Published in final edited form as:

J Am Geriatr Soc. 2007 December ; 55(12): 1981–1988. doi:10.1111/j.1532-5415.2007.01473.x.

How Would Terminally Ill Patients Have Others Make Decisions for Them in the Event of Decisional Incapacity? A Longitudinal Study

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Abstract

OBJECTIVES—To determine the role terminally ill patients would opt to have their loved ones and physicians play in healthcare decisions should they lose decision-making capacity and how this changes over time.

DESIGN—Serial interviews.

SETTING—The study institutions were The Johns Hopkins Medical Institutions in Baltimore, Maryland, and St. Vincent's Hospital, in New York.

PARTICIPANTS—One hundred forty-seven patients with cancer, amyotrophic lateral sclerosis, or heart failure, at baseline and 3 and 6 months.

RESULTS—Patients' baseline decision control preferences varied widely, but most opted for shared decision-making, leaning slightly toward independence from their loved ones. This did not change significantly at 3 or 6 months. Fiftyseven percent opted for the same degree of decision control at 3 months as at baseline. In a generalized estimating equation model adjusted for time, more-independent decision-making was associated with college education ($P = .046$) and being female ($P = .01$), whereas more-reliant decision-making was associated with age ($P < .001$). Patients leaned toward more reliance upon physicians to make best-interest determinations at diagnosis but opted for physicians to decide based upon their own independent wishes (substituted judgment) over time, especially if college educated.

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Author Contributions: Sulmasy and Hughes: study concept and design, acquisition of subjects and data, data analysis, interpretation of data, and preparation of manuscript. Thompson: study concept and design, data analysis, interpretation of data, and preparation of manuscript. Astrow: study concept and design, acquisition of subjects and data, data analysis, and interpretation of data. Terry: interpretation of data. Kub: study concept and design, acquisition of subjects and data, interpretation of data, and preparation of manuscript. Nolan: study concept and design, acquisition of subjects and data, interpretation of data, and preparation of manuscript.

Conflict of Interest: We also gratefully acknowledge the generous financial support of the Fan Fox and Leslie R. Samuels Foundation through a grant administrated by Partnership for Caring, a grant from the National Institute for Nursing Research (1 R01 NR005224-01A1), and the support of the ALS Research Center of Johns Hopkins University. The opinions and findings in this manuscript are those of the authors and do not necessarily represent the views of the Fan Fox and Leslie R. Samuels Foundations or the National Institute for Nursing Research.

Sponsor's Role: The funder had no role in design, methods, recruitment, analysis, or preparation of the manuscript.

CONCLUSION—Terminally ill patients vary in how much they wish their own preferences to control decisions made on their behalf, but most would opt for shared decisionmaking with loved ones and physicians. Control preferences are stable over time with respect to loved ones, but as they live longer with their illnesses, patients prefer somewhat less reliance upon physicians.

Keywords

decision-making; end of life; decisional incapacity; surrogates; ethics

Many patients, as they approach death, are unable to speak for themselves. Healthcare professionals usually turn to loved ones to speak on behalf of such patients, generally without any notion of the manner in which these patients would have healthcare professionals or loved ones approach these decisions. The two major standards suggested in the ethical and legal literatures are the best interests standard (deciding what they think would be best for the patient) and substituted judgment (attempting to discern what the patient would have wanted and deciding accordingly, whether through a living will or other knowledge of the patient's values).^{1,2}

The literature in medical ethics and many legislative and judicial opinions have privileged substituted judgment as the preferred manner of deciding for others, yet one study has suggested that patients receiving dialysis would give surrogates wide latitude in making such decisions.³ Another study has shown that a slight majority of terminally ill patients would prefer that the decision be made by a loved one even if it contradicted a hypothetically "perfect" living will.⁴ Moreover, multiple studies have demonstrated that substituted judgments are far from perfectly accurate.^{5,6}

It is known that patients who have intact decisionmaking capacity vary considerably in their decision control preferences.⁷⁻¹⁰ Some make decisions independently, some defer decision-making authority to loved ones or physicians, and most would opt for shared decisionmaking.

It has recently been shown, similarly, that patients with terminal diagnoses vary considerably in the role they would assign to their loved ones and physicians should they no longer be able to speak for themselves.¹¹ Some would have substituted judgments, and others would have their loved ones or physicians decide what they believe is best, but most would have some combination of these two approaches. The stability of the patient's choice of decision-making style has not been studied.

Advance directives have, in the opinion of many, failed to deliver on their promise to improve healthcare decisionmaking at the end of life.^{12,13} The problems encountered in a simplistic reliance on advance directives have led to calls for a broader approach that has been dubbed "advance care planning."¹⁴ One hypothesis to explain the failure of advance directives is that patients may change their views not just of what interventions they would want, but also of how decisions ought to be made as they become sicker and closer to death. This article reports on a long-term series of measurements of terminally ill patients' decision control preferences regarding decisions made on their behalf. It was hypothesized that, as patients came closer to death, they would be more likely to defer decision-making authority to their loved ones and physicians. Factors associated with patients' decision control preferences for decisions made on their behalf in the event of decisional incapacity were also examined.

METHODS

Sample

The study institutions were The Johns Hopkins Medical Institutions in Baltimore, Maryland, and St. Vincent's Hospital in New York. The two study sites were selected to obtain a sample that was racially, ethnically, and culturally diverse. Eligible inpatients and outpatients at the two study institutions were referred to the investigators between April 2000 and June 2003. Patients were included if they were aged 18 and older, spoke English or Spanish, and could be interviewed within 8 weeks of being diagnosed with amyotrophic lateral sclerosis (ALS) or advanced cancer or within 8 weeks of being hospitalized for class III or IV congestive heart failure (CHF). Cancer patients included those with nonresectable non-small cell lung cancer; stage III or IV pancreatic cancer; or stage IV liver, colon, or gastric cancer. CHF patients must not have been eligible for transplantation. These criteria were selected to obtain a sample of patients with a prognosis of at least 50% 2-year mortality based on the literature¹⁵⁻¹⁸ and the clinical experience of the respective medical specialists at the two study sites. Patients were screened and excluded for altered mental status at each interview using the Short Portable Mental Status Questionnaire¹⁹ and the Confusion Assessment Method.²⁰ Patients were interviewed at enrollment and every 3 months until death or 2 years had elapsed (last interviews June 2005). Because of a large number of early deaths, only the first three interviews are reported on: at enrollment, 3 months, and 6 months.

Instruments

To determine how patients would choose to have medical decisions made regarding their care, a modified version of the Control Preferences Scale, developed and validated previously,^{7, 21} was used. The scale employs picture cards with explanatory text that depicts a 5-point scale of decision control ranging from complete independence (A) through shared decision-making (C) to decision-making that is completely reliant on the physician or loved ones (E). The modification (Figure 1), developed with the assistance of the designer of the original scale, created cards that would reflect patients' decision control preferences with respect to the decisions loved ones and physicians would make on the patients' behalf under the assumption that the patients were unconscious and unable to speak for themselves. The text and cartoons depict a range of approaches from those representing the patients' independent wishes while in the unconscious state (substituted judgment) to relying upon loved ones to decide what is in the patients' best interests. Unconsciousness was chosen as a clinical condition for these scenarios so that it would be clear that the patient lacked all decision-making capacity. In pilot testing this new instrument, test-retest reliability was evaluated by performing serial administrations of the instrument 1 week apart. Overall correlations were found between the first and second administrations of the decision control preference scales of 0.92 for a patient with ALS and 0.76 for a patient with CHF. There was 75% agreement in their first choice decision control preference for each scale, yielding a kappa of 0.47.

In addition, two other previously validated instruments were administered: the McGill Quality of Life Questionnaire^{22,23} and the General Health Questionnaire.^{24,25} Validated Spanish translations of instruments were used where available, or translations were developed where necessary.²⁶ Trained research assistants, one of whom was fluently bilingual in English and Spanish, administered all instruments.

Procedures

Of the 313 patients found eligible for the study, 147 (47%) were included in the final sample. Of the 166 who were not included in the final sample, 114 (36% of eligible patients) refused to participate in the study, 35 (11%) could not be reached, six (2%) died before they could be interviewed, five (2%) had family members who controlled access to the patient by phone or

physical presence and refused to allow us to ask the patient for consent to participate, three (1%) were unable to complete the interview, and three (1%) did not participate for other reasons. There were no significant differences between participants and nonparticipants in terms of race ($P = .11$), sex ($P = .30$), diagnosis ($P = .48$), age ($P = .63$), or study site ($P = .31$). Participants were assured of confidentiality with the exception that, if they indicated that they would harm themselves, the investigator would immediately inform their attending physician. The Johns Hopkins Medical School and the St. Vincent's Hospital institutional review boards approved the study.

Data Analysis

Control preferences were treated as a continuous variable, with the patients' first choice at each time point scored as A (most independent) = 1, B = 2, C = 3, D = 4, and E (most reliant) = 5. Treating control preferences as a continuous variable is justified, because the method assumes that this scale represents a continuous psychological dimension,^{7,21} and the distribution of the data followed an approximate Gaussian distribution as indicated by the Shapiro-Wilk test for normality. Using the most conservative estimate, based only upon the 85 subjects who survived 6 months and had complete data at all of the first three time points, there was a power greater than 80%, with a two-sided alpha of 0.05 to detect a shift of 0.31 in the control preferences scale over this time period.

To create advanced multivariable regression models, generalized estimating equations (GEEs) were used. This method allowed proper account of the within-subjects correlation between time points in the regression models to be taken.²⁷ All independent variables that were associated with control preferences at $P < .10$ were tested in the multivariable models. Education was dichotomized into at least some college education versus no college. Interactions were tested for, and significant interaction terms were included in the final models. The GEE models presented included all data available for all 147 patients at all of the first three time points. GEE models are population averaged, requiring only the assumption that dropouts are random. The robustness of the conclusions was tested by estimating alternative models under two different sets of assumptions to handle data that were missing because of death or lack of patient capacity. Because similar results were noted in alternative GEE models using only the 85 patients who survived for all 6 months and in alternative GEE models that brought forward to 6 months the 3-month control preference scores for patients who did not survive 6 months, only the full models are presented in this article.

The directionality of any within-subjects change in control preferences was assessed using the Stuart-Maxwell test.²⁸ The control preferences variable was also analyzed as a categorical variable, trichotomized into independent (A or B), shared (C), and reliant (D or E). The association between mortality and control preferences was calculated using the chi-square (χ^2) test.

All calculations were performed using the SPSS software package (SPSS Release 12.0.1, Chicago, IL), except the GEE model, for which STATA (Release 9.0, StataCorp, 2005, College Station, TX) was used.

RESULTS

The characteristics of the 147 patients who participated as subjects in this project are shown in Table 1. Their mean age was 62, approximately two thirds were white and two thirds were men. Thirty-five percent were college educated.

Overall 2-year mortality was 84%. Mortality rates for all diagnoses were higher than the 50% mortality predicted by the literature but lowest for patients with CHF (92% for cancer, 81% for

ALS, and 60% for CHF, $P<.001$). Because the GEE models were developed based on data for the first 6 months, it is important to note that 119 patients survived for 3 months (19% mortality) and 103 survived for 6 months (30% mortality). Because of the high mortality and frequency of cognitive incapacity, only 85 of the 147 subjects who gave interview data at baseline were able to do so again at 3 months and at 6 months. However, the GEE method is a population-averaged technique that takes into account all data available for all patients at all time points, mitigating the effects of dropouts.

Figure 2 depicts the baseline decision control preferences of patients with respect to the physician and the family. “A” represents the most independent state (decisions “based upon my own personal wishes”) and “E” the most reliant (decisions based upon what physicians or loved ones “think is best”). In other words, “A” represents pure substituted judgment and “E” pure best interests standard. As can be seen, patients presented a wide variety of decision control preferences in the event of decisional incapacity. Few would have opted for a pure substituted judgment or a pure best interests approach by their physicians or their loved ones, and most opted for a mixture of the two approaches, although patients were significantly more likely to lean toward opting for independence (substituted judgments) from their loved ones (mean decision control preference score 2.61 ± 1.23) and toward reliance (best interests judgments) upon their physicians (3.26 ± 1.05 , $P<.001$).

Decision Control Preferences Regarding Loved Ones

Patients enrolled in this study did not change their decision control preferences significantly with respect to their loved ones over time, with a mean of 2.61 (95% confidence interval (CI) = 2.41-2.80) at baseline, a mean of 2.56 (95% CI = 2.31-2.82) at 3 months, and a mean of 2.53 (95% CI = 2.25-2.81) at 6 months ($P=.89$). These data were also analyzed by retrospectively examining for a time trend, setting the independent variable as time before death; similar stability was found in these analyses.

Although the mean with respect to loved ones was constant from baseline to 3 and 6 months, reporting means alone is insufficient for describing any potential shift in individual control preferences over time. When the control preferences variable was examined categorically, it was found that 57% did not change their control preferences from baseline to 3 months and that 59% of the patients who could be interviewed at 6 months did not change from 3 to 6 months. This implies that more than one-third changed their preferences. Nonetheless, these changes tended to be a shift of only a single “notch” on the scale. Only 15% changed from an independent decision control preference (A or B) to a reliant style (D or E) or from a reliant style to independent style over the first 3 months. Furthermore, there was no systematic directionality to any of these changes as measured according to the Stuart-Maxwell test ($P=.73$, baseline to 3 months; $P=.89$, baseline to 6 months; $P=.75$, 3 to 6 months).

As shown in Table 2, in a GEE model controlling for time, older patients were significantly more likely to opt for a style of decision-making in which loved ones made decisions based upon what they thought best for the patient. Women and college-educated patients were more likely to lean toward substituted judgments. Diagnosis, health status, quality of life, race, marital status, religion, and religiosity were not associated with decision control preferences of patients regarding the role they would have their loved ones play in the event of decisional incapacity.

Decision Control Preferences Regarding Physicians

Decision control preferences with respect to the physician’s role in the event of decisional incapacity shifted toward significantly more independence from the physician over time, going

from the baseline mean of 3.27 (95% CI = 3.08-3.45) to 2.78 (95% CI = 2.55-3.01) at 3 months and 2.84 (95% CI = 2.58-3.10) at 6 months ($P < .001$).

As shown in Table 3, in a multivariate GEE model, these control preferences changed significantly from baseline to 3 months, with patients opting for somewhat more independence from their physicians' judgments about their best interests but did not change significantly again from 3 to 6 months. Women and patients with ALS were more likely to opt for decisions that leaned toward substituted judgments from physicians, whereas older patients were more likely to lean toward relying on their physicians' opinions about what would be in their best interests. In univariate analyses, college education was significantly associated with more-independent control preferences. A significant interaction was noted between college education and time ($P = .03$). As shown in Figure 3, college-educated patients continued to progress toward opting for more-independent decision-making from their physicians at 6 months. At baseline, patients with at least some college education and those with less education had similar adjusted mean decision control preferences with respect to their physician (3.17, 95% CI = 2.88-3.46 for college educated patients; 3.32, 95% CI = 3.10-3.54 for those with a high school education or less), although at 6 months, college-educated patients had shifted, leaning toward more substituted judgments (adjusted mean = 2.37, 95% CI = 1.94-2.79), whereas less-educated patients were still opting for more of a mixed approach, leaning very slightly toward best interests (adjusted mean = 3.16, 95% CI = 2.85-3.48). Health status, quality of life, race, marital status, religion, and religiosity were not associated with decision control preferences of patients regarding the role they would have their physicians play in the event of decisional incapacity.

Mortality and Control Preferences

Baseline control preferences were not associated with mortality. Mortality at 3 months was 24% (14/58) for patients with initially independent decision control preferences, 18% (6/34) for those who would opt to share decision control, and 38% (8/21) for those who would rely on their loved ones ($P = .23$ according to χ^2). Although the numbers were smaller, additional mortality from 3 to 6 months was 24% (10/42) for patients with independent control preferences, 8% (8/17) for those who would opt to share decision control, and 29% (5/17) for those who would rely upon their loved ones ($P = .17$ according to χ^2).

DISCUSSION

This study found that terminally ill patients' decision control preferences in the event of decisional incapacity vary widely but that most patients would have decisions made according to a mixture of substituted judgment and reliance on the opinions of their physicians and loved ones about their best interests. Soon after diagnosis, patients were slightly more disposed toward having their loved ones make substituted judgments, whereas they were slightly more disposed toward deferring to their physician's judgments about their best interests. Contrary to the study's hypothesis, these decision control preferences remained stable over time. A notable exception was that college-educated patients tended to move toward endorsing more substituted judgment (i.e., less reliance upon their physician's views about their best interests) the longer they lived with their terminal illnesses.

The authors are not aware of any previous studies regarding the stability of terminal patients' views regarding how they would want decisions about their care to be made in the event of decisional incapacity. Patients' views about what they would want (their preferences for specific life-sustaining interventions) have been studied previously and found to be stable, yet a substantial minority of patients change their preferences about life-sustaining interventions, especially if observed over longer periods of follow-up and if the patient's initial preference was in favor of the life-sustaining intervention in question.²⁹⁻³⁵ Although it has recently been

observed that patients' preferences for medical interventions change as their functional status declines with time,³⁶ the results of the current study suggest that the style of decision-making for which patients would opt should they become unable to speak for themselves is independent of quality of life, health status, and length of time lived with a terminal illness.

The stability found in the terminally ill patients' decision control preferences should they become incapacitated is good news for advance care planning. Holding discussions with patients early in these illnesses about how they would want decisions to be made on their behalf appears to be a reasonable thing to do. What patients said 6 months earlier tends to be what they continue to say. This study confirms that this stability applies to individuals and not just to an aggregate sum, because a GEE model, which measured within-subject control preferences repeated over time, was used. Furthermore, a small fraction of the individuals participating in the study changed their control preferences over 6 months. Although it is always important to be sure that patients have not changed their minds about the roles they would assign to loved ones or physicians (and the study's results indicate that this would be particularly important for college-educated patients with respect to their physicians), no evidence was found of extensive, systematic shifts in decision control preferences as patients continued to live with these progressive, terminal conditions.

However, these results also challenge the special status substituted judgment currently enjoys as the decision-making model of choice for incapacitated patients. The vast majority of the terminally ill patients studied wanted a mixture of substituted judgment and best interest judgment to inform decisions made on their behalf. Taken together, these results suggest that surrogate decision-makers have a complex task. Patients could opt to use instruments such as durable powers of attorney or healthcare proxies to appoint decision-makers, who could be informed not only of what interventions the patients would want but also how the patient would have them to decide. Surrogates might benefit from knowing how the patient would have them balance their own judgments about the patient's best interests, their knowledge of the patient's wishes, and the input of the physician. It is not known how well surrogates could perform this complex task, but this is probably a more-accurate description of what they do in real clinical settings. The stability found in the current study demonstrates that there is an opportunity to inform surrogates of the patient's control preferences early in the course of a terminal disease with some assurance that these control preferences are unlikely to change radically. Nonetheless, because a minority of patients change their control preferences, the matter ought periodically to be revisited.

Age, Sex, Education, and Diagnosis

It is not surprising that older patients would be more reliant upon their families' and physicians' judgments about what would be in their best interests in the event of decisional incapacity. Older patients are more reliant upon their physicians when their decision-making capacity is intact, both in the general population⁷ and among women who have been newly diagnosed with breast cancer.¹⁰

Women in our study tended to have more-independent decision-making styles. This may be because they are most frequently in the roles of caregiver and decision-maker themselves. It has been shown previously that the majority of surrogate healthcare decision-makers are women.⁵ Women often outlive their husbands, who may have relied upon them, but might then find themselves with no spouse upon whom they might rely and might be reluctant to rely upon their adult children.

College-educated patients, although still (broadly) opting for shared decision-making, were consistent in leaning toward asking for substituted judgments from loved ones. Patients in the current study, when asked to assume that they had lost decision-making capacity, leaned

somewhat toward asking for best interest judgments from physicians. Other studies, assuming intact decision-making capacity, have shown that higher levels of education are associated with more-independent decision-making styles with respect to physicians.^{7,10} The current study found that, under the assumption they had lost decision-making capacity, only over time did college-educated patients tend toward more independence from physicians, seeking more substituted judgment the longer they lived with their illnesses. Perhaps this represents a growing emphasis on their own autonomy as they come closer to death. Alternatively, this might simply represent the fact that educated patients more clearly understand that physicians could not effectively perform a substituted judgment early in the illness, because they might not know the patient well enough. Under such circumstances, all they might wish, at first, from the physician would be an opinion. Later, as the physician-patient relationship matures, trust and knowledge of the patient develops, and substituted judgment becomes possible. Corroborating this hypothesis, it has been reported elsewhere that, in the event of decisional incapacity, newly diagnosed, terminally ill patients want the input of the family to be weighed more heavily than that of the physician, even though they want the physician to render an opinion regarding their best interests and their loved ones to provide a substituted judgment.¹¹

Diagnosis was not associated with decision control preferences with respect to loved ones, although patients with ALS were more likely to tend toward independence from their physicians than patients with cancer or CHF, opting for more substituted judgments. Patients with ALS seemed, in general, favorably disposed to independent decision-making. Previous studies have shown that patients with ALS are likely to have advance directives,^{37,38} and most want to participate in medical decision-making,³⁵ although they are resigned to the fact that they have little control over their disease.³⁹ Perhaps the manner in which the disease deprives patients of their motor agency makes them especially keen to assert their agency through the making of medical decisions.

Mortality

Greater patient independence has been associated with better patient outcomes in managing several chronic conditions.⁴⁰⁻⁴³ Although this study was not powered to address this matter, no evidence was found that decision control preferences are associated with mortality. Patients with these fatal conditions tended to die equally whether they reported independent, reliant, or shared decision-making styles. Moreover, this finding effectively excludes the possibility that the differential survival of patients with an independent decision-making style could explain the change observed toward more-independent control preferences over time.

Limitations

This study has some important limitations. Although three different terminal illnesses were studied in two different settings, the generalizability of these findings is not certain. Because the method was hypothetical, it is also not certain how validly these data represent the actual beliefs of patients, although the hypothetical situation of being unable to speak for oneself is common at the end stages of these diseases. Also, the instruments were based on previous work, in which the notion of decision control preferences and the pictorial representations were developed over several years of careful study, beginning with qualitative studies based in grounded theory. The method has been used extensively in other settings. Finally, the sample size was small. There was enough power to detect changes in control preferences over time of a magnitude thought to be important, although small differences in some of the subgroup analyses cannot be excluded, such as differential mortality based upon style of decision-making, for which there was a power of only 0.5 to detect a difference at $\alpha = 0.05$. However, the expense and difficulties involved in performing a longitudinal study in terminally ill patients make it unlikely that larger studies will be conducted.

Implications

These results suggest that most terminally ill patients would opt for a mixture of substituted judgment and best-interest judgment to inform decisions made on their behalf and that this “meta-preference” remains stable over time, although the fact that patients vary suggests that, before asking patients what they would want (a question that implicitly privileges substituted judgment), it might be better to begin advance care planning by asking patients how they would like decisions to be made on their behalf. Older patients, in particular, tend to want more decisions made using a best-interest standard. Legal and clinical policies might then broaden the task of the surrogate beyond the provision of substituted judgment, encouraging a patient-centered style appropriate for patients who would opt to share decision-making with loved ones or rely completely upon loved ones’ judgments. Future studies might address whether these results can be confirmed in other patient populations, whether patients and their loved ones find it useful to discuss not merely what interventions the patients might choose but how patients would like decisions to be made on their behalf, and whether clinicians can be taught to facilitate such discussions.

ACKNOWLEDGMENTS

We would like to thank Lora Clawson, Jennifer Horner, Richard Kimball, Leana Rogers, and Kenneth Texeira for their assistance with data collection.

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Figure 1.
 (1.1) Patient-family instrument. (1.2) Patient-physician instrument. Copyright 1999, Johns Hopkins University, illustrations as adapted by Cassio Lymn, Art as Applied to Medicine.

Figure 2. Baseline distribution of decision control preferences of terminally ill patients in the event of decisional incapacity, with respect to physicians and with respect to loved ones. A = most independent, E = most reliant. Control preferences with respect to physicians are more reliant, $P < .001$.

Figure 3. Temporal changes in mean decision control preference scores with respect to the role physicians should play in decision-making in the event of patient unconsciousness according to patient education level. Lower scores indicate more independence (substituted judgment), higher scores more reliance (best interests), and 3.0 indicates shared decision-making. HS = high school.

Table 1

Characteristics of the Patient Sample (N = 147)

Characteristic	Value
Age, mean $\pm$ standard deviation	62.2 $\pm$ 12.5
Sex, n (%)	
Male	93 (63.3)
Female	54 (36.7)
Race, n (%)	
White	94 (64.8)
Black or African American	34 (23.4)
Other	17 (11.7)
Diagnosis, n (%)	
Cancer	60 (40.8)
Amyotrophic lateral sclerosis	32 (21.8)
Congestive heart failure	55 (37.4)
Marital status, n (%)	
Married	71 (48.3)
Widowed	22 (15.0)
Divorced or separated	27 (18.4)
Other	27 (18.4)
Education, n (%)	
Grade school or less	33 (23.1)
High school	61 (41.5)
College or more	52 (35.4)
Religion, n (%)	
Protestant	57 (38.8)
Catholic	53 (36.1)
Jewish	5 (3.4)
Other	22 (15.0)
None	9 (6.1)
Attends religious services, n (%)	
$\geq$ Weekly	64 (43.8)
<Weekly	82 (56.2)

Table 2
Generalized Estimating Equation Model for Decision Control Preferences with
Respect to Loved Ones in the Event of Decisional Incapacity

Variable	Coefficient	95% Confidence Interval	P-Value
Time			
3 months	-0.05	-0.34 to 0.24	.73
6 months	-0.06	-0.38 to 0.25	.70
Age			
51-60	+0.27	-0.19 to 0.72	.25
61-70	+0.49	0.06 to 0.93	.03
>70	+0.81	0.37 to 1.26	<.001
Female	-0.39	-0.69 to -0.08	.01
College education	-0.31	-0.62 to -0.01	.046

Note: Negative coefficients indicate more independence (substituted judgment), and positive coefficients indicate more reliance upon others (best interests).

Table 3
Generalized Estimating Equation Model for Decision Control Preferences with
Respect to Physicians in the Event of Decisional Incapacity

Variable	Coefficient	95% Confidence Interval	P-Value
Time			
3 months	-0.43	-0.75 to -0.11	.009*
6 months	-0.16	-0.51 to 0.19	.38
Aged >70	+0.31	-0.006 to 0.63	.06
Female sex	-0.37	-0.67 to -0.07	.02*
Diagnosis			
Cancer (reference)	—	—	—
Amyotrophic lateral sclerosis	-0.36	-0.72 to -0.002	.049*
Congestive heart failure	-0.05	-0.38 to -0.28	.77
College education	-0.18	-0.55 to 0.19	.35
College-by-time interaction			
3 months	-0.10	-0.63 to 0.44	.72
6 months	-0.64	-1.2 to -0.06	.03*

Negative coefficients indicate more independence (substituted judgment) and positive coefficients indicate more reliance upon others (best interests).

* $P < .05$.