

Barriers to Completion of Health Care Proxies

An Examination of Ethnic Differences

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Background: Advance directives have not been uniformly used by different segments of the US population and studies have consistently shown a lower prevalence of advance directives among African Americans and Hispanics compared with non-Hispanic whites.

Objective: To examine barriers to completion of health care proxies for different ethnic groups.

Methods: One hundred ninety-seven subjects aged 65 years or older self-identified as African American (n = 65), Hispanic (n = 65), or non-Hispanic white (n = 67) attending a geriatrics and internal medicine outpatient clinic of a large New York City teaching hospital were administered a questionnaire. Questionnaires were developed to examine potential barriers to completion of health care proxies. Barriers were drawn from the literature and from focus groups.

Results: Significant predictors of proxy completion using logistic regression analysis included knowledge of

health care proxies, availability of a health care agent, exposure to mechanical ventilation, age, and self-reported health status as fair to poor. Subjects who believed that a health care agent was irrelevant in the setting of involved family were significantly less likely to have completed a health care proxy. Although there were significant differences in the baseline completion rates of health care proxies for the 3 ethnic groups, ethnicity did not predict prior appointment of a health care agent in multivariate analysis.

Conclusions: Differences in health care proxy completion rates across white, African American, and Hispanic elderly individuals in this New York City population seem to be related to potentially reversible barriers such as lack of knowledge and the perceived irrelevance of advance directives in the setting of involved family. Enhanced educational efforts of both health care personnel and patients could increase the rate of formal health care proxy appointment.

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ADVANCE DIRECTIVES (health care proxies and living wills)¹⁻⁴ provide patients with a means to preserve some control over their medical care should decisional capacity be lost. Advance directives have not been uniformly used by different segments of the US population and studies have consistently shown a lower baseline prevalence of advance directive completion for African Americans and Hispanics compared with non-Hispanic whites (primarily with respect to living wills).⁵⁻¹¹ The reasons for this variability in completion rates are unclear. Ethnic differences in knowledge about advance directives,^{8,10,12} differences in access to health care and associated opportunities to complete advance directives,¹³⁻¹⁵ absence of appropriate surrogates,¹⁶ and concerns about placing undue burdens on surrogates¹⁷ have all been cited as potential explanations. It is also possible that members of disenfranchised eth-

nic groups perceive advance directives as a means of limiting their access to health care.¹⁰ Finally, it may be that advance directives are perceived as an unnecessary and overly formal approach to decisions that have traditionally rested with family members. The objective of this study was to explore differences regarding knowledge and completion of health care proxies among 3 ethnic and racial groups. To this end, we sought to identify confounding variables that might explain observed differences in the prevalence of advance directives, particularly health care proxies, among different ethnic groups.

RESULTS

SUBJECT CHARACTERISTICS

Two hundred twenty-two subjects were approached for consent to participate of whom 197 (88%) agreed to be interviewed. Nonrespondents were equally

SUBJECTS AND METHODS

SUBJECTS

Subjects were recruited from the geriatrics and internal medicine outpatient clinics of a large New York City teaching hospital serving a multiethnic and socioeconomically diverse patient population. Interviews were conducted with a consecutive series of patients older than 65 years without a diagnosis of dementia who identified themselves as either African American, Hispanic, or non-Hispanic white from September 1996 through March 1997. Prospective subjects were approached either before or immediately following their physician appointment for consent to participate. Consenting patients were administered a 47-item questionnaire by a single research assistant. The research assistant was white, fluent in Spanish, and had had extensive experience in interviewing and conducting research with different ethnic populations. Completion of the questionnaire typically required 25 minutes.

QUESTIONNAIRE DEVELOPMENT

We designed a questionnaire to examine the relationship between a series of hypothesized barriers to completion of health care proxies and subjects' actual completion of these documents. Questionnaire development occurred in several steps. First, we reviewed the literature on advance directives, particularly those studies^{7-11,18} that included non-white subjects, to identify potential barriers. Then, we conducted focus groups with 20 elderly subjects (African American [n = 7], Hispanic [n = 6], or white [n = 7]) recruited from a New York City seniors center that serves a population similar to the study sample. In the focus groups, we asked participants about their understanding of advance directives in general and health care proxies in particular, their reasons for noncompletion (eg, personal or religious beliefs, family reasons, or logistical factors) and their understanding of how decisions are made when patients lose decisional capacity. At the conclusion of the focus group, barriers identified in previous studies that had not emerged spontaneously during the discussion were posed to the groups to elicit their reactions and comments (a full description of the methodology and results of this qualitative study has been reported elsewhere¹⁹). Both barriers previously identified in the literature and those raised by the focus group participants were included in the questionnaire. The final instrument assessed knowledge of health care proxies, experience with the health care system, beliefs about trustworthiness of physicians, burdens on proxy decision makers, relevance of formally appointed decision makers, availability of individuals willing to serve as surrogates, comfort discussing end-of-life medical care, and whether the respondent had ever appointed someone to serve as their health care proxy (**Table 1**).

Knowledge of health care proxies was assessed by an initial question that asked subjects if they were familiar with

the term *health care proxy*. Subjects responding affirmatively were then asked 6 additional knowledge questions based on the New York State proxy law. Following this section, an explanation of health care proxies was provided to participants.

Beliefs regarding trust in the health care system, burdens placed on potential agents, and irrelevance of health care proxies when there were involved families were each assessed by 4 statements set on a 4-point Likert scale. Items on the trust scale included such statements as: "I trust the doctors to make the right decisions about my medical care if I were to be very ill or in a coma" and "I worry that I won't be treated as well as other people in the hospital if I were to be very sick or dying." Items in the burden and irrelevance scales included such statements as "I am comfortable asking only one family member or one close friend to make medical decisions for me if I could not make them for myself" and "My family will always make sure that I am treated right by the doctors," respectively.

Reliability estimates for each of these 3 scales, as assessed by Cronbach α , were .81 (burden), .63 (irrelevance), and .74 (trust). Cronbach α reflects the degree to which items in a scale are interrelated and ranges from 0 to 1. Good internal consistency is reflected by scores of .7 or greater. A factor analysis (principal components with a variance maximization rotation) of the 12 items that assessed the 3 barriers resulted in 3 discrete factors. Except for 2 irrelevance items that loaded with the trust statements, items representing each of the 3 barriers formed separate factors. The 2 irrelevance items were eliminated. The revised Cronbach α was .67.

The questionnaire was written in simple English and translated into Spanish, and piloted within the clinics to ensure comprehension of language and content. Questionnaires were administered in the subjects' preferred language.

STATISTICAL ANALYSIS

Analysis of variance and χ^2 procedures were used to examine differences in the independent variables (**Table 1** and **Table 2**) across the 3 ethnic groups. Multiple logistic regression analyses were performed to analyze the relationship between the independent variables and patients' completion of a health care proxy. First, a single variable analysis was performed including only ethnicity and each variable of interest (**Tables 1** and **2**) using completion of a health care proxy as the dependent variable. All variables with $P \leq .15$ in the single variable analysis were examined jointly in the next step of model building. Variables that were no longer of borderline significance ($P > .10$) when the other variables were entered were eliminated from the model. After controlling for variables retained in the model, variables not previously significant in the single variable analysis were added to the model and those of borderline significance ($P < .10$) were retained.

The study protocol was approved by the Institutional Review Board of the Mount Sinai School of Medicine, New York, NY.

distributed across the 3 ethnic groups and did not differ by age or sex. Patient characteristics are presented in **Table 2**. Most Hispanic respondents (88%) were of Puerto Rican origin and 52% of Hispanic subjects spoke English.

KNOWLEDGE AND COMPLETION OF HEALTH CARE PROXIES

White subjects were significantly more likely to state that they knew about health care proxies (57%) compared with

Table 1. Potential Barriers to Completion of Health Care Proxies for 197 Subjects*

Potential Barriers	White (n = 67)	African American (n = 65)	Latino (n = 65)	P
Knowledge of health care proxies				
No knowledge of health care proxies	29 (43)	40 (62)	52 (80)] <.001
1-4 Knowledge questions correctly answered	17 (25)	16 (25)	10 (15)	
5-6 Knowledge questions correctly answered	21 (31)	9 (14)	3 (5)	
Trust in physicians and experience with health care				
Trust physicians and the health care system (trust/strongly trust)	56 (84)	53 (81.5)	26 (40)	<.001
Previously admitted to hospital	66 (99)	64 (99)	59 (91)	.05
Admitted to or visited friend or family in an intensive care unit	46 (69)	43 (66)	42 (65)	.78
Previously receiving ventilatory support or visited friend or family receiving ventilatory support	18 (27)	34 (52)	21 (32)	.006
Mean physician visits in last year (range)	5.3 (1-20)	4.7 (1-15)	4.8 (1-15)	.53
Burden, irrelevance, and availability of health care proxies				
A health care proxy is burdensome on the designated surrogate (agree/strongly agree)	47 (70)	43 (66)	48 (59)	.22
A health care proxy is relevant even if one has an involved family (agree/strongly agree)	59 (88)	53 (81)	28 (43)	<.001
Family member or friend available to serve as a health care proxy	62 (93)	59 (92)	30 (46)	<.001
Comfort discussing end-of-life care and health care proxies				
Comfortable talking about end-of-life care	59 (88)	60 (92)	32 (49)	<.001
Want to talk about end-of-life care with medical doctor	54 (81)	46 (71)	30 (46)	<.001

*Values are number (percentage) unless otherwise stated.

African Americans (39%) and Hispanics (20%) ($P < .001$) and were more likely to have formally assigned a health care agent (46%), compared with 31% of African Americans and 20% of Hispanics ($P < .001$).

TRUST IN PHYSICIANS AND EXPERIENCE WITH HEALTH CARE

Hispanics reported significantly less trust in physicians and the health care system than did African Americans and whites. Forty percent of Hispanic subjects trusted physicians and the health care system compared with 84% of whites and 82% of African Americans ($P < .001$). African Americans were more likely to have had experience with mechanical ventilation compared with whites or Hispanics ($P = .006$). No significant differences were noted across the 3 groups with respect to the number of physician office visits, history of hospitalization, or experience with care in an intensive care unit (Table 1).

BURDEN, IRRELEVANCE, AND AVAILABILITY OF HEALTH CARE PROXIES

All 3 groups agreed that appointment as a health care proxy was a potential burden for the designated agent (Table 1). Hispanics were significantly less likely to believe that a health care proxy was a necessary instrument in the setting of involved family ($P < .001$). Likewise, Hispanics were significantly less likely to have a family member or friend whom they believed could make medical decisions for them in the event that they could not make such decisions for themselves (54% compared with 93% of whites and 92% of African Americans; $P < .001$). This finding persisted in a subsequent regression analysis that controlled for the potential burden on the health care agent and discomfort with talking about end-of-life care ($P < .001$).

Table 2. Patient Characteristics for 197 Subjects*

Characteristic	White (n = 67)	African American (n = 65)	Latino (n = 65)
Women	60 (89.6)	54 (83.1)	54 (83.1)
Median age, y (range)†	82 (66-93)	79 (65-96)	76 (65-89)
Religion†			
Catholic	8 (12.1)	13 (20)	49 (75.4)
Protestant	5 (7.6)	32 (49.2)	13 (20)
Jewish	47 (71.2)	0 (0)	1 (1.5)
Other	6 (9.1)	20 (30.8)	2 (3.1)
English speaking	67 (100)	65 (100)	34 (52)
Education†			
Elementary school	1 (1.5)	8 (12.3)	28 (43.1)
High school	26 (38.8)	41 (63.1)	27 (41.5)
College	40 (59.7)	16 (24.6)	10 (15.4)
Mean years lived in the United States (range)†	75.4 (41-93)	71.9 (3-96)	45.8 (1-89)
Self-perceived health rating			
Good-excellent	29 (43.3)	28 (43.1)	24 (36.9)
Fair	29 (43.3)	22 (33.8)	29 (44.6)
Poor	9 (13.4)	15 (23.1)	12 (18.5)
Health care proxy completed†	31 (46)	20 (31)	12 (20)

*Values are number (percentage) unless otherwise stated.

† $P < .001$.

COMFORT DISCUSSING END-OF-LIFE CARE

Comfort about discussing end-of-life care also differed among the 3 groups. White and African American subjects were significantly more comfortable talking about end-of-life care than Hispanic subjects (88% of whites and 92% of African Americans compared with 49% of Hispanics; $P < .001$). Eighty-one percent of whites wanted to discuss end-of-life care with their physician compared with 71% of African American and 46% of Hispanic subjects ($P < .001$).

Table 3. Predictors of Health Care Proxy Completion

Variables	Odds Ratio (95% Confidence Interval)
Ethnicity*	
African American	1.01 (0.35-2.90)
Hispanic	0.43 (0.13-1.46)
Knowledge of health care proxy†	
1-4 Knowledge questions answered correctly	13.63 (4.60-40.32)
5-6 Knowledge questions answered correctly	30.12 (8.04-112.86)
Potential health care agent available	2.35 (1.13-4.88)
Health care proxy irrelevant if involved family	0.32 (0.11-0.89)
Exposure to mechanical ventilatory support	3.17 (1.12-8.93)
Age	1.08 (1.01-1.16)
Self-reported health status as fair to poor	3.08 (1.21-7.87)

*Referent category is white.

†Referent category is no knowledge of health care proxies.

PREDICTORS OF HEALTH CARE PROXY COMPLETION

Results of the regression analysis equation are presented in **Table 3**. For all subjects, positive predictors of health care proxy completion included knowledge of health care proxies ($P < .001$), availability of a friend or family member to serve as a proxy ($P < .001$), previous exposure to ventilatory support (either self or a family member) ($P = .03$), older age ($P = .02$), and health status perceived as fair or poor ($P = .03$). Subjects who believed that health care proxies were not necessary if they had involved family were significantly less likely to have appointed a health care proxy ($P = .04$). Ethnicity was not significantly associated with proxy completion after controlling for the variables listed earlier.

COMMENT

African American and Hispanic patients attending a geriatrics and internal medicine hospital-based group practice were significantly less likely than white patients to have appointed a health care agent. These results confirm previous reports that African Americans and Latinos are less likely to complete advance directives than non-Hispanic whites.⁵⁻¹¹ Our results suggest that the differences in advance directive prevalence that were observed in this study were strongly related to factors such as knowledge of health care proxies, availability of a potential health care agent, beliefs about the necessity of a formally appointed health care agent in the presence of involved family, experience with life-prolonging medical technology (eg, mechanical ventilation), age, and self-perceived health status.

Several studies have reported increased familiarity with health care proxies among whites compared with other ethnic groups. Our study suggests that a priori knowledge of health care proxies is one of the strongest independent predictors of health care proxy completion when other factors are controlled. Although we ini-

tially wondered if these differences might be explained by language barriers, a secondary analysis in the Hispanic group suggested that the inability to speak English did not explain the low proxy appointment rate in this group. Several other explanations may be postulated. First, it is possible that the physicians in our practice sites were more likely to discuss advance directives with white patients, perhaps because of mistaken beliefs about the relevance of these documents for whites compared with other ethnic groups. Alternatively, it is possible that differences in exposure to advance directives (eg, through media, educational seminars, or workshops) within the different ethnic communities may have accounted for the differences that we observed. Finally, as Murphy et al¹² have suggested, it may be that the ethnic groups studied may be differentially motivated to actively seek information about advance directives resulting in different knowledge levels.

Subjects who believed that health care proxies were not needed when one had involved family also were significantly less likely to have assigned a health care agent. This belief was particularly strong within the Hispanic group (67% believed this compared with 12% of whites and 19% of African Americans). This finding may perhaps be understood within the cultural concept of familism common among Hispanic groups. Familism dictates that one's family is central, requires obligations to one's family member before outsiders, and emphasizes family unity.^{20,21} Thus, in the setting of a strong family system, it is possible that Hispanics may believe that a health care proxy is irrelevant, perhaps even harmful, as it has the potential to remove decision making from the family unit or isolate one family member as the primary decision maker.

Not surprisingly, the lack of an available surrogate was also a significant predictor of whether a subject had completed a health care proxy, particularly among Hispanic patients. Whereas it is possible that most Hispanic subjects had no family or friends who could serve as an agent, a more plausible explanation for this finding may be that Hispanic subjects were more reluctant to ask a relative or friend to serve as their health care agent than were whites or African Americans.

This study identified several other variables that were significantly associated with subjects' completion of health care proxies. Older subjects and subjects who perceived themselves to be in poorer health were more likely to have completed a health care proxy than younger or healthier patients across all 3 ethnic groups. These findings are perhaps not surprising given the results of previous studies that have demonstrated higher advance directive completion rates for subjects more likely to face serious health care decisions (eg, people with cancer or the acquired immunodeficiency syndrome, or the elderly).¹⁸ Subjects with personal experience with life-prolonging technology (eg, mechanical ventilators) were also more likely to have completed a health care proxy, perhaps because such experiences illustrate the relevance of advance directives in a more concrete manner than hypothetical discussions in a physician's office. Other demographic variables such as religion, education level, and number of years lived in the United States also did not predict health care proxy comple-

tion. These latter findings are consistent with previous studies^{16,22} performed involving this patient population.

Discomfort with advance care planning was particularly strong within the Hispanic group. Our findings are similar to those of Murphy et al¹² who noted that Mexican Americans did not want physicians to discuss death and dying because doing so might be harmful to the patient. It may be that similar beliefs dictated the responses of the mainly Puerto Rican subjects in our study.

There are several limitations to this study. Our study was undertaken in a large urban New York City teaching hospital and the results may not be generalizable to other institutions and other settings. Nonetheless, our findings are in agreement with those previously reported in other practice settings. Second, we relied on self-reports as our measure of health care proxy completion rather than chart review. However, the proxy completion rates that we obtained in this study are consistent with those found in a prior study performed with this same patient population in which self-reports were confirmed by review of the subjects' actual advance directive document.^{16,23} Third, although we hypothesized that lack of access to health care might be a significant barrier to completion of advance directives, we were unable to examine this barrier in this study population because all subjects were receiving primary medical care. Fourth, although we attempted to eliminate selection bias by eliciting oral consent and interviewing the patients in their preferred language, it is possible that some African American or Hispanic subjects may have felt uncomfortable or refused to participate because the interviewer was white. Finally, since ethnicity is not a unidimensional concept, caution is mandated in the interpretation of our findings.

Despite skepticism about the ability of advance directives to influence clinical decision making,²⁴ advance directives currently remain the primary means of guiding medical care for patients without decisional capacity. Most studies that have included ethnic minorities in their samples report a lower prevalence of advance directive completion in comparison with non-Hispanic whites. An understanding as to why this occurs and of the influence of ethnicity on the decision to execute advance directives is particularly important in view of the changing demographics in the United States. In New York City, for example, African Americans and Hispanics now compose 50% of the metropolitan population.²⁵ Before accepting formal advance directives as the only legal standard by which medical decisions are to be made for patients lacking decisional capacity, it is important to understand why such a large segment of society may not complete these documents. This study suggests that poor completion rates among patients with access to health care are due at least in part to potentially reversible barriers such as lack of knowledge of health care proxies and the perceived irrelevance of advance directives in the setting of involved family, indicating that enhanced educational efforts of both health care personnel and patients could increase the rate of formal health care proxy appointment. Further research is needed to determine whether these barriers also predominate among commu-

nity-based elderly individuals who do not have adequate access to health care.

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