Published in final edited form as:
Cancer. 2009 February 1; 115(3): 689–697. doi:10.1002/cncr.24046.

Race, treatment preferences, and hospice enrollment. Eligibility criteria may exclude patients with the greatest needs for care

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Abstract

Background—The requirement that patients give up curative treatment makes hospice enrollment unappealing for some patients, and may particularly limit use among African American patients.

Objectives—To determine whether African-American patients with cancer are more likely than white patients are to have preferences for cancer treatment that exclude them from hospice, and whether they are less likely to want specific hospice services.

Methods—283 patients receiving treatment for cancer at six oncology clinics within the University of Pennsylvania Cancer Network completed conjoint interviews measuring their perceived need for five hospice services and their preferences for continuing cancer treatment. Patients were followed for six months or until death.

Results—African American patients had stronger preferences for continuing their cancer treatments on a 7-point scale even after adjusting for age, sex, finances, education, ECOG performance status, quality of life, and physical and psychological symptom burden (adjusted means 4.75 vs. 3.96; β coefficient 0.82; 95% confidence interval 0.22-1.41; p=0.007). African-American patients also had greater perceived needs for hospice services after adjusting for these characteristics (adjusted means 2.31 vs. 1.83) (β coefficient 0.51; 95% confidence interval 0.11-0.92; p=0.01). However, this effect disappeared after adjusting for household finances.

Conclusions—Hospice eligibility criteria may exclude African-American patients disproportionately despite greater perceived needs for hospice services in this population. The mechanisms driving this health disparity likely include both cultural differences and economic characteristics, and consideration should be given to redesigning hospice eligibility criteria.

Patients with cancer have substantial needs for care throughout the course of illness, from diagnosis through the end of life.[1-8] Hospice offers a comprehensive program of services designed to meet these needs, including a visiting nurse, respite care, a chaplain, a home health aide, and a counselor. Approximately 500,000 patients with cancer enroll in hospice every year, and evidence indicates that hospice enrollment is associated with improved patient and family outcomes and higher satisfaction with care.[9-14]

African-American patients are less likely than white patients to utilize hospice.[15-17] Although these disparities are well-described, it is not known why they exist. It is possible that African Americans delay or avoid hospice enrollment because of the requirement that

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they forgo curative treatment.[18] This criterion forces patients to make a “terrible choice” between continued treatment and hospice services,[19–21] a choice widely believed to obstruct timely hospice use.[22–25] The criterion has been part of the Medicare Hospice Benefit since its creation 25 years ago, and since almost all hospice are Medicare-certified, they follow Medicare eligibility criteria for all patients regardless of age or insurance. This barrier may be particularly significant for African-Americans, who are more likely than whites to want various life-prolonging interventions.[26–29] However, it is not known if they also have more aggressive cancer treatment preferences, and if such preferences help explain the disparity in hospice utilization.

An alternative explanation for the under-utilization of hospice among African Americans is that they might be less likely to want the services that hospice provides. No studies have evaluated this possibility either. Although some studies suggest that African Americans have less favorable attitudes towards hospice,[30–34] their perceived needs for hospice services have not been described.

It is important to determine why these disparities in hospice enrollment exist.[35, 36] If they are the result of aggressive treatment preferences among African Americans, then lower rates of hospice utilization are arguably unfair, and represent a real disparity in care that could be eliminated by redesigning hospice eligibility criteria. On the other hand, if African Americans are less likely to want hospice services, then changes to the benefit are not necessary, and, instead, modifications to the services offered may be warranted. Therefore, the goal of this study was to define and compare preferences for cancer treatment and perceived needs for hospice services among African American and white patients.

Methods

Setting and sample

We conducted this study in a population of patients with cancer because cancer is the most common hospice admitting diagnosis (approximately 50%).[37] Patients with cancer were recruited over 18 months from six oncology clinics within the University of Pennsylvania Comprehensive Cancer Center Network. Patients were eligible if they had clinical or radiological evidence of active cancer, were receiving chemotherapy or radiation therapy, and had a life expectancy of six months or less if they were to discontinue cancer-directed treatment, according to their oncologist. These patients met the prognostic eligibility criterion for hospice, which requires that patients have a prognosis of six months or less if their disease runs its usual course (e.g. without treatment).[18] Nursing staff at each clinic assisted a rotating team of three interviewers to identify and approach eligible patients. This study was approved by the Institutional Review Boards of participating sites.

Data Collection

After providing informed consent, patients completed separate structured interviews using Tablet PCs. First, they provided demographic data, including self-described race, age, marital status, and household finances (e.g. money available at the end of the month).[38] In addition, patients completed the Global Distress Index of the Memorial Symptom Assessment Scale,[39] the Functional Assessment of Cancer Therapy-General,[40] the Medical Outcomes Survey Social Support Scale,[41], a single-item global rating of health,[42] the Eastern Cooperative Oncology Group performance status scale (ECOG-PS)[43, 44] and an assessment of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs).[45, 46]

Patients' perceived needs for hospice services were assessed using a conjoint interview, which refers to a process by which subjects are asked to make choices among goods or services by considering several attributes jointly.[47] One advantage of this approach over direct ratings is that the value of each service is determined while considering other services, revealing preferences in a more naturalized setting rather than eliciting them one by one. Second, whereas direct rating tasks often suffer from ceiling effects, in conjoint tasks subjects must choose those services that are most important.

For these interviews, we used Sawtooth Software's Adaptive Conjoint Analysis package (ACA for Windows, version 4.0, Sawtooth Software, Sequim, Washington). Adaptive Conjoint Analysis is a hybrid[48–50] method of conjoint analysis that uses an interactive self-administered computer program to decrease respondent burden, while preserving the psychometric advantages of conjoint techniques. Like classic conjoint methods, hybrid conjoint methods like ACA determine the importance that subjects place on various services by examining the choices that they make between pairs of services. In addition, though, hybrid methods also use subjects' direct ratings of the importance of those services, which substantially reduces the number of choices that each person is required to make. Although they were developed for use in marketing,[47] conjoint techniques and hybrid modifications have been used increasingly to study health-related preferences.[51–58] Their validity, reliability, and predictive power are well-established.[59, 60]

Patients reviewed a brochure describing five of the hospice services that are required by Medicare: a visiting nurse, a chaplain, a home health aide, a counselor, and respite care.[18] (Figure 1) These services were selected based on previous studies that found they are among the most valuable to patients.[61–63] The subsequent interview used abbreviated (4-6 word) descriptions of each service, and patients kept the brochure open for rapid reference. To assess patients' perceived needs for each service, they were asked to consider how much each service would help them if it were offered at that time. (Figure 2.) First, they rated the importance of each service on a scale from 1 (“Not at all important”) to 7 (“Extremely important”). Second, they evaluated pairs of programs presented side-by-side, each containing two or three services, and rated their preference on a 1-9 scale (“1-Strongly prefer the program on the left”; “5-Indifferent” “9-Strongly prefer the program on the right”).

Patients' preferences for cancer treatment were assessed by asking whether they would want to continue receiving their current cancer treatment in order to achieve various probabilities of surviving for six months (almost 100%, 90-99%, 50-89%, 10-49%, 1-9%, and almost 0%). This question was adapted from previous work in seriously ill populations.[64, 65] These probabilities were varied systematically (from lowest to highest and then back to the second-lowest) to balance order effects. The lowest probability of six-month survival was recorded for which a patient would be willing to continue receiving treatment. Responses were used to create a 7-level ordinal variable describing the strength of a patient's treatment preferences (one level for each of the six responses above, plus one for those patients who would not want to continue treatment even for an almost 100% chance of surviving for six months). This last category was used to create a dichotomous variable that identified patients who would not want treatment even for an almost 100% probability of surviving for six months and who thus would have been eligible for hospice.

Data analysis

Using the scale described above, preferences for aggressive cancer treatment were compared using a Wilcoxon-rank sum test in bivariate analysis. Adjusted analysis of preferences was done using an ordinal logistic regression model. Based on respondents' direct ratings and their choices among service options, Adaptive Conjoint Analysis uses least squares regression to calculate the utility, or usefulness, of each service for each patient.[66] These utilities reflect the perceived need that a patient has for each service, and higher utilities correspond to a greater perceived need. We analyzed patients' perceived needs for each of the five services individually, as well as patients' perceived needs for all five services combined (their total utilities). Because utilities were not normally distributed we used the Wilcoxon rank sum test to compare perceived needs among patient subgroups, and linear regression models with a log transformation and exponentiated coefficients to identify variables that were independently associated with service needs. Variables with a significance value of less than 0.25 were considered for inclusion in a multivariable linear regression model,67 also with a log transformation and exponentiated coefficients.

A sample of 283 patients would be adequate to detect a small difference in the summed utilities of all five hospice services between African-American and white patients, assuming at least 20% of the sample would be African American (ability to detect 0.33 standardized difference, $\alpha=0.05$, two-sided). Stata software (Stata for Windows, version 8.0, Stata Co., College Station, TX) was used for all statistical analysis.

Results

Patient characteristics

Patients who agreed to participate (300/352; 85%) were similar to those who refused with respect to age, ECOG performance score, race, and education (data not shown). However, women were significantly more likely to participate compared to men (152/169, 92% vs. 148/183, 82%; Fisher's exact test p=0.02). Of the 300 patients who consented, this sample was restricted to those patients (n=283; 94%) who self-identified as either African-American (n=81;29%) or white (n=202;71%). The characteristics of these patients are described in Table 1.

Patient race and cancer treatment preferences

African-American patients had stronger preferences for aggressive cancer treatment (using the scale of choices from 1 to 7) compared to white patients (median 6 vs. 4, Wilcoxon rank sum test p=0.006). That is, they were willing to continue their treatment in return for a smaller likelihood of six-month survival. In an ordinal logistic regression model, African American patients had stronger preferences for aggressive cancer treatment (adjusted means 4.75 vs. 3.96; β coefficient 0.82; 95% confidence interval 0.22-1.41; p=0.007) after adjusting for age, sex, household finances, education, ECOG performance status, quality of life (FACT-G), and physical and psychological symptom burden (physical and psychological subscales of the GDI, respectively). Compared to white patients, African American patients were also less likely to say that they would refuse all cancer treatment even if it were associated with an “almost 100%” probability of surviving for six months (5/81, 6% vs. 32/202, 16%; odds ratio 2.86; 95% CI 1.04-9.74; p=0.03).

Patient race and perceived needs for hospice services

Compared to white patients, African American patients reported greater needs for all hospice services combined (median utilities 2.26 vs. 1.79; Rank sum test p=0.005). African-American patients assigned higher utilities to all hospice services except a home health aide (Figure 3).

In a multivariable regression model, African-American race remained associated with greater perceived needs for services after adjusting for age, education, ECOG performance status, dependencies in ADLs, and physical and psychological symptom burden (GDI physical and psychological subscales, respectively) (adjusted mean utilities 2.31 vs. 1.83) (β coefficient 0.51; 95% confidence interval 0.11-0.92; p=0.01). This model did not include economic factors, which were considered separately, below.

To describe the relationship between perceived needs for hospice services and economic factors, which are often closely associated with race,[68] we used household finances as an indicator of economic status (not enough/enough/more than enough money left at the end of the month). In unadjusted analysis, patients with fewer financial resources had greater perceived needs for hospice services (more than enough money left over: 1.51; enough money left over: 2.34 not enough money left over: 2.53). When the perceived needs of African American and white patients were compared after adjusting for household finances, there was no significant difference (adjusted mean utilities 2.38 vs. 1.75; β =0.24; 95% CI -0.22-0.70; p=31). Similarly, in a combined model that included household finances as well as all of the patient characteristics used in earlier models, African Americans did not have greater perceived needs for hospice services.

In sub-analyses, we compared the perceived needs for hospice services of African American (n=76) and white patients (n=170) whose preferences excluded them from hospice. In these groups, African American patients had significantly greater perceived needs than white patients did (total utilities 2.34 vs. 1.81; rank sum test p=0.006). We also compared the perceived needs of African-American patients whose treatment preferences made them ineligible for hospice (n=76) and white patients whose treatment preferences were consistent with hospice (n=32). After controlling for health status by adjusting for age, ECOG performance status, dependencies in ADLs, and GDI physical and psychological subscale scores, ineligible African-American patients had greater perceived needs for hospice services than eligible whites did (adjusted means 2.31 vs. 1.73; β coefficient 0.70; 95% confidence interval 0.05-1.35; p=0.03). However, after adjusting for household finances these two groups had similar utilities for hospice services (1.91 vs. 1.83; β coefficient -0.34; 95% confidence interval -0.56-0.11 p=0.27). Because of the small number of African American patients whose preferences made them eligible for hospice (n=5) a comparison of these patients' perceived needs with those of ineligible African Americans was not possible.

Discussion

The Medicare hospice benefit and similar benefits of other insurers were designed to ensure that patients in the last six months of life have access to high-quality palliative care. However, African-American patients are less likely to utilize hospice than white patients. This study suggests that disparities in hospice utilization among patients with cancer may be the result of cancer treatment preferences among African American patients that make them ineligible despite greater perceived needs for hospice care. In particular, this study offers three main insights into these disparities in hospice access.

First, we found that African-American patients with cancer are more likely than white patients to want aggressive cancer treatment. This difference in preferences persists after adjusting for clinical and demographic characteristics. This result is important because although other studies have observed racial differences in preferences for life-sustaining technologies,[26-29] they have not examined preferences for cancer treatment. Preferences for aggressive cancer care, as well as other aggressive technologies, could be linked to medical distrust, quality of care, or to communication issues between patients and providers.

Second, we found that African-American patients with cancer had greater perceived needs for specific hospice services compared to white patients. This difference appears to be independent of clinical characteristics (e.g. symptom burden, performance status) that are associated with greater needs. Furthermore, African American patients whose treatment preferences would have excluded them from hospice had greater perceived needs than did white patients who would have been eligible.

Third, we found that that the greater perceived need for hospice services among African Americans was attributable largely to differences in self-reported finances. That is, the observed differences in perceived needs between African American and white patients may reflect financial resources since those reporting the fewest financial resources also report the greatest need for services. This finding is consistent with other studies suggesting that the mechanisms driving health disparities include not only cultural differences associated with race but also economic characteristics that may be fundamentally unrelated to race.36, 68, 69 Thus, these economics factors should be further explored to understand why poorer patients want more services. For instance, it is possible that wealthier patients have more resources for care at the end of life, and use these resources to obtain services outside of hospice. If so, then wealthier patients may be better able to avoid the "terrible choice" requiring that they forgo treatment in order to receive hospice benefits. However, this is not known.

Together, these findings suggest that the hospice eligibility criteria of Medicare and other insurers requiring patients to give up cancer treatment contribute to racial disparities in hospice utilization. Moreover, these criteria do not select those patients with the greatest needs for hospice services. To the degree that this eligibility requirement prevents hospice utilization by those patients with the greatest needs, it fails to fulfill its purpose and should be reconsidered. It is also unfair: other Medicare-supported services do not require that patients forgo one treatment in order to get another.70 Instead, this study suggests that hospice access could be made fairer by using eligibility criteria that are more directly need-based. For instance, eligibility might be better determined by assessing needs for specific hospice services such as pain or symptom management. This would make eligibility for hospice similar to eligibility for the Medicare Home Care Benefit, which is perhaps the closest Medicare program.70

This study has several limitations. First, the results reported here are based on patients' self-reported needs for hospice services, but it is possible that these patients could not adequately appreciate how the services described here could benefit them.63 However, patients arguably are the best judges of their own needs, even if those assessments are imperfect.

Second, this study assessed only five hospice services. It is possible that the finding of greater perceived needs reported here by African-American patients would not be found for other services that hospice provides (e.g. delivery of medications or durable medical equipment). Although this is possible, there is no reason to believe that the pattern observed for the five services described here are unique.

Third, this study did not assess actual choices about hospice enrollment, which may be influenced by factors like the availability of family members who can assist with home care. A patient without adequate informal caregiving support and supervision at home may be less likely to enroll. Therefore, further research is needed to define which patient characteristics, such as the availability of family support, influence actual choices about hospice enrollment.

For 25 years, hospice services have been restricted to patients in the last six months of life who are willing to give up curative treatment.18 Although this restriction was intended to control costs, it has substantially reduced access to hospice for many patients who have needs for hospice services, and a disproportionate number of these patients are African American. This eligibility criterion should be reconsidered, and needs-based criteria should be considered in order to make hospice eligibility criteria both fairer and more consistent with eligibility criteria for other health insurance benefits.70

Acknowledgments

Acknowledgements of research support: The authors are in part supported by an MRSGT-08-013-01-CPPB American Cancer Society Mentored Scholar Research Grant (Fishman), University of Pennsylvania's NIH-funded Center of Excellence for Cancer Communication Research Grant (Fishman), an R01CA109540 (Casarett), a VA Advanced Research Career Development Award, a Presidential Early Career Award for Scientists and Engineers (Casarett), and by the Abramson Cancer Center (O'Dwyer), the Center for Clinical Epidemiology and Biostatistics (Fishman) and the Center for Health Equity Research and Promotion (Casarett, Fishman).

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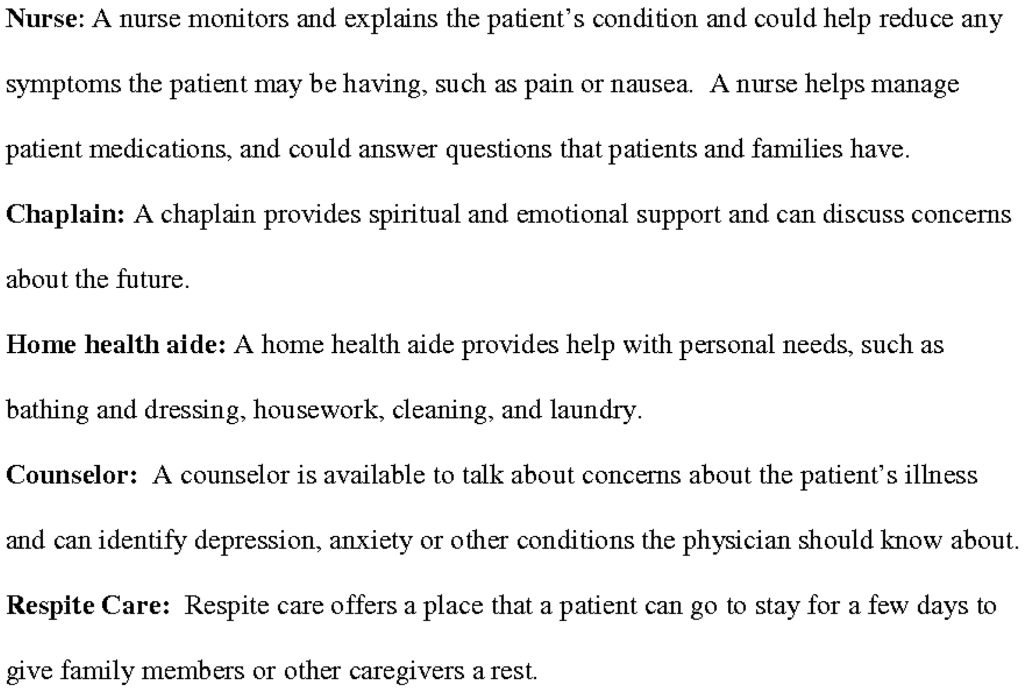


Nurse: A nurse monitors and explains the patient's condition and could help reduce any symptoms the patient may be having, such as pain or nausea. A nurse helps manage patient medications, and could answer questions that patients and families have.

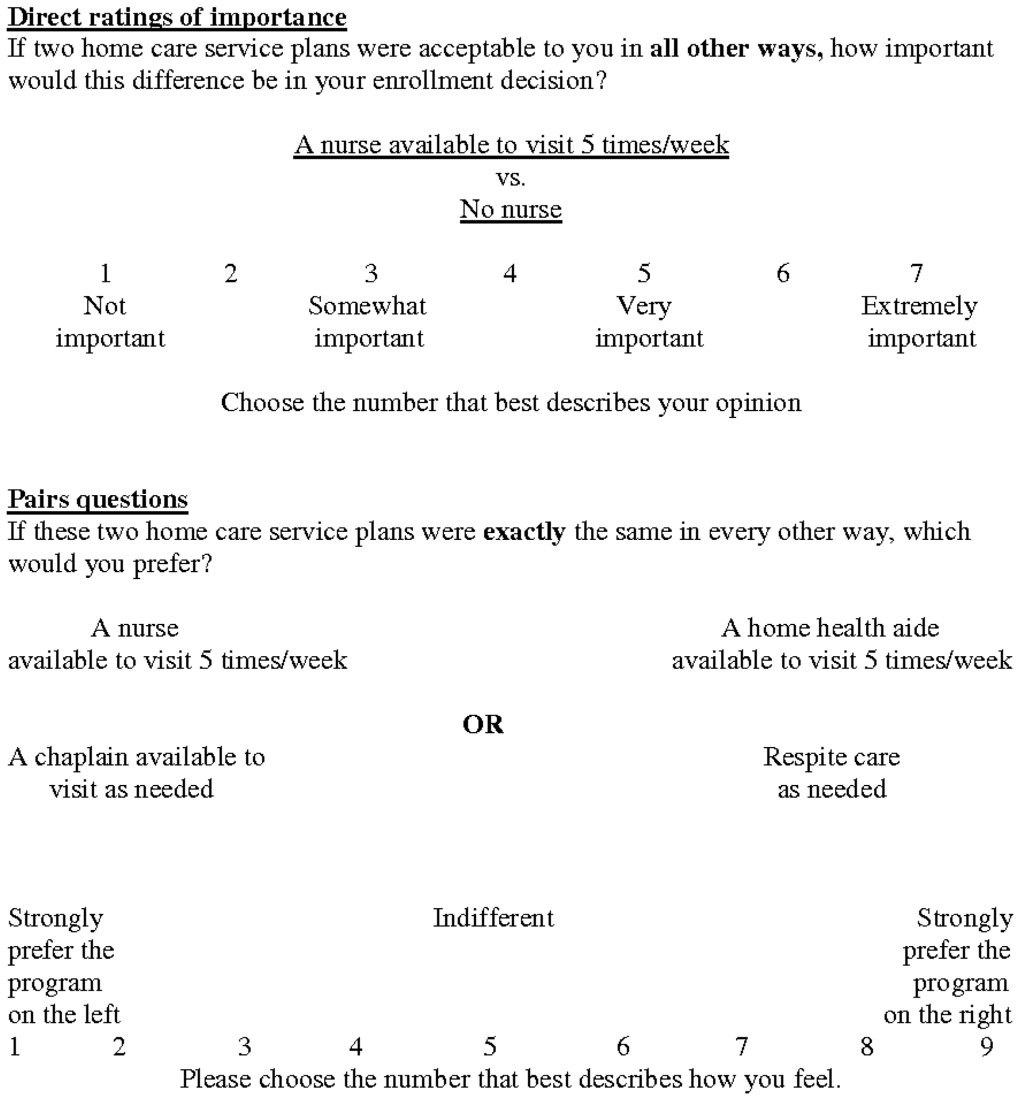
Chaplain: A chaplain provides spiritual and emotional support and can discuss concerns about the future.

Home health aide: A home health aide provides help with personal needs, such as bathing and dressing, housework, cleaning, and laundry.

Counselor: A counselor is available to talk about concerns about the patient's illness and can identify depression, anxiety or other conditions the physician should know about.

Respite Care: Respite care offers a place that a patient can go to stay for a few days to give family members or other caregivers a rest.

Figure 1. Descriptions of hospice services



Direct ratings of importance

If two home care service plans were acceptable to you in **all other ways,** how important would this difference be in your enrollment decision?

A nurse available to visit 5 times/week
vs.
No nurse

1	2	3	4	5	6	7
Not important		Somewhat important		Very important		Extremely important

Choose the number that best describes your opinion

Pairs questions

If these two home care service plans were **exactly** the same in every other way, which would you prefer?

A nurse available to visit 5 times/week		A home health aide available to visit 5 times/week
	OR	
A chaplain available to visit as needed		Respite care as needed

Strongly prefer the program on the left				Indifferent				Strongly prefer the program on the right
1	2	3	4	5	6	7	8	9

Please choose the number that best describes how you feel.

Figure 2. Examples of questions used in conjoint interviews to measure patient's perceived needs (direct ratings of importance and comparisons of pairs of services)

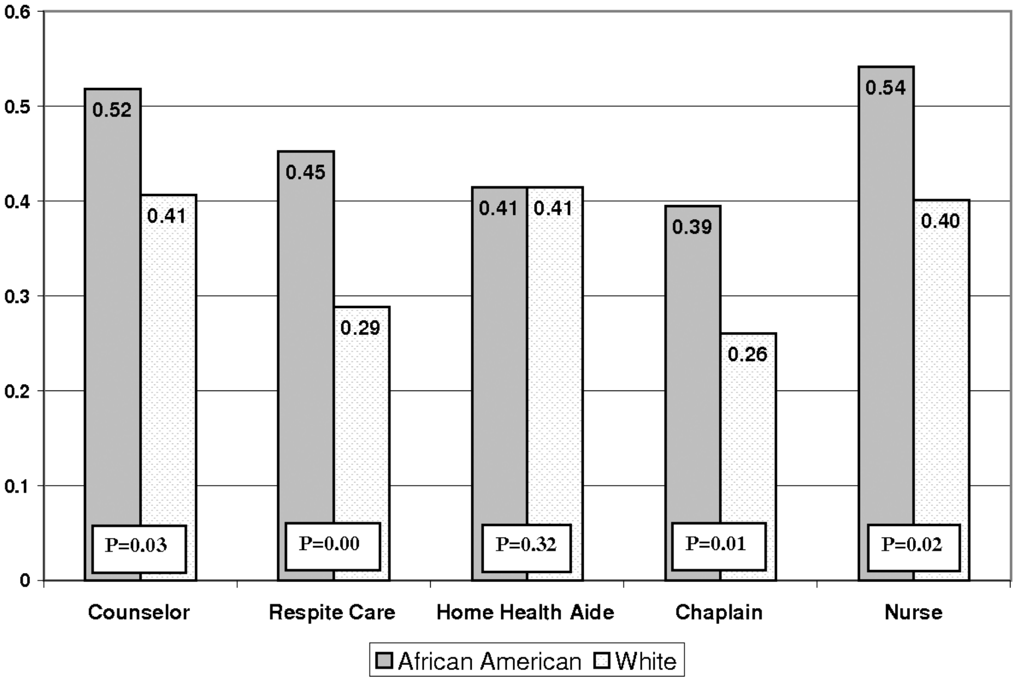


Figure 3. Patient utilities for hospice services

Table 1

Patient characteristics

	Overall (N=300)	African American (N=81)	White (N=202)	P-values
Sex	N (%)	N (%)	N (%)	P=0.10
Male	148 (49)	47 (58)	95 (47)	
Age: Mean (Range)	58(20-89)	63 (31-89)	57 (20-89)	P=0.002
Over 65	84 (28)	33 (41)	49 (24)	
Marital status				P=0.20
Single	45 (15)	19 (23)	23 (11)	
Married	174 (58)	28 (35)	136 (67)	
Divorced/separated	45 (15)	19 (23)	23 (11)	
Widowed	22 (7)	9 (11)	13 (6)	
Living w/ partner	14 (5)	6 (7)	7 (3)	
Household finances (funds available at the end of the month)				P<0.001
Has money left over	142 (47)	14 (17)	122 (60)	
Has just enough to make ends meet	80 (27)	29 (36)	47 (23)	
Does not have enough money to make ends meet	52 (17)	27 (33)	20 (10)	
Refused	26 (9)	11 (14)	13 (6)	
Educational level				P<0.001
Did not graduate from high school	24 (8)	14 (17)	8 (4)	
High school	85 (28)	32 (40)	50 (25)	
Some college or technical school	76 (25)	19 (23)	53 (26)	
College	55 (18)	8 (10)	43 (21)	
Graduate school	60 (20)	8 (10)	48 (24)	
ECOG performance score				P=0.13
0	90 (30)	23 (28)	64 (32)	
1	32 (11)	6 (7)	23 (11)	
2	124 (41)	32 (40)	85 (42)	
3	46 (15)	17 (21)	26 (13)	
4	8 (3)	3 (4)	4 (2)	
Cancer type				P=0.91
Breast	84 (28)	20 (25)	58 (29)	
Gastrointestinal	53 (18)	15 (19)	35 (17)	
Hematologic	37 (12)	4 (5)	31 (15)	
Lung	36 (12)	9 (11)	26 (13)	
Prostate	35 (12)	20 (25)	14 (7)	
Oropharynx	29 (10)	8 (10)	19 (9)	
Genitourinary	18 (6)	1 (1)	16 (8)	

	Overall (N=300)	**African American (N=81)**	**White (N=202)**	**P-values**
Sarcoma	5 (2)	4 (5)	1 (0.5)	
Melanoma	2 (1)	0 (0)	2 (1)	
Glioblastoma	1 (0)	0 (0)	0 (0)	
Global distress index symptoms				
Lack of appetite	111 (37)	34 (42)	69 (34)	P=0.22
Lack of energy	204 (68)	51 (63)	150 (69)	P=0.30
Pain	164 (55)	50 (62)	101 (50)	P=0.07
Drowsiness	171 (57)	47 (58)	113 (56)	P=0.75
Constipation	94 (31)	30 (37)	55 (27)	P=0.10
Dry Mouth	137 (46)	43 (53)	83 (42)	P=0.07
Sadness	116 (39)	29 (36)	80 (40)	P=0.55
Worrying	170 (57)	47 (58)	115 (57)	P=0.87
Irritability	121 (40)	32 (40)	80 (40)	P=0.99
Nervousness	116 (39)	30 (37)	78 (39)	P=0.81
Continue cancer treatment w/probability of survival				P=0.002
Almost 100%	140 (47)	48 (59)	86 (43)	
90-99%	22 (7)	9 (11)	11 (5)	
50-89%	34 (11)	3 (4)	28 (14)	
10-49%	50 (17)	16 (20)	31 (15)	
1-9%	9 (3)	0 (0)	9 (4)	
Almost 0%	7 (2)	0 (0)	5 (2)	
No treatments	38 (13)	5 (6)	32 (16)	`