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Examining Predictors of Preference for Hospice Care among Older Adults

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Abstract

Purpose of the study—The purpose of this study was to identify predictors of preference for hospice care and explore whether the effect of these predictors on preference for hospice care were moderated by race.

Design and Methods—An analysis of the North Carolina AARP End of Life Survey (N=2,487) was conducted using a multinomial logistic model to identify predictors of preference for hospice care as indicated by one of three response options: yes, no, or don't know.

Results—Gender, race, age, income, knowledge of Medicare coverage of hospice, presence of an advance directive, end-of-life care concerns, and religiosity/spirituality predicted hospice care preference. Religiosity/spirituality however, was moderated by race. Race interacted with religiosity/spirituality in predicting hospice care preference such that religiosity/spirituality promoted hospice care preference among White respondents, but not Black respondents.

Implications—Efforts to address disparities in hospice access and care should consider pre-existing preferences for end-of-life care and account for the complex demographic, social, and cultural factors that help shape these preferences.

Keywords

Hospice; end-of-life care; decision-making; older adults

Hospice care is a model of palliative care at the end of life that uses an interdisciplinary team approach to focus on preserving patient quality of life.[1] This model of care has seen tremendous growth in the past two decades and is often preferred over alternatives such as chemotherapy, surgery and hospitalization.[1–3] Indeed, hospice care is associated with greater family satisfaction, lower cost and better bereavement outcomes when compared to more

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aggressive treatment approaches.[4–6] It is estimated, however, that more than 40% of individuals who are eligible for hospice do not receive it.[7]

Furthermore, disproportionately lower numbers of African Americans and women tend to enroll in hospice even after receiving a life-limiting prognosis.[1,8] Possible explanations for these differences in care have been traced to individual differences, cultural values, public misconception and lack of information.[9–12] Similar racial and gender differences have been observed in beliefs about hospice prior to the onset of a life threatening illness.[12–14] These pre-existing preferences for care may help to explain the disparities in hospice utilization.[15]

This study used secondary data from an AARP end-of-life survey conducted in North Carolina to address three broad issues. The primary objective of this study was to explore and identify variables that reliably account for respondent preferences for hospice care. A secondary goal was to confirm whether racial differences in hospice care preference in our single state sample mirrored known differences in utilization at the national level. Namely, we wanted to test the hypothesis that Black respondents in our sample were less likely to prefer hospice care because similar racial disparities in hospice use have been well documented nationwide. Building from this, our third aim was to identify potential variables moderated by race in predicting respondent preferences for hospice care. This final objective contributes to the existing knowledge base because many questions remain about race-based differences in attitudes toward, and utilization of, hospice care.

Background

Hospice care has consistently demonstrated positive patient and family outcomes when compared to non-palliative care alternatives. For example, hospice has been shown to have superior pain and symptom management, improved family-provider communication, greater family satisfaction, and an increased likelihood that the patient's wishes will be honored.[6,16] Although hospice may not be ideal for all dying persons, it is for these reasons that disparities in hospice utilization are disconcerting – and further research exploring end of life preferences is warranted. There is surprisingly little research on the demographic and psychosocial factors that influence individual preferences for hospice care. Much of what we know, rather, is based on factors associated with hospice utilization – not pre-existing preferences for care.

According to the available literature, a combination of individual characteristics, attitudes, beliefs and behaviors contribute to a person's preference for hospice. Race, of course, is a well-known contributing factor. For example, among a sample of oncology patients, Fishman et al.[17] found that African American patients tended to prefer continued cancer treatment, thereby precluding them from hospice care under most circumstances. They also identified sex, age, and household finances as important, potentially influential, characteristics to take into account when studying end of life treatment preferences.

Chen and colleagues[18] found that age, education level, and treatment goals were associated with hospice enrollment. More specifically, older adults, persons with lower educational attainment, and those interested in preserving their quality of life were more likely to enroll in hospice care. The study also reported that the presence of an advance directive and spirituality were marginally associated with hospice use – with higher ratings of spirituality, and having an advance directive, being related to enrollment in hospice.[18] End of life treatment preferences have also been linked with knowledge of hospice care,[14] attitudes about care,[14] and the potential burden of treatments effects.[19]

Our study was informed by a conceptual model (see Figure 1) developed from the literature and the authors' clinical experience. We hypothesized that individual characteristics, attitudes, beliefs and behaviors would contribute to hospice preference in specific ways. In terms of the goals of end-of-life care, we expected individuals who valued quality-of-life over quantity-of-life would also be more likely to prefer hospice care. Similarly we believed that those who place a high importance on being comfortable in their final days of life would favor hospice care, given its reputation for high quality pain and symptom management. Individuals who indicated a preference to die at home or avoid institutional placement (e.g., nursing home admission) were expected to be more likely to prefer hospice because hospice is the dominant home-based end-of-life care. Because the majority of people do not want to be a financial burden on their family at the end of life, we also hypothesized that respondents who know that hospice care is covered by Medicare would tend to prefer its services. Furthermore, because most advance directives provide instructions on limiting invasive, high-burden treatments, we expected that persons who engaged in advance care planning would, in turn, express a greater preference for hospice. These hypothesized relationships, coupled with the conceptual framework, informed the research questions and initial selection of variables for inclusion in the analysis. Thus, based on the overarching study objectives and review of the literature, we tested the following hypotheses:

> *Hypothesis 1*. Individual characteristics, attitudes, beliefs, and behaviors will predict hospice care preference among older adults. In particular the following were expected to be associated with respondent preference for hospice: high importance of comfort; desire to avoid institutional placement; preference to die at home; high importance of being off machines; knowledge of health care coverage; and evidence of advance care planning.
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> *Hypothesis 2*. Black respondents will be less likely to express a desire for hospice than White respondents (similar to known racial differences in hospice utilization).
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>> *Hypothesis 2a*. If hypothesis #2 is confirmed – The effect of attitudes, beliefs, and behaviors on predicting hospice will be moderated by race.

METHOD

A sample of 8,000 American Association of Retired Persons (AARP) members living in North Carolina were randomly selected to participate in an end of life survey, using a questionnaire modeled after the Missoula Demonstration Project Community Survey.[20] For a six week period in Winter 2002, respondents were contacted up to four times via mail with a pre-notification postcard, initial survey, reminder postcard, and second survey. The self-report survey measured concerns and attitudes toward end-of-life issues of which 3,586 responded, yielding a response rate of 45%.

Individual Characteristics

Respondents reported demographic information such as gender, age, race, ethnicity, income, employment status, educational attainment, marital status, and health. Age was measured in years and recoded into four categories: *50 to 59*, *60 to 69*, *70 to 79*, and *80 and above*. Due to a lack of variability and low cell counts in the variables race and ethnicity, the sample was restricted to only include respondents who were Black or White. Income was assessed with a single item, "What was your annual household income before taxes in 2001?" of which respondents selected one of eight income categories ranging from less than $10,000 to $75,000 or more. For the purposes of our analysis, employment was coded as a binary variable indicating active income generation or no income generation. Self-rated health was measured by responses to the item, "In general, how would you rate your own health now?" Response options were rank-ordered on a 4-point continuum ranging from "*excellent,"* "*very good,"* "*good,"* to "*poor or fair."* (Note: The original questionnaire had separate categories of poor and fair. However, these two categories were already combined in the dataset at hand.) Serious chronic illness was measured by self-report with respondents indicating whether they currently have a serious chronic illness (Yes/No). A single item, "Do you consider yourself..." "*not at all religious/spiritual,"* "*not very religious/spiritual,"* "*somewhat religious/spiritual,"* or "*very religious/spiritual"* was used to measure respondents' religiosity and spirituality.

Attitudes and Beliefs

Comfort with Issues Related to Death/Dying—Two items were used to measure respondents' attitudes toward end-of-life experiences. The first item was "How comfortable are you with talking about death?" The second item, "When you think about death and dying, how concerned are you that: You will be a burden to your family or friends?" evaluated social concerns about being a burden to others at the end of life. These items were rated on a four-point response scale, ranging from "*not at all concerned" to* "*very concerned."*

Preferred Place of Death—A respondent's preferred place of death was assessed using responses to the statement: "How afraid, if at all, are you of dying in an institution such as a nursing home or hospital." Four possible responses were offered, ranging from "not at all" to "very".

Priorities for End-of-Life Care—Three items were used to measure the importance respondents' placed on issues related to end-of-life care with the same question stem, "How important would each of the following be to you when dealing with your own dying?" The items were "Being able to stay in your home," "Being physically comfortable," and "Being off machines that extend life such as life support." Respondents could endorse one of four possible responses: "*not at all important"*, "*not very important"*, "*somewhat important"*, or "*very important"*.

Knowledge of Healthcare Coverage—Medicare provides per-diem coverage for hospice care when beneficiaries meet the eligibility criteria for hospice (i.e., they have a prognosis of 6 months or less, and forego curative treatment). Accuracy in knowledge about

Medicare coverage was assessed among respondents by asking: "To the best of your knowledge, does Medicare pay for hospice services?". Insurance coverage was measured with the item, "Are you currently covered by any health care insurance or program including insurance through work/retirement, the military, Medicare, or some other government program?" to which respondents endorsed either *yes* or *no*.

Behaviors - Advance Care Planning

Two items were used to assess respondents' advance care planning: "A Health Care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event you become incapacitated" and "a living will in which you state the kind of health care you want or don't want under certain circumstances." A single variable measuring whether participants completed an advance directive was coded. Respondents also indicated with whom they have talked about their wishes for care at the end of life. We used these responses to construct a binary variable to indicate whether respondents had talked to at least one person about their end-of-life wishes.

Primary Outcome: Preference for Hospice

Respondent's preference for hospice was the primary outcome of interest. Preference for hospice care was measured using the item, "If you were dying, would you want hospice support?" Respondents could endorse one of three possible responses - *yes*, *no*, or *don't know*. The outcome was therefore treated as a trichotomous variable as *no* and *don't know* are characteristically different.

Inclusion Criteria

To be included in the sample, respondents had to be 50+ years, either Black or White, and have responded to the outcome variable about hospice preference. Using these criteria the original sample was reduced by 17.5% from 3,586 to N=2,960.

Preliminary Analysis

Descriptive statistics were computed for all variables and stratified by race. T-tests and χ^2 goodness-of-fit tests were conducted to examine race differences. An analysis of missing patterns in the data was also conducted. Of the 2960 respondents in the sample, 893 (30.2%) had missing data on at least one item. On average, 1.49 variables (range=1–8) had missing values. Black respondents and females tended to have more missing data than White and male respondents. Respondents who were older, had lower incomes and/or education, had no insurance or poorer health also tended to have more missing responses. Furthermore, the odds of having missing items were associated with respondents' comfort talking about death and concerns of being a burden. The results generalize only to the population of responders with complete data (N=2,487). As the variable serious chronic illness had substantial missingness and was significantly correlated with self-rated health (r=.43, p<.0001), it was removed from the primary analysis. Ethnicity was also removed due to low cell counts.

Primary Analysis

To identify predictors of hospice care preference, a multinomial model was used to examine the effect of key predictors on the odds of choosing *yes*, indicating a preference for hospice care. With three valid responses to the outcome, two odds - the ratio of the probability of endorsing *no* against the probability of endorsing *yes* and the ratio of the probability of endorsing *don't know* against the probability of endorsing *yes* - were modeled simultaneously using the multinomial model.

There were three modeling steps: reduction, building and refinement. First, the polytomous or ordered categorical predictors were examined for linearity using Likelihood Ratio Tests (LRTs). Second, variable selection was done by sequentially adding groupings of variables to the model and testing each addition using LRTs. Finally, to identify variables whose effects on predicting hospice care were moderated by race, interactions of race with key predictors were entered and tested for their contribution to the model using LRTs; these included gender, age, income, presence of an advanced directive, having talked with someone about death, knowledge of Medicare coverage of hospice, insurance coverage, desire for physical comfort, and religiosity/spirituality.

In the modeling process, the sample was fixed at N=2,487. To test for linearity of ordered categorical predictors, two models are fit where: (a) the predictor of interest was treated as categorical and (b) the predictor of interest was treated as continuous. The baseline model included all predictors as categorical variables and competing models each had a single linear predictor. Non-significant LRTs supported the linearity of the following predictors: *age*, *income*, *level of education*, *self-rated health*, *comfort talking about death*, *fear of death in an institution*, *being physically comfortable*, *being off machines*, *religiosity/spirituality*, and *concern of being a burden. Staying in own home* was the only variable that exhibited nonlinearity.

Predictors were grouped in the following order with demographics given greater precedence: (a) age, gender and race (b) income and income × age (c) education (d) marital status (e) completed an advance directive, talked to someone about death, knowledge of Medicare and covered by insurance (f) self-rated health (g) comfortable talking about death and fear of death in institution (h) importance of staying in own home, physical comfort and being off machines (i) religiosity/spirituality and (j) concern of being a burden. These groups were entered into the model in the stated order and tested for their contribution to the overall model. If associated LRTs were significant, the group was retained in the model. In the final model, predictor groups (a), (b), (e), (h) and (i) were selected. Of the variables in this model, there were race differences in gender, age, income, knowledge of coverage, presence of an advance directive, and religiosity/spirituality. Race-based interactions with these variables were then examined one-at-a-time.

RESULTS

Descriptive Statistics

Table 1 presents sample characteristics for demographic variables stratified by respondent race. The sample had an average age of 66 years and was relatively healthy, with 81.4% of respondents indicating they were in good health or better. Respondents were generally well-insured with 96.1% reporting that they were covered by health insurance, which is common for samples of older adults at, or near, retirement age. Black respondents tended to report lower income levels and educational attainment compared to White respondents. In terms of marital status, Black individuals reported being separated or widowed more often than persons who identified themselves as White.

With regards to knowledge of coverage and the presence of written advance directives, a lower proportion of Black respondents had completed advance directives compared to Whites (26.8% vs. 59.5% respectively, $p<.0001$). Black individuals were also less likely to know that Medicare covers hospice costs (19.5% vs. 27.6% for White respondents, $p=.007$). Additionally, Black respondents reported significantly lower levels of self-rated health compared to White respondents. In terms of attitudes and beliefs, Black respondents tended to report less fear of dying in an institution, higher levels of religiosity/spirituality, and more extreme responses to concerns about being a burden to family or friends compared to White respondents. As expected, a smaller proportion of Black respondents compared to White respondents preferred hospice support (64.2% vs. 79.2% respectively, $p<.0001$); more Black individuals than White also endorsed *don't know* when asked to state their preference for hospice support (31% vs. 16.9%, $p<.0001$). However, the proportion of Black and White respondents who expressed a clear preference against hospice was nearly equal (4.5% and 4.0%, respectively, $p<.0001$). Taken together, these preliminary findings suggest that compared to White respondents, Blacks respondents are less likely to prefer hospice care – but this difference is largely because Black respondents were less certain about their preference.

Table 2 presents results from the logistic regression analyses, including parameter estimates and odds ratios of the final model. In general, gender ($p<.0001$), age ($p=0.004$), income ($p=0.02$), knowledge of Medicare coverage ($p<.001$), insurance coverage ($p=0.01$), importance of staying in own home ($p=0.04$), importance of physical comfort ($p=0.01$) and importance of being off machines to extend life ($p=0.04$) predicted hospice care preference. The age × income effect was significant ($p=0.01$) and the race × religiosity/spirituality effect was marginally significant ($p=0.06$).

From Table 2, the odds of men choosing *no* and *don't know* over *yes* for hospice care were 2.9 and 1.5 times versus women, respectively. The odds of those with poor knowledge of Medicare coverage choosing *no* and *don't know* over *yes* were 2.0 times that of those with good knowledge. Similarly, the odds of those who do not have insurance coverage of choosing *no* and *don't know* over *yes* were 2.7 and 1.8 times that of those with insurance coverage. A one unit increase in importance of physical comfort reduced the odds of choosing *no* and *don't know* over *yes* by a factor of 0.6 and 0.8 respectively. Being female, having accurate knowledge of Medicare coverage, being covered by insurance, and placing importance in physical comfort promoted hospice care preference. Placing importance in being off machines to extend life only reduced the predicted odds of *don't know* against *yes* (see Table 2).

The effect of placing importance in staying in one's own home had a significant effect on the two model odds. Of the twelve possible pairwise comparisons, three were significant. The odds of choosing yes for hospice care against no for those who indicated somewhat important were 4.1 times that of those who indicated not at all important (p=0.008). Those who found staying at home to be *very important* were 30% more likely (e.g., an OR of 1.3) than those who found it only *somewhat important* to endorse the use of hospice (p=0.03). Curiously, the odds of choosing yes for hospice care over *don't know* for individuals who indicated *somewhat important* for staying at home was 0.6 times that of individuals who indicated not very important (p=0.046). Note that this effect was close to the 0.05 level of significance and may be spurious.

The interaction effects of income × age and race × religiosity/spirituality were significant for the odds of choosing *no* against *yes* for hospice care only. Figure 2 depicts these interactions as OR (holding all other variables in the model at their mean); the income × age effect and race × religiosity/spirituality effect are to the left and right of Figure 1. For those low in the income group, increasing age by one year is associated with an increase in the odds of choosing *no* over *yes* for hospice care by a factor of 1.1. There was no effect of age on hospice care preference for those with medium incomes. From Figure 2, the odds of choosing *no* against *yes* for those in the high income bracket decreased by a factor of 0.9 with every one year increase in age. The effect of religiosity/spirituality on hospice care preference was significant only among White respondents. From Figure 2, a one unit increase in religiosity/spirituality among Whites was associated with a decrease in the odds of choosing *no* over *yes* for hospice care by a factor of 0.6. The commensurate OR for Black individuals was 5.6. Although the effect of religiosity/spirituality on hospice care preference among Black respondents was not significant, the relatively large effect was noteworthy; and non-significance may have been the result of the small sample size (8% of sample was made up of Black individuals).

DISCUSSION

Variables that Reliably Account for Hospice Preference

Several variables significantly predicted hospice care preference. In general, the individual characteristics of gender, race, age and income were important predictors. Beyond these individual characteristics, attitudes and beliefs (e.g., preference for comfort and knowledge of Medicare coverage) and behaviors (i.e., having completed an advance directive) were also associated with hospice care preference. In terms of behaviors, Black respondents were less likely to have completed an advance directive than Whites, but there was not an interaction effect between race and having an advance directive on preference for hospice. However, low counts of Black responders may have contributed to a lack of sufficient statistical power and the non-significant finding. These findings suggest that while one's preference for hospice care may be influenced by personal characteristics, there are also potentially modifiable attitudes, beliefs and behaviors that affect one's preference. These modifiable factors may be important targets for future interventions to improve informed decision-making and reduce disparities in hospice care.

In our sample, men were less likely to prefer hospice care than women. This suggests that gender-based differences in utilization may be influenced by more than simple biological differences (e.g., men are at greater risk of sudden death). Perhaps, the holistic, comfort-focused nature of hospice care is perceived as more feminine than alternate forms of end-of-life care; and therefore, a less attractive option for men. The fact that women tended to prefer hospice reflects differences in utilization at the national level as more than half (56%) of hospice enrollees are women.[1] It is notable that, although a majority of hospice patients are women, this still represents a disproportionally lower percentage of women when taking into account gender differences among cohorts of older adults. For example, in 2006 women made up 58% of the US population age 65+ and 69% age of those 85+.[21]

Income was found to interact with age to predict hospice preference. For those in the high income group, the likelihood of preferring hospice decreased as age increased. Conversely, for those in the low income group, older respondents were less likely to prefer hospice. This may reflect changing concerns about treatment affordability since dying patients frequently do not want to become a financial burden on their family. As age advances, expensive curative care or non-traditional treatment options may become less attractive to those with fewer means, and yet a more viable choice for those from higher socio-economic positions. Recent research has observed that out-of-pocket expenses for end of life care in the United States are exceptionally high.[22]

The fact that the importance of physical comfort predicted respondents' preference for hospice was not wholly unexpected. However, this finding lends evidence for support of current approaches to advance care planning using a goal-oriented discussion to guide decision-making (Kaldjian, Curtis, Shinkunas & Cannon, 2009). The underlying assumption behind goal-oriented advance care planning is that treatment preferences follow from an individual's goals of care. If comfort is a high-priority goal, then hospice or palliative care will likely be preferred. Similarly, if longevity is the more pressing goal, then hospitalization and life support measures might be preferred. Although more evidence is needed, our findings suggest that a desire for physical comfort is linked to an individual's preference for hospice.

Racial Differences in Preference Mirror Differences in Utilization

While nearly two-thirds (64.2%) of Black respondents indicated a preference for hospice, they were less likely to endorse a desire for hospice services compared to White respondents. Thus, racial differences in preference for hospice care mirrored disparities in utilization at the national level. Indeed, pre-established preferences for care may help to explain differing rates of hospice use by minorities. Additionally, Black respondents tended to endorse *don't know* more than Whites. It is plausible that factors such as comfort with issues related to death and dying, knowledge about coverage, and written advance directives may be key determinants in understanding how people formulate their opinions of, and preferences for, hospice care. Additionally, Black respondents in the sample seemed more disadvantaged (in terms of socioeconomic status) than White individuals. However, the interaction of these variables with race did not reliably predict hospice care preference.

Previous studies identified spirituality as a key factor in explaining racial differences in beliefs about hospice (Johnson, Kuchibhatla & Tulsky, 2009; Johnson et al., 2008). Similarly, religiosity/spirituality seems to play an important role in explaining racial differences in hospice care preference in our sample. Although Black respondents were more religious than Whites, religiosity/spirituality had no effect on Black respondents' preference for hospice care. Instead, religiosity/spirituality among White individuals promoted their choice for hospice care. Perhaps, the concepts of end-of-life care and religiosity/spirituality are treated more independently among Black individuals compared to Whites. For White respondents, greater levels of spirituality and likelihood to prefer hospice may be indicative of lower levels of death anxiety (e.g., related to beliefs about an afterlife). This effect may also be explained, in part, by the fact that spiritually inclined African Americans may be more likely to trust that the circumstances of their death is "in God's hands"; and, perhaps, aggressive medical interventions are more likely to be considered instruments of "God's hand" – and therefore should be attempted despite low rates of success (Crawley et al., 2000; Jenkins, Lapelle, Zapka & Kurent, 2005; Johnson, Elbert-Avila & Tulsky, 2005).

Variables that Account for Racial Disparities in Preference

Black respondents were more likely than their White counterparts to indicate *don't know* regarding their preference for hospice. In our sample, it appears that uncertainty by Black respondents better explains observed racial differences in the preference for hospice care rather than clear preferences against hospice care. Perhaps White respondents were more inclined to reach cognitive closure (Kruglanski, 2004; Kruglanski & Webster, 1996) regarding their wishes for care at the end of life, while Black respondents were more comfortable with ambiguity about their treatment preferences. Responses of *don't know* could also indicate individual differences in decision-making characteristics such as indecisiveness or a need for more information about the illness context or alternatives to hospice care. Perhaps, giving other response options may disaggregate different attitudes from the catch-all response of *don't know* such as *don't want to answer* or *undecided*. Furthermore, future research should explore how uncertainty and ambiguity about care preferences impact decision-making and the utilization of care at the end of life.

In our study the interaction between race and religiosity/spirituality confounded our ability to make assertions about the main effects of race. According to findings by Johnson et al. (2008) and Greiner, Perera, and Ahluwalia (2003), racial differences regarding hospice preference and use disappeared when adjusting for other potential predictors. As corroborated by the results of our study, this non-significant race effect suggests that socio-cultural factors such as education, knowledge of coverage, fear of dying in an institution, completion of advance directives, and religiosity/spirituality may account for observed racial differences in hospice preferences and utilization. Thus, race alone is an insufficient explanation for existing disparities in hospice preference and utilization. Furthermore, these findings highlight the need for researchers and clinicians to develop a more nuanced understanding of health disparities in end-of-life care. In particular, more research on the impact of religiosity and spirituality on racial differences in preference for end of life care is needed. Future studies may also be designed to investigate potential mediators of the race effect so as to identify explanatory variables than relate to the underlying mechanism driving the race effect. Related to this, advances are needed in statistical methodology to perform a valid and interpretable mediation analysis within the context of a multinomial logistic regression. We were unable to do this in our analysis because these methods have not yet been properly developed.

Interestingly, previous research suggests a lack of knowledge about hospice only accounts for a small portion (7%) of the variance due to racial disparities in beliefs about hospice care, while demographic attributes and cultural factors (e.g., distrust of the healthcare system, spirituality) account for nearly three quarters (74%) of the variance (Johnson et al., 2009; Johnson et al., 2008). While striving to overcome barriers to hospice such as prejudicial attitudes, systematic hindrances, and a lack of accurate information, is a worthy endeavor, it is equally important to acknowledge that variations in utilization and preferences may be the result of culturally inculcated differences that require no intervention at all. In other words, racial differences related to hospice care may be unconcerning – as long as patients (or their proxy decision-makers) are fully informed about their treatment options, the associated risks and benefits are communicated, and systemic barriers do not limit access. Thus, while many individuals prefer hospice care, it may not be the ideal or appropriate course of care for all eligible persons.

Our findings should be considered within the context of the study’s limitations. Despite a relatively robust sample size, the generalizability of results is limited. Non-response bias and violation of MCAR restrict inferences to the population of responders with complete data on the examined variables and suggests the possibility of systematic bias. We suspect, for example, that because the survey focused on end-of-life topics, people who were comfortable with discussing issues of death and dying are likely overrepresented in the sample and, thus, the prevalence of preferring hospice may be somewhat inflated. The response rate for the survey was only 45% and non-responders may have been uncomfortable broaching end-of-life topics. Similarly, in an in-depth exploration of item non-response, we found that *comfort in talking about death* predicted missing values ($\chi^2(1) = 8.343$, $p = .004$; OR = 0.845[95% CI = 0.753, 0.947]). Respondents who were more comfortable discussing death were less likely to leave survey items blank. Similarly the high level of missing data for income may have biased our findings.

Additionally, the sample population was limited to the state of North Carolina and data may not reflect hospice care preferences nationwide. The study sample was also exclusive to AARP members, and, thus, findings may not be generalizeable to the larger population of older adults in North Carolina as AARP members are likely to be better educated and have higher income levels. The proportion of Black individuals in the sample was also notably lower (8%) than their representation in the larger population of North Carolina residents (>20%). The study was also cross-sectional which did not allow us to ascertain causality; nor were we able to distinguish whether age-related differences are due to maturation or cohort effects. Respondents were not presented with alternatives to hospice care (such as curative care or experimental treatments); this does not reflect the full array of care options that is typically available at the end of life. Similarly, using a single item to measure respondent preferences for hospice likely oversimplifies the complexities involved in choosing hospice care at the end of life. The item did not provide context about health, quality of life, family preferences, or the risks and benefits of other care options – all of which are known to impact end-of-life decision-making (Agency for Healthcare Research and Quality, 2010). The variable "religiosity/spirituality" also used a single-item measure, which confounded the separate impact of religiosity and spirituality. However, religiosity and spirituality are conceptually distinct. Future research should explore the relative impact of these concepts on end-of-life preferences and decision-making. Despite these limitations, African Americans were sizably represented in our sample and these data provide useful information for researchers, practitioners, and policymakers who are interested in addressing disparities in care at the end of life and honoring the preferences of those who are seriously ill.

Conclusion

This study involved a secondary analysis of the AARP North Carolina End of Life Survey (2003) to better examine how individual characteristics and perceptions of death and dying predict respondents' prospective preference for hospice care. Gender, race, age, income, knowledge of coverage, presence of an advance directive, end-of-life care concerns and religiosity/spirituality were found to predict a preference for hospice. Racial differences, however, were moderated by respondents' religiosity/spirituality. More specifically, race interacted with religiosity/spirituality in predicting hospice care preference such that religiosity/spirituality promoted hospice care preference among White respondents, but not Blacks. Future studies may be designed to address the stated limitations and drawbacks inherent in this analysis. For example, longitudinal studies would be useful to monitor developmental changes in attitudes towards hospice care over time. Additionally, race differences in religiosity/spirituality may be better understood by documenting racial differences in religious beliefs, practices and affiliations. Furthermore, the study of racial differences may also benefit from establishing measurement invariance in key constructs such as religiosity/spirituality and attitudes towards end-of-life services and care. Efforts to address disparities in hospice access and care should consider pre-existing preferences for end-of-life care and account for the complex demographic, social, and cultural factors that help shape these preferences.

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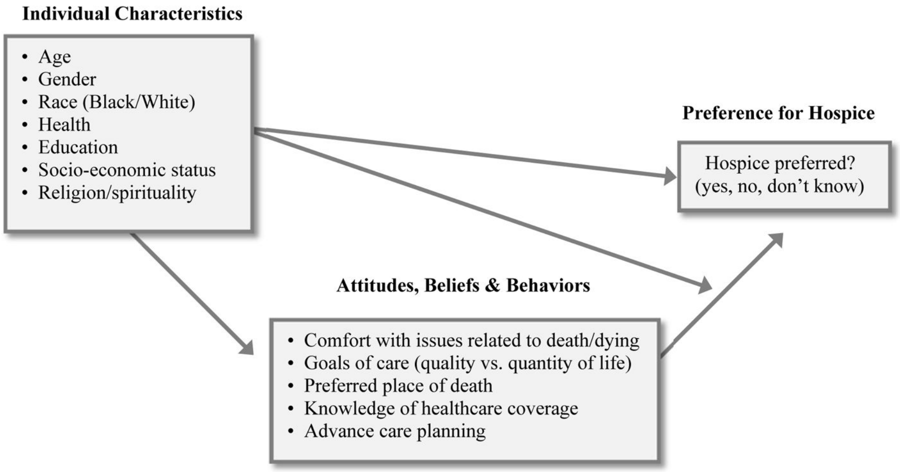

Figure 1.

Conceptual Model for Predictors of Hospice Care Preference

Note: This model focuses exclusively on person-level attributes relevant to a relatively healthy population of older adults – i.e., prior to the advent of a serious or life-threatening illness.

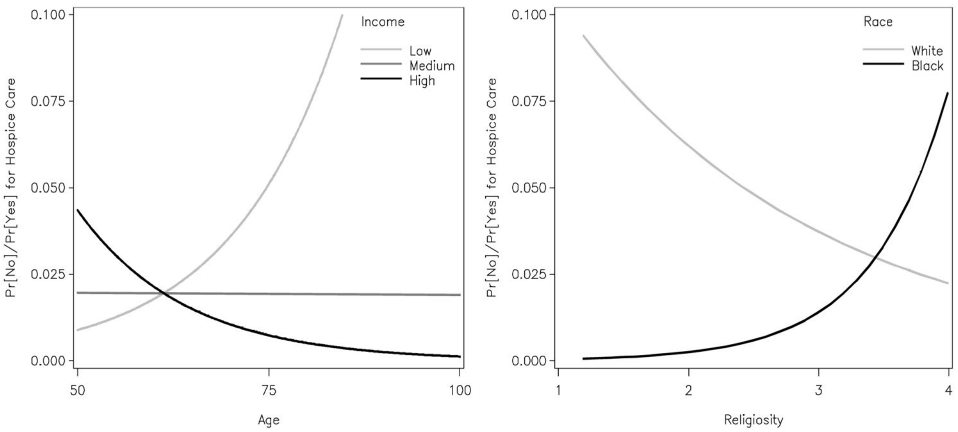

Figure 2.

Effects of Income x Age and Race x Religiosity/Spirituality on Hospice Care Preference

Values of medium, low and high for income are the sample mean values ±1 SD. For those low in income, increasing age by one year is associated with an increase in the odds of choosing no over yes for hospice care by a factor of 1.1 (95% *CI* = 1.0; 1.1). There was no effect of age on hospice care preference for those with medium incomes. From Figure 2, the odds of choosing no against yes for those high in income decrease by a factor of 0.9 (95% *CI* = 0.9; 1.0) with every increasing age. The effect of religiosity/spirituality on hospice care preference was significant only among Whites. From Figure 2, a one unit increase in religiosity/spirituality among Whites is associated with a decrease in the odds of choosing no over yes for hospice care by a factor of 0.6 (95% *CI* = 0.5; 0.8) The commensurate OR for Blacks is 5.6 (95% *CI* = 0.6; 48.4).

Table 1

Sample Characteristics Stratified by Race (Black/White)

Characteristic	**Total**	**Black**	**White**	***p*-value**
Sample size (N)	2960	246 (8.3)	2714 (91.7)	
Age[2]	66 (50–100)	65 (50–100)	66 (50–96)	0.2839
Gender (Male)	1506 (51.0)	95 (39.1)	1411 (52.0)	<.0001
Ethnicity (Hispanic)	17 (0.6)	1 (0.4)	16 (0.6)	0.7291
Income				<.0001
Less than $10,000	113 (4.2)	29 (12.6)	84 (3.4)	
$10,000 to under $20,000	297 (10.9)	44 (19.1)	253 (10.2)	
$20,000 to under $30,000	352 (13.0)	38 (16.5)	314 (12.6)	
$30,000 to under $40,000	417 (15.3)	41 (17.8)	376 (15.1)	
$40,000 to under $50,000	331 (12.2)	25 (10.9)	306 (12.3)	
$50,000 to under $60,000	276 (10.2)	16 (7.0)	260 (10.5)	
$60,000 to under $75,000	251 (9.2)	13 (5.7)	238 (9.6)	
$75,000 or more	682 (25.1)	24 (10.4)	658 (26.4)	
Education				<.0001
Less than high school	115 (4.0)	28 (11.8)	87 (3.3)	
High school grad/GED	512 (17.7)	54 (22.8)	458 (17.2)	
Some college	998 (34.5)	80 (33.8)	918 (34.6)	
College graduate	665 (23.0)	33 (13.9)	632 (23.8)	
Post graduate	604 (20.9)	42 (17.7)	562 (21.2)	
Marital Status				<.0001
Single or never married	120 (4.1)	10 (4.2)	110 (4.1)	
Married or living together	1995 (67.7)	128 (53.3)	1867 (69.0)	
Separated or divorced	333 (11.3)	47 (19.6)	286 (10.6)	
Widowed	497 (16.9)	55 (22.9)	442 (16.3)	
Completed Advance Directive	1681 (56.8)	66 (26.8)	1615 (59.5)	<.0001
Covered by Insurance	2834 (96.1)	227 (93.4)	2607 (96.4)	0.0218
Self-rated Health				<.0001
Excellent	487 (16.5)	11 (4.5)	476 (17.6)	
Very good	1077 (36.6)	75 (30.6)	1002 (37.1)	
Good	833 (28.3)	94 (38.4)	739 (27.4)	
Poor or fair	549 (18.6)	65 (26.5)	484 (17.9)	

[1] Percentages are computed based on N = 2960.

[2] Mean age in years (range). An independent t-test was used to assess potential race differences in age.

Table 2

Parameter Estimates and Odds Ratios of Effects on Hospice Care Preference

	If you were dying, would you want hospice support?					
	No vs. Yes			**Don't Know vs. Yes**		
Parameter	**Estimate**	**(SE)**	**OR^a**	**Estimate**	**(SE)**	**OR^a**
Intercept	**−10.30**	**(4.78)**	--	1.47	(1.61)	--
White	7.68	(4.24)	--	0.75	(1.13)	--
Age (in years)	**0.07**	**(0.03)**	--	0.04	**(0.01)**	--
Male	**1.06**	**(0.26)**	**2.9**	**0.43**	**(0.12)**	**1.5**
Income	**0.87**	**(0.33)**	--	0.22	(0.18)	--
Age x Income	**−0.01**	**(0.01)**	--	−0.003	(0.003)	--
Completed Advanced Directive	−0.33	(0.23)	0.7	−0.24	(0.12)	0.8†
Talked with Someone about Death	0.15	(0.35)	1.2	0.01	(0.18)	1.0
Knowledge of Medicare Coverage	**−0.70**	**(0.29)**	**0.5**	**0.77**	**(0.15)**	**0.5**
Covered by Insurance	**−0.99**	**(0.44)**	**0.4**	**−0.58**	**(0.26)**	**0.6**
Staying at Home (Not at All vs. Very)	0.89	(0.49)	2.4	−0.07	(0.40)	0.9
Staying at Home (Not Very vs. Very)	0.04	(0.41)	1.0	−0.25	(0.25)	0.8
Staying at Home (Somewhat vs. Very)	−0.53	(0.29)	0.6	**0.27**	**(0.13)**	**1.3**
Being Physically Comfortable	**−0.51**	**(0.20)**	**0.6**	**−0.25**	**(0.12)**	**0.8**
Being Off Machines	−0.21	(0.18)	0.8	**−0.25**	**(0.10)**	**0.8**
Religiosity/Spirituality	1.72	(1.10)	--	0.21	(0.31)	--
White x Religiosity/Spirituality	−2.23	(1.11)	--	−0.47	(0.32)	--

Model estimates with p-values < .05 are in bold.

[†] $p = 0.0534$.

[a] OR = odds ratios; Odds ratios for effects with interactions are not presented.

Note: Sample size was $N = 2487$. $-2LL = 2999.97$, $AIC = 303.97$ and $BIC = 3015.50$