ORIGINAL ARTICLES

Racial and Ethnic Differences in Preferences for End-of-Life Treatment

Amber E. Barnato, MD, MPH, MS[1], Denise L. Anthony, PhD[2], Jonathan Skinner, PhD[3], Patricia M. Gallagher, PhD[4], and Elliott S. Fisher, MD, MPH[3,5]

[1]Center for Research on Health Care, University of Pittsburgh, Pittsburgh, PA, USA; [2]Department of Sociology, Dartmouth College, Hanover, NH, USA; [3]Center for the Evaluative Clinical Sciences, Dartmouth Medical School, Hanover, NH, USA; [4]Center for Survey Research, University of Massachusetts, Boston, MA, USA; [5]VA Outcomes Group, White River Junction, VT, USA.

BACKGROUND: Studies using local samples suggest that racial minorities anticipate a greater preference for life-sustaining treatment when faced with a terminal illness. These studies are limited by size, representation, and insufficient exploration of sociocultural covariables.

OBJECTIVE: To explore racial and ethnic differences in concerns and preferences for medical treatment at the end of life in a national sample, adjusting for sociocultural covariables.

DESIGN: Dual-language (English/Spanish), mixed-mode (telephone/mail) survey.

PARTICIPANTS: A total of 2,847 of 4,610 eligible community-dwelling Medicare beneficiaries age 65 or older on July 1, 2003 (62% response).

MEASUREMENTS: Demographics, education, financial strain, health status, social networks, perceptions of health-care access, quality, and the effectiveness of mechanical ventilation (MV), and concerns and preferences for medical care in the event the respondent had a serious illness and less than 1 year to live.

RESULTS: Respondents included 85% non-Hispanic whites, 4.6% Hispanics, 6.3% blacks, and 4.2% "other" race/ethnicity. More blacks (18%) and Hispanics (15%) than whites (8%) want to die in the hospital; more blacks (28%) and Hispanics (21.2%) than whites (15%) want life-prolonging drugs that make them feel worse all the time; fewer blacks (49%) and Hispanics (57%) than whites (74%) want potentially life-shortening palliative drugs, and more blacks (24%, 36%) and Hispanics (22%, 29%) than whites (13%, 21%) want MV for life extension of 1 week or 1 month, respectively. In multivariable analyses, sociodemographic variables, preference for specialists, and an overly optimistic belief in the effectiveness of MV explained some of the greater preferences for life-sustaining drugs and mechanical ventilation among non-whites. Black race remained an independent predictor of concern about receiving too much treatment [adjusted OR=2.0 (1.5–2.7)], preference for dying in a hospital [AOR=2.3 (1.6–3.2)], receiving life-prolonging drugs [1.9 (1.4–2.6)], MV for 1 week [2.3 (1.6–3.3)] or 1 month's [2.1 (1.6–2.9)] life extension, and a preference not to take potentially life-shortening palliative drugs [0.4 (0.3–0.5)]. Hispanic ethnicity remained an independent predictor of preference for dying in the hospital [2.2 (1.3–4.0)] and against potentially life-shortening palliative drugs [0.5 (0.3–0.7)].

CONCLUSIONS: Greater preference for intensive treatment near the end of life among minority elders is not explained fully by confounding sociocultural variables. Still, most Medicare beneficiaries in all race/ethnic groups prefer not to die in the hospital, to receive life-prolonging drugs that make them feel worse all the time, or to receive MV.

KEY WORDS: race; ethnicity; terminal care; mechanical ventilation; Medicare.
J Gen Intern Med 24(6):695–701
DOI: 10.1007/s11606-009-0952-6

Compared to whites, blacks are more likely to die in the hospital and to use intensive care[1,2], and life-sustaining treatments such as mechanical ventilation (MV), hemodialysis, and feeding tubes[3]. They also incur higher medical care costs in their last 12 months than whites[4–6]. Some, but not all, of these differences in end-of-life utilization are due to blacks' living in regions with higher overall end-of-life treatment intensity and spending[7] and their use of higher intensity hospitals[2,3]. Further, some of these differences may be due to minorities' lower uptake of services and strategies, such as hospice[8–11] and advance care plan documents in nursing homes[12] that change the acute care "default" near the end of life.

Some of the differences may be due to systematically different preferences for treatment at the end of life among

Electronic supplementary material The online version of this article (doi:10.1007/s11606-009-0952-6) contains supplementary material, which is available to authorized users.

Source of support: Funding was provided by the National Institute on Aging (NIA) grant P01 AG19783 and the Robert Wood Johnson Foundation 050488. Dr. Barnato was supported by NIA career-development grant K08 AG021921.
Received November 28, 2007
Revised October 9, 2008
Accepted February 27, 2009

minorities. Several studies using local samples have found that blacks and Hispanics are more likely to anticipate wanting life-sustaining treatments, even in the context of terminal illness or persistent vegetative state[13–18]. Few of these studies have explored the potential sociocultural confounders of this association. In this study we describe preferences for end-of-life treatment by race/ethnicity in a national sample of Medicare beneficiaries and explore the independent effect of race/ethnicity after controlling for variables hypothesized to impact preference for and use of health services[19–21].

METHODS

Study Population

The study population was a national sample of Medicare beneficiaries. The sampling frame was all community-dwelling Medicare beneficiaries in the 20% denominator file who were age 65 or older on July 1, 2003, alive and entitled to part A, part B, or both, between July 1, 2003, and June 30, 2004, and residents of a US Hospital Referral Region (HRR) in 2003 and 2004 (N=6,384,199). We drew a simple random sample of 4,000 beneficiaries as well as a simple random over-sample of 700 blacks from this frame. We obtained names and addresses from the Centers for Medicare and Medicaid Services (CMS), and identified telephone numbers from an electronic telephone matching service and directory assistance.

Survey

Development and Administration. We designed the survey instrument to assess beneficiaries' general concerns and preferences for care in the event of a terminal illness. We also collected information on socio-demographics, health status, social networks, and perceptions of quality and access to health care. See Barnato et al. and Fowler et al. for detailed description of survey development and cognitive testing[22,23] and Table A1 (available online) for the wording of all survey questions used in the current study.

We fielded the dual-language (English/Spanish), mixed-mode survey between March and October, 2005. If we could not contact the beneficiary by phone after a minimum of six call attempts to administer the computer-assisted telephone interview (CATI), we mailed a questionnaire that paralled the telephone interview along with a $5 cash incentive. We mailed a thank you/reminder postcard 2 weeks later and sent non-respondents a replacement questionnaire packet (without a cash incentive) about 4 weeks after the initial mailing. We calculated response rate using the American Association for Public Opinion Research RR1 formula[24].

Measures

Race and Ethnicity. We categorized self-reported race and ethnicity into mutually exclusive groups of non-Hispanic white, black, Hispanic, or "other," assigning multi-racial or ethic respondents using the hierarchy: black>Hispanic> other (Asian, Native Hawaiian or Pacific Islander, American Indian/ Alaskan Indian/Alaskan Native, or Other)>non-Hispanic white. If respondents endorsed a racial category but had missing data for Hispanic ethnicity, we assumed they were non-Hispanic; this included 28 blacks, 100 whites, and 14 "others." Of the 2,847 responents, 2,810 could be categorized into one of these four race/ethnicity groups.

Medicare Beneficiaries End-of-Life Concerns and Preferences. We used responses to five survey questions to create seven dichotomous dependent variables for the current study; two related to concerns and five related to preferences (Table A1, available online). When dichotomizing responses, we treated answers other than "yes" or "no" (e.g., "not concerned" or "I don't know") as missing data. The concern variables were: concern about receiving too little medical treatment in the last year of life or receiving too much medical treatment. The preferences variables were: preference for dying in an acute care hospital, for life-prolonging drugs that have side-effects, for palliative drugs with potential for life shortening, and for mechanical ventilation to prolong life. We created a summative "positive attitude toward life prolongation" by summing the more intensive responses (concern about too little medical care, preference for dying in the hospital, for life prolongation, against potentially life-shortening palliation, and for mechanical ventilation).

Covariates. The survey collected extensive information about the beneficiary that could confound the relationship between race/ ethnicity and end-of-life medical treatment preferences. Using a behavioral model of health-care utilization[19–21], we conceptualized these variables as *predisposing* (age, sex, education, financial strain, self-efficacy, preference for specialists, and belief in the effectiveness of mechanical ventilation), *enabling* (living arrangements, social networks), *need* (self-assessed health status and pain), *provider access and utilization* (personal physician, emergency department, and physician visits), *perceptions of their providers* (physicians spends enough time, didn't get tests/treatment desired, quality of care), *health-care environment* (age-sex-race standardized spending in the last 6 months of life among beneficiaries residing in the HRR), and *perceptions of the health-care environment* (amount and quality of care in the community).

Statistical Analysis

We used ordinary least-squares regression for continuous variables and the chi-square test for categorical variables and EOL concerns/preferences to test for differences by race/ ethnicity. We performed multivariable logistic regression for each of the seven dichotomized dependent variables and multivariable ordinal logistic regression on the summed index of six measures, treating race/ethnicity as the primary independent variable. All models were controlled for age and self-assessed health status; additional covariates included those associated with the dependent variable in univariate analyses (inclusion p-value$\leq$0.2) and retained in the multivariable model after manual stepwise backward selection (retention p-value$\leq$0.05). We incorporated sampling weights in all analyses and used STATA 9.1 (StataCorp, College Station, TX).

Human Subjects and Role of the Funding Sources

The study was approved by the the Committee for the Protection of Human Subjects (CPHS) at Dartmouth Medical School and the Institutional Review Board (IRB) of the University of Massachussets and deemed exempt from the requirement for written informed consent. This manuscript was reviewed by the CMS to ensure protection of beneficiary confidentiality. The authors had full independence from the funding agency, the National Institute on Aging, and CMS in the design, conduct, analysis, and reporting, and all authors had full access to the primary data.

RESULTS

Survey response

Among the 4,700 sampled, 90 were ineligible (dead, institutionalized, or cognitively impaired). Among these 4,610 potentially eligible beneficiaries (including those never successfully contacted), 2,847 responded for an overall response rate of 62%. The non-contact rate was 4%, and the refusal rate was 5%. The response rate for the black over-sample was lower than the national random sample (48% vs. 65%). The lower response rate among blacks was attributable to a lower contact rate; the refusal rate was lower among blacks.

We obtained phone numbers for 75% of the sample. Slightly more than half of all respondents (55%) responded by phone, the remainder (45%) by mail. Compared to non-Hispanic whites, blacks were more likely to respond by phone and Hispanics more likely to respond by mail. Those with higher education levels were more likely to respond by phone. Item-level non-response was significantly higher for mail compared to phone mode for all end-of-life concerns and preferences.

Sample Characteristics

The respondents included 2,105 non-Hispanic whites (74.9%), 113 Hispanics (4.0%), 489 blacks (17.4%), and 103 persons of other race/ethnicity (3.7%). We compare the weighted distribution of sample characteristcs to the sampling frame from which it was drawn in Table 1. Compared to the population, our weighted sample had fewer persons age 85+ (9.8% vs 14.7%) and fewer blacks (6.3% vs 8.1%). Hispanic ethnicity data are underreported in the enrollment file[25] and thus not strictly comparable to our survey self-report data.

As expected, the different race/ethinic groups varied considerably in variables known to influence health care use (See Table A2, available online). For example, all non-white minorities reported lower education and greater financial strain, less confidence in their ability to manage their health conditions, and an overly-optimistic view of the effectiveness of MV (specifically, 9.2% of Hispanics and 7.9% of blacks, compared to 3.6% of non-Hispanic whites believed that more than half of patients "requiring a respirator to keep them alive will get back to normal activities"). Non-white minorities were less likely to have a personal doctor, more likely to feel the doctor didn't spend enough time with them and to report not receiving some medical care they wanted in the last 12 months (nevertheless, their perceptions of their health care quality were similar to those of non-Hispanic whites). Although blacks and Hispanics were more likely to live in hospital referral regions with higher spending for Medicare beneficiaries, they felt that the amount and quality of medical care their community received was lower than others their age.

Table 1. Sample characteristics

Characteristic	Sample weighted mean or proportion and 95% confidence interval (n=2,847)	Sampling Frame mean or proportion (n=6,384,199)
Age	75.6 (75.4 – 75.9)	76.5
Age 65–69, %	21.4 (19.8 – 23.0)	20.3
Age 70–74, %	27.2 (25.5 – 28.9)	25.6
Age 75–79, %	23.5 (21.9 – 25.2)	22.4
Age 80–84, %	18.1 (16.7 – 19.7)	17.0
Age 85+ , %	9.8 (8.8 – 11.1)	14.8
Male, %	42.5 (40.6 – 44.4)	41.5
Non-Hispanic white, %	85.0 (83.7 – 86.1)	86.6
Black, %	6.3 (5.8 – 6.9)	8.1
Hispanic, %	4.6 (3.8 – 5.5)	1.8
Other, %	4.2 (3.4 – 5.0)	3.5
Less than HS education, %	21.4 (19.8 – 23.0)	19.3*

**Imputed from mean US Census ZIP level education*

End-of-life Concerns and Preferences by Race

We report respondents' concerns and preferences by race, and the correlations among these variables, in Tables A3 and A4, respectively (available online). The majority of Medicare beneficiaries of all race/ethnic groups say that in the event of a terminal illness with less than a year to live they would want to die at home and would not want to receive life-prolonging drugs with uncomfortable side effects or mechanical ventilation for 1 week's or 1 month's life extension. Fewer blacks (25.6%) than whites (42.1%) were worried about receiving too little medical treatment in the event of a terminal illness (and, conversely a greater proportion were worried about receiving too much treatment: 61.5% vs. 42.8%). However, with respect to particular end-of-life treatments, minorities were more likely to prefer intensive options than whites. Specifically, 17.7% of blacks and 15.2% of Hispanics want to die in a hospital, compared to 8% of non-Hispanic whites. More blacks (28.1%) and Hispanics (21.2%) than whites (15%) would want life-extending drug treatment with uncomfortable side effects. Conversely, fewer blacks (49.3%) and Hispanics (56.6%) than whites (74.2%) would want palliative medications that might be life shortening. Finally more blacks (36.1%, 23.5%) and Hispanics (29%, 21.6%) than whites (19.3%, 10.8%) would want to receive ventilator support for 1 month's or 1 week's life extension, respectively.

In regression models adjusted for variables confounding the relationship between race and preferences for end-of-life medical treatment black race remained a significant predictor of all responses (Table 2). Only Hispanics' preferences to avoid palliative drugs that might be life shortening and to die in the hospital remained significantly different than non-Hispanic whites. Blacks ($p<0.0001$) and Hispanics ($p=0.009$) had more positive attitudes towards life prolongation than non-Hispanic whites, as measured by the summed index of responses.

Several additional findings deserve note (See Table A5, available online). Women of all racial/ethnic groups were less likely to worry about receiving "too little" medical treatment at the end of life and were less likely to want life-prolonging drugs. Those with less than a high school education were less likely to want palliative drugs that might be life shortening. Greater financial strain was associated with worry about receiving too much medical treatment at the end of life, and also with preference for dying in the hospital, for life-prolong-

Table 2. Relationship of Race/Ethnicity and Concerns and Preferences for end-of-life Medical Treatment*

	Adjusted odds ratio, compared to non-Hispanic whites (95% confidence interval)†		
	Black	**Hispanic**	**Other**
Concerned re: too little medical care	0.5 (0.4 – 0.7)	0.7 (0.4 – 1.2)	0.7 (0.4 – 1.2)
Concerned re: too much medical care	2.0 (1.5 – 2.7)	1.4 (0.9 – 2.5)	1.3 (0.8 – 2.2)
Want to spend last days in a hospital	2.3 (1.6 – 3.2)	2.2 (1.3 – 4.0)	2.1 (1.1 – 4.0)
Want life-prolonging drugs	1.9 (1.4 – 2.6)	1.2 (0.7 – 2.1)	0.6 (0.3 – 1.2)
Want palliative drugs	0.4 (0.3 – 0.5)	0.5 (0.3 – 0.7)	0.8 (0.4 – 1.3)
Want a respirator for 1 weeks' life extension	2.1 (1.6 – 2.9)	1.4 (0.8 – 2.5)	1.7 (1.0 – 3.1)
Want a respirator for 1 months' life extension	2.3 (1.6 – 3.3)	1.8 (0.91 – 3.4)	1.4 (0.68 – 3.0)

**All models adjusted for age and health status; individual models additionally adjusted for other significant predictors of each concern/preference, which may include sex, education, financial strain, self efficacy, preference for specialists, belief in the effectiveness of mechanical ventilation, living along, church attendance, less than weekly contact with friends or family, never attending social or community activities, daily pain/discomfort, and having a personal doctor*

†Odds ratios should not be interpreted as rate ratios for these concerns/preferences with prevalence>5%

ing drugs, and avoiding potentially life-shortening palliative drugs. A greater self-efficacy score was associated with a marked decrease in wanting to die in the hospital or to receive mechanical ventilation for 1 week's life extension. Those respondents who preferred specialists over primary care providers were more likely to prefer to die in the hospital, and to receive mechanical ventilation for 1 month's or 1 week's life extension. An overly optimistic belief about the likelihood of return to normal activities after mechanical ventilation for life-support was associated with preference for life-prolonging drugs, against potentially life-shortening palliative drugs, and for mechanical ventilation for 1 month's or 1 week's life extension. Living alone predicted a preference for in-hospital death and against mechanical ventilation for 1 month's life extension. Those who attended church daily were less likely to want potentially life-shortening palliative drugs compared to those who never attend church, as were those with less than weekly personal contact with friends or family. Compared to those in excellent health, those with poorer health were more likely to worry about receiving too much medical treatment at the end of life. Having a condition that often caused pain or discomfort was associated with a greater odds of prefering palliative drugs.

DISCUSSION

The majority of Medicare beneficiaries of all race/ethnic groups say that in the event of a terminal illness with less than a year to live they would want to die at home and would not want to receive life-prolonging drugs with uncomfortable side effects or mechanical ventilation for 1 weeks' or 1 months' life extension. However, there were differences in the distribution of preferences for end-of-life medical treatment by race/ethnicity even after controlling for potentially mediating or confounding demographic and sociocultural variables. Specifically, black beneficiaries were more likely than Hispanic and non-Hispanic white beneficiaries to prefer life-prolonging drugs and mechanical ventilation; both blacks and Hispanics were more likely than whites to prefer spending their last days in the hospital and to avoid potentially life-shortening palliative drugs.

Although blacks were more likely than whites to want life-sustaining treatments, they also were more worried about receiving too much medical treatment in their last year of life. We wondered if this was a reflection of concern among the majority of black beneficiaries who don't prefer aggressive end-of-life treatment that the higher population prevalence of preferences for life-sustaining treatments among blacks would result in "statistical discrimination"[26,27] by providers that would lead to more medical treatment than most blacks would prefer. Our data did not support this hypothesis, since there were no group-level differences in treatment preferences (for life-prolonging drugs, for palliative drugs, or for mechanical ventilation) among blacks who were and were not worried about receiving "too much" end-of-life treatment. There was a positive correlation between preferences for more intensive end-of-life treatment (preference for death in the hospital, for life-prolonging drugs, and for mechanical ventilation) and concern about "too much" end-of-life treatment among white respondents, but not among black respondents. The correlation among whites is paradoxical—we imagined those who would want more intensive treatment might be worried about receiving too little treatment and vice versa—but perhaps those who want more intensive treatment anticipate the possibility of "overdoing" it? That the correlation was not found among black respondents may reflect insufficient statistical power in the black cohort or point to systematic differences in the interpretation of the question about "too much" treatment by blacks and whites and a flaw in our survey question design. Without race-specific cognitive testing information about this survey item, we cannot interpret this finding; it deserves further exploration.

The concepts of race and ethnicity in the health services literature are imprecise constructs[28] that conflate culture (e.g., beliefs, values, and customs), socioeconomic status, and "racialism" [i.e., "the ways in which we see, value, and behave toward others according to (some notion) of race"][29])[30]. For example, Johnson et al. used a combination of sociocultural variables to completely explain black-white differences in advance directive completion rates and attitudes towards hospice[31]. We sought to approach the explanation of differences in responses to our hypothetical treatment preference questions by using the conceptual framework of the behavioral model of health-care utilization and found several interesting relationships. Among variables hypothesized to predispose individuals to use health services, lower education, financial strain, preference for specialists, and an overly optimistic belief in the effectiveness of mechanical ventilation were each associated with one or more preferences for "more intensive" end-of-life treatment. Among these, the most mutable (and powerful) is the belief in mechanical ventilation, which may be a proxy for belief in health care technology more generally. Over 27% of blacks believed that 50% or more of persons receiving this life-sustaining treatment were returned to their normal activities, compared to 17% of non-Hispanic whites. In reality, 56% of patients who require mechanical ventilation for 48 h or more are dead at 1 year, and almost 60% of the survivors require caregiver assistance at 1 year[32]. This, of course, is in stark contrast to the popular representations of life-sustaining treatments[33]. Even among those with a more clinically realistic estimation of the effectiveness of mechanical ventilation, blacks were twice as likely as Hispanics and non-Hispanic whites to want a ventilator for life extension of 1 month or 1 week.

Among variables hypothesized to enable the use of health-care services, living alone was associated with a preference for dying in the hospital and not wanting mechanical ventilation. Daily church attendance and less than weekly contact with friends and family were associated with a preference against palliative drugs that might be life shortening. In our sample, relative to non-Hispanic whites, Hispanics and those of other race/ethnicity were less likely to live alone, and blacks were more likely. Some studies have implicated low support for in-home care as one factor in the low uptake of the Medicare hospice benefit among blacks[34]. Among terminal cancer patients, those with greater religiosness are more likely to prefer life-sustaining treatments[35]. The relationships between social networks and preferences for life-sustaining treatments have not been previously explored.

Among variables hypothesized to affect need, those in less than excellent health were more likely to worry about receiving too much medical treatment near the end of life, but self-reported general health did not otherwise affect our measures of preference for end-of-life care. Those reporting a conditon that frequently caused pain or discomfort were more likely to prefer pallative drugs, even if they might be life shortening.

Among provider variables, having a personal doctor was associated with greater concern about receiving “too much” medical treatment. Although blacks and Hispanics were much more likely than non-Hispainic whites to report that their doctor had never or only sometimes spent enough time with them, that there was medical care, tests, or treatment that they did not receive in the last year, and that they believed their community received care of lesser amount and quality, none of these factors was associated with our measures of end-of-life concerns and preferences. Interestingly, we found no differences by race/ethnicity in perceptions of the quality of *one's own* health care, but significant differences in perceptions of the amount and quality of health care in *one's community*.

Our survey has limitations, including survey and item-non-response, reliance upon a hypothetical scenario, and intentionally over-simplified preference questions[3]. Non-response may limit generalizability. The non-contact rate was much higher among minorities, as was ineligibility due to inability to complete the survey (generally cognitive impariment or severe physical debility). Item non-response was much higher for the mail survey than the phone survey, and Hispanics were more likely to complete the survey by mail. This could confound our analyses by race/ethnicity if respondents with a stronger preference for (or against) life-sustaining treatments did not respond to these items. Other potential mode effects include greater pressure for social desirability and greater cognitive demands for phone, compared to mail surveys.

We created simplified survey questions, which may not predict actual treatment choices or receipt. Indeed, in a cross-sectional analysis of these data, higher regional end-of-life expenditures did not predict preferences for more intensive treatment[22]. We did not use decision theoretical approaches such as the standard gamble to ensure all respondents considered the same alternative when offered a choice like mechanical ventilation or drugs for life-prolonging or palliation, nor did we quantify the strength of preferences. The alternative to the treatment offered held in the minds of respondents may have varied systematically by race/ethnicity, given different experiences with the health-care system. Additionally, we created artificial dichotomies; for example, we asked about life-prolonging drugs that “make you feel worse all the time” and palliative drugs that “make you feel better, [but] might shorten your life.” Life-prolonging treatments are not necessarily uncomfortable; indeed, many alleviate symptoms, and palliative treatments may extend life[36]. Although we used a simplified dichotomy for research purposes, we recognize the danger in perpetuating the myth, held by many acute care providers (and perhaps among minority populations), that palliative care is a means to limit life-sustaining treatment or allow death[37]. The implications of this misconception are important for all patients with life-limiting chronic illnesses, but particularly for minorities whose pain is even more undertreated[38–41].

Another weakness was the lack of a measure of “trust” in the health-care system, a much vaunted[31,42–44] but controversial[45,46] mechanism for differences in health-care use by race/ethnicity. We hypothesized that beneficiaries' perceptions of the amount and quality of the health care received by their community were a measure of perceived equity that would capture a related construct. However, our community measure suffers from lack of specificity; some respondents may have considered those in their neighborhood, others may have considered a broader interpretation of “people like me” (e.g., religious or ethnic community). Finally, we used a hierarchical approach to assigning race/ethnicity; specifically, we did not treat Hispanic ethnicity as distinct from race, as is customary, nor did we allow multi-racial categories. So doing simplified our analytic models, but further oversimplifies the constructs of race and ethnicity.

In summary, most Medicare beneficiaries say they would not want drugs with uncomfortable side effects or mechanical ventilation for life extension in the event of a terminal illness. Preference for life-extension, and mechanical ventilation in particular, is associated with an overly optimistic belief in its effectiveness, a misperception that we as providers should seek to rectify because it may have important implications for decision making[47]. From an epidemiologic perspective, our findings reproduce those from smaller regional studies that blacks are more likely than non-Hispanic whites to prefer more intensive treatment near death[13–18]. Despite our efforts to control for a broad array of demographic and sociocultural variables, these findings may reflect unmeasured confounding since our survey items are imperfect measures of the concepts that we sought to measure, such as experience and perceptions of providers and the health-care system. And, of course, our findings should not be interpreted as permission to generalize; end-of-life treatment decisions always should be customized to individual preferences and goals of care.

Acknowledgments: *The Center for Survey Research at the University of Massachusetts, Boston, contributed to questionnaire design and conducted the survey. This study was presented at the 2006 annual meeting of the Society for General Internal Medicine. The authors thank Judith R. Lave and Robert M. Arnold for their suggestions and feedback on earlier drafts.*

Conflict Of Interest Summary: *None of the authors has any affiliations with or financial involvement, within the past 5 years and foreseeable future (e.g., employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties) with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript.*

Corresponding Author: *Amber E. Barnato, MD, MPH, MS; Center for Research on Health Care, University of Pittsburgh, 200 Meyran Avenue, Suite 200, Pittsburgh, PA 15312, USA (e-mail: aeb2@pitt.edu).*

REFERENCES

1. **Pritchard RS, Fisher ES, Teno JM, et al.** Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment [see comments]. J Am Geriatr Soc. 1998; 4610: 1242–50.
2. **Barnato AE, Berhane Z, Weissfeld LA, Chang CH, Linde-Zwirble WT, Angus DC.** Racial variation in end-of-life intensive care use: a race or hospital effect? Health Serv Res. 2006;in press.
3. **Barnato AE, Chang CC, Saynina O, Garber AM.** Influence of race on inpatient treatment intensity at the end of life. J Gen Intern Med. 2007; 223: 338–45.
4. **Hogan C, Lunney J, Gabel J, Lynn J.** Medicare beneficiaries' costs of care in the last year of life. Health Aff. 2001; 204: 188–95.
5. **Levinsky NG, Yu W, Ash A, et al.** Influence of age on Medicare expenditures and medical care in the last year of life. JAMA. 2001; 28611: 1349–55.
6. **Shugarman LR, Campbell DE, Bird CE, Gabel J, Louis TA, Lynn J.** Differences in medicare expenditures during the last 3 years of life. J Gen Intern Med. 2004; 192: 127–35.
7. **Baicker K, Chandra A, Skinner JS, Wennberg JE.** Who You Are And Where You Live: How Race And Geography Affect The Treatment Of Medicare Beneficiaries. Health Aff (Millwood). 2004.
8. **Greiner KA, Perera S, Ahluwalia JS.** Hospice usage by minorities in the last year of life: results from the National Mortality Followback Survey. J Am Geriatr Soc. 2003; 517: 970–8.
9. **Johnson KS, Kuchibhatla M, Tanis D, Tulsky JA.** Racial differences in hospice revocation to pursue aggressive care. Arch Intern Med. 2008; 1682: 218–24.
10. **Stewart AL, Teno J, Patrick DL, Lynn J.** The concept of quality of life of dying persons in the context of health care. Journal of Pain & Symptom Management. 1999; 172: 93–108.
11. **Johnson KS, Kuchibhatala M, Sloane RJ, Tanis D, Galanos AN, Tulsky JA.** Ethnic differences in the place of death of elderly hospice enrollees. J Am Geriatr Soc. 2005; 5312: 2209–15.
12. **Degenholtz HB, Arnold RA, Meisel A, Lave JR.** Persistence of racial disparities in advance care plan documents among nursing home residents. J Am Geriatr Soc. 2002; 502: 378–81.
13. **Degenholtz HB, Thomas SB, Miller MJ.** Race and the intensive care unit: disparities and preferences for end-of-life care. Crit Care Med. 2003; 315 Suppl: S373–8.
14. **Diringer MN, Edwards DF, Aiyagari V, Hollingsworth H.** Factors associated with withdrawal of mechanical ventilation in a neurology/neurosurgery intensive care unit. Crit Care Med. 2001; 299: 1792–7.
15. **Garrett JM, Harris RP, Norburn JK, Patrick DL, Danis M.** Life-sustaining treatments during terminal illness: who wants what? J Gen Intern Med.. 1993; 87: 361–8.
16. **Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP.** Ethnicity and attitudes towards life sustaining technology. Soc Sci Med. 1999; 4812: 1779–89.
17. **Mebane EW, Oman RF, Kroonen LT, Goldstein MK.** The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision-making. J Am Geriatr Soc. 1999; 475: 579–91.
18. **O'Brien LA, Grisso JA, Maislin G, et al.** Nursing home residents' preferences for life-sustaining treatments. Jama. 1995; 27422: 1775–9.
19. **Andersen RM.** (Center for Health Administration Studies, University of Chicago). Behavioral model of families' use of health services. 1968. Report No.: 25.
20. **Andersen RM.** Revisiting the behavioral model and access to medical care: does it matter? J Health Soc Behav.. 1995; 361: 1–10.
21. **Phillips KA, Morrison KR, Andersen R, Aday LA.** Understanding the context of healthcare utilization: assessing environmental and provider-related variables in the behavioral model of utilization. Health Serv Res. 1998; 333 Pt 1: 571–96.
22. **Barnato AE, Herndon MB, Anthony DL, et al.** Are regional variations in end-of-life care intensity explained by patient preferences? A Study of the US Medicare Population. Med Care. 2007; 455: 386–93.
23. **Fowler FJ Jr., Gallagher PM, Anthony DL, Larsen K, Skinner JS.** Relationship between regional per capita Medicare expenditures and patient perceptions of quality of care. Jama. 2008; 29920: 2406–12.
24. Standard Definitions: Final Dispositions for Case Codes and Outcome Rates for Surveys Lenexa, KS: American Association for Public Opinion Research; 2004.
25. **Arday SL, Arday DR, Monroe S, Zhang J.** HCFA's racial and ethnic data: current accuracy and recent improvements. Health Care Financ Rev. 2000; 214: 107–16.
26. **Balsa AI, McGuire TG, Meredith LS.** Testing for statistical discrimination in health care. Health Serv Res. 2005; 401: 227–52.
27. **Balsa AI, McGuire TG.** Statistical discrimination in health care. J Health Econ. 2001; 206: 881–907.
28. **LaVeist TA.** Beyond dummy variables and sample selection: what health services researchers ought to know about race as a variable. Health Serv Res. 1994; 291: 1–16.
29. **Freeman HP.** Commentary on the meaning of race in science and society. Cancer Epidemiol Biomarkers Prev.. 2003; 123: 232s–36s.
30. **Crawley LM.** Racial, cultural, and ethnic factors influencing end-of-life care. J Palliat Med.. 2005; 8Suppl 1: S58–69.
31. **Johnson KS, Kuchibhatla M, Tulsky JA.** What Explains Racial Differences in the Use of Advance Directives and Attitudes Toward Hospice Care? J Am Geriatr Soc. 2008.
32. **Chelluri L, Im KA, Belle SH, et al.** Long-term mortality and quality of life after prolonged mechanical ventilation. Crit Care Med. 2004; 321: 61–9.
33. **Diem SJ, Lantos JD, Tulsky JA.** Cardiopulmonary resuscitation on television. Miracles and misinformation. N Engl J Med.. 1996; 33424: 1578–82.
34. **Gordon AK.** Deterrents to access and service for blacks and Hispanics: the Medicare Hospice Benefit, healthcare utilization, and cultural barriers. Hosp J. 1995; 102: 65–83.
35. **Balboni TA, Vanderwerker LC, Block SD, et al.** Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. J Clin Oncol. 2007; 255: 555–60.
36. **Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K.** Comparing hospice and nonhospice patient survival among patients who die within a three-year window. J Pain Symptom Manage. 2007; 333: 238–46.
37. **Rodriguez KL, Barnato AE, Arnold RM.** Perceptions and utilization of palliative care services in acute care hospitals. J Palliat Med. 2007; 101: 99–110.
38. **Anderson KO, Richman SP, Hurley J, et al.** Cancer pain management among underserved minority outpatients: perceived needs and barriers to optimal control. Cancer. 2002; 948: 2295–304.
39. **Todd KH, Lee T, Hoffman JR.** The effect of ethnicity on physician estimates of pain severity in patients with isolated extremity trauma. Jama. 1994; 27112: 925–8.
40. **Todd KH, Samaroo N, Hoffman JR.** Ethnicity as a risk factor for inadequate emergency department analgesia. Jama.. 1993; 26912: 1537–9.
41. **Cleeland CS, Gonin R, Baez L, Loehrer P, Pandya KJ.** Pain and treatment of pain in minority patients with cancer. The Eastern Cooperative Oncology Group Minority Outpatient Pain Study. Ann Intern Med. 1997; 1279: 813–6.

42. **Caralis PV, Davis B, Wright K, Marcial E.** The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. J Clin Ethics. 1993; 42: 155–65.
43. **Hauser JM, Kleefield SF, Brennan TA, Fischbach RL.** Minority populations and advance directives: insights from a focus group methodology. Camb Q Healthc Ethics. 1997; 61: 58–71.
44. **Murphy ST, Palmer JM, Azen S, Frank G, Michel V, Blackhall LJ.** Ethnicity and advance care directives. J Law Med Ethics. 1996; 242: 108–17.
45. **McKinley ED, Garrett JM, Evans AT, Danis M.** Differences in end-of-life decision making among black and white ambulatory cancer patients. J Gen Intern Med. 1996; 1111: 651–6.
46. **Hardin R.** Trust and Trustworthiness. New York, NY: Russell Sage Foundation; 2002.
47. **Fried TR, Bradley EH, Towle VR, Allore H.** Understanding the treatment preferences of seriously ill patients. N Engl J Med. 2002; 34614: 1061–6.