An Empirical Study of Surrogates' Preferred Level of Control over Value-laden Life Support Decisions in Intensive Care Units

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Rationale: Despite ongoing ethical debate concerning who should control decisions to discontinue life support for incapacitated, critically ill patients, the perspectives of surrogate decision makers are poorly understood.

Objectives: To determine (1) what degree of decisional authority surrogates prefer for value-sensitive life support decisions compared with more technical biomedical decisions, and (2) what predicts surrogates' preferences for more control over life support decisions.

Methods: This was a prospective study of 230 surrogate decision makers for incapacitated, mechanically ventilated patients at high risk of death. Surrogates reported their preferred degree of decisional authority using the Degner Control Preferences Scale for two types of decisions: a value-sensitive decision about whether to discontinue life support and a decision regarding which antibiotic to prescribe for an infection.

Measurements and Main Results: The majority of surrogates (55%, 127/230; 95% confidence interval, 49–62%) preferred to have final control over the value-sensitive life support decision; 40% (91/230) wished to share control equally with the physician; 5% (12/230) of surrogates wanted the physician to make the decision. Surrogates preferred significantly more control over the value-sensitive life support decision compared with the technical decision about choice of antibiotics ($P < 0.0001$). Factors independently associated with surrogates' preference for more control over the life support decision were: less trust in the intensive care unit physician, male sex, and non-Catholic religious affiliation.

Conclusions: Surrogates vary in their desire for decisional authority for value-sensitive life support decisions, but prefer substantially more authority for this type of decision compared with technical, medical judgments. Low trust in physicians is associated with surrogates preferring more control of life support decisions.

Keywords: surrogate decision making; critical care; ethics; decisions; end-of-life care

Surrogate decision making in intensive care units (ICUs) is fraught with difficulty. Surrogates experience conflict with physicians (1, 2), difficulty identifying patients' treatment preferences (3), long-term psychiatric symptoms (4, 5), and

AT A GLANCE COMMENTARY

Scientific Knowledge on the Subject

There are few empirical data on the perspective of surrogates about who should have authority for value-sensitive decisions regarding the use of life support. Prior studies report surrogates' preferred role in ICU decision-making in general, encompassing both end-of-life decisions and biomedical decisions.

What This Study Adds to the Field

Our objectives were to determine what degree of decisional authority surrogates prefer for value-sensitive life support decisions compared to more technical biomedical decisions, and what predicts surrogates' preferences for more control over life support decisions. These results suggest that surrogates may prefer more decisional control for value-laden decisions in ICUs than previously believed. Surrogates who had less trust in the treating physicians preferred more control over the final decision regarding withdrawal of life support.

lingering doubts about the decisions made (6). As clinicians seek to improve the quality of surrogate decision making, a key question arises: to whom should responsibility fall for decisions about whether to forego life-sustaining treatment? The 2003 *Challenges in End-of-Life Care in the ICU* consensus statement, generated from expert opinion, advocates a shared decision making model (7), in which surrogate decision makers and physicians share the responsibility of making decisions on behalf of incapacitated ICU patients.

There are few empirical data on the perspective of surrogates about who should have authority for value-sensitive decisions regarding the use of life support. The main work cited in professional society statements is that of Heyland and colleagues, who elicited surrogates' preferred role in ICU decision making *in general*, encompassing both end-of-life decisions and biomedical decisions (8). Anderson and colleagues also used general ICU medical decision making as a basis to obtain surrogates' decision-making preferences (9). However, there are conceptual differences between biomedical decisions, which largely depend on technical medical knowledge (e.g., which antibiotic is most effective in treating hospital-acquired pneumonia) and value-sensitive decisions, which hinge on both biomedical facts and on individuals' values and preferences about trade-offs between quantity and quality of life. It is therefore difficult to know whether the data cited in the 2003 consensus statement apply to the value-sensitive life support decisions that arise commonly in ICUs.

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We therefore sought to determine (1) the degree of decisional authority preferred by surrogates for a paradigmatic value-sensitive life support decision, (2) whether decision-making preferences are sensitive to the type of decision (highly value-laden vs. predominantly biomedical decision), and (3) what factors predict surrogates' preference for higher degrees of authority for life support decisions.

METHODS

From January 2006 to October 2007 we performed a prospective cohort study of surrogate decision makers for critically ill patients in four ICUs at the University of California San Francisco Medical Center. Study methods have been previously described (10).

Study investigators identified eligible patients and their surrogates by screening daily in each ICU. The four ICUs include mixed patient populations, with one neurologic ICU, one cardiac ICU, and two medical-surgical ICUs. Eligible subjects were the surrogate decision makers of incapacitated adult patients with respiratory failure requiring mechanical ventilation and an Acute Physiology and Chronic Health Evaluation (APACHE) II score greater than 25. The surrogates of patients dying within 48 hours of initiating mechanical ventilation were not eligible per Institutional Review Board requirements. If multiple individuals identified themselves as the surrogate for a patient, then we enrolled those who rated their role in decision making to be significant. Therefore, each patient could have more than one surrogate enrolled. To be considered, surrogates needed to be at least 18 years old and speak and read English well enough to not require an interpreter. Subjects provided written consent for all study procedures.

Covariates

Subjects completed a written, self-administered questionnaire containing items about demographic information, past experiences as a surrogate, and whether the surrogate had discussed treatment preferences with the patient. We also assessed surrogates' perceptions of their communication with, trust in, and conflict with the patient's treating physician using the quality of communication scale (11), the validated physician trust scale (12), and a single-item conflict scale (13). Subjects also answered questions regarding religiosity about the perceived influence of God on their health, using the God Locus of Health Control Scale, with higher scores indicating a stronger belief in God's role in health (14, 15). Written depression screening was accomplished with the Patient Health Questionnaire-2 (16), along with measurement of dispositional optimism by means of the Revised Life Orientation Test (17). Higher Revised Life Orientation Test scores indicate more dispositional optimism. Subjects also completed validated measures of health literacy (Short Test of Functional Health Literacy in Adults) (18) and view of patient and doctor roles (Patient Provider Orientation Scale). The Patient Provider Orientation Scale is a mean score ranging from 1 to 6, with higher scores reflecting a preference toward a more "patient-centered" approach to healthcare compared with a more "biomedical model" (19). A measure of the patient's prehospitalization function was obtained using the Katz Activities of Daily Living score (range, 0–6). Higher scores indicate higher degrees of functional independence.

Intervention

Subjects were presented with two clinical vignettes regarding treatment choices to be made for their loved one in a hypothetical clinical scenario: a life support decision and an antibiotic decision. The vignettes and response elements are provided in Figure 1.

Primary Outcome Measure

Surrogates completed the validated Degner Control Preferences Scale to indicate their preferred level of involvement in the decision-making process for each scenario (20). The Control Preferences Scale is a tool used to assess what role individuals prefer for medical decision making and is rooted in the theory that there is a continuum of desired control among decision makers (21). The Control Preferences Scale is composed of five potential roles in clinical decision making. For both clinical vignettes, these five roles were available as choices on a

1 through 5 scale, with increasing physician control in the decision-making process assigned higher values on the scale (20).

Analysis

We generated descriptive statistics for patients' and surrogates' demographics, covariates, and the main outcome measure (Degner Control Preferences Score) for the two clinical scenarios. The preferred level of decisional authority was initially measured as five separate categories, and for the multivariate analyses was dichotomized for ease of interpretation. Surrogates were adjudicated to prefer final authority over the decision if they chose either of the following two responses: "1. I prefer that I make the final decision about [wording varied based on vignette]" or "2. I prefer that I make the final decision after seriously considering the doctor's opinion" (see Figure 1). The other three responses on the scale were categorized as surrogate preference to have the physician involved in the decision making, which included the patient sharing the responsibility for the decision and the physician having ultimate authority for the decision. This analytic approach allows a focus on the clinically important question of what factors may lead surrogates to prefer a high degree of decisional authority.

We used the Wilcoxon signed-rank test to perform within-subject comparisons to determine if there were differences in subjects' preferred level of involvement in the life support decision compared with the antibiotic decision. We also applied a paired *t* test to calculate the *P* value for the difference in surrogates' preferred level of involvement between the two decisions.

To determine factors associated with surrogates' preferences to have final decision-making authority for life support decisions, we used a hierarchical logistic regression model, which accommodated the possibility of a clustering effect among surrogates nested within patients nested within physicians. We first fit a series of models with a single covariate to identify variables of interest. Variables with a *P* < 0.20 at this stage of modeling were considered for inclusion in models with multiple covariates. Final models were selected based on significance of covariates. In situations in which two covariates were highly correlated, only one of the two was retained in the model. All analyses were conducted using STATA 8.0 (College Station, TX).

RESULTS

Of 222 eligible patients, 20 were excluded at the attending physician's request and 27 of the patients' surrogates declined to participate. There were no significant differences in age, sex, race, or APACHE II score between enrolled patients and those who were eligible but not enrolled at the request of the physician or surrogate. For the remaining 175 patients, 230 surrogate decision makers were enrolled, with 40 patients having more than one self-identified surrogate (Figure 2).

Subjects' demographic characteristics and a summary of other covariates are shown in Table 1. More than half of the surrogates had prior experience as a surrogate decision maker (52%), and 60% had prior discussions with the patient about treatment preferences. Two-thirds (68%) of surrogates met criteria for possible depression on the Patient Health Questionnaire-2. The mean physician trust score was 20.9 (SD, 3.6; range, 9–25), with higher scores indicating higher trust in physician. The average quality of communication score was 83 (SD, 16.1; range, 0–100), with higher scores reflecting surrogates' perceptions of better communication by the ICU physician. Patient demographics are summarized in Table 2.

Figure 3 summarizes surrogates' preferred role in the value-laden life support decision. The majority of surrogates (55%, 127/230; 95% confidence interval, 49–62%) preferred to have final control over the value-sensitive life support decision, 40% (91/230) wished to share control equally with the physician, and 5% (12/230) wanted the physician to have final control. The Control Preferences Scale also provides information about whether surrogates wish to hear the physician's opinion about

a. Life Support Decision Vignette from Questionnaire

Please imagine the following situation:

Your spouse or partner is very sick in the intensive care unit and cannot speak for him/herself. Also imagine that you are his/her only relative. He/she is very likely to die, but there is a very small chance he/she would survive with continued treatment. If he/she survived, he/she would have physical and cognitive disabilities that made it so that he/she was dependent on others for basic tasks such as bathing, paying bills and preparing meals. If he/she survived, he/she would have some difficulty thinking, but he/she might be able to communicate with you and others.

People have different opinions about whether or not they would accept intensive medical treatment in the scenario outlined above. Some patients in this situation would want to continue intensive medical treatment, while others would prefer treatment focused on keeping them comfortable.

How do you think the decision about whether or not to continue intensive medical treatment should be made? (Please choose the one phrase from below that best describes your opinion):

1. I prefer that I make the final decision about whether or not to continue intensive medical treatment
2. I prefer that I make the final decision after seriously considering the doctor's opinion
3. I prefer that the doctor and I share responsibility for deciding whether or not to continue intensive medical treatment.
4. I prefer that the doctor makes the final decision but seriously consider my opinion.
5. I prefer that the doctor decides whether or not to continue intensive medical treatment.

b. Antibiotic Decision Vignette from Questionnaire

Please imagine the following situation:

Your spouse or partner is very sick in the intensive care unit. He or she has an infection that needs to be treated with antibiotics. There are several different antibiotics that might work and they are all equally effective. How do you think the decision should be made about which antibiotic to use? (Please choose the one phrase from the list below that best describes your opinion):

1. I prefer that I make the final decision about which antibiotic to use.
2. I prefer that I make the final decision after seriously considering the doctor's opinion.
3. I prefer that the doctor and I share responsibility for deciding which antibiotic to use.
4. I prefer that the doctor makes the final decision but seriously consider my opinion.
5. I prefer that the doctor decides which antibiotic to use

Figure 1. Vignettes and response elements.

treatments. Ninety percent of subjects wished to receive the physician's recommendation (defined as selecting response choices 2–5) (Figure 3).

Figure 3 also summarizes surrogates' preferred role in the technical judgment about antibiotic selection. Surrogates preferred significantly more control for the value-sensitive life support decision compared with the technical medical decision about antibiotics; the mean score on the Control Preferences Scale for the value-laden life support decision was 2.4 ± 0.8 versus 3.9 ± 1.1 for the antibiotic decision ($P < 0.0001$), with a lower score indicating a preference for more decisional control.

Univariate analysis of factors associated with the preference for more decision control in value-laden decisions revealed six covariates to be significant: younger age, male sex, non-Catholic religion, a higher Patient Provider Orientation Scale score, a lower physician trust score, and a lower score for quality of physician communication. Table 3 summarizes the univariate

odds ratios for predictor variables associated with preferences for maintaining a high decisional responsibility, defined as the surrogate preferring to decide alone or to decide after strongly considering the physician's opinion. Multivariate analysis revealed three factors significantly associated with surrogates' preference for a higher degree of decisional control for the value-sensitive decision: low levels of trust in their loved one's physician, male sex, and being a member of a non-Catholic religion (Table 4).

DISCUSSION

We found substantial variability in the role surrogates prefer in making value-sensitive life support decisions for incapacitated, critically ill patients, with a slight majority preferring to have final control of the decision. Surrogates with low levels of trust in the treating physicians were more likely to prefer to retain final authority for value-laden life support decisions.

Our results suggest that surrogates may prefer more decisional control for value-laden decisions in ICUs than previously believed. For example, Heyland and colleagues found that only 22% of subjects wished to maintain final authority over decisions in ICUs (8). Similarly, Anderson and colleagues reported that only 25% of surrogates preferred to be the person making the final medical decisions (9). Azoulay and colleagues found that 53% of surrogates did not wish any involvement in decisions to forego life support in ICUs (22). What may explain the different findings? Both Heyland and colleagues and Anderson and coworkers elicited surrogates' perspectives on decision making in general, combining both end-of-life decisions and technical medical decisions into their questions (8, 9). The data we report herein suggest that the type of decision influences surrogates' preferred role, with surrogates preferring more control over value-laden decisions compared with more technical medical decisions. Azoulay and colleagues studied a qualitatively different type of decision: whether to stop futile treatment when there was "no hope of recovery" (22). We studied decisions about what constitutes a state worse than

Figure 2. Flow diagram describing the enrollment of surrogates.

TABLE 1. SURROGATE CHARACTERISTICS

Covariate	N = 230
Age, yr	Mean 46.5, SD 14.6
Sex	
Male	74 (32.2)
Hispanic	
No	195 (85.5)
Race	
Caucasian	138 (64.8)
African-American	23 (10.8)
Asian	34 (16.0)
Other	18 (8.4)
Education	
Less than high school	2 (0.9)
Some high school	13 (5.7)
High school graduate	44 (19.2)
College	124 (54.1)
Postgraduate, graduate, professional education	46 (20.1)
Language	
English	185 (80.4)
Other language	45 (19.6)
Religion	
Catholic	75 (35.5)
Other Christian	77 (36.5)
Other religion	13 (6.2)
None/agnostic	46 (21.8)
Importance of religion	
Very important	101 (47.9)
Fairly important	57 (27.0)
Somewhat important	37 (17.5)
Not at all important	16 (7.6)
Relationship to patient	
Spouse	56 (24.4)
Child	86 (37.4)
Sibling	24 (10.4)
Friend	4 (1.7)
Parent	25 (10.9)
Other relative	18 (7.8)
Other relationship	17 (7.4)
STOFHLA (score of 1–36, higher score indicates more health literacy)	Mean 33.2, SD 5.2
GLHC summary score (score of 6–36, higher score indicates stronger belief in God's role in health)	Mean 20.9, SD 9.3
LOTR (score of 0–24, higher score indicates more optimistic)	Mean 17.1, SD 3.7
PPOS score (score of 1–6, higher score indicates more patient-centered)	Mean 3.9, SD 0.9
PHQ2 Score	
Indicates depression	156 (68.1)
Past surrogate experience	
Yes	119 (52.0)

Definition of abbreviations: GLHC = God Locus of Health Control Scale; LOTR = Revised Life Orientation Test; PHQ2 = Patient Health Questionnaire-2; PPOS = Patient Provider Orientation Scale; STOFHLA = Short Test of Functional Health Literacy in Adults.

Data are presented as no. (%) unless otherwise noted.

death, which are qualitatively more value-laden and difficult than the decision to stop a clearly futile treatment. It is also possible that Azoulay and colleagues' findings from France are due to differences in prevailing cultural norms between Europe and the United States regarding medical decision making (23, 24). Our findings are in accord with a recent qualitative study by White and colleagues, which reported wide variability in surrogates' beliefs about what role physicians should play in value-sensitive life support decisions (25).

The results of the current study provide empirical support for the conceptual distinction between physicians sharing their opinion with surrogates and physicians having final authority over value-laden decisions. Specifically, although very few

TABLE 2. PATIENT CHARACTERISTICS

Characteristics	N = 175
Age, yr	Mean 59, SD 18.2
Male	98 (56)
Race	
Caucasian	102 (63)
African American	17 (10.5)
Asian	33 (20.5)
Other	10 (6)
Admission diagnosis	
Respiratory failure	48 (27.5)
Neurologic failure	46 (26)
Cardiac failure or shock (including sepsis)	44 (25)
Gastrointestinal failure (including pancreatitis)	14 (8)
Hepatic failure	13 (7.5)
Metastatic cancer	7 (4)
Renal failure	3 (2)
APACHE II score (on enrollment)	Mean 29, SD 4.6
Primary service	
Nonsurgical	98 (59)
Surgical	67 (41)
DNR order on enrollment	28 (16)
Withdrawal of life-sustaining therapy	67 (38)
Mortality	75 (43)

Definition of abbreviations: APACHE II = Acute Physiology and Chronic Health Evaluation II; DNR = do not resuscitate.

Data are presented as no. (%) unless otherwise noted.

surrogates wished to cede all decisional authority to physicians, 90% wished to receive the physician's opinion about whether to forego life-sustaining treatment. Understanding the conceptual distinction between "who deliberates" and "who decides" may help physicians better match their practice to the preferences of individual surrogates.

We also found that surrogates who had less trust in the treating physicians preferred more control over the final decision regarding withdrawal of life support. Although this

Figure 3. Surrogates' preferred involvement in life support decision and antibiotic decision. * $P < 0.0001$.

TABLE 3. UNADJUSTED ODDS RATIOS FOR INDEPENDENT SURROGATE VARIABLES ASSOCIATED WITH SURROGATE PREFERENCE FOR DECISIONAL AUTHORITY

Independent Variable	OR (95% CI)
Older age (per 5-yr intervals of increasing age)	0.91 (0.83–0.99)
Male sex	1.96 (1.10–3.48)
Hispanic	0.99 (0.47–2.07)
Race	
White vs. nonwhite	0.79 (0.45–1.40)
African American vs. non-African American	1.62 (0.65–4.00)
Increasing level of education (5 categories)	1.07 (0.78–1.46)
Primary language is English	1.53 (0.80–2.95)
Catholic religion	0.31 (0.18–0.57)
Increasing level of religious influence on life	0.83 (0.62–1.11)
Relationship to patient	
Spouse vs. nonspouse	0.63 (0.34–1.14)
Child vs. nonchild	1.12 (0.65–1.92)
Parent vs. nonparent	1.04 (0.45–2.39)
Increasing STOFHLA score by 5-point intervals	1.08 (0.85–1.38)
Increasing GLHC summary score by 5-point intervals (indicating stronger belief in God's role in health)	0.92 (0.80–1.06)
Increasing LOTR score (more optimistic) by 5-point intervals	0.85 (0.61–1.20)
Increasing PPOS score, by 1 point (more patient-centered)	1.45 (1.09–1.92)
PHQ2 score indicates depression	1.10 (0.63–1.92)
Has past surrogate experience	0.81 (0.48–1.36)
Had discussion in past with patient about treatment preferences	0.59 (0.34–1.01)
Physician can predict if patient will live or die (increasing agreement on 1–6 scale)	0.85 (0.71–1.01)
Increasing agreement on 1–6 scale that sometimes physicians do not tell family members the truth about prognosis	1.05 (0.89–1.24)
Increasing agreement on 1–6 scale that it is important physician is honest about prognosis	0.99 (0.70–1.41)
Increasing agreement on 1–6 scale that prefer physician does not discuss chance of survival	0.88 (0.72–1.07)
Increasing conflict with physician on 0–10 scale	1.09 (0.97–1.24)
Surrogate felt discriminated against in the past 12 mo	2.24 (0.58–8.66)
Increasing physician trust score by 5-point intervals	0.57 (0.40–0.80)
Increasing QOC score by 5-point intervals	0.90 (0.83–0.98)

Definition of abbreviations: CI = confidence interval; GLHC = God Locus of Health Control Scale; LOTR = Revised Life Orientation Test; OR = odds ratio; PHQ2 = Patient Health Questionnaire-2; PPOS = Patient Provider Orientation Scale; QOC = quality of communication; STOFHLA = Short Test of Functional Health Literacy in Adults.

Scoring: 1 = surrogate decides; 0 = physician involved in decision making. Boldface type indicates covariates that were significantly associated with surrogate preference for higher degree of decisional control.

finding will not surprise clinicians who have experienced how loss of trust can undermine collaborative decision making, it is the first empirical evidence of this association among surrogate decision makers. These cross-sectional data cannot establish a causal association; however, they raise the possibility that surrogates' role preferences may be dynamic rather than static and constructed by their experiences with the health care team. Future prospective studies are needed to establish whether such a causal relationship exists. If so, it would strengthen the rationale for research on how to forge trusting relationships with families in ICUs. We speculate that a starting point may be for physicians to conceptualize trust building as an important

goal in their interactions with surrogates and to structure their communication to accomplish this.

Our data suggest that physicians need to develop two skills that are not currently part of the core competencies of critical care clinicians. First, the variability in surrogates' role preferences suggest that physicians should develop the ability to elicit surrogates' preferred role in decision making. Existing evidence suggests that physician rarely inquire about surrogates' preferred role in decision making (26). Second, physicians should develop comfort with having different levels of authority for decisions based on the surrogates' preferences and the clinical context.

TABLE 4. MULTIVARIATE ANALYSIS OF PREDICTORS ASSOCIATED WITH PREFERRED DECISIONAL RESPONSIBILITY

Predictor	Regression Coefficient	95% Confidence Interval	P Value
Male sex	0.72	0.02 to 1.41	0.043
Increasing age	−0.10	−0.21 to 0.01	0.073
African American race	0.12	−0.93 to 1.16	0.825
Catholic religion	−1.05	−1.75 to −0.35	0.003
Increasing PPOS (higher patient orientation score)	0.18	−0.18 to 0.53	0.325
Have d/w patient treatment preferences	−0.49	−1.16 to 0.19	0.158
Increasingly agree that physician can predict death	−0.04	−0.26 to 0.18	0.719
Increasingly agree that physician not always honest	−0.04	−0.26 to 0.18	0.724
Increasing physician trust	−0.57	−1.05 to −0.10	0.018
Increasing QOC score	0.00	−0.12 to 0.12	0.968

Definition of abbreviations: d/w = discussed with; PPOS = Patient Provider Orientation Scale; QOC = quality of communication. Boldface type indicates covariates that were significantly associated with surrogate preference for higher degree of decisional control.

We wish to highlight our opinion that surrogates' preferred level of control over value-laden decisions is one among several considerations that are ethically relevant to the question of what role they should ultimately play in life support decisions. At least four other considerations are ethically relevant, including considerations of distributive justice, physicians' obligations to act for the good of their patients and to respect patients' previously stated treatment preferences, and cultural norms around medical decision making. Occasionally, one or more of these considerations may require physicians to assume more control over value-laden decisions than surrogates prefer. This step should not be taken without justification, however, because recent evidence suggest that surrogates are at higher risk of adverse psychiatric outcomes from the ICU experience when there is discordance between their preferred and actual role in decision making (4). We propose that physicians' default approach to value-laden decision-making should be to tailor their role to the preferences of the surrogate, and to depart from this only if compelled to by a stronger ethical obligation, such as those outlined above.

We also found that male subjects and non-Catholic subjects preferred significantly more control for value-laden decisions compared with female subjects and Catholic subjects, respectively. No previous studies of surrogate decision makers have examined these associations. However, several studies of patients (rather than surrogates) suggest that male sex is associated with a preference for less control in medical decision making (27–30). This discrepancy raises the possibility that the association between sex and decisional authority may be modified by whether one is acting as a surrogate or one is making decisions for oneself. The precise mechanism to explain this is unclear. Both associations should be interpreted with caution pending further research to replicate the finding and understand the explanatory mechanisms.

A somewhat surprising finding from this study is that a small minority of surrogates (12%) wished to retain final authority for the decision concerning antibiotic selection. However, these findings are qualitatively similar to those of other studies examining adult patients' preferred level of control over biomedical decisions. For example, in a large, population-based survey study in Canada, Levinson and colleagues found that a substantial minority of subjects disagreed with the statement that general medical decisions should be left up to doctors (31). Two studies using a similar metric to that used in the present study also found that a small minority of subjects desired to retain final control over largely technical medical judgments, including the decision about which antibiotic to use to treat an infection (30, 32). In our experience, very few physicians involve surrogates in seemingly routine clinical decisions in ICUs, and doing so would be logistically complex. Because this is the first study documenting this finding in surrogates, additional research is warranted to confirm it and to understand the reasons that underlie this preference.

This study has several strengths. We studied surrogates of actual patients at high risk of death who were actively engaged in the process of surrogate decision making; we speculate that this increases the likelihood that participants' responses represent considered judgments about their preferred role in decision making. The sample was diverse in terms of ethnicity, level of education, and prior experience as a surrogate. We used a validated outcome measure of preferences for decisional control. We also used two conceptually distinct types of decisions to assess how control preferences vary according to the nature of the decision.

This study has several limitations. We used written clinical scenarios to illustrate the types of decisions under study.

Although we believe this is a methodological improvement over prior research that did not specify the type of decision under study, it is possible that surrogates' stated role preferences could differ in actual clinical situations. We found that nearly two-thirds of the subjects screened positive for possible depression, which is a higher prevalence than other studies in ICUs. This may be due to our use of a brief depression screening tool to measure depressive symptoms rather than a longer instrument, which maximized sensitivity at the expense of specificity. The study was conducted in one region of the United States and therefore may not be generalizable to areas in which there are different cultural perspectives on the physician–family relationship. Because we studied only surrogates of patients at high risk of death, it is possible that their attitudes may not represent those of surrogates of patients in less dire clinical circumstances. Nonetheless, it is arguably most important to understand the preferences of surrogates actively facing difficult decisions about life-sustaining treatment.

In conclusion, this report provides new empirical data to inform the debate about how physicians should approach the process of surrogate decision making in ICUs. The vast majority of surrogates wish to be active participants in the decision-making process, although not all wish to have complete authority for the final decision. The variability in surrogates' role preferences highlights the need to assess surrogate decision makers' preferences and to tailor the decision-making process accordingly.

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