes, perceptions, and knowledge of hospice care has focused predominantly on patients and providers in institutions and community-based care settings. Little is known about patients receiving home health services, despite growing trends toward noninstitutional care in the United States. This study of home health clients who are eligible for hospice, but not currently receiving it, found few differences between racial groups with regard to attitudes about end-of-life care. An alarming proportion of African American

and white home health clients held erroneous ideas about hospice care and had not discussed this option with their providers. These findings suggest that increased referrals to home-based hospice care among home health clients depend on the availability and professional dissemination of accurate, spiritually sensitive information.

Keywords: home health services; visiting nurse services; racial disparities; knowledge of hospice; attitudes toward end of life

The enrollment of patients in appropriate end-of-life care, where the focus of services can transition from aggressive, curative treatment to the palliation of symptoms and psychosocial and spiritual preparation for death, can benefit both patients and family caregivers immensely. Despite significant increases since 1975, however, hospice care is still underused in America. In 2000, only 25% of Americans were under hospice care at the time of their death.¹

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A significant body of literature reports and assesses the roots of observed racial disparities in hospice use.¹⁻³ Encouragingly, the percentage of African American hospice patients more than doubled between 1990 and 2000, jumping from 6% to 14.6%.¹ The percentage of white hospice patients fell slightly as the proportion of multiracial, Asian, and Hispanic hospice patients grew from 2003-2004² according to the National Hospice and Palliative Care Organization.⁴ Despite the overall increase in minority hospice patients, variations in use by socioeconomic status and race persist. For example, in a study of hospice usage among older adults with breast, colorectal, lung, or prostate cancer, Lackan et al⁵ found a decrease from 1990 to

¹ The data includes: white, black, multiracial, Hispanic and Asian/Pacific. Given patterns in census and other data collection activities, we may speculate that African Americans are more likely to select multiracial than the other nonwhite groups. However, it is impossible to know for sure in this sample.

1999 in utilization differences associated with types of insurance, urban residence, marital status, and income. However, during the same time, this same study found no change in the variation in hospice use for racial groups and persons with different levels of education.

The research presented here is unique in that its focus is on home health patients with a poor prognosis, a population yet to be examined. Though small in size, the study compares the responses of non-Hispanic white and African American patients regarding their respective attitudes, beliefs, and expectations about hospice care and end-of-life issues. This research is part of a larger study, a collaboration between the New York Academy of Medicine (NYAM) and the Visiting Nurse Service of New York (VNSNY), which examines factors that might explain the disparate hospice referral patterns found among minority patients within VNSNY. The larger initiative includes the development and testing of a pilot intervention to increase hospice referral rates of eligible patients, particularly minority patients. A more detailed discussion of the implementation and impact of the intervention will be described in a separate paper.

The results reported here highlight the attitudes and expectations of patients in home care before they obtain hospice care. These results offer a unique perspective on patients who might be expected to transition from traditional home care to home hospice and provide information for providing end-of-life care for these individuals.

Background

Disparities in the use of hospice services among racial minorities has been studied from many perspectives and has been attributed to variations in health care beliefs, cultural barriers and racial bias, lack of insurance, lack of information, low referral rates from visiting nurses and nursing homes, lower socioeconomic status, and a general mistrust of the medical system. However, no studies have been able to define the relative influence of these factors on hospice usage.

In one of the earliest studies of disparities in attitudes toward hospice, Neubauer and Hamilton⁶ found that race was the only independent variable significantly related to items intended to measure *attitudes* toward death and dying and by extension, to hospice care. Whites were more likely to hold attitudes and beliefs that are considered amenable to acceptance

of hospice, such as preference to die at home, desire not to live as long as possible under almost any circumstance, and belief that death should not be avoided at all costs. These findings have formed the foundation of subsequent research on racial disparities. For example, Reese et al,⁷ Waters,⁸ and others have posited that African Americans prefer aggressive, life-sustaining therapies as opposed to palliative care. However, in each of these studies, attitudes were not linked to actual usage patterns.

Studies of racial variation in hospice usage are often focused on attitudes and perceptions that may serve as barriers to care. Qualitative studies, primarily using focus groups and interviews, have been conducted with patients, family members, and religious leaders in the community,⁷⁻⁹ providers in hospitals,^{10,11} and providers in health maintenance organizations¹² to ascertain perceptions, knowledge, and attitudes of African Americans toward hospice and end-of-life care. In addition, there is evidence that the communication styles of providers, such as physicians, nurses, and social workers, may contribute to low rates of hospice usage, particularly with regard to minorities.^{12,14} Moreover, aside from the demonstrated inadequacy of provider-patient communication concerning hospice, there is evidence that physicians are often unable (or unwilling) to accurately estimate how long a patient is likely to live, a prerequisite of eligibility for hospice care.^{15,16}

Discussions with VNSNY Adult Home Health Program nurses identified several other possible barriers to referral to hospice. Physicians, the nurses observed, were averse to raising the issue of hospice, thereby avoiding discussion that the patient is suffering from a terminal illness and leaving the nurse in a difficult quandary. The nurses expressed discomfort in approaching the topic of hospice care with patients and families and believed they lack the knowledge and assessment skills necessary to recommend hospice care. In addition, their patients, the nurses believed, were not sufficiently knowledgeable about hospice care and furthermore, held attitudes that were inconsistent with hospice practices.

Study Setting and Methods

Study Setting

The Visiting Nurse Service of New York is the largest nonprofit home health provider in the United States. It deploys a staff of 2450 nurses, 690 rehabilitation therapists, 600 social workers, and 5980 home health

aides, who provide care to people of all ages and socioeconomic backgrounds. In 2005, VNSNY served 92 818 patients (105 493 cases). The Adult Home Health Program deploys 87 teams in 5 New York City boroughs, and in Nassau and Westchester Counties. Each team consists of a manager and a core group of front-line registered nurses (RNs), therapists, and social workers, plus home health aides.

Referrals from VNS Adult Home Health Program to the VNS Hospice Program represent 23% of all referrals to the Hospice Program. Other referral sources to the VNSNY Hospice Program include hospitals (47% in 2005), skilled nursing facilities and physicians (each at 12%), and others (6%). This somewhat low referral rate to VNSNY Hospice from the VNSNY adult program was a primary motivator for examining the potential barriers that impede and hinder referrals from home health care to hospice care.

Survey Sample

A purposive sample of 32 patients admitted to the VNSNY adult home care program between January 1 and May 31, 2005 were surveyed. The literature provides scant attention to research on home hospice, focusing instead on institution-based hospice care in hospitals and nursing homes. Moreover, attention is frequently directed to caregivers, providers, and administrators rather than the patients themselves. For the present study, inclusion criteria were white, African American, and Hispanic home health patients who spoke English and who, on admission, were assessed as having: (1) a life expectancy of less than 6 months; (2) a poor prognosis, with little to no recovery expected; (3) access to a phone; and (4) the ability to complete a 30-minute interview (ie, not severely dependent in activities of daily living). In addition, each potential subject was given a cognitive screen using the Mini-Mental Health Index and was able to give informed consent. Initially, patients who did not have an informal caregiver living in the home were excluded, since a complementary interview was to be conducted with informal caregivers. This requirement, however, was dropped because of the low number of informal caregivers available for interview.

The final sample included 19 African American (non-Hispanic), 13 white (non-Hispanic), and 4 Hispanic respondents. The Hispanic respondents were excluded from the analysis reported here because the number was too small for separate analysis, and

based on a review of their responses, it was concluded that they should not be combined with the white or African American group.

Survey Instrument

Based on a review of the literature, a survey instrument on potential barriers and reasons for disparities in home hospice use was developed. Four domains were identified that may influence end-of-life care and explain why non-white patients differ from their white counterparts regarding hospice use: (1) demographic and clinical characteristics; (2) general attitudes toward health care; (3) spirituality and religious beliefs; and (4) hospice knowledge and perceptions. We constructed the instrument, to the extent possible, using questions from previously validated scales or questions fielded in other studies.^{7,17,18} Responses to the majority of the questions were measured using a 4-point Likert scale.

Procedures

Potential respondents were identified on a weekly basis using information in VNSNY clinical and administrative databases. If a patient met study eligibility criteria, a member of the VNSNY study team contacted the appropriate home health nurse to ask that the patient be informed, either by phone or on their next visit, that a member of the VNSNY research project team would be calling to discuss the study. The purpose of having the nurse inform the patient of the impending call from project staff was to allay any fear or distrust and increase patient participation. The nurse also assessed the patient's ability to participate in a 30-minute phone conversation. With the nurse's approval, a member of the study team then called patients to discuss the study and obtain written consent for release of personal health information (PHI) to NYAM team members who were conducting the phone interviews. A password-protected spreadsheet containing the information necessary to initiate the phone interview was sent to a NYAM team member each week. Both the VNSNY and NYAM Institutional Review Boards approved the study protocols and procedures.

Analytic Methods

Demographic and health status information was obtained from each respondent's admission assessment

(through the Outcome and Assessment Information Set, or OASISⁱⁱ) and linked to each participant's survey responses. The Outcome and Assessment Information Set is a standardized clinical assessment instrument collected on admission to home care and at subsequent points over the course of a patient's stay.

As indicated above, the survey contained many questions that asked respondents to assess, using a 4-point Likert scale (1 = strongly agree, 2 = agree, 3 = disagree, and 4 = strongly disagree), their level of agreement with a statement. In this analysis, "strongly agree" and "agree" were combined into a single "agree" category. All other responses, including "don't know" and "refused," were grouped into a "does not agree" category. "Don't know" and "refused" were rare, and only 2 questions had 4 such responses (the maximum for all Likert-response questions). Fischer exact test was used to determine the probability of observing the differences reported in the text and tables, with *P* values reported for 2-tailed tests of statistical significance.

Results

The median age for the sample was 67, though African American respondents were significantly younger (median age = 64) than non-Hispanic whites (median age = 78). Whites were more likely (62% vs 26%) to have had some or to have completed college and much more likely to get their primary health care at a private doctor's office (92% vs 37%) rather than a clinic, though neither correlation was statistically significant at conventional levels. The 2 groups were similar with regard to gender and marital status. Medicare was more likely to be a payer for whites than African Americans; African Americans were more likely to have Medicaid or private insurance, but the association was not statistically significant.

Clinical Characteristics

Data on primary diagnosis, which originated from the OASIS database, found that 57% of the respondents had primary diagnoses other than cancer or other leading causes of death in the United States,^{iii,19}

ⁱⁱ See http://www.cms.hhs.gov/OASIS/01_Overview.asp for more information on the OASIS system.

ⁱⁱⁱ Centers for Disease Control lists the leading causes of death as heart diseases, cerebrovascular diseases, cancer, respiratory diseases, liver diseases, diabetes, and HIV.

although a greater share had these as either a primary or secondary diagnosis. In our sample, there was little variation between African American and non-Hispanic white respondents with regard to primary diagnosis.

As a group, 44% of all respondents reported daily or constant pain, and 37% reported pain scores of 4 or more on a scale of 0 to 10. However, African Americans were significantly more likely to report these levels of pain than whites ($P = .037$ and $P = .035$, respectively). In addition, 40% of the respondents reported shortness of breath with moderate or minimal exertion, 28% reported daily bouts with anxiety, and 16% displayed at least 1 symptom of depression. African Americans were significantly more likely to suffer from shortness of breath with exertion ($P = .047$) and to report feeling anxious on a daily basis ($P = .044$), but with regard to depressive feelings, there was no difference between the groups. In short, these data suggest that African American respondents are frailer and more debilitated than whites.

Attitudes Toward Providers and Services

When asked to characterize their beliefs about patient-provider communications, almost three-quarters of all the respondents (72%) believed that "providers and patients should share control over health care," 75% stated that their "providers listened to their hopes and dreams," and only 28% stated, "I feel my health care provider should pay more attention to my wishes" (Table 1). These data suggest some compatibility between patient and provider communications. However, there are signs that provider-patient relationships are rocky: only about one-fifth of both white and African American respondents reported that their provider had sensitively discussed their religion/spirituality. More striking, almost 20% of the respondents believed they would receive better care if they were a different race/ethnicity and, most notable, all those who agreed with this statement were African American ($n = 6$).

The finding that African Americans feel they receive inferior care confirms the findings of Crawley et al,²⁰ Jackson et al,⁹ Reese et al,⁷ and others who have stated that disparities in hospice use may stem from historic mistrust, among minorities, of the medical care system. Although African Americans in the present study may have mistrusted the adequacy of their care, they hold similar views as white respondents

Table 1. Attitudes and Expectations Toward Providers and Treatments of African American and White Home Health Patients Eligible for Hospice Care

	White, Non-Hispanic (n = 13)	Black/ African American (n = 19)	Total (N = 32)	P
Providers				
Agree that providers should pay more attention to my wishes for medical care	15%	37%	28%	.249
Agree that providers have listened to hopes, dreams, fears and beliefs as much as I wanted	77%	74%	75%	1.00
Believe that patient and doctor should share control over medical care equally	62%	79%	72%	.721
Agree that I would receive better care if different race/ethnicity	0%	32%	19%	.059
Hopes and Expectations for current medical treatment				
Agree that medical treatment will make me feel more comfortable	85%	89%	88%	1.00
Agree that medical treatment will help me become more active	85%	95%	91%	.552
Agree that medical treatment will cure my illness	62%	58%	59%	1.00

regarding expectations and attitudes about patient-provider communications.

Treatment Preferences and Expectations of Medical Care at End of Life

Our sample found no statistically significant differences between African American and non-Hispanic whites with regard to attitudes and preferences for end-of-life care and decision making. Majorities of both groups reported a preference to die at home (75%), to continue treatment in the last days even with pain and discomfort (53%), and to believe that patients should be pain-free and comfortable (75%). Moreover, there was no significant variation in regard to willingness to talk about death, to write down their wishes, and not to wait to make decisions “if the doctors could not cure you and you were very ill.” Some of these views are compatible with hospice care philosophy—such as preference to die at home, willingness to speak about death, and to be free of pain—and others are less congruent with hospice philosophy, such as the desire to continue treatments, even if aggressive.

Religion and Spirituality

Much of the literature on hospice care states that African American patients are more likely to believe that religion and spirituality are important in their lives and that these religious convictions may influence

hospice care.^{3,7,8,11} The responses of this sample of home health patients were somewhat consistent with previous findings (Table 2). A large majority of both African American (100%) and white (69%) respondents in our sample reported that religion and spirituality are important, and this variation is statistically significant ($P = .020$).

Other questions regarding spirituality and religiosity, however, found that African Americans and whites may differ, but not significantly. For example, African Americans were more likely than non-Hispanic whites to state that it is “important for the treatment plan to address spiritual concerns.” However, fewer respondents reported that their “spiritual beliefs affect the type of medical care I choose,” and the small variation between the non-Hispanic whites and African Americans was not statistically significant. In short, both groups held similar attitudes toward religious/spiritual beliefs and their importance in treatment decisions, though, overall, African Americans were more likely to believe that religious/spiritual issues were generally important in their lives.

Knowledge and Perception of Hospice Care

In addition to research on the impact of cultural and spiritual attitudes and beliefs on hospice care, the literature also suggests that use of hospice care is associated with knowledge and access.^{1,21,22} In the

Table 2. Attitudes Toward Spirituality and End of Life Decision Making by African American and White Home Health Patients Eligible for Hospice Care

	White, Non-Hispanic (n=13)	Black/ African American (n=19)	Total (N=32)	P
Religion/Spirituality				
Religion and spirituality are somewhat or very important in my life	69%	100%	88%	.020*
It is somewhat or very important for my treatment plan to address spiritual concerns	46%	68%	59%	.281
Yes, spiritual beliefs affect the the type of medical care I choose	23%	16%	19%	.666
End of Life				
<i>Last days</i> [†]				
Agree that medical care in the home is not as good as the hospital	31%	58%	47%	.166
Agree that doctors should generally try to keep their patients alive on machines for as long as possible	23%	42%	34%	.450
Agree that people should continue to treat an illness with limited hope for a cure, even if it results in significant pain and discomfort	62%	47%	53%	.491
Agree that people should be pain-free and comfortable during the last days of life, even if treatment must be discontinued	85%	68%	75%	.420
My preference is to spend last days in my own home	85%	68%	75%	.420
<i>Decision making</i> [‡]				
Agree that it is best to wait until the situation arises to make decisions about treating very serious illness rather than writing them down in advance	39%	21%	28%	.427
Agree that people don't need to write down wishes about medical care because family will know what to do when time comes	31%	5%	16%	.132
Agree that people should avoid talking about serious illness or death before they occur	15%	21%	19%	1.00

* $\leq .05$

† This subset of questions was introduced by the following statement: I'd like to hear your opinion on medical treatment and services available to people with life-threatening illnesses while at or near the end of their life.

‡ This subset of questions was introduced by the following statement: I'd like to hear your views about the help you would like to receive if the doctors could not cure you, and you were feeling very ill.

present study, respondents were asked simply, "Have you heard of hospice?" As Table 3 indicates, a slim majority of respondents (56%) stated that they had heard of hospice, and those who had heard of it were largely positive about the idea (83%). Having heard of hospice was strongly correlated with higher levels of education ($P = .012$) and receiving primary health care in a physician's office ($P = .029$), findings that are consistent with other studies.^{5,21} These data suggest that a significantly large group of adults, even those with serious illnesses and a poor prognosis and receiving home care, are still uninformed about hospice. These findings present an opportunity and challenge to raise awareness of hospice care, regardless of where the patient receives primary care.

Somewhat greater percentages of married respondents, older respondents, and women had heard of hospice, but none of these associations was

statistically significant. Moreover, just over half of the white respondents (56%) and 44% of the African American respondents had heard of hospice care, a variation which approaches statistical significance ($P = .075$).

Having heard of hospice, however, did not necessarily indicate an understanding or having accurate knowledge of hospice services. When asked, "How did you hear of hospice?" 28% reported hearing about it from a family member, 17% could not recall how they heard of it, and 56% heard of it from some other source such as TV, common knowledge, or flyers. No respondent reported hearing about it from his or her physician or other health care provider. This alarming finding suggests that even those who hear of hospice care are likely to hold inaccurate or incomplete knowledge of the service. Indeed, additional questions on the survey bore this out.

Table 3. Knowledge of Hospice by Demographic, Education, and Payment Variables for Home Health Patients Eligible for Hospice Care

	Heard of Hospice?		Total (N = 32)	P
	Yes (n = 18)	No (n = 14)		
Age				
≤65	33%	57%	44%	.222
66-75	22%	29%	25%	
>75	44%	14%	31%	
Gender				
Male	22%	50%	34%	.142
Female	78%	50%	66%	
Years of education				
High school graduate or less	39%	86%	59%	.012*
Some college/college graduate	61%	14%	41%	
Race/Ethnicity				
White, non-Hispanic	56%	21%	41%	.075
Black/African American	44%	79%	59%	
Marital Status				
Married or domestic partner	41%	29%	35%	.595
Widowed	29%	21%	26%	
Single and other	29%	50%	39%	
Primary place for health care				
Private doctor's office	78%	36%	59%	.029*
Other (hospital, clinic, no one place)	22%	64%	41%	
Current payment for home care				
Any Medicare	67%	57%	63%	.515
Medicaid only	6%	21%	13%	
Private only/other	28%	21%	25%	

* ≤.05

When asked specifically about aspects of hospice care and philosophy, respondents who were aware of hospice held inconsistent and inaccurate information (Table 4). Those who heard of hospice responded that: "hospice means giving up" (17%); "hospice care means you get no treatment" (6%); "hospice care is only for when there is no hope" (56%); "hospice care is only for people who believe they are dying" (56%); and "medical care in the home is not as good as in hospital" (22%). These responses suggest that respondents perceive "treatment" and "care" as curative or interventional and that respondents did not distinguish between curative and palliative treatments as the focus of hospice-home care. In addition, there were no significant differences between white and African Americans in this area of inquiry.

Discussion

This exploratory study of 32 non-Hispanic white and African American home health patients provides

valuable information from which to speculate about possible barriers to access to hospice care from home care. Much of the previous research posits that African Americans hold beliefs, preferences, and attitudes that would diminish their likelihood of consenting to hospice care. This study found that non-Hispanic whites and African Americans hold similar views about end-of-life care, such as preferring to die at home, wanting a pain-free and comfortable death, and a willingness to forgo painful treatments or surgery if there is little hope. Moreover, we found few differences among non-Hispanic whites and African Americans with regard to spiritual/religious beliefs and the role of religion in medical decision making.

There were some important differences between the white and African Americans respondents with regard to mistrust of the medical establishment, a finding consistent with previous research. However, the overall assessment of provider-patient communications was generally positive for both whites and African Americans.

With respect to knowledge of hospice care, the survey found some, but not statistically significant,

Table 4. Perceptions of Hospice by Home Health Patients Eligible for Hospice Who Heard of Hospice

	Heard of Hospice (n = 18)
<i>Source of hospice knowledge</i>	
I heard about hospice care from a doctor, nurse, advertisement/brochure, or insurance company	0%
I heard about hospice care from a family member	28%
I heard about hospice care from a source other than the ones listed above	56%
I can't recall how I heard about hospice care	17%
<i>Perceptions</i>	
Agree that hospice care means giving up	17%
Agree that hospice care means you get no treatment	6%
Agree that hospice care is only for when there is no hope	56%
Agree that hospice is only for people who believe they are dying	56%
General feeling about hospice care is positive	83%

differences between whites and African Americans. "Level of education" and "location of primary care" were found to be more potent factors than race in predicting those who had heard of hospice care. However, even those who had heard of hospice often held inaccurate or inconsistent views of the service. These erroneous beliefs may be linked to the source of their information, which is often a family member, friend, or printed materials. In any case, a patient's knowledge of hospice does not translate into admission to hospice care without referral from providers.

Most alarming is the apparent neglect by physicians, nurses, and other providers in having honest communications with their home care patients who have a poor prognosis. A slim majority of the respondents had heard of hospice care, and none reported hearing of it from their physicians. Despite generally positive attitudes about communications with their providers, respondents seemed to be unaware that their current conditions rendered them eligible for hospice care and had not had serious counseling from their physicians about end-of-life decision making. Silvera et al²¹ and others have noted that misunderstandings about end-of-life choice and hospice care are pervasive and that physicians are not informing

patients of options. Schim et al¹³ found similar results regarding nurses, noting that nurses require additional training in communicating "bad news" to patients and understanding the psychosocial needs of hospice patients and their families. Aside from issues of discomfort with discussing end-of-life issues, there is also evidence that physicians are (or at least feel) unable to accurately predict that a patient will die within 6 months.^{12,15} Similarly, about two-thirds of hospice patients die within 30 days, which suggests that they are admitted to hospice very late in the disease trajectory. In short, it appears that providers only refer patients who are already close to death.

The findings from the study must be interpreted cautiously, as the methods have serious limitations. The small sample limits ability to generalize to a wider population. Indeed, because of small representation, Hispanic respondents were eliminated from this analysis. In addition, the other exclusion criteria render the findings not generalizable to all home care patients eligible for hospice care. Nonetheless, this exploratory study of home health clients who are eligible but not currently in hospice care provides a unique look at a vulnerable, often neglected population. The results clarify a number of issues related to the transition from home care to hospice care. These issues include the critical importance of provider communication in increasing knowledge of hospice and end-of-life issues among patients receiving home care and the similarities among patients—regardless of race—in respect to end-of-life decisions and the value they place on spiritual/religious beliefs when choosing among health care options.

In short, the findings of this study suggest that, regardless of racial background, home health patients hold religious and other values that are in accord with hospice philosophy, and barriers to care revolve around information and communication. Patients in home care who are eligible for hospice care may fall through the gaps since there are fewer incentives (high occupancy rates) and gatekeepers (such as discharge planners) to make and act on referrals. Moreover, providers and payers must develop accurate and easily accessible information to share with their patients about the benefits of hospice. These findings have particular relevance in view of evidence that home health is a growing segment of the health care delivery system, particularly in the number of Medicaid Home Health participants and Medicaid Home Health Expenditures between 1999 and 2003.²³ The Deficit Reduction Act

of 2006, which gives states the option to use this model for an expanded range of home- and community-based services in their state Medicaid plans without having to obtain a waiver, will likely heighten interest in research that improves the quality of home health services.

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