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

Sara K. Johnson, MD¹; Christopher A. Bautista², Seo Yeon Hong³; Lisa Weissfeld, PhD⁴; Douglas B. White, MD, MAS⁵

¹ Department of Medicine, University of California, San Francisco

² University of California San Francisco, School of Medicine

^{3, 4} Department of Biostatistics, University of Pittsburgh

⁵ Department of Critical Care Medicine, University of Pittsburgh Medical Center

Word count: 3098

Running title: Surrogates' Preferred Level of Control of Life Support Decisions

Sources of Support: Dr. White was supported by a Greenwall Foundation Bioethics Faculty Scholars Award and a Paul Beeson Career Development Award from the National Institute on Aging.

The funding sources had no role in the study design or conduct; data collection, management, analysis, interpretation; or manuscript preparation, review, or approval. The authors have no conflicts of interest or financial disclosures.

Some of the descriptive data from this study was previously presented in poster format: Bautista CA, Evans LR, Luce JM, Lo B, White DB. *Are physicians' recommendations to limit life support beneficial or burdensome? Bringing empirical data to the debate.* Society of General Internal Medicine (SGIM) National Meeting. Miami, FL. May 2009.

Corresponding author: Douglas B. White, MD, MAS University of Pittsburgh Medical Center Department of Critical Care Medicine 3550 Terrace St. Scaife Hall, Room 608 HPU010604 Pittsburgh, PA 15261 United States Tel: 412-864-3757 Fax: 412-647-8060 Email: whitedb@upmc.edu



ABSTRACT

Background: 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.

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

Design: 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.

Results: The majority of surrogates (55%, 127/230, [95% CI: 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 to 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 ICU physician, male gender, and non-Catholic religious affiliation.

Conclusion: 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 to technical, medical judgments. Low trust in physicians is associated with surrogates preferring more control of life-support decisions.

Key words: surrogate decision making, critical care, ethics, decisions, end-of-life care

INTRODUCTION

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

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 versus 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 intensive care units 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 APACHE II score >25. The surrogates of patients dying within 48 hours of initiating mechanical ventilation were not eligible per IRB 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 (QOC) 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 (GLHC), 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 (PHQ-2) [16], along with measurement of dispositional optimism by means of the Revised Life Orientation Test (LOTR) [17]. Higher LOTR scores indicate more dispositional optimism. Subjects also completed validated measures of health literacy (S-TOFHLA) [18] and view of patient and doctor roles (Patient Provider Orientation Scale). The Patient Provider Orientation Scale (PPOS) is a mean score ranging from 1-6, with higher scores reflecting a preference towards a more "patient-centered" approach to healthcare compared to a more "biomedical model" [19]. A measure of the patients' pre-hospitalization function was obtained using the KATZ ADL 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 about [wording the doctor's opinion" (see Figure 1). The other 3 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 to 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 where 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, gender, 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 (see Figure 2).

Subjects' demographic characteristics and a summary of other covariates are shown in <u>Table 1</u>. Over 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 PHQ-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 (QOC) 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 <u>Table 2</u>.

Figure 3 summarizes surrogates' preferred role in the value-laden life support decision. The majority of surrogates (55%, 127/230, [95% CI: 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 treatments. 90% of subjects wished to receive the physician's recommendation (defined as selecting response choices 2-5 (**Figure** <u>3</u>).

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 to 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 6 covariates to be significant: younger age, male gender, non-catholic religion, a higher PPOS score, a lower physician trust score, and a lower score for quality of physician communication. <u>Table 3</u> 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 consider 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 gender, and being a member of a non-catholic religion (<u>Table 4</u>).

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 thought. For example, Heyland and colleagues found that only 22% percent 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 Anderson elicited surrogates' perspectives on decision-making in general, combining both end-oflife 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 to more technical medical decisions. Azoulay and colleagues studied a gualitatively 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 death, which are gualitatively 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 US 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 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 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 amongst 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.

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 to 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 gender is associated with a preference for less control in medical decision-making [27-30]. This discrepancy raises the possibility that the association between gender 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, though 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.

References

- 1. Abbott, K.H., et al., *Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support.* Crit Care Med, 2001. **29**(1): p. 197-201.
- 2. Azoulay, E., et al., *Prevalence and factors of intensive care unit conflicts: the conflicus study.* Am J Respir Crit Care Med, 2009. **180**(9): p. 853-60.
- 3. Shalowitz, D.I., E. Garrett-Mayer, and D. Wendler, *The accuracy of surrogate decision makers: a systematic review.* Arch Intern Med, 2006. **166**(5): p. 493-7.
- 4. Gries, C.J., et al., *Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU.* Chest, 2010. **137**(2): p. 280-7.
- 5. Azoulay, E., et al., *Risk of post-traumatic stress symptoms in family members of intensive care unit patients.* Am J Respir Crit Care Med, 2005. **171**(9): p. 987-94.
- 6. Kirchhoff, K.T., et al., *The vortex: families' experiences with death in the intensive care unit.* Am J Crit Care, 2002. **11**(3): p. 200-9.
- 7. Thompson, B.T., et al., *Challenges in end-of-life care in the ICU: statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: executive summary.* Crit Care Med, 2004. **32**(8): p. 1781-4.
- 8. Heyland, D.K., et al., *Decision-making in the ICU: perspectives of the substitute decision-maker.* Intensive Care Med, 2003. **29**(1): p. 75-82.
- 9. Anderson, W.G., et al., *Passive decision-making preference is associated with anxiety and depression in relatives of patients in the intensive care unit.* J Crit Care, 2009. **24**(2): p. 249-54.
- 10. Evans, L.R., et al., *Surrogate decision-makers' perspectives on discussing prognosis in the face of uncertainty.* Am J Respir Crit Care Med, 2009. **179**(1): p. 48-53.
- 11. Curtis, J.R., et al., *Patient-physician communication about end-of-life care for patients with severe COPD.* Eur Respir J, 2004. **24**(2): p. 200-5.
- 12. Dugan, E., F. Trachtenberg, and M.A. Hall, *Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession.* BMC Health Serv Res, 2005. **5**: p. 64.
- 13. Breen, C.M., et al., *Conflict associated with decisions to limit life-sustaining treatment in intensive care units.* J Gen Intern Med, 2001. **16**(5): p. 283-9.
- 14. Wallston, K.A., *The validity of the multidimensional health locus of control scales.* J Health Psychol, 2005. **10**(5): p. 623-31.
- 15. Wallston, K.A., et al., *Does God determine your health?* Cognitive Therapy and Research, 1999. **23**(2): p. 131-142.
- 16. Kroenke, K., R.L. Spitzer, and J.B. Williams, *The Patient Health Questionnaire-2: validity of a two-item depression screener.* Med Care, 2003. **41**(11): p. 1284-92.
- 17. Scheier, M.F., C.S. Carver, and M.W. Bridges, *Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the Life Orientation Test.* J Pers Soc Psychol, 1994. **67**(6): p. 1063-78.
- 18. Baker, D.W., et al., *Development of a brief test to measure functional health literacy.* Patient Educ Couns, 1999. **38**(1): p. 33-42.
- 19. Krupat, E., et al., *The practice orientations of physicians and patients: the effect of doctorpatient congruence on satisfaction.* Patient Educ Couns, 2000. **39**(1): p. 49-59.
- 20. Janz, N.K., et al., *Patient-physician concordance: preferences, perceptions, and factors influencing the breast cancer surgical decision.* J Clin Oncol, 2004. **22**(15): p. 3091-8.
- 21. Degner, L.F., J.A. Sloan, and P. Venkatesh, *The Control Preferences Scale*. Can J Nurs Res, 1997. **29**(3): p. 21-43.
- 22. Azoulay, E., et al., Half the family members of intensive care unit patients do not want to share in the decision-making process: a study in 78 French intensive care units. Crit Care Med, 2004. **32**(9): p. 1832-8.

- 23. Ferrand, E., et al., *Withholding and withdrawal of life support in intensive-care units in France: a prospective survey. French LATAREA Group.* Lancet, 2001. **357**(9249): p. 9-14.
- 24. Vincent, J.L., *Forgoing life support in western European intensive care units: the results of an ethical questionnaire.* Crit Care Med, 1999. **27**(8): p. 1626-33.
- 25. White, D.B., et al., Are physicians' recommendations to limit life support beneficial or burdensome? Bringing empirical data to the debate. Am J Respir Crit Care Med, 2009. **180**(4): p. 320-5.
- 26. White, D.B., et al., *Expanding the paradigm of the physician's role in surrogate decision-making: an empirically derived framework.* Crit Care Med, 2010. **38**(3): p. 743-50.
- 27. Arora, N.K. and C.A. McHorney, *Patient preferences for medical decision making: who really wants to participate?* Med Care, 2000. **38**(3): p. 335-41.
- 28. Degner, L.F. and J.A. Sloan, *Decision making during serious illness: what role do patients really want to play?* J Clin Epidemiol, 1992. **45**(9): p. 941-50.
- 29. Hamann, J., et al., *Participation preferences of patients with acute and chronic conditions.* Health Expect, 2007. **10**(4): p. 358-63.
- 30. Stiggelbout, A.M. and G.M. Kiebert, A role for the sick role. Patient preferences regarding information and participation in clinical decision-making. CMAJ, 1997. **157**(4): p. 383-9.
- 31. Levinson, W., et al., *Not all patients want to participate in decision making. A national study of public preferences.* J Gen Intern Med, 2005. **20**(6): p. 531-5.
- 32. Garfield, S., et al., *Can patients' preferences for involvement in decision-making regarding the use of medicines be predicted?* Patient Educ Couns, 2007. **66**(3): p. 361-7.



Covariate	N=230 (%)	
Age	Mean 46.5, SD 14.6	
Gender (%)		
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)	
Post-graduate, 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	Mean 20.9, SD 9.3	
score indicates stronger belief in God's role in		
health)		
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	Mean 3.9. SD 0.9	
more patient-centered)		
PHO2 Score (%)		
Indicates depression	156 (68.1)	
Past Surrogate Experience (%)		
Yes	119 (52.0)	

TABLE 1-Surrogate Characteristics

Characteristics	N=175		
Age	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 (upon enrollment)	Mean 29 (SD 4.6)		
Primary Service			
Non-surgical	98 (59%)		
Surgical	67 (41%)		
DNR order upon enrollment	28 (16%)		
Withdrawal of Life-sustaining Therapy	67 (38%)		
Mortality	75 (43%)		

TABLE 2: Patient Characteristics



FIGURE 1: Vignettes and Response elements

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 2: Flow diagram describing the enrollment of surrogates



FIGURE 3: Surrogates' Preferred Involvement in Life Support Decision and Antibiotic Decision

TABLE 3: Unadjusted Odds Ratios for Independent Surrogate Variables Associated with Surrogate Preference for Decisional Authority (1=surrogate decides, 0=MD involved in decision-making)

Independent Variable	OR [95% Confidence Interval]		
Older Age (per 5 yr intervals of increasing	0.91 [0.83-0.99]		
age)			
Male Gender	1.96 [1.10-3.48]		
Hispanic	0.99 [0.47-2.07]		
Race			
Caucasian v. non-Caucasian	0.79 [0.45-1.40]		
African American v. non-AA	1.62 [0.65-4.00]		
Increasing Level of Education	1.07 [0.78-1.46]		
(5 categories)			
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 v. non-spouse	0.63 [0.34-1.14]		
Child v. non-child	1.12 [0.65-1.92]		
Parent v. non-parent	1.04 [0.45-2.39]		
Increasing STOFHLA Score	1.08 [0.85-1.38]		
(by 5 point intervals)			
Increasing GLHC summary Score by 5 point	0.92 [0.80-1.06]		
intervals (indicating stronger belief in God's			
role in health)			
Increasing LOTR score (more optimistic) by 5	0.85 [0.61-1.20]		
point intervals			
Increasing PPOS score, by 1 point (more	1.45 [1.09-1.92]		
patient-centered)	1 10 [0 (2 1 02]		
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	0.586 [0.342-1.005]		
treatment preferences	0.95 [0.71, 1.01]		
MD can predict if pt will live or die (increasing	0.85 [0.71-1.01]		
agreement on 1-o scale)	1.05 [0.90, 1.24]		
increasing agreement on 1-o scale that	1.05 [0.89-1.24]		
members the truth about prognosis			
Increasing agreement on 1.6 scale that it is	0.00[0.70,1.41]		
important physician is honest shout prognosis	0.99 [0.70-1.41]		
Increasing agreement on 1.6 scale that prefer	0.88[0.72, 1.07]		
MD does not discuss chance of survival	0.00[0./2-1.0/]		
Increasing conflict with MD on 0-10 scale	1 09 [0 97-1 24]		
Surrogate felt discriminated against in the past	2 24 [0 58-8 66]		
12 months	2.27 [0.30-0.00]		
Increasing MD trust score by 5 point	0 57 [0 40-0 80]		
intervals	v.s/ [v. t v-v.ov]		
Increasing OOC score by 5 point intervals	0 90 [0 83-0 98]		
mercusing 200 score by 5 point mer vais	0.00_0.00_0		

TABLE 4: Multivariate Analysis of Predictors Associated with Preferred Decisional Responsibility

Predictor	Regression Coefficient	95% Confidence Interval	P-value
Male gender	0.72	0.02 to 1.41	0.043
Increasing Age	-0.10	-0.21 to 0.01	0.073
AA 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 MD can predict death	-0.04	-0.26 to 0.18	0.719
Increasingly agree that MD not always honest	-0.04	-0.26 to 0.18	0.724
Increasing MD trust	-0.57	-1.05 to -0.10	0.018
Increasing QOC score	0.00	-0.12 to 0.12	0.968

-0.26 -1.05 to -0.. -0.12 to 0.12