# Ethnicity and Attitudes Toward Patient Autonomy

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**Objective.**—To study differences in the attitudes of elderly subjects from different ethnic groups toward disclosure of the diagnosis and prognosis of a terminal illness and toward end-of-life decision making.

**Design.**—Survey.

**Setting.**—Thirty-one senior citizen centers within Los Angeles County, California.

**Respondents.**—A stratified quota sample of 200 subjects aged 65 years and older self-identified as being from each of four ethnic groups: European American, African American, Korean American, or Mexican American (N=800).

**Main Outcome Measures and Results.**—Korean Americans (47%) and Mexican Americans (65%) were significantly less likely than European Americans (87%) and African Americans (88%) to believe that a patient should be told the diagnosis of metastatic cancer. Korean Americans (35%) and Mexican Americans (48%) were less likely than African Americans (63%) and European Americans (69%) to believe that a patient should be told of a terminal prognosis and less likely to believe that the patient should make decisions about the use of life-supporting technology (28% and 41% vs 60% and 65%). Instead, Korean Americans and Mexican Americans tended to believe that the family should make decisions about the use of life support. On stepwise multiple logistic regression, ethnicity was the primary factor related to attitudes toward truth telling and patient decision making.

**Conclusions.**—Korean-American and Mexican-American subjects were more likely to hold a family-centered model of medical decision making rather than the patient autonomy model favored by most of the African-American and European-American subjects. This finding suggests that physicians should ask their patients if they wish to receive information and make decisions or if they prefer that their families handle such matters.

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FOR THE past 25 years, ethical and legal analysis of medical decision making in the United States has revolved around the idea of patient autonomy. The principle of patient autonomy asserts the rights of individuals to make informed decisions about their medical care. Thus, patients should be told the truth regarding their diagnosis and prognosis, as well as the risks and benefits of proposed treatments, and should be allowed to make choices based on this information. Although this ethical ideal is imperfectly realized in actual practice, the standard of care in this country is to tell patients the truth about even fatal illnesses,[1,2] to obtain their informed consent for major procedures,[3,4] and to involve them in decisions about withholding resuscitation.[5,6] The ideal of patient autonomy is so powerful that attempts have been made to extend patient control over medical decision making even to those circumstances in which the patient has lost the capacity to make decisions through advance care directives, such as the durable power of attorney for health care.[7-11] A federal statute, the Patient Self-determination Act, has been enacted to enhance and preserve patient autonomy. Recently, however, it has been suggested that this focus on patient autonomy has become overly narrow and that other values, such as family integrity[12-14] and physician responsibility,[15,16] have been ignored. In particular, some have argued that this preoccupation with individual rights to the exclusion of other values may reflect a cultural bias on the part of the Western medical and bioethics communities.[13,14,17] To determine the attitudes of individuals of varying ethnic backgrounds toward patient autonomy in medical decision making, we surveyed 800 Korean-American, Mexican-American, African-American, and white (European-American) subjects as part of a larger study examining the attitudes of older Americans of varying ethnicities toward health care and medical decision making.

## MATERIALS, SUBJECTS, AND METHODS

### Materials

The Ethnicity and Attitudes Toward Advance Care Directives Questionnaire is an hour-long instrument whose content and format was developed after an extensive review of the relevant anthropologic and medical literature, as well as consultation with clinicians, anthropologists, and experts in health beliefs. The instrument includes both previously validated scales and scales designed specifically to measure issues relevant to this study.

**See also pp 826 and 844.**

New sections were tested for internal (construct and content) and external validity, including extensive pilot testing. Once finalized, the instrument was translated into Korean and Spanish and back-translated into English by an independent agency with experience in translation of medical and technical documents.

In this article, we focus on the relationship between attitudes toward patient autonomy and demographic factors, including ethnicity, age, religion, level of education, and income. We also evaluate functional status (as measured by the Duke Activity Status Index[18] and the Katz Index of Activities of Daily Living[19]), acculturation (as measured by the

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Marin Short Acculturation Scale[20]), access to health care,[21] and the subject's experience with illness and with withholding and withdrawing care (as measured by subscales developed specifically for this project). 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 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[21] relating to structural barriers (such as difficulty obtaining physician appointments and in obtaining transportation to appointments) and financial barriers (including insurance status) to care. Experience with health care was measured by asking subjects if they had ever been admitted to a hospital or an intensive care unit, had received mechanical ventilation. Subjects were also asked whether close friends or family members had undergone these experiences. If so, subjects were asked if they visited the family member while they were hospitalized, in the intensive care unit, or receiving mechanical ventilation.

The dependent variable—attitudes toward patient autonomy—was measured as responses to a series of questions regarding attitudes toward truth telling (diagnosis and prognosis) and toward decision making with respect to the use of life support (Table 1).

### Subjects

Interviews were conducted with 200 individuals aged 65 years and older who identified themselves as belonging to one of the following four ethnic groups: African American, European American, Korean American, and Mexican American (N=800). Care was taken to include an equal number of men and women within each group and to maintain a similar age distribution across all four groups. Because a simple random sample of individuals older than 65 years would have yielded a sample that was heavily skewed in terms of sex and age, a stratified quota sampling technique was used. Attempts were made to minimize selection bias by sampling from a wide range of sites. Participation was strictly voluntary, and respondents were given $20 in exchange for their time. This study was approved by the University of Southern California Institutional Review Board.

### Procedure

All interviewers were trained by one of us (S.T.M.) during a half-day seminar. The interviewers' ethnic backgrounds matched those of the four groups of interest. Korean-American and Mexican-American interviewers were bilingual. Interviews were conducted in a one-on-one private setting. A list of senior citizen centers in Los Angeles County was obtained from the Los Angeles County Agency on Aging. To ensure that ethnicity and not income would be the primary variable differentiating our respondents, we further reduced our sampling frame to 31 sites located in areas with comparable socioeconomic distributions. Directors in 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 a flyer, an interviewer proceeded to determine eligibility. If the individual met the eligibility criteria of minimum age of 65 years and self-identification as a member of one of the four ethnic groups of interest, they were given a consent form and an appointment was made with an interviewer of the same ethnic background. Respondents were interviewed at the time of enrollment or an appointment for a more convenient time was made. Although Mexican-American and Korean-American respondents were given a choice of being interviewed in English or their native language, all subjects chose their native language.

### Statistical Analyses

Differences in the independent and dependent variables across the four ethnic groups were assessed with the use of analysis of variance or $\chi^2$ procedures. For the analyses of variance, pairwise comparisons between ethnic groups used Scheffé's multiple comparison procedure with a significance level of $P<.001$.

Estimates of the odds ratio (OR) were calculated for each independent variable with the use of univariate logistic regression analysis. The OR is the extent to which being a member of a specific category increases or decreases the probability of an individual agreeing with the patient autonomy model of truth telling and patient decision making. Indicator variables were used for independent variables that were categorical. Odds ratios greater than 1 represent how much more likely it was for subjects in a specified category to believe that a patient should have autonomy with regard to knowing their diagnosis and prognosis and making a decision regarding life-prolonging machines. The significance level was also set at $P<.001$.

Table 1.—Measures of Patient Autonomy

**Diagnosis**: A physician diagnoses a person as having cancer that has spread to several parts of their body.

(a) The physician believes that the cancer cannot be cured. Should he or she tell the patient that they have cancer? Yes or No

(b) Should the physician tell the patient's family about the cancer? Yes or No

**Prognosis**: The physician believes that the patient will probably die of the cancer.

(a) Should the physician tell the patient that he or she will probably die? Yes or No

(b) Should the physician tell the patient's family that the patient will probably die of the cancer? Yes or No

**Decision regarding life-prolonging technology:** The patient becomes very ill and a decision must be made about whether to put the patient on life-prolonging machines. The machines will prolong the patient's life for a little while but will not cure the illness and may be uncomfortable. Who should make the decision about whether to put the patient on the machine?

(a) It should be mainly the physician's decision.

(b) It should be mainly the family's decision.

(c) It should be mainly the patient's decision.

In addition, stepwise multiple regression analyses were performed for each dependent variable to assess which of the independent variables "best" predicted attitudes toward truth telling and medical decision making. Finally, within-group $\chi^2$ analyses were performed to identify factors significantly related to measures of autonomy after controlling for ethnicity. For these multivariate and within-group analyses, the significance level was set at $P<.05$.

## RESULTS

### Ethnic Differences in Attitudes Toward Patient Autonomy

Table 2 describes the characteristics of the survey sample, and the Figure displays the effect of ethnicity on measures of attitudes toward patient autonomy. Korean Americans (47%±4% [SE]) were less likely than African Americans (89%±2%) and European Americans (87%±2%) to believe that a patient with metastatic cancer should be told the truth about that diagnosis ($P<.001$). Similarly, Korean Americans (35%±3%) were less likely than African Americans (63%±3%) and European Americans (69%±3%) to believe that the patient should be informed of a terminal prognosis and were also less likely to believe that the patient should make the decision about the use of life-supporting technology (28%±3% vs 60%±3% and 65%±3%, all $P<.001$). Instead, most Korean Americans (57%±3%) believed that the family should make decisions about the use of life support.

Mexican Americans tended to fall between African Americans and Korean Americans, with 65%±3% supporting truth telling in diagnosis (statistically different from European Americans and African Americans at the $P<.001$ level). Forty-eight percent (±3%) of Mexican

Americans believed that the patient should be told the truth about the prognosis, and only 41% (±3%) chose the patient as primary decision maker. Forty-five percent (±3%) of Mexican Americans believed that the family should make such decisions. Although the groups differed in their opinions about whether the patient should be told the truth, 90% or more of the subjects in all ethnic groups believed that the family should be told the truth about the patient's diagnosis and prognosis. The difference was that the Korean-American and Mexican-American subjects were more likely to believe that only the family, and not the patient, should be told the truth.

To determine whether acculturation (as measured by the Marin Short Acculturation Scale) affected the attitudes of Mexican Americans toward truth telling and decision making, subjects were categorized as "high" (score $\geq 3$) vs "low" (score $<3$) acculturation. The majority (79%) of the Mexican-American subjects had low Marin Short Acculturation Scale scores. Acculturated Mexican Americans (ie, those who spoke and read more English and associated more with "Anglos") were more likely to believe that the patient should be told the truth about the diagnosis (83% vs 60%, $P$=.005) and prognosis (62% vs 44%, $P<.05$). Choice of patient as primary decision maker was not affected by acculturation (36% vs 42%, $P$=.42). Analyses could not be performed for Korean Americans because 100% of this group had scores below 3 on the Korean version of the Marin Short Acculturation Scale.

To better understand the relationship between acculturation and socioeconomic status in the Mexican-American population, we analyzed the correlation between the Marin Short Acculturation Scale score, personal income, and education. Mexican-American subjects with annual incomes above \$10 000 ($P<.01$) or more than 6 years of education ($P<.001$) were more likely to have a high Marin Short Acculturation Scale score. Acculturation does not appear to be a simple function of years lived in the United States. The majority (66%) of Korean Americans had lived in the country for more than 10 years. Likewise, more than 90% of the Mexican-American sample had lived in the United States at least 10 years; of those, 78% had a low Marin Short Acculturation Scale score.

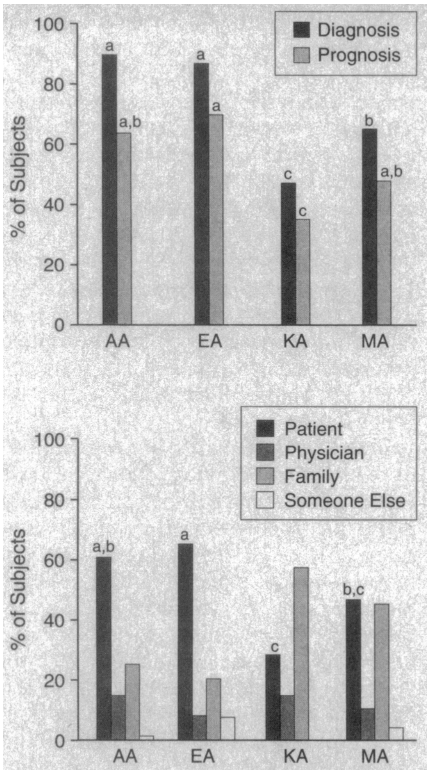
## Univariate Logistic Regression Analyses of Factors Related to Patient Autonomy

Differences in attitudes toward patient autonomy among the ethnic groups are borne out in the logistic regression analyses presented in Table 3. Relative to European Americans, Korean Americans and Mexican Americans were less likely to favor telling the truth about diagnosis and prognosis and less likely to choose the patient as primary decision maker (ORs $<1$, $P<.001$). Religion and socioeconomic status were also related to our measures of patient autonomy. Because these variables were strongly associated with ethnicity, multivariate and within-group analyses were performed and are reported below. With respect to age, the oldest subjects (aged 81 years and older) were less likely to believe that the patient should be told the truth about a terminal prognosis than were the youngest subjects (ORs $<1$, $P<.001$). Subjects with personal experience with illness and withholding and withdrawing care were more likely to favor truth telling (ORs $>1$, $P<.001$). No relationships were found for sex, functional status, and access to care.

Table 2.—Demographic Characteristics of Ethnic Groups (n=200/Group; N=800)*

| | Ethnic Group, No. (%) | | | | |
|---|---|---|---|---|---|
| **Characteristic** | **African American** | **European American** | **Korean American** | **Mexican American** | ***P*** |
| Age, y | | | | | |
| 64-70 | 57 (29) | 57 (28) | 57 (29) | 64 (32) | .96 |
| 71-75 | 56 (28) | 49 (25) | 54 (27) | 57 (29) | |
| 76-80 | 49 (25) | 57 (28) | 53 (27) | 46 (23) | |
| ≥81 | 38 (19) | 37 (19) | 36 (18) | 33 (17) | |
| Religion | | | | | |
| Protestant/Christian | 188 (94) | 81 (40) | 39 (19) | 5 (2) | <.001 |
| Catholic | 4 (2) | 58 (29) | 10 (5) | 195 (98) | |
| Jewish | 0 | 48 (24) | 0 | 0 | |
| Buddhist | 0 | 0 | 92 (46) | 0 | |
| Other | 8 (4) | 13 (7) | 59 (30) | 0 | |
| Schooling, y | | | | | |
| 1-6 | 23 (11) | 6 (3) | 53 (29) | 116 (61) | <.001 |
| 7-12 | 132 (66) | 103 (51) | 89 (49) | 57 (30) | |
| >12 | 45 (23) | 91 (46) | 39 (22) | 16 (8) | |
| Personal annual income | | | | | |
| <\$10 000 | 106 (55) | 87 (45) | 192 (96) | 153 (84) | <.001 |
| \$10 000-\$25 000 | 81 (42) | 80 (42) | 8 (4) | 25 (14) | |
| >\$25 000 | 5 (3) | 25 (13) | 0 | 5 (3) | |
| Functional status | | | | | |
| Katz Index | 11.9 (0.4)$^a$ | 11.4 (1.0)$^b$ | 11.8 (0.6)$^a$ | 11.3 (1.2)$^b$ | <.001 |
| Duke Index | 22.0 (10.6)$^b$ | 23.5 (10.9)$^{a,b}$ | 20.6 (8.6)$^b$ | 27.4 (9.9)$^a$ | <.001 |
| Personal experience with illness | | | | | |
| 0=none | 22 (11)$^a$ | 9 (5)$^a$ | 88 (44)$^b$ | 45 (23)$^a$ | <.001 |
| ≥1=some | 178 (89) | 191 (95) | 112 (56) | 155 (77) | |
| Personal experience with withholding care | | | | | |
| 0=none | 166 (83)$^{b,c}$ | 89 (45)$^a$ | 181 (91)$^c$ | 136 (68)$^b$ | <.001 |
| ≥1=some | 34 (17) | 111 (55) | 19 (9) | 64 (32) | |
| Access to care | | | | | |
| Structural | 4.3 (2.1)$^a$ | 3.6 (2.2)$^a$ | 3.4 (1.8)$^a$ | 6.3 (2.9)$^b$ | <.001 |
| Financial | 0.3 (0.3)$^b$ | 0.1 (0.2)$^a$ | 0.5 (0.0)$^c$ | 0.4 (0.2)$^d$ | <.001 |

*Means with the same letter (a, b, or c) are not significantly different at the $P<.001$ level with use of the Scheffé multiple comparison procedure.



Top, The percentages of African-American (AA), European-American (EA), Korean-American (KA), and Mexican-American (MA) subjects who believe that the physician should inform the patient that they have cancer (diagnosis) and that the physician should inform the patient that they will probably die (prognosis). Bottom, The percentages of subjects who believe that the decision about whether to put the patient on a life-support machine should be made by the patient, physician, family, or someone else. Differences in percentages of subjects who believed in patient autonomy with regard to diagnosis, prognosis, and the use of a life-support machine were assessed with use of one-way analysis of variance. Pairwise comparisons across ethnic groups used Scheffé's multiple comparison procedure, with a significance level set at $P<.001$. For each measure of patient autonomy, ethnic groups that were not significantly different are indicated in the figure with the same letter (a, b, or c).

### Stepwise Multiple Logistic Regression Analyses of Factors Related to Patient Autonomy

To further examine the relative contribution of each of the factors related to our measures of autonomy, we performed a stepwise logistic regression (Table 4). Because no associations were found for sex, functional status (Katz Index of Activities of Daily Living and Duke Activity Status Index), and access to care indexes in the univariate analysis (Table 3), these variables were not included in the model. Years of schooling and income were analyzed as continuous (rather than categorical) variables.

For all three measures of attitudes toward patient autonomy, the primary factor related to attitude was ethnicity. Relative to European Americans (the reference group), Korean Americans and Mexican Americans were least likely to favor truth telling about the diagnosis and prognosis and least likely to believe that the patient should make the decision about the use of life support. After controlling for ethnic differences, the second most important factor associated with attitudes toward truth telling was years of education. Patients with more education were more likely to favor telling the truth about the diagnosis and prognosis. In contrast, years of education did not predict who would be selected to make the decision about the use of life-sustaining technology. Finally, patients with some personal experience with illness were more likely to favor truth telling with respect to diagnosis.

### Within-Group Analyses of Factors Related to Patients Autonomy

To further explicate the relationship between socioeconomic status, ethnicity, and attitudes, we performed within-group $\chi^2$ analyses to examine the relationship between these and our measures of patient autonomy within each ethnic group. Socioeconomic status (as measured by income and years of schooling) was not related to attitudes in the European-American and African-American groups. In the Korean-American and Mexican-American groups, however, some relationships emerged. Mexican Americans with more years of education ($\geq 7$ years) were more likely to believe that the patient should be told the diagnosis (79% vs 57%, $P<.05$), and those with higher annual incomes ($\geq$\$10 000) were more likely to favor truth telling about the diagnosis (93% vs 61%, $P<.001$) and prognosis (70% vs 45%, $P<.01$). Korean Americans with higher levels of education were more likely to believe that the patient should make the decision about the use of life support (32% vs 19%, $P<.05$). Similarly, within-group analyses of age revealed that although age was not related to attitudes in the European-American and African-American subjects, it was a predictor in the Korean-American and Mexican-American groups. Older Korean Americans and Mexican Americans (81 years or older) were less likely than younger subjects of the same ethnicity to favor telling the patient the diagnosis (25% vs 52%, $P<.01$, for Korean Americans; 45% vs 69%, $P<.01$, for Mexican Americans).

In the European-American and Korean-American groups, religion was related to differences in attitudes toward some of the autonomy indexes. In the European-American group, Protestants were more likely than non-Protestants to believe that the patient should be told about a terminal prognosis (81% vs 61%, $P<.01$) and were more likely to believe that the patient should be the primary decision maker (73% vs 59%, $P<.05$). Jewish subjects were less likely than non-Jewish subjects to believe in telling the truth about the prognosis (52% vs 75%, $P<.01$). In the Korean-American group, Buddhists were less likely to believe that the patient should be told the prognosis (27% vs 41%, $P<.05$). The African-American and Mexican-American groups had very little religious diversity, with 98% of the Mexican-American group being Catholic and 94% of the African-American group being Protestant; thus, further analyses of religious differences within these groups could not be conducted.

## COMMENT

Korean-American and Mexican-American subjects were less likely than European-American and African-American subjects to believe that the patient should be told the truth about the diagnosis and prognosis of a serious illness and were less likely to believe that the patient should make decisions about the use of life support. Within the Korean-American and Mexican-American groups, older subjects and those with lower socioeconomic status tended to be opposed to truth telling and patient decision making even more strongly than their younger, wealthier, and more highly educated counterparts.

Our study suggests that the attitudinal differences among these ethnic groups are related to cultural rather than demographic variables, such as socioeconomic status, which tend to vary with ethnicity. In the Mexican-American group, in which the subjects had variable levels of acculturation, more acculturated subjects were more likely to share the patient autonomy model with the European-American and African-American subjects. As they begin to speak, think, and read more in English, and associate more with Anglos, they tend to take on the attitudes that are expressed by the English-speaking groups in our study. Socioeconomic status does not predict attitudes in the European-American and African-American groups. Instead, socioeconomic status may be acting as a marker for acculturation. Wealthier, more educated Mexican Americans are more likely to speak English and be in contact with values promoted in the English-speaking sectors of American society and more likely to adopt those values with respect to medical decision making.

There are several limitations to the generalizability of our data. Subjects aged

Table 3.—Odds Ratios (95% Confidence Intervals) of Measures of Autonomy

| | Tell Diagnosis | Tell Prognosis | Decision Maker About Life Support |
|---|---|---|---|
| Ethnic group | | | |
| European American | 1.0 | 1.0 | 1.0 |
| African American | 1.2 (0.7-2.3) | 0.8 (0.5-1.1) | 0.8 (0.6-1.2) |
| Mexican American | 0.3* (0.2-0.5) | 0.4* (0.3-0.6) | 0.4* (0.3-0.6) |
| Korean American | 0.1* (0.1-0.2) | 0.2* (0.1-0.4) | 0.2* (0.1-0.3) |
| Sex | | | |
| Male | 1.0 | 1.0 | 1.0 |
| Female | 1.1 (0.8-1.4) | 0.8 (0.6-1.1) | 1.2 (0.9-1.5) |
| Age, y | | | |
| 64-70 | 1.0 | 1.0 | 1.0 |
| 71-75 | 1.1 (0.7-1.7) | 0.8 (0.6-1.2) | 0.9 (0.7-1.4) |
| 76-80 | 1.0 (0.7-1.6) | 0.9 (0.6-1.4) | 0.8 (0.6-1.2) |
| ≥81 | 0.7 (0.4-1.0) | 0.6* (0.4-0.9) | 0.7 (0.5-1.1) |
| Religion | | | |
| Protestant/Christian | 1.0 | 1.0 | 1.0 |
| Catholic | 0.6* (0.4-0.8) | 0.7 (0.5-1.0) | 0.6* (0.5-0.9) |
| Jewish | 1.0 (0.5-2.2) | 0.7 (0.4-1.3) | 1.3 (0.7-2.4) |
| Buddhist | 0.2* (0.1-0.3) | 0.2* (0.1-0.4) | 0.4* (0.2-0.6) |
| Schooling, y | | | |
| 1-6 | 1.0 | 1.0 | 1.0 |
| 7-12 | 2.1* (1.4-3.0) | 1.3 (0.9-1.8) | 1.8 (1.2-2.5) |
| >12 | 3.3* (2.1-5.4) | 2.0* (1.4-3.1) | 2.5* (1.7-3.8) |
| Personal annual income | | | |
| <$10 000 | 1.0 | 1.0 | 1.0 |
| $10 000-$25 000 | 4.3* (2.7-7.0) | 2.4* (1.7-3.4) | 2.4* (1.7-3.3) |
| >25 000 | 3.1 (1.2-8.0) | 2.3 (1.1-4.8) | 2.0 (1.0-4.1) |
| Functional status | | | |
| Katz Index | 0.9 (0.8-1.1) | 1.0 (0.8-1.1) | 1.1 (0.9-1.3) |
| Duke Index | 1.0 (1.0-1.0) | 1.0 (1.0-1.0) | 1.0 (1.0-1.0) |
| Experience with | | | |
| Illness | 3.0* (2.1-4.3) | 2.1* (1.5-3.0) | 1.3 (0.9-1.9) |
| Withholding care | 2.1* (1.3-3.0) | 1.8* (1.3-2.6) | 1.5 (1.0-2.1) |
| Access to care | | | |
| Structural | 1.0 (0.9-1.0) | 1.0 (0.9-1.0) | 1.0 (1.0-1.0) |
| Financial | 1.1 (1.1-1.1) | 1.1 (1.0-1.1) | 1.0 (0.9-1.1) |

*Odds ratio significantly different from 1, $P<.001$.

Table 4.—Stepwise Multiple Logistic Regression Analysis of Factors Predictive of Measures of Autonomy

| Step | Variable | Odds Ratio (95% Confidence Interval) | P | Model P |
|---|---|---|---|---|
| | | **Diagnosis** | | |
| 1 | Ethnic group | | | |
| | European American | 1.0 | ... | <.001 |
| | African American | 1.4 (0.7-2.7) | .31 | |
| | Mexican American | 0.5 (0.2-0.9) | <.02 | |
| | Korean American | 0.2 (0.1-0.3) | <.001 | |
| 2 | Years of schooling | 1.1 (1.0-1.1) | <.01 | |
| 3 | Personal experience: illness | 1.7 (1.0-2.5) | <.03 | |
| | | **Prognosis** | | |
| 1 | Ethnic group | | | |
| | European American | 1.0 | ... | <.001 |
| | African American | 0.8 (0.5-1.3) | .39 | |
| | Mexican American | 0.6 (0.3-0.9) | <.03 | |
| | Korean American | 0.3 (0.2-0.4) | <.001 | |
| 2 | Years of schooling | 1.0 (1.0-1.1) | <.05 | |
| | | **Patient as Decision Maker** | | |
| 1 | Ethnic group | | | |
| | European American | 1.0 | ... | <.001 |
| | African American | 0.8 (0.5-1.2) | .27 | |
| | Mexican American | 0.3 (0.2-0.6) | <.001 | |
| | Korean American | 0.2 (0.1-0.3) | <.001 | |

65 years and older are more likely to be faced with serious health care decisions for themselves or their loved ones; younger subjects may hold different views. Moreover, to prevent skewing our population toward younger, female subjects, we used a quota sampling technique rather than a true random sample of the entire elderly population of these four ethnic groups. Although we attempted to minimize selection bias by sampling from a wide variety of sites, our subjects may not represent all portions of those groups. Finally, our sample was from urban southern California; the attitudes of the elderly may differ by geographic location.

The decision-making style exhibited by most of the Mexican-American and Korean-American subjects in our study might best be described as family centered. Although the patient autonomy model does not exclude family involvement, in this family-centered model, it is the sole responsibility of the family to hear bad news about the patient's diagnosis and prognosis and to make the difficult decisions about life support. Several prior studies of the issue of telling the diagnosis of cancer with different ethnic groups have yielded similar results. In one recent report, an Italian oncologist described the approach toward decision making in Italy as one in which the patient is frequently "protected" from bad news by the family and physicians.[22] Autonomy is not viewed as empowering. Rather, it is seen as isolating and burdensome to patients who are too sick and too ignorant about their condition to be able to make meaningful choices. In a survey from Greece, only a third of those questioned believed that patients should be told the truth about a terminal illness.[23] As in our study, older subjects with less education were more likely to be opposed to truth telling. Anecdotal reports also note the tendency of Chinese and Ethiopian families to oppose truth telling on the grounds that it harms the patient by causing them to lose hope.[24,25] Other studies have shown that Latinos are more likely than Anglos to believe that cancer is a death sentence.[26] Finally, studies of physicians' attitudes and practice show that those in Spain, France, Japan, and Eastern Europe rarely tell patients with cancer their diagnosis or prognosis, usually informing the family instead.[27-29]

Thus, belief in the ideal of patient autonomy is far from universal. In this country, as recently as 1961, Oken[30] documented that 90% of physicians did not inform their patients of the diagnosis of cancer. By 1979, when this survey was repeated, this attitude had completely reversed. By 1979, 97% of physicians made it their policy to inform patients with cancer of their diagnosis.[1] Most of the literature that discusses this change views it as simple progress from an uninformed paternalism to a more enlightened and respectful attitude toward patients. Indeed, there have been many benefits to more open discussion and increased patient involvement in medical decision making. It is probably impossible to completely deceive seriously ill patients when, despite all reassurance, they continue to deteriorate physically and to require hospitalization and medical care. Acknowledgment of the truth lets patients express their feelings and receive the emotional and spiritual comfort appropriate to the crisis they are experiencing. Allowing patients to choose from the range of treatment options available ensures that the treatment will conform to their preferences. However, the high value placed on open expression of emotion and on the rights of individuals to control their destiny are not necessarily shared by all segments of American society. For those who hold the family-centered model, a higher value may be placed on the harmonious functioning of the family than on the autonomy of its individual members. Although the patient autonomy model is founded on the idea of respect for persons, people live, get sick, and die while embedded in the context of family and culture and inevitably exist not simply as individuals but in a web of relationships. Insisting on the patient autonomy model of medical decision making when that model runs counter to the deepest values of the patient may ironically be another form of the paternalistic idea that "doctor knows best."

Many questions remain to be answered about how this family-centered model functions in actual practice. Do patients who are not told the diagnosis usually know it anyway? Is this information later communicated by verbal or nonverbal means? Is the interaction between patient and family different when the patient is the head of the household? What is the perceived harm when the medical community violates cultural conventions and insists on telling the truth to the patient? What disruptions occur in the coping mechanisms of the individual and the family? In what ways does acculturation change the beliefs of patients of various ethnicities, ie, how are the cultures of immigrants transformed and combined with the culture of their adopted country? We plan to explore these and other issues through in-depth ethnographic interviews with 10% of the study sample.

The purpose of our study was not to convince ethicists that there should be one set of moral rules for Korean Americans and another for European Americans, and we do not expect that the information we have obtained will allow physicians to predict with certainty the attitude of any given person from a particular ethnic group. As our study demonstrates, much diversity of opinion about these issues occurs not only between ethnic groups but also within each ethnic group. Rather, we believe that it is vital to uncover the usually unspoken beliefs and assumptions that are common among patients of particular ethnicities to raise the sensitivity of physicians and others who work with these groups. Understanding that such attitudes exist will allow physicians to recognize and avoid potential difficulties in communication and to elicit and negotiate differences when they occur. In particular, we suggest that physicians ask patients if they wish to be informed about their illness and be involved in making decisions about their care or if they prefer that their family handles such matters.[31] In either case, the patient's wishes should be respected. Allowing patients to choose a family-centered decision-making style does not mean abandoning our commitment to individual autonomy or its legal expression in the doctrine of informed consent. Rather, it means broadening our view of autonomy so that respect for persons includes respect for the cultural values they bring with them to the decision-making process.

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