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Ethnicity and Advance Care Directives

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Advance care directives for health care have been promoted as a way to improve end-of-life decision making. These documents allow a patient to state, in advance of incapacity, the types of medical treatments they would like to receive (a living will), to name a surrogate to make those decisions (a durable power of attorney for health care), or to do both. Although studies have shown that both physicians and patients generally have positive attitudes about the use of these documents,[1] relatively few individuals have actually completed one.[2]

What underlies this discrepancy between attitudes and behavior with regard to advance care directives? One obvious explanation is lack of access. Emanuel et al. estimated that approximately 90 percent of the population desire an advance care directive,[3] and they pointed to access as the major barrier. Yet interventions that increase accessibility have typically failed to yield more than a 20 percent completion rate.[4] Thus, it appears that access is not the sole determinant of advance care directive completion.

A second and related factor often cited to account for the relatively low completion rate is knowledge. It has been argued that if individuals simply had sufficient information about advance directives, they would complete one. The bulk of existing research, however, does not support this proposition. For instance, in a random study of 302 patients, Jacobson et al. found that although 90 percent of them knew about living wills, only 20 percent had actually completed one.[5] Moreover, in a study by Sachs, Stocking, and Miles,[6] fifty-two patients were specifically given both information on advance care directives and copies of forms for living wills and durable powers of attorney for health care. Six months after this intervention, the study group found no difference in the rate of completion between patients who had information about and access to advance directives and a control group. As these authors conclude, factors other than information and access appear to be involved.

One often overlooked factor may be that attitudes toward advance care directives are closely tied to one's values and beliefs, which, in turn, may be associated with one's cultural or ethnic background. Typically, studies of advance care completion involve predominantly white middle-class respondents. Indeed, in the study by Emanuel et al., individuals with a "language barrier" were systematically excluded, resulting in a sample in which 25 percent of the respondents had a postgraduate level of education.[7] That almost all (93 percent) of these respondents desired an advance care directive has been widely cited to support legislation of advance directives.

Studies that have included patients from diverse ethnic backgrounds reveal that this is a far from universal consensus.[8] For instance, one survey of HIV-infected patients found that in comparison with their white counterparts, "nonwhite" patients were only half as likely to complete such documents.[9] Similarly, although 91 percent of white patients in a Veterans Administration hospital expressed an intent to complete an advance directive, only 66 percent of blacks in that hospital expressed a similar intent.[10] As Lynn and Teno note, such results produce concern that the meaning and usefulness of advance directives might be linked to a "middle-class" approach to health care.[11]

These conflicting results raise the following question: If all individuals were equally educated with regard to advance directives, and the requisite documents were readily available, would we see a uniformly high completion rate

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across all ethnic groups? Our research explores the relationships between ethnicity and attitudes toward, knowledge of, and completion of advance directives for health care.

Methods

Participants

Interviews were conducted with 800 individuals, ages sixty-five and older, who identified themselves as belonging to one of the following four ethnic groups: African American, European American, Korean American, and Mexican American (200 in each ethnic group). Care was taken to include an equal number of males (100) and females (100) within each ethnic group and to maintain a similar age distribution across all groups. Because a simple random sample of individuals over the age of sixty-five would have yielded a sample that was heavily skewed both in terms of gender and age, a stratified quota sampling technique was employed.

Attempts were made to minimize selection bias by sampling from a wide range of sites. A list of senior citizen centers in Los Angeles County was obtained from the Los Angeles County Agency on Aging. Medical sites and those directly affiliated with a church were avoided. To ensure that ethnicity and not income would be the primary variable differentiating our respondents, we further reduced our sampling frame to thirty-one sites located in areas with comparable socioeconomic distributions. Directors at each site were contacted for permission to recruit at the center. Recruitment procedures included flyers, handouts, direct approach, and announcements at times of congregate activities such as meals. Once an individual expressed interest, either in response to a direct solicitation or by calling a telephone number listed on the flyer, an interviewer proceeded to determine eligibility. If the individual met the minimum age requirement of sixty-five and identified himself/herself as a member of one of the four groups of interest, they were provided with a consent form and an appointment was set up with an ethnically matched interviewer. Participation was voluntary, and respondents were given $20 for their time. This study was approved by the University of Southern California Institutional Review Board.

Procedure

All interviewers were trained by one of the authors of the instrument. The interviewers' ethnicity matched those of the four groups of interest, and the Korean American and Mexican American interviewers were bilingual. Interviews were conducted in a one-on-one private setting. Respondents were interviewed either at the time of enrollment or at a scheduled appointment. Although Mexican American and Korean American respondents were given a choice of whether they wanted to be interviewed in English or their native language, all respondents chose to be interviewed in Spanish and Korean respectively.

Materials

The "Ethnicity and Attitudes Toward Advance Care Directives Questionnaire" is an hour-long instrument whose content and format was developed after extensive review of relevant anthropological and medical literature, as well as after consultation with clinicians, anthropologists, and experts in health beliefs. The instrument includes scales specifically designed to measure issues relevant to this study as well as previously validated scales. New scales underwent testing for internal (construct and content) and external validity, including extensive pilot testing. Once finalized, the instrument was translated into Korean and Spanish and then back into English by an independent agency with experience in translating and ensuring equivalency of medical and technical terms.

Knowledge of, Attitude Towards, and Possession of Advance Care Directives. Table 1 lists the interview questions that were asked to ascertain the respondent's knowledge of, attitude toward, and possession of an advance care directive. With respect to knowledge, two of the interview questions specifically asked about advance care directives. If the respondent mentioned anything about a "living will," or a "durable power of attorney," or a form that allowed a patient to name a surrogate to make health care decisions, then that respondent was classified as having *knowledge* of advance care directives.

The respondent's attitude about advance decision making was obtained from four items in the questionnaire, each measured on a four-point Likert scale. The four individual items are: (1) whether one should wait until the situation arises to make decisions about treating very serious illness or should write them down in advance; (2) whether doctors should discuss death and dying with their patients, because doing so could be harmful to the patient; (3) whether it is necessary to write down wishes about medical care, because family members will know what to do when the time comes; and (4) whether it is best to avoid talking about serious illnesses or death before they occur. A factor analysis revealed that these four items all measured a single underlying factor or construct. Consequently, the four items were recoded as 1 = "agree" or 0 = "disagree," and then averaged to create a summary *attitude score* with a range of 0 to 1. The higher the attitude score, the more negative the respondent's attitude is considered to be with regard to issues related to advance decision making.

Possession of an advance care directive was established

A. *Knowledge (1 = if respondent scores 1 on questions 1 or 2 or both; 0 = otherwise).*
- What is a living will? (1 = if respondent mentions anything about a form that states his/her wishes about health care; 0 = otherwise).
- What is durable power of attorney for health care? (1 = if respondent mentions anything about designating someone to make health care decisions for him/her, or if he/she mentions anything about a form that states his/her wishes about his/her health care, or anything about durable power of attorney being a type of living will; 0 = otherwise).

B. *Attitude (questions 1 through 4 were recoded as 1 = "agree" or 0 = "disagree" and then averaged to create an attitude score with a range from 0 to 1; the higher the score, the more negative the attitude).*
- It is best to wait until the situation arises to make decisions about treating very serious illness, rather than writing them down in advance (1 = agree strongly, 2 = agree somewhat, 3 = disagree somewhat, 4 = disagree strongly).
- Doctors should not discuss death and dying with their patients because doing so could be harmful to the patient (1 = agree strongly, 2 = agree somewhat, 3 = disagree somewhat, 4 = disagree strongly).
- It is not necessary for people to write down their wishes about medical care because their family will know what to do when the time comes (1 = agree strongly, 2 = agree somewhat, 3 = disagree somewhat, 4 = disagree strongly).
- It is best to avoid talking about serious illnesses or death before they occur (1 = agree strongly, 2 = agree somewhat, 3 = disagree somewhat, 4 = disagree strongly).

C. *Possession (1 = yes if respondent answers yes to question 1, and scores a 1 on the Knowledge item; 0 otherwise).*
- Have you made a living will (a form you fill out on which you write down what your wishes would be if you become very ill)? Interviewers were instructed to probe for possession of either a living will or a durable power of attorney.

Table 1. Questionnaire Items Measuring Knowledge of Advance Care Directive, Attitude Toward Advance Decision Making, and Possession of an Advance Care Directive.

from a single question: "Have you made a living will?" If the respondent had no knowledge of living wills, the interviewer was instructed to clarify with the respondent that a "living will" is a document, such as a "durable power of attorney," that describes the respondent's wishes regarding health care decisions if the respondent became very ill. Respondents who claimed possession of an advance care directive, but did not demonstrate knowledge of advance care directives, were excluded from the statistical analysis. With this restriction, 24 of the 800 (3 percent) (four African Americans, eleven European Americans, four Korean Americans, and five Mexican Americans) were dropped from the statistical analysis.

Other Measures. Knowledge of, attitude toward, and possession of an advance care directive were examined in relation to demographic factors, including ethnicity, age, religion, level of education, and income. These variables were categorized as follows: age (64 to 70, 71 to 75, 76 to 80, and 81+ years), religion (Protestant/Christian, Catholic, Jewish, Buddhist, Other), level of education (1 to 6, $\geq$ 7), and personal income ($<$ \$10,000, $\geq$ \$10,000). To obtain a measure of the respondent's involvement in his/her respective religion group, a religiosity scale (low versus high) was derived from four questions about membership in a church or temple and frequency of attendance.

Functional status (as measured by the Katz Index of Activities of Daily Living[12]), acculturation (as measured by the Marin Short Acculturation Scale[13]), access to health care, and the respondent's experience with illness and with withholding and withdrawing care (as measured by subscales developed specifically for this project) were also measured as described below. The Katz Index, which measures the ability of respondents to perform the activities of daily living (eating, dressing, bathing, walking, and using the bathroom), was dichotomized at the median with "low" (Katz Index $\leq$ 11.6) and "high" (Katz Index $>$ 11.6) groupings. The Marin Short Acculturation Scale, originally developed for use with a Latino population, consists of items that measure language use, use of English language media (television and radio), and the ethnic social relations. For use with the Korean population, the word "Korean" was substituted for "Spanish" or "Latino." Access to health care was based on four items from the Edgecombe hypertension study[14] relating structural barriers (such as difficulty obtaining physician appointments and in obtaining transportation to appointments) and financial barriers to health care (that is, insurance status). Personal experience with health care was measured by asking respondents if they personally had ever been admitted to a hospital or an intensive care unit (ICU), been placed on mechanical ventilation, or had experienced mechanical ventilation. To obtain the respondents' personal experience with withholding and withdrawing care, respondents were asked if close friends or family members had undergone these experiences and, if so, whether they visited the family member while they were hospitalized, either in the ICU or while on mechanical ventilation.

Results

All analyses were conducted at the .05 significance level. In other words, the statistical probability of finding a difference of this magnitude among groups when, in fact, no difference actually exists, is less than one in twenty. For each of the advance care directive variables (knowledge of, attitude toward, and possession of advance care directives), analysis of variance or chi-square procedures were used to test for differences across demographic factors (ethnicity, age, religion, religiosity, level of education, and income), functional status (Katz), personal experience with illness and withholding and withdrawing care, and access to health care.

Next, stepwise logistic regression analyses were conducted to relate the likelihood of possession of advance care directives (dependent variable) to each of the demographic, functional status, personal experience, and access to health care factors (independent variables) found to be significant in the above analyses. Attitude toward advance decision making was also considered to be a competing variable for inclusion in the regression model. However, because "possession of" an advance care directive was defined to include only those respondents who also had "knowledge" of advance directives (see Table 1), "knowledge" was not included in the regression model.

From the logistic regression analyses, an estimate of the odds ratio (OR) was calculated for each variable found to be statistically significant. The OR is the extent to which being a member of a specific category increases or decreases the probability of an individual possessing an advance care directive. Independent variables that were categorical were treated as indicator variables and handled in the following manner: if a variable had k possible outcomes, then $k - 1$ indicator variables were defined. One category was selected as the "reference" category and remained at a fixed value of 1 (for instance, European American was the reference category for ethnicity). The OR, then, represents the degree to which respondents in the remaining categories differed from the reference category (for instance, the degree to which Korean American, Mexican American, and African American attitudes differed from those of European Americans.) ORs were calculated for each category relative to the "reference" category. Thus, ORs represent how much more (> 1) or less (< 1) likely it is for respondents in a specified category to possess an advance care directive in comparison with the reference category. For these analyses, if any indicator variable entered the model, then all indicator variables representing the categorical variable were forced into the model to give appropriate estimates of the ORs. Stepwise logistic regression analyses were carried out for all ethnic groups combined (in which case, ethnicity was one of the independent variables), and within selected ethnic groups, characterized by the extent of knowledge about advance care directives.

Factors related to knowledge of, attitude toward, and possession of an advance care directive: univariate analysis

Table 2 and Figure 1 present the relationship of ethnicity to knowledge of, attitude toward, and possession of an advance care directive. African Americans (12 percent) and Korean Americans (13 percent) had significantly less knowledge of advance care directives than European Americans (69 percent) and Mexican Americans (47 percent) ($p < .0001$) did (see Figure 1a). Korean Americans (mean ± standard deviation (SD) = 0.69 ± 0.31) and Mexican Americans (0.66 ± 0.28) were more likely to have a negative attitude toward advance decision making than either African Americans (0.19 ± 0.27) or European Americans (0.31 ± 0.33) ($p < .0001$) (see Figure 1b). European Americans (28 percent) and Mexican Americans (10 percent) were more likely to possess an advance care directive than African Americans (2 percent) or Korean Americans (0 percent) ($p < .0001$) were (see Figure 1c). When comparing across ethnic groups the rates of possessing an advance care directive for individuals who had knowledge of advance directives, European Americans (40 percent) had the highest number of individuals with "knowledge" who actually possessed an advance directive ($p < .0001$) (Figure 1c). By comparison, only 22 percent of the Mexican Americans and 17 percent of the African Americans with knowledge of advance care directives possessed one. None of the 20 Korean Americans with knowledge of living wills possessed an advance directive.

Table 2 also presents the relationship of demographic factors, personal experience with illness, personal experience with withholding and withdrawing care, access to health care, and functional status to knowledge of, attitude toward, and possession of an advance care directives. No significant differences were found for gender or age. Jewish respondents were more likely to have knowledge about advance care directives, less likely to have a negative attitude toward advance decision making, and more likely to possess an advance directive ($p < .001$). Respondents with lower socioeconomic status (as determined by years of schooling and/or personal income), no personal experience with illness or withholding care, and no private insurance were less likely to have knowledge about advance care directives, more likely to have a negative attitude toward advance decision making, and less likely to possess an advance directive ($p < .05$). Finally, respondents who were more limited in activities of daily living (as measured by the Katz Index) were more likely to possess an advance directive ($p < .001$).

Factors related to possession of an advance care directive: stepwise multivariate analysis

We conducted a stepwise logistic regression analysis to determine factors related to possession of an advance care directive, after controlling for differences in ethnicity. Korean Americans were excluded from this analysis because none of the respondents possessed an advance directive. Independent variables that were candidates for the analy-

	Knowledge			*Attitude*		*Possession*	
Characteristic	*n*	*%*	*p-value*	*mean*	*p-value*	*%*	*p-value*
Ethnic Group							
European American	189	69%	< .0001	.31	< .0001	28%	< .0001
African American	196	12%		.19		2%	
Mexican American	195	47%		.66		10%	
Korean American	196	13%		.69		0%	
Gender							
Male	388	34%	.45	.47	.60	9%	.19
Female	368	36%		.46		11%	
Age (years)							
64 to 70	231	35%	.80	.43	.09	8%	.74
71 to 75	211	36%		.44		10%	
76 to 80	198	37%		.49		11%	
81+	136	32%		.52		11%	
Religion Raised							
Protestant/Christian	302	30%	< .0001	.27	< .0001	11%	< .001
Catholic	260	49%		.58		13%	
Jewish	45	62%		.38		18%	
Buddhist	89	18%		.57		4%	
Religiosity							
≤ 6.7 (low)	300	42%	< .01	.39	< .0001	13%	< .01
> 6.7 (high)	476	31%		.51		8%	
Years of Schooling							
1 to 6	194	28%	< .01	.64	< .0001	4%	< .001
≥ 7	552	39%		.39		13%	
Personal Income							
< $10,000	525	29%	< .0001	.54	< .0001	7%	< .001
≥ $10,000	218	45%		.27		15%	
Personal Experience: Illness							
0 (none)	160	24%	< .001	.61	< .0001	3%	< .001
1+ (some)	615	38%		.42		12%	
Personal Experience: Withholding Care							
0 (none)	717	34%	.13	.47	< .01	9%	< .01
1+ (some)	59	44%		.32		20%	
Access to Health Care: Structural Barriers							
≤ 4.2 (few)	477	33%	.12	.43	< .01	11%	.37
> 4.2 (many)	299	38%		.51		9%	
Access to Health Care: Insurance							
Government	465	26%	< .0001	.56	< .001	6%	< .0001
Private	292	47%		.30		18%	
Functional Status: Katz							
≤ 11.6 (low)	202	41%	.06	.52	.02	16%	< .001
> 11.6 (high)	574	33%		.44		8%	

Table 2. Characteristics Related to Knowledge of Advance Care Directives, Attitude Toward Advance Decision Making, and Possession of an Advance Care Directive.

Note: Twenty-four respondents (four African Americans, eleven European Americans, four Korean Americans, and five Mexican Americans) indicated possessing an advance care directive, but had no knowledge of what a living will was. They were excluded from the statistical analyses.

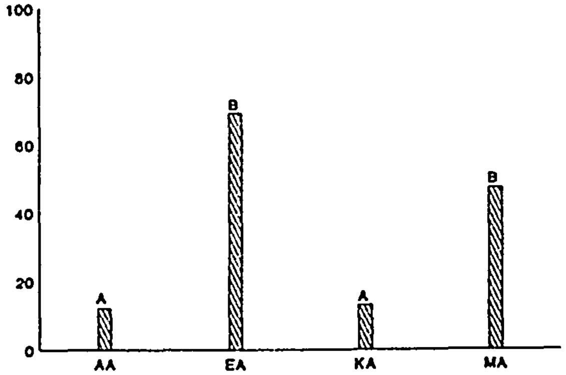

Figure 1a. Knowledge of Advance Care Directives.

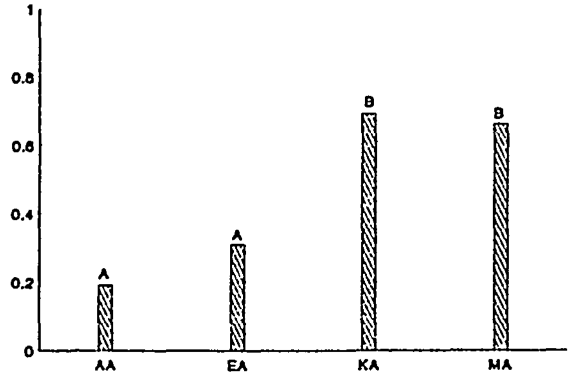

Figure 1b. Attitude Toward Advance Decision Making.

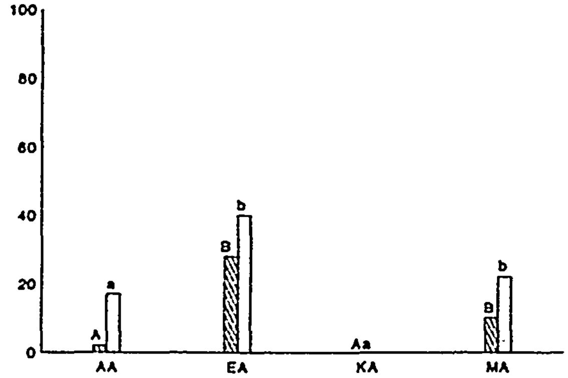

Figure 1c. Possession of an Advance Care Directive.

Figure 1. Distribution across ethnic groups concerning knowledge of advance care directives (Fig. 1a), attitude toward advance decision making (Fig. 1b), and possession of an advance care directive (Fig. 1c). AA = African American, EA = European American, KA = Korean American, and MA = Mexican American. For all three variables, the distributions are significantly different across ethnic groups by the analysis of variance ($p < .0001$). Multiple comparisons denoted by different letters (A or B, or a or b) indicate which ethnic groups are significantly different at the .05 level.

sis included those found to be significant in Table 2, along with the attitude toward advance decision making. Two analyses were carried out, one controlling for ethnicity, the second for socioeconomic status (as determined by personal income and years of schooling).

Factors found to be significantly and independently related to the likelihood of possession of an advance care directive are presented in Table 3. After controlling for ethnic differences, respondents who were less likely to possess an advance directive had a negative attitude toward advance directives, had government-assisted insurance, and had a higher level of functioning. Respondents who were more likely to possess an advance care directive were those with personal experience with illness and more years of schooling.

After controlling for socioeconomic status (income and years of schooling), ethnicity was the second most significant predictor of possession of an advance care directive. After controlling for socioeconomic status *and* ethnicity, similar results were obtained with regard to personal experience with illness, attitude toward advance directives, and government-assisted insurance.

Factors related to possession of advance care directive: stratified analysis

Table 4 presents the results of a stepwise logistic regression analysis examining factors predictive of the likelihood of possessing advance care directives within the European American and Mexican American ethnic groups. Because few African Americans and Korean Americans possessed an advance directive (Table 2), statistical analyses within these ethnic groups were not conducted. For the European Americans, the single most significant predictor for possessing a living will was their attitude toward advance decision making. Compared with respondents with a positive attitude, respondents with a negative attitude were more than 90 percent less likely to possess an advance care directive ($p < .001$). After controlling for attitude, the second most significant predictor was personal experience with illness. Compared with respondents with no experience, respondents with some experience were 80 percent more likely to possess an advance directive.

For the Mexican Americans, two factors—years of schooling and acculturation—competed for the primary predictor of possessing an advance care directive. Because these two factors are closely related, two models were generated (Table 4). One model consisted of the following factors: years of schooling and personal experience with illness. Mexican Americans with more education and some personal experience with illness were more likely to possess an advance directive. The second model consisted of the Marin Short Acculturation Scale and personal experience with illness. Mexican Americans who were more acculturated and who had some personal experience with illness were more likely to possess an advance care directive.

Discussion

Of the 271 respondents who knew what an advance care directive is (that is, they could provide a correct definition of a living will or a durable power of attorney for health care), seventy-seven (28 percent) actually possessed such a document. Rates of possession among subjects with knowledge, however, varied dramatically across ethnic groups. European Americans had the highest percentage of individuals who possessed an advance directive (40 percent of those with knowledge). By comparison, only 22 percent of the Mexican Americans, 17 percent of the African Americans, and 0 percent of the Korean Americans with knowledge possessed an advance directive (Figure 1c).

Step	*Variable*	*OR (95% CI[a])*	*p-value*	*Model p-value*
	Adjusted for Ethnicity			
0	European American[b]	1.0	—	< .0001
	Mexican American	0.8 (0.5, 1.5)	.50	
	African American	0.1 (0.0, 0.4)	< .0001	
1	Attitude toward advance decision making	0.1 (0.0, 0.2)	< .0001	
2	Personal experience with illness	2.0 (1.4, 2.7)	< .0001	
3	Years of schooling	1.2 (1.1, 1.3)	< .001	
4	Government insurance	0.2 (0.1, 0.8)	.02	
5	Functional status	0.8 (0.6, 1.0)	.04	
	Adjusted for Socioeconomic Status			
0	Income	1.2 (0.6, 2.3)	.65	< .0001
	Years of schooling	1.1 (1.0, 1.2)	< .01	
1	European American[b]	1.0	—	
	Mexican American	2.2 (1.0, 4.7)	.04	
	African American	0.1 (0.0, 0.2)	< .0001	
2	Personal experience with illness	1.8 (1.3, 2.5)	< .001	
3	Attitude: advance decision making	0.1 (0.1, 0.5)	< .001	
4	Government insurance	0.2 (0.1, 1.0)	.05	

Table 3. Factors Related to Possession of an Advance Care Directive: Stepwise Multivariate Logistic Regression Analysis.

[a] *Cumulative Index.*

[b] *Korean Americans were excluded from this analysis because none possessed a living will.*

Why is it that members of these ethnic groups were less likely than their European American counterparts to possess an advance care directive? One premise underlying the current research is that diverse cultural groups may bring specific values and beliefs to bear in making decisions regarding death and dying. This premise is supported in the present study.

Compared with European Americans, Mexican Americans as a group had a relatively negative attitude toward the concept of advance decision making (Figure 1b and Table 2). Mexican Americans were significantly more likely to endorse items such as "Doctors should not discuss death and dying with their patients because doing so could be harmful to the patient" and "It is not necessary for people to write down their wishes about medical care because their family will know what to do when the time comes." This finding supports a previous finding, using the same population of respondents, that demonstrates that Mexican Americans tend to place greater emphasis on family-centered, as opposed to patient-centered, decision-making styles.[15]

Mexican Americans with knowledge of advance care directives and who possess one tended to be more acculturated as measured by the Marin Short Acculturation Scale (Table 4). A median split of the Mexican American respondents shows that those with relatively high acculturation were almost seven times more likely to possess an advance care document. Thus, the more Mexican Americans associate with Anglos and speak, think, and read in English, the more similar their attitudes become to those expressed by our European American respondents.

Korean Americans were almost completely unaware of advance directives, and reported negative reactions toward the concept of advance care planning more generally. In fact, in our sample none possessed an advance directive. This finding is supported by research showing that, like Mexican Americans, Korean Americans tend to have a negative sentiment toward telling a patient the truth about a diagnosis and prognosis and believe that the family, not the patient, should make important health care decisions.[16]

Unlike Mexican Americans and Korean Americans, African Americans generally tended to have a positive attitude about advance care planning. At the same time, however, relatively few African Americans had knowledge of advance care documents (12

Step	Variable	OR (95% CI[a])	p-value	Model p-value
		European American		
1	Attitude toward advance decision making	0.1 (0.0, 0.3)	< .0001	< .0001
2	Personal experience with illness	1.8 (1.1, 2.8)	.02	
		Mexican American		
Model 1				
1	Years of schooling			< .0001
	1 to 6	1.0	—	
	≥ 7	1.3 (1.1, 1.4)	< .001	
2	Personal experience with illness	1.7 (1.0, 3.0)	.05	
Model 2				
1	Marin score			< .001
	Low	1.0	—	
	High	9.2 (2.0, 42.5)	< .005	
2	Personal experience with illness	1.2 (1.0, 1.4)	.03	

Table 4. Factors Related to Possession of an Advance Care Directive Among Those with Knowledge: Within Group Analysis.

[a] *Cumulative Index.*

percent of our entire sample), and the rate of possession among this group was extremely low (2 percent). Moreover, among African Americans who knew what a living will or a durable power of attorney for health care is, only 17 percent possessed such a document—less than half the possession rate among knowledgeable European Americans (40 percent). One possible explanation for this finding is that although African Americans are fairly positive about advance care planning in general, they have negative feelings about formal advance care directives. We are currently exploring this and other hypotheses in extensive qualitative interviews with 10 percent of the original sample.

One striking finding of our study is the discrepancy in knowledge about advance care documents between African Americans and European Americans. Although virtually all of the European American and African American respondents were born in the United States and are native English speakers, 69 percent of the European Americans were familiar with the concept of advance care directives as compared with only 12 percent of the African Americans (Table 2, Figure 1a). This discrepancy may be an artifact of our sample, which was not completely random, because it was drawn from thirty-one senior citizen sites in Los Angeles County. We did, however, attempt to evaluate whether the availability of seminars, workshops, and literature about advance care directives was the primary factor underlying this difference in knowledge between European Americans and African Americans. One of the larger sites that offered educational seminars on advance directives served roughly equal numbers of African Americans and European Americans. Although these advance care directive seminars were theoretically equally accessible to members of both ethnic groups, a post hoc analysis of respondents from this site revealed that 55 percent of the European Americans had knowledge of living wills compared with only 15 percent of the African Americans ($p < .01$). Thus, our data suggest that when access is held constant, various ethnic groups may be differentially motivated to seek out information actively. This highlights an often overlooked fact, namely, that the acquisition of knowledge is not a passive process but one that requires engaging the intended audience.

Advance directives seem to fit best with the prevailing beliefs of European Americans. European Americans tend to have both knowledge of and positive attitudes toward advance care planning (28 percent of the total sample of 200 had completed a formal advance directive, and this figure increases to 40 percent among those with knowledge). As indicated in the logistic regression, the factor most predictive of completion for European Americans who had prior knowledge of advance care directives was having a positive attitude. A second factor that is predictive of possession of an advance directive among European Americans (as well as more acculturated Mexican Americans) was the respondent's personal experience with illness (Table 4). The prevailing sentiment among our European American respondents seems to be that advance care directives are basically a "good thing" that should be completed when the need arises.

To evaluate whether ethnicity is a proxy for socioeconomic status, we conducted a stepwise logistic regression analysis controlling for income and education (Table 3). Holding income and education constant, ethnicity still emerges as an independent factor predictive of possession. This suggests that the differences observed among the four ethnic groups in this research cannot simply be explained by income or education alone.

Conclusion

The intent of this research is not to identify one set of moral rules for each ethnic group nor to encourage physicians to respond in a stereotypical fashion to their patients based on their ethnicity. It is important to note that although common patterns characterize individuals of the same ethnic group, nevertheless, substantial variance exists within each ethnic group. Our findings, however, together with those of the SUPPORT study,[17] suggest that the process of end-of-life decision making is more complex than previously imagined. The concept of advance care documents may appeal only to certain subsets of the population, limiting the clinical usefulness of living wills and durable powers of attorney for health care. Increasing knowledge of and access to advance care directives may not necessarily increase the completion across all ethnic groups. For members of ethnic groups who tend to avoid discussing death with patients, or who believe that decisions about the use of life support should be made by the family, other avenues of communication about these issues must be found. Rather than narrowly focusing on increasing the completion rate of formal advance directives, we need to listen to the diverse voices of the communities we serve and then to adapt our practices to fit their needs better.

This is perhaps easier to advise than to achieve. One alternative may be to promote the durable power of attorney for health care as an all-purpose way to appoint a substitute decision maker—not just for end-of-life decisions, but for any situation where a person is unable to make decisions for himself/herself. This would decouple the durable power of attorney for health care from its exclusive association with the dying process and recast it as a method of identifying an appropriate surrogate whenever an individual is mentally incapacitated, be it temporarily (for example, after trauma or major surgery) or permanently (as in a persistent vegetative state). A more generic "appointment" document of this sort might have been more acceptable to the Mexican American and Korean American respondents in our study because it might have avoided the need for specific discussions about death and dying (which were perceived as potentially harmful to the patient) and because it might be more compatible with the family-centered decision-making style that these groups tend to favor.[18] It is not clear, however, that this type of advance directive would be accepted by the African American community. Among African Americans, the reasons for completing formal advance directives seem to be more complex, and may involve issues such as distrust of the medical profession or of legal documents, and the belief that such decisions are best left in the hands of God. These, and other issues, are currently being explored in the qualitative portion of this study.

Much energy and time has been devoted to promoting advance directives as a means to improve the care of dying patients. The results of our study, however, cast doubt on the appropriateness of these documents, at least as they are currently formulated, for many patients. Our findings suggest the need for a critical analysis of the value of advance directives and alternative mechanisms to ensure that the strongly felt preferences of patients, when they exist, are not disregarded.

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