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NEUROCRITICAL CARE SOCIETY

ORIGINAL WORK

Predictors of Surrogate Decision Makers Selecting Life-Sustaining Therapy for Severe Acute Brain Injury Patients: An Analysis of US Population Survey Data

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Abstract

Background: Patients with a severe acute brain injury admitted to the intensive care unit often have a poor neurological prognosis. In these situations, a clinician is responsible for conducting a goals-of-care conversation with the patient's surrogate decision makers. The diversity in thought and background of surrogate decision makers can present challenges during these conversations. For this reason, our study aimed to identify predictive characteristics of US surrogate decision makers' favoring life-sustaining treatment (LST) over comfort measures only for patients with severe acute brain injury.

Methods: We analyzed data from a cross-sectional survey study that had recruited 1588 subjects from an online probability-based US population sample. Seven hundred and ninety-two subjects had randomly received a hypothetical scenario regarding a relative intubated with severe acute brain injury with a prognosis of severe disability but with the potential to regain some consciousness. Seven hundred and ninety-six subjects had been randomized to a similar scenario in which the relative was projected to remain vegetative. For each scenario, we conducted univariate analyses and binary logistic regressions to determine predictors of LST selection among available respondent characteristics.

Results: 15.0% of subjects selected LST for the severe disability scenario compared to 11.4% for the vegetative state scenario ($p = 0.07$), with those selecting LST in both groups expressing less decisional certainty. For the severe disability scenario, independent predictors of LST included having less than a high school education (adjusted OR = 2.87, 95% CI = 1.23–6.76), concern regarding prognostic accuracy (7.64, 3.61–16.15), and concern regarding the cost of care (4.07, 1.80–9.18). For the vegetative scenario, predictors included the youngest age group (30–44 years, 3.33, 1.02–10.86), male gender (3.26, 1.75–6.06), English as a second language (2.94, 1.09–7.89), Evangelical Protestant (3.72, 1.28–10.84) and Catholic (4.01, 1.72–9.36) affiliations, and low income (< $25 K).

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Conclusion: Several demographic and decisional characteristics of US surrogate decision makers predict LST selection for patients with severe brain injury with varying degrees of poor prognosis. Surrogates concerned about the cost of medical care may nevertheless be inclined to select LST, albeit with high levels of decisional uncertainty, for patients projected to have severe disabilities.

Keywords: Intensive care units, Decision making, Palliative care, Family, Choice behavior, Brain injuries

Introduction

Many patients admitted to intensive care units (ICUs) with severe acute brain injury (SABI, e.g., ischemic stroke, intracerebral hemorrhage, traumatic brain injury, subarachnoid hemorrhage, hypoxic–ischemic encephalopathy, etc.) are projected to have poor neurologic prognoses despite aggressive management [1, 2]. Surrogate decision makers work with medical teams to exercise substituted judgment on behalf of these patients to make decisions regarding the continuation of life-sustaining treatment (LST), including tracheostomy and/or gastrostomy tube placement, versus transitioning to comfort measures only (CMO) [3–5]. Despite how common these decisions are for neurologic patients in ICUs, studies examining characteristics of surrogates that predict their choices in these situations have been limited [6–9]. There have been urgent calls in the neurocritical care community for additional research on factors that may influence surrogates to choose LST or CMO [10, 11], with hopes that such understanding may facilitate improvements in ICU family support.

A recently conducted general US population survey characterized surrogates for hypothetical, intubated older adult SABI patients with varying degrees of poor prognosis into distinct groups based on their top concerns regarding goals-of-care decision making [12]. The initial analysis of these data assigned respondents into "decisional groups," each with different top concerns. For respondents who were given a prognostic scenario of a patient projected to have severe disability—but with the possibility of regaining limited consciousness—four distinct, separate decisional groups emerged with relative concerns regarding [1] patient's advanced age, [2] family agreement on a decision, [3] prognostic accuracy, and [4] cost of care. For a different cohort of respondents who were given a scenario of a patient projected to remain in a vegetative state, the identified groups included the four listed above, as well as a separate, fifth group relatively concerned about religious beliefs. In addition to characterizing participants into decisional groups, the survey also asked participants to indicate whether they would personally select LST versus CMO for the hypothetical patients and their level of decisional certainty.

The purpose of this follow-up analysis was to discover independent predictors of LST selection among potential SABI surrogate decision makers in a variety of prognostic scenarios. Both traditional demographic and socioeconomic predictors, as well as the decisional group memberships as described above in the previous study, were included as potential predictors.

Methods

This study is a secondary analysis of a dataset from a previously published online cross-sectional survey, conducted from February 18 to 29 in 2016 among the US population age 30 years or older [12]. The study was approved by the Yale Human Investigation Committee.

Dataset Description

A summary of relevant details regarding how the dataset was obtained and initially analyzed is provided below [12]. For survey sampling, 1588 adults 30 years or older were recruited from GfK (now Ipsos) KnowledgePanel. KnowledgePanel is a probability-based online panel designed to cover 97% of US households by utilizing address-based sampling and providing panel members who do not have computers or Internet service with both [13]. The study had a 44.6% response rate among the KnowledgePanel members contacted for participation.

Study participants were randomized to one of the two survey versions. Both surveys asked a participant to consider an 85-year-old, previously healthy, close family member admitted to an ICU following a severe intracerebral hemorrhage who remains intubated and poorly responsive despite two weeks of care without limitations. Although the two surveys included very similar language regarding the hypothetical patient's injury, each presented a different prognostic outcome. One version stated that the patient would most likely remain unresponsive, with a small but unlikely chance that the patient could gradually recover the ability to speak, eat, recognize others, and/or travel in a wheelchair with time (the "severe disability" survey, SD, Supplement 1). The other version stated a less common but more severe scenario that the patient would remain bedbound and unresponsive long-term with certainty (the "vegetative state" survey, VS, Supplement 1). For both surveys, participants were then informed that they would be responsible for guiding the medical team to pursue tracheostomy and gastrostomy placement (LST) or CMO for the patient.

Following the clinical scenario, participants for both surveys answered a series of Best–Worst Scaling questions designed to elicit their top decision-making concerns regarding the goals-of-care decision [14, 15]. Participants were also asked whether they would ultimately favor LST or CMO for the patient, certainty in their decision, and demographic information.

Latent class analysis was performed on the Best–Worst Scaling data from the two surveys separately, with data undergoing iterative proportional fitting to weight and further match the sample geodemographically to the US population age 30 years and older [16]. For participants taking the SD survey, this analysis yielded four distinct decisional groups: (1) those relatively concerned with their loved one being too old to be kept alive and severely disabled; (2) those relatively concerned with family agreement on goals of care; (3) those relatively concerned that the doctor's prognosis may be incorrect; and (4) those relatively concerned with paying for long-term care. For participants taking the VS survey, the latent class analysis yielded five distinct decisional groups: Four of the groups were similar to those for the SD survey, with a fifth group relatively concerned about acting according to religious beliefs. The result of this original analysis allowed each survey participant in the dataset to be assigned as a member of a decisional group that best fits their survey responses.

Sample

For the analysis described in this manuscript, all survey participants in the original dataset described above were included.

Variables

For each survey participant, information on age, gender, race, education, household size, household Internet access, region of residence, marital status, employment status, and annual income was obtained directly from KnowledgePanel records. All other demographic variables for participants were obtained directly from the survey. Each participant's decisional group assignment from the original study was considered as a predictor variable, in addition to the demographic data listed above. Participants who had been randomized to the SD survey were labeled as a member of one of the four decisional groups resulting from the original survey analysis, while those randomized to the VS survey were each labeled as a member of one of the five groups that that survey analysis revealed.

Age data were available via KnowledgePanel both as a continuous variable and as categorical age groups. Household size and years in the USA were reported as continuous variables. All other variables were categorical.

Outcome

The primary outcome of this study was participant selection of LST versus CMO for the randomized hypothetical scenario. A secondary outcome was the participant's self-reported certainty in their selection measured as a categorical variable with participants choosing "Very Certain," "Certain," "Uncertain," or "Very Uncertain."

Statistical Analysis

Data from the SD survey and the VS survey were analyzed separately. Weights included from the original analyses were incorporated into all analyses. For each survey, univariate associations of demographic characteristics and decisional group assignments with LST versus CMO selection were first tabulated, using standard methods for continuous and categorical variables. Variables with p-values 0.1 or lower in the univariate analyses were then included in subsequent binary logistic regressions exploring independent predictors of LST selection for each of the two prognostic scenarios. Only those surveys with complete data were included in the binary regressions. All analyses were conducted using SAS software v14 (SAS Institute Inc., Cary, NC).

With regard to sample size, this dataset was powered for the previously published initial latent class analyses, and the post hoc analyses in this manuscript were exploratory.

Results

Survey Randomization

Table 1 summarizes demographic information for the SD and VS survey participants. There were no demographic differences between the participants randomized to either survey. The samples for both survey versions reflected the geodemographic distribution of the US population aged 30 years or older after weighting.

Summary of Survey Outcomes

Table 1 also summarizes LST versus CMO selection among the SD and VS survey participants. A higher percentage of participants presented with the SD scenario selected LST (104 of 785 participants answering the survey question, weighted percentage = 15.0%) compared to participants presented with the VS scenario (81/793, 11.4%, $p = 0.07$).

For the SD survey, a higher percentage of participants selecting LST reported being "Uncertain" or "Very uncertain" with their decision (55/104, 51.3%) compared to the percentage among participants selecting CMO (71/681, 10.1%, $p < 0.0001$). This difference was also observed

Table 1 Comparison of participants randomized to the severe disability versus vegetative state surveys

	Severe disability	Vegetative state	*p*
n	792	796	
Data provided by KnowledgePanel			
Age, mean (SD), years	53.6 (14.3)	53.3 (14.2)	0.73
Age groups, *n* (%)			
30–44	160 (31.8)	149 (30.6)	0.87
45–59	272 (33.9)	272 (35.1)	
60 +	360 (34.3)	375 (34.3)	
Gender, *n* (%), male	369 (47.7)	385 (47.7)	1.00
Race, *n* (%)			
White, non-Hispanic	593 (67.5)	605 (67.6)	1.00
Other	199 (32.5)	191 (32.4)	
Education, *n* (%)			
Less than high school	72 (11.9)	64 (11.7)	1.00
High school	242 (29.9)	269 (30.0)	
Some college	227 (26.1)	200 (26.1)	
Bachelor's degree or higher	251 (32.1)	263 (32.2)	
Household size, mean (SD), persons	2.61 (1.4)	2.59 (1.6)	0.79
Household head, *n* (%), yes	698 (85.9)	719 (87.2)	0.54
Housing type, *n* (%)			
One-family house	623 (75.2)	626 (74.8)	0.98
Apartment building	132 (19.8)	134 (19.9)	
Other: mobile home, boat, etc.	37 (5.1)	36 (5.3)	
Household Internet access, *n* (%), yes	621 (76.7)	657 (76.6)	0.98
Region of residence, *n* (%)			
Northeast	147 (18.1)	147 (18.1)	1.00
Midwest	189 (21.5)	199 (21.5)	
South	294 (37.2)	280 (37.3)	
West	162 (23.2)	170 (23.1)	
Marital status, *n* (%)			
Married or living with partner	507 (64.4)	517 (63.0)	0.83
Widowed	58 (5.9)	54 (5.3)	
Divorced or separated	123 (14.1)	119 (15.5)	
Never married	104 (15.5)	106 (16.2)	
Employment status, *n* (%)			
Working	399 (55.9)	385 (56.0)	0.29
Not working—retired	243 (23.6)	261 (24.0)	
Not working—disabled	55 (5.9)	66 (8.0)	
Not working—other	95 (14.5)	84 (12.1)	
Income, *n* (%)			
Under $24,999	139 (17.5)	135 (17.6)	0.86
$25,000–$74,999	315 (38.2)	328 (38.4)	
$75,000–$149,999	279 (35.9)	262 (34.4)	
$150,000 or more	59 (7.8)	71 (9.2)	
Data obtained by survey			
Years in the USA, *n*	783.5	785.8	
Years, mean (SD)	51.5 (16.5)	51.2 (16.2)	0.77
First language, *n*	789.5	793.2	
Non-English, *n* (%)	36 (7.0)	40 (7.6)	0.63
Religion, *n*	786.7	785.8	

Table 1 (continued)

	Severe disability	Vegetative state	*p*
Evangelical Protestant, *n* (%)	100 (12.5)	98 (11.1)	0.71
Catholic	178 (22.6)	197 (26.0)	
Other Christian	282 (33.5)	278 (32.9)	
Other faith	75 (10.2)	71 (9.7)	
Not affiliated with religion	153 (21.0)	146 (20.4)	
Frequency of religious services, *n*	788	788	
Once a year or less, *n* (%)	351 (45.5)	343 (44.7)	0.48
A few times a year	140 (18.5)	123 (16.0)	
A few times a month	69 (8.3)	73 (10.1)	
Once a week or more	228 (27.7)	249 (29.2)	
Prior experience caring for disabled, *n*	790	793	
Yes, *n* (%)	209 (23.3)	220 (25.0)	0.47
Previously made similar decision, *n*	785	786	
Yes, *n* (%)	289 (31.8)	290 (33.3)	0.55
Outcome of prior similar decision, *n*	286	288	
LST, *n* (%)	35 (14.9)	26 (11.4)	0.32
Goals-of-care decision in survey			
Decision for patient in survey, *n*	785	793	
LST, *n* (%)	104 (15.0)	81 (11.4)	0.07
Certainty of decision, *n*	791	796	
Very certain, *n* (%)	389 (45.7)	418 (48.1)	0.72
Certain	273 (37.8)	267 (36.3)	
Uncertain/Very uncertain	129 (16.5)	111 (15.6)	

All counts in the table are raw survey numbers, while all percentages factor in the weights assigned to each participant

All means are weighted means

For "Data obtained by survey" and "Goals-of-care decision in survey," the *n* listed next to each variable heading are the number of participants responding to each question

LST selection of life-sustaining treatment by survey participant, *SD* standard deviation

among responses to the VS survey (40/81, 46.0% vs. 69/712, 11.4%, $p < 0.0001$).

Univariate Analysis of Severe Disability Survey

Table 2 lists univariate comparisons of participant characteristics between those choosing LST versus CMO for the SD survey. Participants choosing LST tended to be less likely to identify as non-Hispanic white (55.1% vs. 69.7%, $p = 0.01$), less educated (e.g., less than high school education, 24.2% vs. 9.7%, $p = 0.001$), and less likely to have Internet access (67.8% vs. 78.3%, $p = 0.03$).

The distribution of survey participants' membership in decisional groups (i.e., concern regarding patient age, family agreement, prognostic accuracy, and cost of care) differed significantly between those selecting LST versus CMO ($p < 0.0001$), with 43.2% of participants selecting LST being in the "prognostic accuracy" concern group versus 16.9% of those selecting CMO. Of note, 28.2% of participants selecting LST were in the "cost-of-care" concern group, versus 16.6% of those selecting CMO.

Binary Logistic Regression of Severe Disability Survey

Table 3 contains the results of a binary logistic regression model conducted to identify independent predictors of LST selection among SD survey participants. Having less than a high school education was predictive of LST selection in comparison to having a bachelor's degree or higher (adjusted odds ratio = 2.87, 95% confidence interval = 1.23–6.76). In contrast, the confidence intervals for the odds ratios for race and household Internet access did not meet thresholds for significance.

Affiliation with the "prognostic accuracy" decisional concern group was a strong predictor of LST selection (7.64, 3.61–16.15), compared with affiliation with the reference group most concerned that the patient in the hypothetical scenario was too old to live with significant disability. Affiliation with the "cost-of-care" decisional concern group was also predictive of LST selection in comparison with the same reference group (4.07, 1.80–9.18).

Table 2 Univariate comparison of participants selecting life-sustaining therapy (LST) versus comfort measures only (CMO) for the severe disability survey (n = 785)

	LST	CMO	p
n (%)	104 (15.0)	681 (85.0)	
Data provided by KnowledgePanel			
Age, mean (SD), years	53.4 (14.2)	53.6 (14.3)	0.16
Age groups, *n* (%)			
30–44	29 (43.2)	131 (30.0)	0.05
45–59	36 (30.5)	233 (34.5)	
60 +	39 (27.1)	317 (35.4)	
Gender, *n* (%), male	53 (52.5)	311 (46.6)	0.30
Race, *n* (%)			
White, non-Hispanic	64 (55.1)	525 (69.7)	0.01
Other	40 (44.9)	156 (30.3)	
Education, *n* (%)			
Less than high school	18 (24.2)	53 (9.7)	0.001
High school	31 (29.3)	209 (30.0)	
Some college	29 (23.6)	195 (26.5)	
Bachelor's degree or higher	26 (22.8)	224 (33.8)	
Household size, mean (SD), persons	2.59 (1.7)	2.61 (1.4)	0.06
Household Internet access, *n* (%), yes	70 (67.8)	547 (78.3)	0.03
Region of residence, *n* (%)			
Northeast	18 (14.4)	128 (18.8)	0.15
Midwest	19 (17.8)	168 (22.0)	
South	48 (48.3)	243 (35.3)	
West	19 (19.5)	142 (23.9)	
Marital status, *n* (%)			
Married or living with partner	65 (65.3)	438 (64.4)	0.54
Widowed	5 (4.2)	52 (6.1)	
Divorced or separated	16 (11.9)	106 (14.5)	
Never married	18 (19.5)	85 (14.8)	
Employment status, *n* (%)			
Working	59 (60.5)	337 (55.2)	0.15
Not working—retired	23 (16.5)	218 (25.0)	
Not working—disabled	5 (4.0)	50 (6.3)	
Not working—other	17 (19.0)	76 (13.6)	
Income, *n* (%)			
Under $24,999	22 (22.9)	116 (16.6)	0.19
$25,000–$74,999	44 (42.4)	266 (37.7)	
$75,000–$149,999	31 (29.7)	247 (37.2)	
$150,000 or more	7 (5.1)	52 (8.4)	
Data obtained by survey			
Years in the USA, *n*	104	675	
Years, mean (SD)	51.2 (16.2)	51.5 (16.5)	0.07
First language, *n*	104	680	
Non-English, *n* (%)	7 (11.0)	29 (6.3)	0.20
Religion, *n*	103	679	
Evangelical Protestant, *n* (%)	20 (16.8)	79 (11.9)	0.07
Catholic	26 (25.4)	151 (22.2)	
Other Christian	41 (39.1)	238 (32.4)	
Other faith	7 (8.9)	67 (10.5)	
Not affiliated with religion	9 (9.8)	144 (23.1)	
Frequency of religious services, *n*	104	678	
Once a year or less, *n* (%)	35 (33.7)	315 (47.7)	0.12
A few times a year	19 (21.7)	120 (17.9)	
A few times a month	11 (9.8)	57 (8.0)	
Once a week or more	39 (34.8)	186 (26.3)	
Prior experience caring for disabled, *n*	103	681	
Yes, *n* (%)	28 (26.5)	180 (22.9)	0.52
Previously made similar decision, *n*	104	675	
Yes, *n* (%)	29 (26.3)	260 (32.9)	0.20
Outcome of prior similar decision, *n*	29	257	
LST, *n* (%)	17 (67.7)	18 (7.4)	< 0.0001
Decisional group, *n*	104	681	
Concern regarding patient age, *n* (%)	15 (12.0)	256 (38.6)	< 0.0001
Concern regarding family agreement	17 (16.6)	198 (16.9)	
Concern regarding prognostic accuracy	49 (43.2)	119 (16.9)	
Concern regarding cost of care	23 (28.2)	108 (16.6)	

All counts in the table are raw survey numbers, while all percentages factor in the weights assigned to each participant. All means are weighted means

For "Data obtained by survey," the n listed next to each variable heading are the number of participants responding to each question/exercise

Outcome of prior similar decision = for participants indicating that they had previously made a similar decision, selection of LST vs. CMO for that prior decision

CMO comfort measures only, *LST* life-sustaining treatment, *SD* standard deviation

Univariate Analysis of Vegetative State Survey

Table 4 lists univariate comparisons of participant characteristics between those choosing LST versus CMO for the VS survey. The group of respondents selecting LST for this clinical scenario was younger (mean age 49.3 years, standard deviation 16.3; vs 53.9 years, 16.0, $p = 0.01$), had a higher percentage of males (68.9% vs. 45.2%, $p < 0.0001$) and non-native English speakers (15.7% vs. 7.0%, $p = 0.04$), and had lived a lower mean number of years in the USA (46.2 years, 20.8 vs. 51.9, 18.31, $p = 0.01$). Those selecting LST also differed from those selecting CMO with respect to employment status (e.g., working, 61.1% vs. 55.1%, $p < 0.03$) and income (e.g., under $25 K, 28.9% vs. 15.8%).

The distribution of survey participants' membership in decisional groups (i.e., concern regarding patient age, family agreement, prognostic accuracy, religious beliefs, and cost of care) also differed significantly between those selecting LST vs. CMO ($p = 0.01$). Of note, 44.4% of participants selecting LST were affiliated with the "prognostic accuracy" concern group, versus 27.1% of those selecting CMO. Furthermore, 18.9% of participants

Table 3 Binary logistic regression for predictors of life-sustaining therapy (LST) selection among the severe disability survey participants

	Odds Ratio	95% Confidence Interval
Age groups		
60 +		
45–59	1.16	0.60–2.22
30–44	2.07	0.70–6.11
Race		
Other		
White, non-Hispanic	0.67	0.39–1.15
Education		
Bachelor's degree or higher		
Some college	1.13	0.57–2.25
High school	1.23	0.58–2.20
Less than high school	2.88	1.23–6.76
Household size	1.10	0.91–1.33
Household Internet access		
No	1.75	0.94–3.25
Years in the USA	1.00	0.96–1.03
Religion, OR		
Not affiliated with religion		
Evangelical Protestant	2.00	0.73–5.48
Catholic	1.91	0.72–5.05
Other Christian	1.84	0.76–4.50
Other faith	1.14	0.39–3.33
Decisional group		
Concern regarding patient age		
Concern regarding family agreement	1.57	0.67–3.68
Concern regarding prognostic accuracy	7.64	3.61–16.15
Concern regarding cost of care	4.07	1.80–9.18

All percentages are weighted percentages

Demographic variables in Table 2 that had $p \leq 0.10$ were included in this analysis

CI confidence interval, *LST* life-sustaining therapy, *OR* odds ratio

selecting LST were affiliated with the "cost-of-care" concern group, versus 12.1% of those selecting CMO.

Binary Logistic Regression of Vegetative State Survey

Table 5 contains the results of a binary logistic regression model conducted to identify independent predictors of LST selection among VS survey participants. Covariates that were predictive of LST selection were the youngest age group (ages 30–44, 3.33, 1.02–10.86, compared to ages 60 +), male gender (3.27, 1.76–6.06), English as a second language (2.94, 1.10–7.89), and Evangelical (3.72, 1.28–10.84) and Catholic (4.01, 1.72–9.36) Christian denominations (in comparison with the "Not affiliated with religion" level). Of note, reporting an annual income of under $25 K was predictive of LST selection, in comparison to all higher income levels.

Overall, affiliations with the five decisional groups were not significant predictors of LST selection in the VS survey multivariate analysis, although affiliation with the "prognostic accuracy" decisional concern group trended toward being predictive of LST (adjusted OR 2.35, 0.94–5.93).

Discussion

When asked to make a goals-of-care decision on behalf of a hypothetical intubated older adult relative with an SABI projected to have severe disability, respondents were more inclined to select tracheostomy and feeding tube placement if they had less than a high school education or belonged in the decisional groups concerned with prognostic accuracy or cost of care. When asked to make a similar decision for a relative projected to remain in a vegetative state, respondents were more inclined toward selecting LST if they were young, were male, spoke English as a second language, were Evangelical Christian or Catholic, or had a low annual income. Overall, respondents selecting LST for either prognostic scenario were more uncertain regarding their decisions compared to those selecting CMO, a finding likely reflective of these respondents having higher levels of conflict among their top concerns in decision making.

These findings, focused on surrogate-level decisions for critically ill brain-injured patients, complement prior research on patient-level demographic predictors of high-intensity care at the end of life. Prior studies examining patient-level variables have reported that male gender, religious affiliation, and lower levels of education are all associated with a patient receiving increased intensity of end-of-life care or expressing a personal preference for such care [17–20]. Of note, prior studies have repeatedly described non-white individuals as less likely to prefer or experience care limitations in scenarios of general severe illness [17, 18, 21–25] and specifically SABI [26–30]. While the exact reasons for these observations have been debated [25, 31–33], this study suggests that in the USA, they may be related to socioeconomic, educational, or religious factors among surrogates that are stronger predictors of LST selection than race/ethnicity itself.

The fact that this dataset includes not only traditional demographics but also information about top decisional concerns distinguishing groups of surrogates from one another, provides several additional insights, particularly in the common situation where a brain-injured patient could likely survive an ICU stay but be left with severe functional disability. By far, the strongest predictor of LST selection in this scenario is a surrogate worrying that the neurologic prognosis given by the medical team

Table 4 Univariate comparison of participants selecting life-sustaining therapy (LST) versus comfort measures only (CMO) for the vegetative state survey (n = 793)

	LST	CMO	*p*
n (%)	81 (11.4)	712 (88.6)	
Data provided by KnowledgePanel			
Age, mean (SD), years	49.31 (16.3)	53.93 (16.0)	0.01
Age groups, *n* (%)			
30–44	24 (44.4)	124 (28.6)	0.01
45–59	32 (34.4)	240 (35.5)	
60 +	25 (22.2)	348 (35.9)	
Gender, *n* (%), male	51 (68.9)	333 (45.2)	< 0.0001
Race, *n* (%)			
White, non-Hispanic	54 (60.0)	549 (68.7)	0.17
Other	27 (40.0)	163 (31.3)	
Education, *n* (%)			
Less than high school	9 (14.4)	54 (11.3)	0.67
High school	34 (33.3)	235 (29.6)	
Some college	18 (25.6)	181 (26.2)	
Bachelor's degree or higher	20 (26.7)	242 (32.8)	
Household size, mean (SD), persons	2.49 (1.6)	2.60 (2.2)	0.56
Household Internet access, *n* (%), yes	62 (74.4)	593 (77.1)	0.60
Region of residence, *n* (%)			
Northeast	19 (22.2)	127 (17.5)	0.12
Midwest	24 (25.6)	175 (21.2)	
South	30 (41.1)	249 (36.8)	
West	8 (11.1)	161 (24.6)	
Marital status, *n* (%)			
Married or living with partner	48 (57.8)	468 (63.8)	0.05
Widowed	5 (4.4)	49 (5.4)	
Divorced or separated	10 (11.1)	108 (16.1)	
Never married	18 (26.7)	87 (14.7)	
Employment status, *n* (%)			
Working	43 (61.1)	340 (55.1)	0.03
Not working—retired	19 (17.8)	241 (24.8)	
Not working—disabled	13 (14.4)	53 (7.3)	
Not working—other	6 (6.7)	78 (12.8)	
Income, *n* (%)			
Under $24,999	24 (28.9)	109 (15.8)	0.03
$25,000–$74,999	34 (40.0)	294 (38.5)	
$75,000–$149,999	18 (24.4)	243 (36.2)	
$150,000 or more	5 (6.7)	66 (9.5)	
Data obtained by survey			
Years in the USA, *n*	78	706	
Years, mean (SD)	46.24 (20.8)	51.93 (18.3)	0.01
First language, *n*	79	711	
Non-English, *n* (%)	9 (15.7)	31 (7.0)	0.04
Religion, *n*	80	708	
Evangelical Protestant, *n* (%)	13 (14.6)	85 (10.6)	0.07
Catholic	29 (37.1)	167 (24.5)	
Other Christian	20 (25.8)	258 (34.0)	
Other faith	9 (11.2)	62 (9.5)	

Table 4 (continued)

	LST	CMO	*p*
Not affiliated with religion	9 (12.4)	136 (21.5)	
Frequency of religious services, *n*	79	707	
Once a year or less, *n* (%)	28 (36.4)	313 (45.6)	0.58
A few times a year	15 (18.2)	108 (15.7)	
A few times a month	8 (11.4)	65 (10.1)	
Once a week or more	28 (34.1)	221 (28.6)	
Prior experience caring for disabled, *n*	80	710	
Yes, *n* (%)	21 (23.6)	198 (25.1)	0.74
Previously made similar decision, *n*	79	704	
Yes, *n* (%)	24 (31.8)	266 (33.2)	0.74
Outcome of prior similar decision, *n*	24	264	
LST, *n* (%)	11 (53.6)	15 (6.0)	< 0.0001
Decisional group, *n*	81	712	
Concern regarding prognostic accuracy, *n* (%)	37 (44.4)	189 (27.1)	0.01
Concern regarding family agreement	9 (11.1)	167 (22.8)	
Concern regarding patient age	9 (13.3)	158 (21.1)	
Concern regarding religion	12 (13.3)	125 (16.7)	
Concern regarding cost of care	14 (18.9)	73 (12.1)	

All counts in the table are raw survey numbers, while all percentages factor in the weights assigned to each participant

All means are weighted means

For "Data obtained by survey," the n listed next to each variable heading are the number of participants responding to each question/exercise

Outcome of prior similar decision = for participants indicating that they had previously made a similar decision, selection of LST vs. CMO for that prior decision

CMO comfort measures only, *LST* life-sustaining treatment, *SD* standard deviation

is inaccurate, a finding that complements prior qualitative and mixed-methods studies [9, 34–36]. However, the finding that the group of surrogates most concerned with the cost of continued care was paradoxically predisposed toward selecting LST highlights the complexity of surrogate goals-of-care decisions in brain injury. Of note, the "cost-of-care" decisional group in the original SD survey study exhibited difficulty with prioritizing distinct concerns during the original Best–Worst Scaling exercise and tended to report all concerns of relatively similar priority [12]. This observation allows for speculation that the relative prioritization of the cost of care among members of this group, compared to the other decisional groups, may in part be a byproduct of general uncertainty regarding decisional priorities and that their relative inclination to select LST is a manifestation of such.

This study has limitations [12]. With a 44.6% completion rate among invited survey respondents, the original study sample may be subjected to non-response sampling bias. The risk of this bias was mitigated by the use of a well-established probability sample of the US population that was further matched to a US geodemographic sample by sample weighting.

Another limitation of the study is the use of surveys presenting hypothetical scenarios. As described in the original survey publication, the surveys underwent extensive content revisions and cognitive testing among ICU surrogates, ICU decision-making experts and lay members of the New Haven community to ensure both their readability and experiential realism. Surveys introducing hypothetical scenarios have been extensively used to elicit important insights into ICU surrogate decision making [6, 37–39]. However, the surveys do rely on the reader's understanding of described situations without the ability to ask clarification questions. The patient–physician interaction plays a key role in goals-of-care conversations. It is possible the lack of conversation between the participant and a provider in a face-to-face discussion with concordant review of pertinent images such as MRI or CT scans contributed to the uncertainty reported by some participants. Finally, the hypothetical scenarios used in the survey refer to a healthy older adult with no comorbidities and may limit the generalizability of results in situations where patients are younger and/or medical comorbidities severe enough to influence prognosis are present.

Conclusion

In the USA, several demographic and decisional characteristics of surrogate decision makers predict their

Table 5 Binary logistic regression for predictors of life-sustaining therapy (LST) selection among the vegetative state survey participants

	Odds Ratio	95% Confidence Interval
Age groups		
60 +		
45–59	1.86	0.78–4.39
30–44	3.33	1.02–10.86
Gender		
Male	3.27	1.76–6.06
Marital status		
Married or living with partner		
Widowed	0.85	0.23–3.12
Divorced or separated	0.69	0.29–1.65
Never married	1.33	0.64–2.79
Employment status,		
Working		
Not working—retired	1.36	0.58–3.17
Not working—disabled	1.52	0.59–3.88
Not working—other	0.34	0.11–1.01
Income		
Under $24,999		
$25,000–$74,999	0.41	0.18–0.96
$75,000–$149,999	0.26	0.10–0.66
$150,000 or more	0.24	0.07–0.80
Years in the USA	1.00	0.97–1.03
English Language,		
Non-English	2.94	1.10–7.89
Religion		
Not affiliated with religion		
Evangelical Protestant	3.72	1.28–10.84
Catholic	4.01	1.72–9.36
Other Christian	2.63	1.00–6.90
Other faith	2.67	0.80–8.93
Decisional group		
Concern regarding patient age		
Concern regarding prognostic accuracy	2.35	0.94–5.93
Concern regarding family agreement	0.77	0.25–2.38
Concern regarding religion	0.95	0.33–2.76
Concern regarding cost of care	1.09	0.35–3.339

Demographic variables in Table 4 that had $p \leq 0.10$ were included in this analysis

CI confidence interval, *LST* life-sustaining therapy, *OR* odds ratio

selection of life-sustaining therapy (LST) for patients with severe brain injury with varying degrees of poor prognosis, including concern regarding prognostic accuracy, low educational level, religious affiliation, and income. Surrogates concerned about the cost of medical care may actually be inclined to select LST, albeit with prominent levels of decisional uncertainty, for patients projected to have severe disability. Recognition of surrogates' expressed or silent concerns about impending financial toxicity [40, 41] and their complicated relationship with goals-of-care decision-making preferences may be an important first step for clinicians and researchers in steering many of these difficult shared decisions toward patient-centeredness.

Future directions based on the results of this project may include developing educational programs for clinicians centered on assessing which latent class analysis group a decision maker most closely aligns with and conducting goals-of-care discussions with the inclinations of that group in mind. Such programs could help prepare clinicians to navigate situations where surrogates who initially seem to be requesting LST nevertheless express strong concern about the cost of long-term care, as these surrogates may be at increased risk for future financial toxicity and/or decisional regret. Extending time allotted for family meetings and allowing such surrogates more time for decision making may help them work through initial their uncertainty, which they may or may not choose to openly express.

Supplementary Information

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Author's Contributions

DYH and LF were involved in conceptualization; AKK, DBW, RGH, and KNS were involved in methodology; DYH, SK, and MS contributed to formal analysis and investigation; AG and AS contributed to writing—original draft preparation; AG, ALS, AKK, SK, MS, HH, DBW, RGH, KNS, LF, and DYH contributed to writing—review and editing; DYH, DBW, RGH, KNS, and LF were involved in funding acquisition; DYH, HH, KNS, and LF were involved in resources; and DYH, HH, KNS, and LF were involved in supervision.

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Conflict of interest
The authors declare that they have no conflict of interest.

Ethical Approval
This study was approved by the Yale Human Investigation Committee (protocols #1406014207 and #1505015893). Because this is a minimal risk study, participants indicated consent by completing the survey after being presented with an introductory page that included all of the essential components of informed consent.

Informed Consent
Informed consent was obtained from all individual participants included in the study.

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