Patients' priorities for treatment decision making during periods of incapacity: quantitative survey

ANNETTE RID, M.D.,[1] ROBERT WESLEY, PH.D.,[2] MARK PAVLICK, R.N., M.S.,[3]
SHARON MAYNARD, M.D.,[4] KATALIN ROTH, J.D., M.D.,[5] AND DAVID WENDLER, PH.D.[6]

[1]Department of Social Science, Health & Medicine, King's College London, London, United Kingdom
[2]Biostatistics & Clinical Epidemiology Service, The Clinical Center, National Institutes of Health, Bethesda, Maryland
[3]St. Elizabeth's Hospital, Washington, District of Columbia
[4]Nephrology Division, University of South Florida Morsani College of Medicine, Lehigh Valley Health Network, Allentown, Pennsylvania
[5]Department of Medicine, George Washington University Medical Faculty Associates, Washington, District of Columbia
[6]Department of Bioethics, The Clinical Center, National Institutes of Health, Bethesda, Maryland

ABSTRACT

Objective: Clinical practice aims to respect patient autonomy by basing treatment decisions for incapacitated patients on their own preferences. Yet many patients do not complete an advance directive, and those who do frequently just designate a family member to make decisions for them. This finding raises the concern that clinical practice may be based on a mistaken understanding of patient priorities. The present study aimed to collect systematic data on how patients prioritize the goals of treatment decision making.

Method: We employed a self-administered, quantitative survey of patients in a tertiary care center.

Results: Some 80% or more of the 1169 respondents (response rate = 59.8%) ranked six of eight listed goals for treatment decision making as important. When asked which goal was most important, 38.8% identified obtaining desired or avoiding unwanted treatments, 20.0% identified minimizing stress or financial burden on their family, and 14.6% identified having their family help to make treatment decisions. No single goal was designated as most important by 25.0% of participants.

Significance of Results: Patients endorsed three primary goals with respect to decision making during periods of incapacity: being treated consistent with their own preferences; minimizing the burden on their family; and involving their family in the decision-making process. However, no single goal was prioritized by a clear majority of patients. These findings suggest that advance care planning should not be limited to documenting patients' treatment preferences. Clinicians should also discuss and document patients' priorities for how decisions are to be made. Moreover, future research should evaluate ways to modify current practice to promote all three of patients primary goals for treatment decision making.

KEYWORDS: Advance care planning, Advance directive, Surrogate decision making, Incapacitated patients, Patient priorities

INTRODUCTION

Clinical practice relies on patient-designated and next-of-kin surrogates to make treatment decisions for incapacitated patients. Surrogates are instructed to make decisions based on a patient's advance directive (AD). In the absence of an AD, surrogates are asked to make the treatment decision they think the patient would have made if he or she had the capacity to do so. This approach aims to promote patient autonomy by basing decisions on the patient's own treatment preferences (Buchanan & Brock, 1989,

Address correspondence and reprint requests to: Annette Rid, Department of Social Science, Health & Medicine, King's College London, East Wing Building, Strand, London WC2R 2LS, United Kingdom. E-mail: annette.rid@kcl.ac.uk

Beauchamp & Childress, 2013). Yet many patients do not complete an AD, and those who do frequently just designate a family member to make decisions for them (Connors et al., 1995; Danis et al., 1996; Teno et al., 1997; Fagerlin & Schneider, 2004; Perkins, 2007). Furthermore, data suggest that many patients want their surrogates to have considerable leeway when making treatment decisions (Sehgal et al., 1992; Kelly et al., 2012; Creswell, 2013).

According to some commentators, these findings suggest that current practice is based on a mistaken understanding of patients' priorities. For example, some regard low completion rates of ADs as a sign that patients do not prioritize "micromanaging" their treatment in the event of incapacity (Hawkins et al., 2005). Many of these commentators claim that patients are more concerned with *who* makes decisions for them rather than *which* treatments they receive (Burt, 2005; Hawkins et al., 2005; Winzelberg et al., 2005; Perkins, 2007; Berger et al., 2008; Torke et al., 2008; Sudore & Fried, 2010; Halpern, 2012; McMahan et al., 2012; Schenker et al., 2014). Others hold that patients prioritize minimizing the burden on their loved ones over being treated consistent with their own preferences and values (Perkins, 2007; Berger et al., 2008; Torke et al., 2008; Sudore & Fried, 2010; White & Arnold, 2011; Halpern, 2012; Kelly et al., 2012). These claims imply that clinical practice should be modified to reflect patients' actual priorities (Fagerlin & Schneider, 2004; Burt, 2005; Winzelberg et al., 2005; Perkins, 2007; Berger et al., 2008; Torke et al., 2008; Sudore & Fried, 2010; White & Arnold, 2011; Halpern et al., 2013; Schenker et al., 2014). Yet, a literature search found little empirical data regarding which goals patients prioritize in the event of incapacity (see Appendix 1).[1]

Several personal essays and qualitative studies explore the decision-making priorities of individuals, but this information is difficult to generalize (High, 1988; Lynn, 1991; Moore et al., 2003; Eliott & Olver, 2007). Other studies address related questions, including patients' preferences for specific treatments or treatment outcomes (Garrett et al., 1993; Phillips et al., 1996; Pearlman et al., 2000; Fried et al., 2002; Sudore et al., 2010; Halpern et al., 2013); patients' goals of care (Rosenfeld et al., 2000; Fried & Bradley, 2003; Kaldjian et al., 2008; Fried et al., 2011; Case et al., 2013); factors patients consider important at the end of life (Mead et al., 1995; Singer et al., 1998; 1999; Steinhauser et al., 2000; Patrick et al., 2001; Hawkins et al., 2005; Heyland et al., 2006; Kaldjian et al., 2008); and how best to identify or document these factors (Doukas & Gorenflo, 1993;

Ditto et al., 1996; Emanuel, 2008; Kirchhoff et al., 2010; Scheunemann et al., 2012), as well as patients' preferences for how treatment decisions should be made (Kelly et al., 2012; McMahan et al., 2013; Daveson et al., 2013). In contrast, we could find no data that explicitly asked patients to indicate, in the event of incapacity, which goal or goals for treatment decision making they prioritize. The present study aims to address this gap in the literature by offering the first quantitative data on patients' priorities for how treatment decisions are made in the event of incapacity. These data provide an opportunity to assess what modifications, if any, are needed to ensure that clinical practice accurately reflects patient priorities.

METHODS

Ethics Statement

The George Washington University and Medical Center Institutional Review Board and the National Institutes of Health (NIH) Office of Human Subjects Protections judged this anonymous survey to be exempt from regulation under the U.S. Code of Federal Regulations (CFR §46.101). With no legal requirement to obtain written informed consent or to obtain ethical approval for modifying the informed consent process, we decided it was ethically appropriate to obtain verbal consent from each individual respondent, considering that the questionnaire was anonymous and posed no more than the minimal risks of boredom or anxiety from answering the questions. Furthermore, even if the study had been covered by the regulations, we would not have been legally required to obtain written informed consent on the grounds that "the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context" (CFR §46.117). Each respondent's completed questionnaire served as written documentation of his or her consent to participate in the survey. Potential respondents received an information sheet that informed them of the voluntary nature of their participation, that declining would have no impact on their clinical care, and that they could skip any questions and stop at any time (see Appendix 2). All respondents gave oral informed consent to participate. Consistent with U.S. regulations (CFR §46.101), this consent procedure was not approved by a research ethics committee.

Survey

Based on the widely accepted principles of respect for autonomy and beneficence (Buchanan & Brock, 1989; Beauchamp & Childress, 2013; Rid, 2010), as

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well as the existing literature (High, 1988; Lynn, 1991; Sehgal et al., 1992; Garrett et al., 1993; Connors et al., 1995; Mead et al., 1995; Danis et al., 1996; Phillips et al., 1996; Teno et al., 1997; Singer et al., 1998; 1999; Pearlman et al., 2000; Steinhauser et al., 2000; Patrick et al., 2001; Fried et al., 2002; Moore et al., 2003; Fagerlin & Schneider. 2004; Burt, 2005; Hawkins et al., 2005; Winzelberg et al., 2005; Heyland et al., 2006; Eliott & Olver, 2007; Perkins, 2007; Berger et al., 2008; Kaldjian et al., 2008; Torke et al., 2008; Rid & Wendler, 2010; Sudore & Fried, 2010; White & Arnold, 2011; Halpern, 2012; Kelly et al., 2012; McMahan et al., 2012; Halpern et al., 2013; Schenker et al., 2014; Creswell, 2013), the authors drafted a survey on patients' goals for treatment decision making in the event of incapacity. After numerous rounds of revision, the draft survey was evaluated by four focus groups of 4−10 participants each and revised following each session. The survey then underwent cognitive pretesting with six patients and two academics, using a "think-aloud" approach to ensure that the questions were understood as intended and revised as necessary. Finally, behavioral pretesting with nine patients and two academics was employed to ensure that the survey could be implemented successfully.

The final survey contained 41 questions covering four domains: (1) personal characteristics, (2) personal experience with and planning for decisional incapacity, (3) goals and priorities regarding treatment decision making during periods of incapacity, and (4) views on new approaches. Here we report the results from domains 1−3 (see Appendix 2 for verbatim questions).

To ensure that the questions were relevant to a broad range of patients from different clinics and units, including those with very different health situations, and to avoid the difficulties associated with projecting one's preferences and values into a distant and emotionally uncertain future (Ditto et al., 2005), we asked respondents to indicate their priorities in a scenario involving decisional incapacity following a car accident ("Please consider the following case: You are in a bad car accident. You are unconscious."). The scenario was described to elicit respondents' preferences for circumstances in which doctors have no clear recommendation to make as to which option would best promote the clinical interests of the patient. This aspect of the scenario was emphasized by a statement that "even your doctors do not know what is best medically."

Outcomes

We asked respondents to indicate the personal importance of eight possible goals for treatment decision making during periods of incapacity. We also asked respondents which goal they regarded as most important, how confident they were about this judgment, and how they would make tradeoffs between key goals (Table 3). Cognitive pretesting revealed that the distinction between receiving and avoiding specific treatments (e.g., resuscitation) and achieving certain goals of care (e.g., avoiding pain) was not significant for respondents. In addition, many respondents better understood questions that addressed their preferences for specific treatments. Hence, the decision-making goal of being treated consistent with one's preferences and values was phrased in terms of "getting the treatments I want" and "avoiding the treatments I do not want."

Predictors

We examined the influence of numerous factors on patients' priorities: sociodemographic and personal characteristics, medical background, previous advance care planning, and personal experience with helping to make treatment decisions for an incapacitated adult (see Tables 1 and 2).

Study Population and Conduct of Survey

The survey was conducted from September of 2009 to August of 2011 at the George Washington University Hospital, a large tertiary care center in Washington, D.C., and at George Washington University Medical Faculty Associates, a multispecialty physician practice. Patients were recruited from six units or clinics so as to capture the views of as broad a range of patients as possible: general medicine, emergency department (ED), dialysis clinic, pain clinic, geriatrics, and oncology. Trained research assistants approached all patients upon entry, with the exception of patients for whom the responsible clinician regarded a 30-minute survey as overly burdensome. The research assistants explained the survey and were available to answer questions. Inclusion criteria were: (1) inpatient or outpatient, (2) 18 years of age or older, and (3) ability to complete a written survey in English. Nonresponders were asked to provide information on their age, gender, and race/ethnicity. The survey was self-administered and anonymous and took an average of 25 minutes to complete.

Data Analysis

Data were entered by the statistician (RW), two research assistants, and one of the PIs (AR). A random sample of 84 surveys (60 for respondents, 24 for nonrespondents) was recoded for external validation. The error rate of 0.25% was judged to be acceptable.

Data analysis was conducted using Stata software (v. SE12.0). We utilized *t* tests, standard ANOVA, or their nonparametric alternatives to compare continuous or ordinal outcomes. Paired continuous or ordinal outcomes were compared using either the paired *t* test or the signed rank test. McNemar's test was employed to compare paired dichotomous outcomes. For contingency tables we employed four different test approaches: (1) Fisher's exact test or χ^2 test for two unordered factors; (2) the Kruskal–Wallis nonparametric test for one ordered and one unordered factor (or Wilcoxon rank sum when the unordered factor had two categories); (3) Cuzick's nonparametric extension of the Wilcoxon rank-sum test when both factors were ordered; and (4) Fisher's exact test or multivariate logistic regression to evaluate possible predictors of dichotomous outcomes.

To evaluate patterns of how respondents ranked the eight goals for treatment decision making, we used hierarchical agglomerative clustering with average linkage and a binary similarity coefficient—equaling the proportion of matches for the eight goals between two respondents—with the aim of classifying respondents into two or three groups (Hastie et al. 2009). We dichotomized respondents' rankings of the goals prior to clustering. To assess the continued significance of univariately significant predictors on outcomes with three or more unordered categories, we used multinomial (polytomous) logistic regression to control for other predictors in the model, using the likelihood ratio test (LRT) (Hosmer & Lemeshow, 2013).

Given the large sample sizes for most analyses, a *p* value less than 0.01 (two-tailed, unless noted otherwise) was considered statistically significant. In the following, we report and discuss especially noteworthy findings. The complete analyses—including analyses of the results as a function of age, race, health status, and all other patient characteristics found in Tables 1 and 2—are given in Appendix 3.

RESULTS

Study Population

Of the 1955 patients who were invited, 1169 agreed to participate (overall response rate of 59.8%). In the ED, 723 patients agreed to participate (response rate = 52.3%), while 567 patients agreed to participate in the five other participating units (response rate = 77.8%). Information on the recruitment site was missing for five responders. A total of 34 surveys were excluded due to a lack of substantive answers. The 1135 surveys employed for analysis came from

a broad range of respondents, including great diversity in current health, quality of life, and age (Tables 1 and 2). There was no significant difference in gender between respondents and nonrespondents. The response rate was higher among younger patients in the ED ($p < 0.001$). Furthermore, Asians and whites in the ED, and Hispanics and whites in non-ED units, were more likely to respond ($p < 0.001$ in each case, comparing combined groups).

Goals for Treatment Decision Making

We asked respondents to consider a scenario in which they were unconscious following a car accident and there were two treatment options. One option was to receive medical treatment with "a low chance of making you better" and "a good chance of making you unable to think clearly and of making you permanently dependent on machines to stay alive." The other option was that "your doctors can make you comfortable and allow you to die." We then asked respondents to rate the personal importance of eight goals for treatment decision making in this scenario.

Six of the eight listed goals were ranked as moderately or extremely important by 80% or more of respondents (Table 3). Cluster analysis revealed two groups of respondents (Figure 1). The vast majority of respondents ($n = 992$) fell into a group that attributed high importance to the goals of getting desired and avoiding unwanted treatments as well as goals relating to their family, thereby essentially reflecting the rankings of the whole sample ("self- and family-regarding" group). A small number of respondents ($n = 42$) fell into a group that primarily focused on the goals of receiving the treatments they wanted and avoiding the treatments they did not want ("self-regarding" group). Significantly more respondents in the second group had a fair or poor relationship with their family compared to the first group (Wilcoxon rank-sum test, $p = 0.005$). There were no other significant differences between the two groups.

Priorities

When asked which of the eight goals for treatment decision making was most important to them, 27.7% identified getting desired treatments and 11.1% identified avoiding unwanted treatments; 12.9 and 7.1% gave priority respectively to minimizing stress and minimizing financial burden on their family; 10.5% prioritized involving their family in making decisions; 4.1% prioritized being treated consistent with their family's preferences; and 25.0% of respondents stated that no goal was most important to them. The vast majority of respondents (96.1%) who identified one goal as most important to them were "pretty" or "very" sure of this priority.

Table 1. *Demographics and personal characteristics of survey respondents (N = 1135 usable respondents; missing* n *per question in the right column)*

Demographics and Personal Characteristics		n (%)*	Missing n (%)
Demographics			
Age	Mean (*SD*)	42.2 (17.2)	21 (1.9)
	Range	18–95	
	<35 yrs	468 (42.0)	
	35–49 yrs	293 (26.3)	
	50–64 yrs	227 (20.4)	
	≥65 yrs	126 (11.3)	
Gender	Female	644 (57.7)	19 (1.7)
	Male	472 (42.3)	
Place of birth	DC, Maryland, Virginia°°	407 (37.4)	46 (4.1)
	Other states and territories°°	554 (50.9)	
	Non-U.S.#	128 (11.8)	
Residence in DC area	≤5 yrs	350 (31.7)	30 (2.6)
	>5 yrs	755 (68.3)	
Race / Ethnicity	Black or African American	472 (42.0)	10 (0.9)
	Native American (American Indian or Alaskan Native)	6 (0.5)	
	Asian	50 (4.4)	
	Native Hawaiian or Pacific Islander	2 (0.2)	
	Hispanic	60 (5.3)	
	White	517 (46.0)	
	Multiple races	18 (1.6)	
Education	Graduate school	292 (25.7)	0 (0)
	College	383 (33.7)	
	High school	430 (37.9)	
	Grade school	25 (2.2)	
	Less than grade school	5 (0.4)	
Income	<$25,000	217 (21.1)	106 (9.3)
	$25,00–49,999	224 (21.8)	
	$50,000–99,999	258 (25.1)	
	$100,000–249,000	243 (23.6)	
	≥$250,000	87 (8.5)	
Personal characteristics			
Marital status	Single, never married	585 (51.8)	5 (0.4)
	Married	313 (27.7)	
	Partnered	51 (4.5)	
	Separated	26 (2.3)	
	Divorced	108 (9.6)	
	Widowed	47 (4.2)	
Relationship with family	Excellent	481 (42.8)	10 (0.9)
	Very good	354 (31.5)	
	Good	203 (18.0)	
	Fair	61 (5.4)	
	Poor	22 (2.0)	
	No family	4 (0.4)	
Religiousness	Not religious at all	226 (20.2)	18 (1.6)
	A little religious	282 (25.3)	
	Moderately religious	397 (35.6)	
	Very religious	212 (19.0)	

* Totals may not sum to 100% due to rounding.
°° Total of 49 states/territories (includes Puerto Rico, Guam, Virgin Islands, Northern Mariana Islands); ≥5 respondents from 29 states.
A total of 56 countries; ≥5 respondents from 6 countries.

Older respondents were more likely to prioritize receiving treatment consistent with their preferences and less likely to prioritize minimizing stress on their family (Kruskal–Wallis test, $p < 0.001$). Respondents with very good or excellent family relationships gave more priority to involving their family in decision making than those who were less close to their families. The latter group cared more about

Table 2. *Health background and relevant experience of survey respondents (N = 1135 usable respondents; missing* n *per question in the right column)*

Health Background and Relevant Experience			n (%)*	Missing n (%)
Health background				
Unit or clinic	Emergency department		697 (61.4)	4 (0.4)
	Medicine		130 (11.5)	
	Rheumatology		73 (6.4)	
	Oncology		62 (5.5)	
	Geriatrics		61 (5.4)	
	Dialysis		58 (5.1)	
	Pain		50 (4.4)	
Current QoL	Excellent		266 (23.7)	14 (1.2)
	Very good		422 (37.6)	
	Good		311 (27.7)	
	Fair		99 (8.8)	
	Poor		23 (2.1)	
Current health	Excellent		174 (15.5)	14 (1.2)
	Very good		360 (32.1)	
	Good		361 (32.2)	
	Fair		178 (15.9)	
	Poor		48 (4.3)	
Regular doctor	No		259 (22.9)	4 (0.4)
	Yes: visits in past 12 months	0	44 (5.1)	1 (0.1)
		1	190 (21.8)	
		2−5	478 (54.9)	
		6−10	103 (11.8)	
		>10	56 (6.4)	
Advance care planning				
Advance care planning	No AD or DPA		795 (71.2)	18 (1.6)
	DPA only		56 (5.0)	
	AD only		82 (7.3)	
	AD and DPA		184 (16.5)	
	If DPA only <u>or</u> AD and DPA: person named	Spouse/partner	105 (43.8)	0 (0)
		Other family member	115 (47.9)	
		Friend	15 (6.3)	
		Someone else	5 (2.1)	
Personal experience				
Personal contact with incapacitated adults	None		537 (48.0)	17 (1.5)
	Just a little		297 (26.6)	
	A moderate amount		157 (14.0)	
	A lot		127 (11.4)	
Personal experience with treatment decision making°°	No		774 (68.3)	4 (0.4)
	Yes: for . . .	Spouse/partner	56 (n/a)	
		Other family member	256 (n/a)	
		Friend	61 (n/a)	
	Yes: as part of. . .	Role as health care professional	26 (n/a)	

AD = advance directive, DPA = durable power of attorney.
* Totals may not sum to 100% due to rounding.
°° Multiple answers possible.

being treated consistent with their own preferences (Kruskal−Wallis test, $p = 0.002$). Multinomial logistic regression showed that increased age and family relationships were strong predictors of patients' priorities even when controlling for other statistically significant factors (age: $p = <0.001$; family relationship: $p =$ 0.0021). Respondents' current health and quality of life had no effect on their priorities.

Tradeoffs Between Goals

We asked respondents to consider two options for making treatment decisions in the event of incapacity:

Table 3. *Goals, priorities, and tradeoffs in treatment decision making (N = 1135 usable respondents unless otherwise noted; missing* n *per question in the right column)*

Goals, Priorities and Tradeoffs		n (%)*		Missing n (%)
Goals#				
		Important	Not important	
1. Getting the txs I would want		1053 (95.5)	50 (4.5)	32 (2.8)
2. Avoiding txs I would **not** want		953 (88.8)	120 (11.2)	62 (5.5)
3. Having my family help my doctors make tx decisions for me		957 (87.6)	136 (12.4)	42 (3.7)
4. Minimizing stress on my family		953 (87.4)	137 (12.6)	45 (4.0)
5. Not being a financial burden on my family		919 (84.7)	166 (15.3)	50 (4.4)
6. Getting the txs my family thinks I would want		872 (80.9)	206 (19.1)	57 (5.0)
7. Not being a financial burden on society		582 (53.7)	501 (46.3)	52 (4.6)
8. Avoiding excessive stress on the doctors and nurses		520 (47.9)	566 (52.1)	49 (4.3)
Priorities°				
No goal "most important"		252 (25.0)		24 (2.1)
Some goal "most important"°°		758 (75.0)		
1. Getting the txs I would want		280 (27.7)		
2. Minimizing stress on my family		130 (12.9)		
3. Avoiding txs I would **not** want		112 (11.1)		
4. Having my family help my doctors make tx decisions for me		106 (10.5)		
5. Not being a financial burden on my family		72 (7.1)		
6. Getting the txs my family thinks I would want		41 (4.1)		
7. Avoiding excessive stress on the doctors and nurses		9 (0.9)		
8. Not being a financial burden on society		8 (0.8)		
Certainty about most important goal§	Very sure	460 (61.9)		15 (1.3)
	Pretty sure	254 (34.2)		
	Pretty unsure	10 (1.4)		
	Very unsure	19 (2.6)		
Tradeoffs between goals				
Family stress versus own tx preferences	Priority to receiving the txs I want	657 (69.1)		184 (16.2)
	Priority to reducing stress on family	134 (14.1)		
	Uncertain	160 (16.8)		

tx = treatment, txs = treatments.
* Totals may not sum to 100% because of rounding.
# The original questionnaire used a 4-point Likert-type scale: (1) extremely important, (2) moderately important, (3) just a little important, (4) not important at all. Responses are summarized as important (1 + 2) and not important (3 + 4).
° Only includes responses if all eight goals were ranked in the previous question ($n=1034$). Missing $n = 24$ for the present question.
°° The following percentages refer to those respondents who ranked all eight goals in the previous questions ($n = 1010$).
§ Only includes responses if one goal was marked as "most important" in the previous question ($n = 758$). Missing $n = 15$ for the present question.

"The first way is more likely to give you the treatment you want, but it is very stressful for your family. The second way is less stressful for your family, but it is less likely to give you the treatment you want." In response, 69.1% preferred the first option, while 14.1% preferred the second option. Among the 122 patients who had previously identified minimizing stress on their family as their primary goal, 42.6% chose option 1 and 27.9% option 2. Respondents who described themselves as strongly religious were more likely to prioritize option 2 (17.3% vs. 10.5% for the less religious group, $p = 0.002$). No other factors predicted respondents' tradeoffs between these goals.

DISCUSSION

Key Findings

Current clinical practice assumes that, during periods of decisional incapacity, patients prioritize being treated based on their own preferences and values (Buchanan & Brock, 1989; Beauchamp & Childress, 2013). Yet many commentators argue that this assumption is mistaken. Some argue that patients care more about involving their family and loved ones in decision making than about being treated consistent with their own preferences and values. Others hold that patients prioritize reducing the
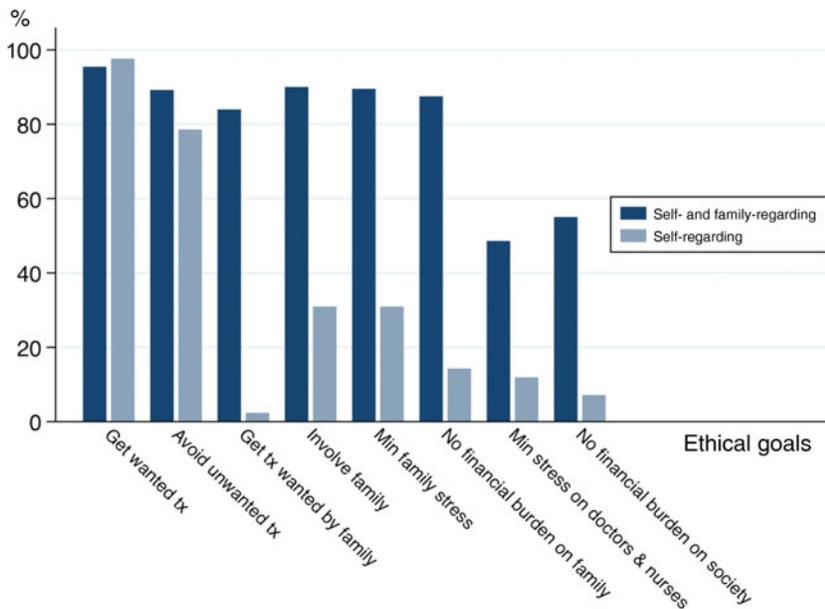
Fig. 1. Cluster analysis of patients' rankings of the ethical goals for treatment decision making. Patient group 1 ($n = 992$) endorsing "self- and family-regarding" goals. Patient group 2 endorsing "self-regarding" goals ($n = 42$). Patients' rankings were dichotomized as extremely or moderately important versus less than moderately important. The analysis was confined to the $n = 1034$ patients who had ranked the importance of all eight goals. tx = treatment; min = minimize.

burden on their families. These claims suggest that, in order to promote patients' actual priorities, clinical practice may need to be modified in fundamental ways (Fagerlin & Schneider, 2004; Berger et al., 2008; Torke et al., 2008; Sudore & Fried, 2010; White & Arnold, 2011; Schenker et al., 2014). However, before making these or other changes to current practice, it is vital to identify patients' actual priorities for treatment decision making.

More than 80% of the patients in our sample indicated that goals related to how they are treated, how decisions are made, and how their treatment or decision making impacts their family are important to them. These data suggest that patients indeed value goals other than which treatments they receive or their treatment outcomes. Yet when asked to identify which goal was most important to them, almost 40% prioritized being treated consistent with their own preferences and values, while 20% prioritized minimizing the burden on their family, and 15% prioritized having their family involved in making decisions.

These findings yield two important insights for current practice and future research. The current emphasis on providing treatment based on the patient's own preferences and values reflects the primary goal of the largest group of patients. However, a significant number of patients would be better served by practices that prioritize reducing the impact on their family or practices that prioritize involving their family in the decision-making process.

Relation to Prior Research

A number of previous studies provide important data on issues that are related to our study, such as pa-

tients' goals of care (Rosenfeld et al., 2000; Fried & Bradley, 2003; Kaldjian et al., 2008; Fried et al., 2011; Case et al., 2013) and factors patients consider important at the end of life (Doukas & Gorenflo, 1993; Mead et al., 1995; Ditto et al., 1996; Singer et al., 1998; 1999; Steinhauser et al., 2000; Patrick et al., 2001; Hawkins et al., 2005; Heyland et al., 2006; Emanuel, 2008; Kaldjian et al., 2008; Kirchhoff et al., 2010; Scheunemann et al., 2012). These studies typically address a broad range of considerations. For example, a seminal survey of the U.S. population identified 26 items that patients considered important at the end of life, including items related to symptoms or personal care (e.g., freedom from pain or anxiety, being kept clean), preparing for the end of life (e.g., having financial affairs in order, knowing what to expect about one's death), and achieving a sense of completion about one's life (e.g., saying goodbye to important people, remembering personal accomplishments, resolving unfinished business) (Steinhauser et al., 2000). By contrast, the present study focused on patients' goals for treatment decision making.

Our data confirm results from earlier research, recently summarized in a systematic review of 40 studies, which showed that patients have three primary goals for treatment decision making during periods of incapacity: involving the family, reducing the burden on the family, and receiving treatment consistent with their own preferences and values (Kelly et al., 2012). Accordingly, our data are also consistent with prior findings that many patients want their surrogates to have considerable leeway in interpreting or overriding previously stated wishes (Sehgal et al., 1992; Akabayashi et al., 2003; Hawkins et al.,

2005; Miyata et al., 2006; Sulmasy et al., 2007; Kelly et al., 2012). These data equally suggest that receiving or avoiding particular treatments, or achieving certain goals of care, is not the only consideration for patients.

However, the existing literature does not provide explicit data on which goals for treatment decision making patients actually prioritize in the event of incapacity. For example, commentators sometimes conclude from the existing data on surrogate leeway that patients do not prioritize receiving treatment consistent with their own preferences (Berger et al., 2008; Torke et al., 2008; Sudore & Fried, 2010; Kim, 2014). Yet whether the "leeway" data support this conclusion depends on *why* patients want their surrogates to have leeway when making decisions. Patients might endorse this approach because they prioritize having their loved ones involved in the decision-making process, or because they prioritize reducing the burden on their family. It is also possible that patients grant their surrogates leeway because they prioritize receiving treatment consistent with their own preferences and values, or they prioritize trying to promote their own clinical interests, and they assume that the best way to promote these goals is to allow their loved ones to decide in the given circumstance. These difficulties are reinforced by the fact that most leeway studies ask patients whether they want their surrogate to override their previously stated wishes *only in situations where doing so promotes their best clinical interests* (Sehgal et al., 1992; Hawkins et al., 2005; Sulmasy et al., 2007). Therefore, without explicit questions regarding patients' fundamental priorities, it is not possible to infer from these data which goals patients prioritize.

Our findings show—for the first time—that patients' fundamental priorities for treatment decision making in the event of incapacity are manifold and complex. While the largest group of patients in our sample indicated that receiving desired and avoiding unwanted treatments was their primary goal, this group did not constitute a clear majority. Moreover, many patients stated that minimizing the burden on their family or having their family involved in making decisions was most important to them. In addition, a significant number of patients did not have a single primary goal. Thus, while almost all patients endorsed these goals for treatment decision making, no single goal was prioritized by all or by even a clear majority.

Practical Implications

Our findings have important implications for practicing clinicians. The data suggest that current practice—with its emphasis on treating patients consistent with their own preferences and values—promotes the priority of the largest group of patients. Yet, this approach also fails to promote the priorities of many other patients (and the overall majority). Clinicians and policies should therefore not be limited to identifying and documenting patients' treatment preferences. Instead, our data suggest that clinicians should encourage patients to also discuss and document their priorities for how they want decisions to be made for them in the event of incapacity. In particular: do they prioritize receiving specific treatments or achieving particular treatment outcomes, having their family involved in making decisions, or minimizing the burden on their families? This approach goes beyond existing proposals to encourage patients to document their preferred level of surrogate leeway (Sehgal et al., 1992; Berger et al., 2008; Sudore & Fried, 2010), in that patients would systematically consider and identify their priorities for treatment decision making.

In addition, our findings suggest that framing discussions about advance care planning around patients' fundamental priorities better reflects most patients' concerns. Although advance directives are often regarded as a means for patients to refuse treatment in the event of incapacity, only 11% of patients in our sample indicated that avoiding unwanted treatments was their most important goal. This suggests that clinicians and policies might increase participation in advance care planning by discussing a broader range of goals for treatment decision making. In addition, framing advance care planning around patients' fundamental priorities allows clinicians to discuss how patients might realize these priorities. For instance, independent data suggest that specifying one's treatment preferences often reduces the burdens on surrogate decision makers (Wendler & Rid, 2011). Thus, for patients who prioritize reducing the stress on their family, clinicians can explain that discussing and documenting their treatment preferences offers an important means to promote this goal.

Questions for Future Research

The present findings that patients prioritize different goals for decision making suggest three important questions for future research. First, is it possible to modify current practice such that it promotes the three goals endorsed by almost all patients? One possibility to evaluate in this regard is whether current practice can be enhanced to treat patients consistent with their own preferences and values, involve their families, and reduce the burden on their families. For example, the Physician Orders for Life-Sustaining Treatment (POLST) program has significantly

increased the completion rates for instructional advance directives among seriously ill patients, while also increasing surrogate involvement in advance care planning and treatment decision making (Hammes & Rooney, 1998; Detering et al., 2010; Bomba et al., 2012). Furthermore, evidence suggests that surrogates experience less stress when they know which treatment the patient would prefer (Hammes & Rooney, 1998; Detering et al., 2010; Wendler & Rid, 2011). Future research should further evaluate to what extent POLST or similar programs promote the three primary goals of patients for treatment decision making (Hammes & Rooney, 1998; Molloy et al., 2000; Detering et al., 2010; Silveira et al., 2010; Bomba et al., 2012).

Similarly, a recent proposal is to supplement the shared decision-making process between families and clinicians and traditional advance care planning with predictions of which treatment course the patient would want, based on the patient's sociodemographic and other characteristics (Rid & Wendler, 2014a). This approach may equally offer a way to involve patients' families, while reducing the burden placed on them. In addition, limited evidence suggests that predictions of a patient's treatment preferences might be more accurate than those of surrogates (Rid & Wendler, 2014b), in which case these predictions would also promote the goal of treating patients consistent with their own preferences and values. Future research is needed to evaluate whether the use of such a "patient preference predictor" realizes these goals, and whether its development and implementation are feasible.

In the event that it is not possible to promote all three goals, the second question for future research is to evaluate whether current practice can be modified in ways that allow patients to systematically document their priorities for how treatment decisions are made. This approach would require building on existing scholarship on how to increase participation in advance care planning (Hammes & Rooney, 1998; Molloy et al., 2000; Detering et al., 2010; Silveira et al., 2010; Bomba et al., 2012). In addition, this approach would need to be supplemented with research to identify practices that promote each of patients' three primary goals. For example, for patients who prioritize minimizing the burden on their family, what approach best promotes this goal?

Third, if these avenues for research prove unproductive, it may be necessary to accept that we cannot promote all of patients' priorities, or individualize decision making to promote the highest priority of a specific patient. Instead, it may be necessary to evaluate which of the three goals is most feasible to promote. This approach resonates with arguments that we have to accept the "false promise of advance directives" (Perkins, 2007) and focus on potentially more feasible goals for treatment decision making, such as reducing the burden on patients' families through better communication and support.

LIMITATIONS

The present findings offer the first opportunity to evaluate current clinical practice, as well as proposed modifications, in light of systematic data on patients' priorities regarding treatment decision making during periods of incapacity. Furthermore, the findings are based on a relatively large and diverse sample of patients, representing a broad range of geographical and other backgrounds, ages, and health states.

At the same time, patients were recruited from a single tertiary care center. In addition, while the response rate was high in the participating clinics (77.8%), it was lower in the emergency department (52.3%). Respondents in the emergency department may have been preoccupied with their current health situation, although most respondents there (84.7%) rated their current health as at least "good." This suggests that we successfully screened for patients who were not in a position to complete a survey.

The survey asked patients to make choices between different goals for treatment decision making that were important to them. While this may have been difficult, patients had the option of not making a choice. Moreover, the vast majority of patients who prioritized one goal were confident in their answer. Next, in some cases, patients' identified goals may have been based on a different goal. For example, a patient may have identified avoiding certain treatments as her primary goal based on the assumption that this approach would be the best way to minimize stress on her family. Finally, the survey employed a quantitative methodology, which has well-known advantages and disadvantages when compared to other methods (Creswell, 2013). Yet given the limitations of existing data on patients' priorities for decision making, and the need for quantitative data to evaluate current practice and proposed changes, the present results address an important gap in the literature.

CONCLUSION

The present survey of a diverse group of 1169 patients suggests that patients prioritize three goals for treatment decision making during periods of incapacity: being treated consistent with their own treatment preferences and values; minimizing the burden on their family; and including their family in the decision-making process. This finding warrants caution regarding any approach to treatment decision making that attempts to promote one goal for *all* patients.

Clinicians and policies should encourage patients to discuss and document their priorities for how they want decisions to be made for them in the event of incapacity. Furthermore, the present results support the need for research into broadening current practice to promote all three goals, or identifying methods that systematically individualize the decision-making process to the priorities of individual patients. If these approaches are unsuccessful, we may be required to focus on determining which of the three goals for treatment decision making is most feasible to promote.

ABBREVIATIONS

AD = advance directive
DPA = durable power of attorney
ED = emergency department
LRT = likelihood ratio test
PI = principal investigator
POLST = Physician Orders for Life-Sustaining Treatment program.
Txs = treatments

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Appendix 1. Literature Search

PubMed Search (English-only).
Search terms: (capacit* or incapacit* or impair*) AND (decision* or choice* or factors or wish* or goal* or values or preference* or priorit* or communicat* or perspective*) AND (terminal care [mh] or terminally ill [mh] or resuscitation [tw] or withholding treatment [mh] or life support care [mh] or end-of-life [tiab]) AND treatment* [tiab].

Appendix 2. Patient Information Sheet and Study Questionnaire

Information about the Research Survey: "Patients' Views on Medical Decision Making"

We invite you to take part in our survey. The survey is paid for by the National Institutes of Health (NIH). Taking part is completely voluntary.

What is the Survey About?

We are interested in your views on how medical decisions should be made for adults who are unable to make their own decisions. For example, adults in car accidents sometimes need treatment when they are unconscious. Some adults with illnesses of the brain need treatment when they cannot talk or understand. Doctors give these patients the treatments they need and the treatments that are best for them.

However, in some cases, it is not clear what is best medically for the patient. For example, sometimes it is not clear whether the benefits of treatment outweigh the burdens. In these cases, the doctors and family members or loved ones must decide how the patient is treated. To help them make the best decisions possible, we are asking patients how they think these decisions should be made.

Are there Any Risks or Benefits to Me from the Survey?

There are no benefits to you. We will not put your name on the survey, so the only risks are the minimal risks of boredom or anxiety while answering the questions. We hope your answers, combined with answers from other patients, will help us improve decision making for patients who are not able to make their own decisions. When we report the results, the people who participated will not be named or identified.

How Long Does the Survey Take?

The survey takes about 20 minutes to complete.

What if I Have Questions?

If you have any questions, please speak with the person who gave you this form. You also can contact the person in charge of the survey, David Wendler, at 301.435.8726 or dwendler@nih.gov. The Office of Human Research of George Washington University, at 202.994.2715, can provide more information about your rights as a research participant.

Do I Have to Do the Survey?

No. Whether you participate is up to you. If you decide not to participate, your medical care will not be affected in any way. If you decide to participate, you may skip any questions that you do not feel comfortable answering.

Please keep a copy of this form in case you want to read it again.

Unit/Department _____

Date __/__/__

V1

Patients' Views on Medical Decision Making

A Joint Survey of

The George Washington University Hospital

and

The Department of Bioethics at the NIH Clinical Center

THE GEORGE
WASHINGTON
UNIVERSITY
HOSPITAL
UHS
Universal Health

NATIONAL INSTITUTES
OF HEALTH

BIOETHICS
AT THE NIH

Before You Start

Your views are important to us. Please take as much time as you need and answer as accurately as possible. If you have any questions, please talk to the person who gave you this survey.

To answer a question, mark an **X** or √ in the box that best matches your view. If a question asks you to write your answer, please try to write clearly.

Please check only one box per question, unless the question asks you to check all the boxes that apply.

Part 1: A Few Questions About You

1. **Are you male or female?**

   ☐ Male
   ☐ Female

2. **In what year were you born?**
   19 __ __

3. **Where were you born? If you were born in the United States, please write the name of the state. If you were born in another country, please write the name of the country.**

   _____

4. **For how many years have you lived in the Washington DC area?** _____

   If you do not currently live in the Washington DC area, please write down where you live and for how many years you have lived there.

   _____

5. **Do you consider yourself Hispanic or Latino?**

   ☐ Yes
   ☐ No

6. **Do you consider yourself (*please check all the boxes that apply*)?**

   ☐ Black or African American
   ☐ Native American (American Indian or Alaska Native)
   ☐ Asian
   ☐ Native Hawaiian or Pacific Islander
   ☐ White

7. **Please check the <u>highest</u> level of education that you have completed.**

   ☐ I completed graduate school
   ☐ I completed college
   ☐ I completed high school
   ☐ I completed grade school
   ☐ I did not complete grade school

8. **Last year, what was the total income in your household before taxes?**

   ☐ Under $25,000
   ☐ $25,000–$49,999
   ☐ $50,000–$99,999
   ☐ $100,000–$249,999
   ☐ More than $250,000

9. **Would you say your <u>current overall</u> health is:**

   ☐ Excellent
   ☐ Very good
   ☐ Good
   ☐ Fair
   ☐ Poor

10. **Would you say your <u>current overall</u> quality of life is:**

    ☐ Excellent
    ☐ Very good
    ☐ Good
    ☐ Fair
    ☐ Poor

11. **Do you have a regular doctor?**

    ☐ Yes
    ☐ No

12. **Approximately how many times have you seen your regular doctor in the past 12 months?**

    ☐ 0 times
    ☐ 1 time
    ☐ 2-5 times
    ☐ 6–10 times
    ☐ More than 10 times
    ☐ I do not have a regular doctor

13. **What is your current marital status?**

    ☐ Single, never married

☐ Married

☐ Partnered

☐ Separated

☐ Divorced

☐ Widowed

14. Would you say your <u>overall</u> relationship with your family is:

☐ Excellent

☐ Very good

☐ Good

☐ Fair

☐ Poor

☐ I do not have a family

15. How religious are you?

☐ Not religious at all

☐ A little religious

☐ Moderately religious

☐ Very religious

Part 2: Your Experience and Planning

16. How much <u>personal contact</u> have you had with any adults who were unable to make their own medical decisions?

☐ No personal contact

☐ Just a little personal contact

☐ A moderate amount of personal contact

☐ A lot of personal contact

17. Have you ever helped to make medical treatment decisions for another adult who was unable to make his or her own decisions?
⟶ *Please check all the boxes that apply*

☐ No

☐ Yes. I helped make treatment decisions for my spouse/partner

☐ Yes. I helped make treatment decisions for a family member other than my spouse/partner

☐ Yes. I helped make treatment decisions for a friend

☐ Yes. I helped make treatment decisions for an incapacitated patient in my role as a health care professional

18. A living will is a form which allows patients to list the treatments they want, and the treatments they do not want, if they ever become unable to make their own decisions. Have you completed a living will for yourself?

☐ Yes

☐ No

19. A DPA (durable power of attorney) is a form which allows patients to name who they want to make medical decisions if they ever become unable to make their own decisions. Have you completed a DPA for yourself?

☐ No: *please go to the next question, <u>Question #20</u>*

☐ Yes. I named my spouse/partner

☐ Yes. I named a family member other than my spouse/partner

☐ Yes. I named a friend

☐ Yes. I named someone else

Please go to <u>Question #42</u> on page 20

Part 3: Your Views

When adult patients become unable to make their own medical decisions, doctors give them the treatments they need and the treatments that are best for them. However, sometimes even doctors do not know what treatment is best for patients who are unable to make their own decisions.

[QUESTION 20: RESULTS NOT REPORTED IN THIS PAPER]

For the next question (Question #21), please consider the following case: You are in a bad car accident. You are unconscious. There are only two options for taking care of you.

Option 1: Your doctors can provide you medical treatment. The treatment has a low chance of making you better. Treatment also has a good chance of making you unable to think clearly and making you permanently dependent on machines to stay alive.

Option 2: Your doctors can make you comfortable and allow you to die.

In this case, even your doctors do not know what is best medically. Some people think treatment is worth trying. Other people think it does not make sense to try treatment. Your doctors do not know whether they should give you treatment or not.

21. In this case (you are unconscious after a bad car accident and even the doctors do not know what is best for you medically), how <u>important to you</u> are the following things?

How important to you is … ?	*Extremely important*	*Moderately important*	*Just a little important*	*Not important at all*
A. Getting the treatments I would want	☐	☐	☐	☐
B. Avoiding treatments I would <u>not</u> want	☐	☐	☐	☐
C. Getting the treatments my family thinks I would want	☐	☐	☐	☐
D. Having my family help my doctors make treatment decisions for me	☐	☐	☐	☐
E. Minimizing the stress on my family	☐	☐	☐	☐
F. Not being a financial burden on my family	☐	☐	☐	☐
G. Avoiding excessive stress on the doctors and nurses	☐	☐	☐	☐
H. Not being a financial burden on society	☐	☐	☐	☐

22. **In the previous question (Question #21), is there one thing on the entire list that is <u>most important</u> to you?**

☐ Yes: *please <u>write</u> <u>the</u> <u>letter</u> of the one thing on the list that is most important to you:_____*

☐ No, there is not one thing on the list that is most important to me

23. **How sure are you about which thing on the list in Question #21 is most important to you?**

☐ Very unsure

☐ Pretty unsure

☐ Pretty sure

☐ Very sure

[QUESTIONS 24-34: RESULTS NOT REPORTED IN THIS PAPER]

35. **Consider a situation where there are only two ways to make treatment decisions for you. The <u>first</u> way is more likely to give you the treatment you want, but it is very stressful for your family. The <u>second</u> way is less stressful for your family, but it is less likely to give you the treatment you want. Which way would you prefer?**

☐ I prefer the first way that is more likely to get me the treatment I want

☐ I prefer the second way that is less stressful for my family

☐ I do not know which of these two ways of making decisions I prefer

Part 4: New Approaches to Decision Making

[QUESTIONS 36-41: RESULTS NOT REPORTED IN THIS PAPER]

Thank you for answering our questions. Your answers are very valuable to us as we try to improve medical decision making for patients who are unable to make their own decisions.

If you are feeling anxious or upset, or if you have any questions about this survey, please talk to the person who gave you the survey. You also can talk to the person in charge of the survey, David Wendler, at 301.435.8726 or dwendler@nih.gov.

Thank you very much!
You are done with the survey
Please do not answer Question #42 through Question #63!

These are the same questions we asked you, but we have worded them in a way that works better for people who have completed a Durable Power of Attorney (DPA)

Part 3: Your Views

When adult patients become unable to make their own medical decisions, doctors give them the treatments they need and the treatments that are best for them. However, sometimes even doctors do not know what treatment is best for patients who are unable to make their own decisions.

[QUESTION 42: RESULTS NOT REPORTED IN THIS PAPER]

43. **For the next question (Question #43), please consider the following case:** You are in a bad car accident. You are unconscious. There are only two options for taking care of you.

<u>Option 1</u>: Your doctors can provide you medical treatment. The treatment has a low chance of making you better. Treatment also has a good chance of making you unable to think clearly and making you permanently dependent on machines to stay alive.

<u>Option 2</u>: Your doctors can make you comfortable and allow you to die.

In this case, even your doctors do not know what is best medically. Some people think treatment is worth trying. Other people think it does not make sense to try treatment. Your doctors do not know whether they should give you treatment or not.

44. In this case (you are unconscious after a bad car accident and even the doctors do not know what is best for you medically), how <u>important to you</u> are the following things?
——⟶ *For these questions, the person you named to make medical decisions for you on your Durable Power of Attorney Form (DPA) is called your <u>DPA</u>.*

How important to you is … ?	*Extremely important*	*Moderately important*	*Just a little important*	*Not important at all*
A. Getting the treatments I would want	☐	☐	☐	☐
B. Avoiding treatments I would <u>not</u> want	☐	☐	☐	☐
C. Getting the treatments my DPA thinks I would want	☐	☐	☐	☐
D. Having my DPA help the doctors make treatment decisions for me	☐	☐	☐	☐
E. Minimizing the stress on my DPA	☐	☐	☐	☐
F. Not being a financial burden on my DPA or family	☐	☐	☐	☐
G. Avoiding excessive stress on the doctors and nurses	☐	☐	☐	☐
H. Not being a financial burden on society	☐	☐	☐	☐

44. In the previous question (Question #43), is there one thing on the entire list that is <u>most important</u> to you?

☐ Yes: *please write the letter of the one thing on the list that is most important to you:_____*

☐ No, there is not one thing on the list that is most important to me

45. How sure are you about which thing on the list in Question #43 is most important to you?

☐ Very unsure

☐ Pretty unsure

☐ Pretty sure

☐ Very sure

[QUESTIONS 46-56: RESULTS NOT REPORTED IN THIS PAPER]

Consider a situation where there are only two ways to make treatment decisions for you. The <u>first</u> way is more likely to give you the treatment you want, but it is very stressful for your DPA. The <u>second</u> way is less stressful for your DPA, but it is less likely to give you the treatment you want. Which way would you prefer?

☐ I prefer the first way that is more likely to get me the treatment I want

☐ I prefer the second way that is less stressful for my DPA

☐ I do not know which of these ways of making decisions I prefer

Part 4: New Approaches to Decision Making

[QUESTIONS 58-63: RESULTS NOT REPORTED IN THIS PAPER]

Thank you for answering our questions. Your answers are very valuable to us as we try to improve medical decision making for adult patients who have become unable to make their own decisions.

If you are feeling anxious or upset, or if you have any questions about this survey, please talk to the person who gave you the survey. You also can talk to the person in charge of the survey, David Wendler, at 301.435.8726 or dwendler@nih.gov.

Thank you very much!

Appendix 3. Results of Statistical Analysis (NS = not statistically significant at $p < 0.01$)

1. Response rates: (1) patient groupings in the emergency department (ED) vs. (2) patient groupings in non-ED units

   - Gender: NS

   - Age: significant difference (in the ED younger patients more likely to respond)

   - Race: significant difference (in the ED Asians and whites more likely to respond than blacks and Hispanics; in non-ED units Hispanics and whites more likely to respond than blacks and Asians)

2. Priorities: (1) respondents who prioritize getting the treatments they want/avoiding the treatments they do not want vs. (2) respondents who prioritize having the family help make treatment decisions vs. (3) respondents who prioritize minimizing stress on the family.
   - Unit: NS
   - Age: significant difference (older respondents more likely to fall into group 1 and less likely to fall into group 3)
   - Gender: NS
   - Race/ethnicity: NS
   - Education: NS
   - Income: NS
   - Relationship status: NS
   - Marital status: NS
   - Relationship with family: significant difference (respondents with good/fair/poor family relationships more likely to fall into group 1; respondents with excellent or very good family relationships more likely to fall into groups 2 and 3)
   - Religiousness: NS
   - Current quality of life: NS
   - Current health: NS
   - Regular doctor: NS
   - Advance care planning: significant difference (respondents who had engaged in some form of advance care planning more likely to fall into group 1)
   - Personal experience with incapacitated adults: NS
   - Personal experience with treatment decision making: NS
   - Certainty about prioritizing particular goal (Q22): NS
   - Age and relationship with family remain significant when controlled for other statistically significant factors (polytomous logistic regression)

3. Clusters: (1) self- and other regarding respondents vs. (2) self-regarding respondents
   - Units: NS
   - Age groups: NS
   - Gender: NS
   - Race/ethnicity: NS
   - Education: NS
   - Income: NS
   - Marital status: NS
   - Relationship status: NS
   - Age-relative relationship status: NS
   - Relationship with family: significant difference (respondents with fair/poor family relationships more likely to fall into cluster 2)
   - Religiousness: NS
   - Current quality of life: NS
   - Current health: NS
   - Regular doctor: NS
   - Advance care planning: NS
   - Personal experience with incapacitated adults: NS
   - Personal experience with treatment decision making: NS

4. Tradeoffs between goals: (1) family stress vs. (2) own treatment preferences vs. (3) no opinion
   - Unit: NS
   - Age: NS
   - Gender: NS
   - Race/ethnicity: NS
   - Education: NS
   - Income: NS
   - Relationship status: NS
   - Marital status: NS
   - Age-relative relationship status: NS
   - Relationship with family: NS
   - Religiousness: significant difference (more religious respondents less likely to prioritize 1 and more likely to prioritize 2)
   - Current quality of life: NS
   - Current health: NS
   - Regular doctor: NS
   - Advance care planning: NS
   - Personal experience with incapacitated adults: NS
   - Personal experience with treatment decision making: NS