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How Clinicians Discuss Critically Ill Patients' Preferences and Values with Surrogates: An Empirical Analysis

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Abstract

Objective—Although shared decision-making requires clinicians to discuss the patient's values and preferences, little is known about the extent to which this occurs with surrogates in intensive care units. We sought to assess whether and how clinicians talk with surrogates about incapacitated patients' preferences and values.

Design—Prospective, cross-sectional study.

Setting—Five ICUs of two hospitals.

Subjects—Fifty-four physicians and 159 surrogates for 71 patients.

Interventions—We audio-recorded 71 conferences in which clinicians and surrogates discussed life sustaining treatment decisions for an incapacitated patient near the end of life. Two coders independently coded each instance in which clinicians or surrogates discussed the patient's previously expressed treatment preferences or values. They subcoded for values that are

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commonly important to patients near the end of life. They also coded treatment recommendations by clinicians that incorporated the patient's preferences or values.

Measurements and Main Results—In 30% of conferences, there was no discussion about the patient's previously expressed preferences or values. In 37%, clinicians and surrogates discussed both the patient's treatment preferences and values. In the remaining 33%, clinicians and surrogates discussed either the patient's treatment preferences or values, but not both. In >88% of conferences, there was no conversation about the patient's values regarding autonomy and independence, emotional well-being and relationships, physical function, cognitive function, or spirituality. On average, 3.8% (SD 4.3, range 0 – 16%) of words spoken pertained to patient preferences or values.

Conclusions—In roughly a third of ICU family conferences for patients at high risk of death, neither clinicians nor surrogates discussed patients' preferences or values about end-of-life decision-making. In <12% of conferences did participants address values of high importance to most patients, such as cognitive and physical function. Interventions are needed to ensure patients' values and preferences are elicited and integrated into end-of-life decisions in ICUs.

Keywords

surrogate decision-making; ethics; patient-centered care; critical care; shared decision-making; preferences and values

Introduction

Decisions about using life support in advanced illness hinge on trade-offs between length and quality of life.(1, 2) Patients' preferences about life support are diverse and informed by a range of considerations such as spiritual beliefs, expected function and level of independence.(3–6) Because most patients are incapacitated during advanced critical illness, clinicians turn to surrogates to assist with decisions.

However, studies indicate that patients often receive care near the end of life that is inconsistent with their values.(7, 8) International critical care societies recommend clinicians use shared decision-making with families to better honor patients' wishes.(9) However, little is known about whether clinicians and families communicate about the patient's values in practice.

How clinicians *should* elicit patients' preferences and values is conceptually well-defined. Bioethical theory holds that three principles should guide decision-making for incapacitated patients.(10) Each corresponds to a different type of information clinicians could elicit. First, decisions should be guided by the *principle of autonomy*, which entails ascertaining and following patients' previously expressed treatment preferences. If the patient has not previously expressed clear treatment preferences, decisions should be guided by the *principle of substituted judgment*, where decision-makers infer what the patient would want based on their understanding of the patient's values. Clinicians should therefore ask about patient values. When surrogates know too little about the patient to use substituted judgment, they should use the *principle of best interests*, choosing what most people would consider to be "good." Although experts debate whether rigid application of this hierarchy is

appropriate, they generally agree that decision-making should involve consideration of patients' values and preferences.

We undertook a study to determine whether and how clinicians elicit incapacitated patients' preferences and values from critically ill patients' surrogates and incorporate them into treatment recommendations. We further characterized how often they discussed eight domains values that the end of life literature identifies to be commonly important to patients.

Materials and Methods

We conducted this study in five ICUs at two California hospitals from 2006–2008. One hospital is a tertiary care center and the other is an academically-affiliated county hospital. We included ICUs with diverse cultures, comprising medical, neurological, cardiac, and two medical-surgical ICUs, to understand the range of communication skills clinicians and surrogates use to discuss incapacitated patients' preferences and values.

Enrollment and screening procedures have been described previously.(11, 12) Briefly, conferences were scheduled at the discretion of the treating team. Conferences were eligible if they occurred on a weekday, involved both physicians and families of incapacitated adult patients, were conducted in English, and the attending physician affirmed an intention to discuss goals of care. Study personnel screened for eligible conferences on weekdays. If the attending physician agreed with participation, study personnel approached surrogates. Prior to audio-recording, all conference participants provided informed consent. The Institutional Review Boards at both institutions approved all study procedures.

Data collection

Meetings were audio-recorded and transcribed verbatim by a medical transcriptionist. Clinicians and surrogates completed questionnaires providing demographic data. We abstracted patient demographics and medical information such as illness severity and length of stay from the medical record. We excluded conferences without any discussion of treatment options from further analysis (n= 2).(12, 13)

Deductive coding scheme for preference and value elicitation

Our study aimed to describe specific communication skills for eliciting and incorporating patients' preferences and values in surrogate decision-making. Therefore, our main analysis used Crabtree and Miller's template style,(14) in which researchers deductively apply a prespecified coding scheme to text. We identified the communication skills of interest based on literature review (10, 15, 16) and a published conceptual framework for values elicitation during end-of-life decision-making.(17) Table E1 (Supplemental Digital Content 1) in the electronic supplement defines its key terms. To ensure content validity, we circulated it among experts in surrogate decision-making and presented it to clinicians at the University of Pittsburgh Medical Center whose practice involves surrogate decision-making.

Four codes identified clinician statements that elicited or incorporated patients' preferences and values (Box). First, we applied a single *preference elicitation* code to clinician inquiries about whether the patient had previously expressed treatment preferences (e.g., "did the

patient ever tell you what she would want if she needed a long-term breathing machine?")

Second, two *values elicitation* codes identified different ways clinicians attempted to understand the patient's health-related values. One was for statements that explored the patient's health-related values directly (e.g., "how would the patient feel about living in a nursing facility?") The other was for requests for a substituted judgment, defined as asking the surrogate to infer the patient's treatment goals (e.g., "what do you think the patient would have wanted?")

Fourth, a code for *preference and value incorporation* identified statements in which clinicians "showed their work" by stating the patient's previously expressed treatment preferences or values as the justification for a treatment recommendation (e.g., "Based on what you've told me about your mother's strong feelings against receiving long term life support, I recommend we shift care toward treatment focused on comfort rather than prolonging her life.")

Box

Codes for eliciting patients' previously expressed treatment preferences and values

Type of Elicitation	Code	Definition
Main Codes		
Preference elicitation	<ul style="list-style-type: none"> Asked about prior treatment preferences 	<ul style="list-style-type: none"> Clinician inquiry about the patient's past statements about treatment s/he would accept or refuse in future health states, usually in the form of a written or oral advance directive. Excludes questions about patient wishes to avoid prolonged life support, which were coded as health-related values.
Values elicitation	<ul style="list-style-type: none"> Explored health-related values direct Asked surrogate to make a substituted judgment 	<ul style="list-style-type: none"> Clinician inquiry or inference about the patient's attitudes, opinions, and beliefs about what is important in the context of treatment decisions. Clinician request for the surrogate to make an inference about the patient's treatment goals
Preference and value incorporation	<ul style="list-style-type: none"> Treatment recommendation based on patient preferences or values 	<ul style="list-style-type: none"> Clinician treatment recommendation that is explicitly based on the patient's previously expressed preferences or values.
Subcodes for domains of health-related values		
	Longevity	<ul style="list-style-type: none"> Extending life, living as long as possible or until a specific goal is reached (e.g., birth in the family,

Type of Elicitation	Code	Definition
		return of a loved one from abroad)
	Maintaining bodily integrity	<ul style="list-style-type: none"> Avoiding prolonged dependence on life-sustaining treatments or having the body cut, attached to machines, or otherwise acted on by outside agents
	Avoiding burdensome symptoms	<ul style="list-style-type: none"> Avoiding pain, dyspnea, nausea, or other symptoms
	Autonomy and independence	<ul style="list-style-type: none"> Being able to make one's own decisions or live at home/not living in a nursing home, avoiding burdening one's friends and family financially, physically, or emotionally with one's care or being willing to accept help when limitations occur
	Emotional well-being & relationships	<ul style="list-style-type: none"> Participating in relationships, contributing to one's social group, including not being a burden on one's family
	Maintaining physical function	<ul style="list-style-type: none"> Maintaining physical independence or specific physical abilities (e.g., driving, athletics, playing a musical instrument)
	Maintaining cognitive function	<ul style="list-style-type: none"> Being able to think clearly
	Adhering to religious or spiritual beliefs	<ul style="list-style-type: none"> Ensuring treatment consistent with religious precepts
	General/Other	<ul style="list-style-type: none"> Any statement coded as values elicitation and not fitting the above domains, including those referring to quality of life in general

One reason clinicians might not ask about preferences and values is that surrogates raise all the relevant issues themselves. Therefore, we also coded for surrogates' statements about the patient's previously expressed treatment preferences and values.

Research demonstrates that patients' end-of-life values (3–6, 16) tend to cluster in eight domains (Box). We subcoded statements about patients' health-related values for the eight

domains to determine how often clinicians and surrogates discuss the range of values that are commonly important to patients near the end of life.

Finally, we coded for statements that alluded to prior discussion about the patient's preferences and values, and for statements in which clinicians attempted to elicit the patient's best interests.

Inductive analysis of conferences lacking both preference and value elicitation

Deductive coding revealed a substantial number of conferences without any discussion of the patient's preferences and values. We analyzed them using an inductive method called qualitative description, which allowed us to describe decision-making in clear, everyday terms without the use of a pre-existing framework.⁽¹⁸⁾ To develop the coding scheme, we used line-by-line coding with multiple coders and iterative meetings to generate and refine categories until we achieved consensus.

Coder training

A physician (LS) and a philosopher (TC) comprised the interdisciplinary coding team. After training on a subset of five transcripts, we coded independently, intermittently double-coding a transcript to avoid developing idiosyncratic coding habits. We double-coded 14 (20%), which we reviewed line-by-line, resolving differences by discussion. To assess inter-rater reliability, we developed 20-item tests for each of the Main Codes in the Box. Coders judged whether or not each item met the code definition. They achieved excellent inter-rater reliability (overall $\kappa = 0.81$). After completing coding, four of the authors (LS, TC, RA, and DW) reviewed all of the main codes and agreed that all statements were correctly classified.

Coding procedures

Coders were masked to participants' identities and survey responses. We coded the transcripts in four stages. First, we identified all statements related to preferences and values. Second, we coded each statement from the first stage according to the deductive coding scheme. Third, we sub-coded statements about patients' health-related values for the eight domains of values. A statement could receive multiple sub-codes if it satisfied the definition of more than one domain of values. For example, asking how important it was to the patient to be "walking and talking and interacting" would be coded as two domains: maintaining physical function, and emotional well-being and relationships. Fourth, we analyzed conferences lacking discussion of preferences and values using qualitative description. We used Atlas.ti 6.2 (Berlin, Germany) for qualitative data management.

Statistical analysis

We used descriptive statistics, including means, standard deviations (SD), and ranges to describe the observed behaviors. To determine the proportion of speech related to the patient's treatment preferences and values in each conference, we divided its number of coded words by its total number of words. Statistical analysis was performed using STATA 13.0 (College Station, TX, USA).

Results

Description of the study group

We audio-taped 73 of 104 eligible conferences (70% participation rate, with 5 physicians and 26 families declining after hearing about the study). We excluded two conferences in which treatment options were not discussed. Conferences occurred an average of 10 days (range 0–56) into the ICU admission, with 25% occurring within the first 48 hours of ICU admission.

Table 1 shows participants' demographic characteristics. Thirteen of 54 physicians led more than one conference. (Ten physicians led two conferences each, two led three, and one led four.) Surrogates had diverse ethnicity and educational attainment. Patients were severely ill, with 73% in-hospital mortality.

Discussion of preferences and values

In 30% of conferences, there was no discussion about the patient's treatment preferences or values (Figure 1). In 37%, clinicians and surrogates discussed both the patient's treatment preferences and values. In the remaining 33%, clinicians and surrogates discussed either the patient's treatment preferences or values, but not both. Table 2 provides examples.

Clinicians asked elicitation questions in 48% of conferences (mean number of questions 1.7 [SD 1.89, range 0 – 7]). Among the 70% of conferences with discussion about the patient's preferences and values, clinicians first raised the topic in 38% of cases and surrogates in 32%. The mean number discrete statements about the patient's preferences and values was 3.0 (SD 3.6, range 0 – 21) per conference. The average proportion of clinicians' and surrogates' speech devoted to values talk was 3.8% (SD 4.3, range 0 – 16%).

When clinicians and surrogates discussed patients' values, they focused on longevity (32%), bodily integrity (17%), and symptom palliation (17%) (Table 3). In >88% of conferences, there was no conversation about the patient's values regarding autonomy and independence, emotional well-being and relationships, physical function, cognitive function, or spirituality.

In none of the conferences without discussion of the patient's treatment preferences or values was there an indication that they had been discussed previously. No discussions were couched in terms of the patient's best interests.

Incorporating preferences and values into treatment recommendations

Clinicians made treatment recommendations in 61% of conferences. In 22%, recommendations were explicitly grounded in the patient's preferences or values. For example: *"we all agreed that she was a fighter and she was strong-willed...that if we told her we could put in the breathing tube for a short amount of time and get her through this, that she would be ok with that."* In 39%, they made recommendations not explicitly grounded in the patient's preferences or values. These recommendations were similar to those in conferences without discussion of the patient's preferences or values, as described below.

Decision-making in the absence of discussion about the patient's preference or values

We observed two approaches to decision-making in the 30% of conferences in which there was no evidence that clinicians and surrogates had discussed the patient's preferences or values. In one approach, clinicians followed what has been termed an informed consent model,(15) informing surrogates about the choice at hand without attempting to understand the patient's preferences or values and without offering treatment recommendations. This approach usually took the form of prognosticating and asking what the surrogate wanted to do. In the other approach, clinicians provided treatment recommendations, which were typically framed as medical judgments or the clinician's personal opinion (examples in Table E2, Supplemental Digital Content 2).

Discussion

We found that clinicians and surrogates did not discuss the patient's preferences or values in nearly one third of ICU family conferences about goals of care for patients with advanced critical illness. In only 37% of conferences did they address both prior preferences and health-related values. Less than 12% of discussions addressed values of high importance to most patients, such as independence, cognitive and physical function, and ability to interact socially.

Critical care societies in Europe and North America recommend that clinicians and surrogates use shared decision-making to negotiate decision-making roles and integrate medical and personal information about the patient into life support decisions.(9) Prior research in has revealed numerous problems with role negotiation (19, 20) and communication about medical information, especially prognosis.(21–23) Our study adds to this work by demonstrating similar problems with communication about personal information. This is important because it suggests a reason for values-discordant end of life treatment, which has been documented for over two decades.(7, 8, 24)

Our study is the first to use theoretical constructs from the psychology and medical decision-making literature to robustly quantify communication about preferences and values. Previous quantitative studies have reported a single dichotomous measure for whether any preference or values elicitation occurred.(25–28) By measuring each behavior separately, we have added substantial detail to what is known about how clinicians elicit preferences and values in ICU family conferences. Notably, although several interventions have been designed to increase values elicitation,(28–33) only one has measured it in the intervention group,(28) and none has measured it in a control. Quantifying communication about preferences and values opens the door for future research assessing how effective interventions are at increasing elicitation and impacting patient and surrogate outcomes.

Why might clinicians fail to discuss patients' preferences and values with surrogates? People rarely discuss their values directly.(34) In our study, it was common for surrogates to initially answer the question, "What do you think the patient would have wanted?" by saying, "I don't know." If clinicians have this experience often and do not know how to probe further, they may stop asking – and may not be able to model such skills for trainees. Data support this explanation: clinicians report little communication training, leaders in the

ICU say that the lack of training is a major barrier to better care, and 100% of interns receiving a brief educational intervention reported learning skills for eliciting values and preferences, underlining that this may be an area in which many feel deficient.(30, 35, 36) From this standpoint, it is notable that residents led a third of conferences in our study (half were accompanied by another clinician). Although allowing residents to practice their skills is important, attendings might consider being present to offer support. Another possible reason is that clinicians may think they know patients' preferences and values and do not need to ask about them.(37) The projection bias, in which people assume that others share their views and values, is common in the psychological literature.(38) Finally, clinicians may not see these decisions as preference-sensitive. They may believe, for legal reasons for example, that the surrogate is really the one whose perspective must be promoted. Or clinicians may view the decisions as biomedical choices about which they are the experts. (13, 39) Identifying which factors exert the strongest influence on clinicians' behavior will be necessary to design effective interventions to improve how they elicit and incorporate patients' values into decisions about life support.

Our study has several limitations. First, it was performed in ICUs in two California hospitals and therefore its results may not be generalizable to other contexts where incapacitated patients are treated or other regions. Second, although our 70% participation rate compares favorably with other studies of surrogate decision-making, selection bias is possible. However, we attempted to capture conferences in which the patient's treatment preferences and values should be most relevant by excluding conferences in which treatment options were not discussed. Furthermore, selection bias, combined with the Hawthorne effect, would tend to enrich the study with examples of physicians' best behavior. Therefore, our data may underestimate the extent of the problem. Third, the sample was relatively small, overrepresented relatively young physicians who specialize in internal medicine or neurology, and some physicians led more more than one conference, so we may not have observed a full range of physicians' behavior. In particular, future studies should include intensivists who conduct such conferences regularly. Fourth, we were unable to investigate associations between preference and value elicitation and outcomes such as patient's and surrogate's long-term outcomes or health care utilization. This is an essential area for future research.

The low observed rate of preference and values elicitation may contribute to important problems with medical care in ICUs. It may be a factor in the overuse of expensive, invasive treatment near the end of life. Existing studies suggest that most patients do not wish to receive aggressive life prolonging treatment in the setting of a poor prognosis,(3) and that surrogates may often have a weak understanding of the link between prognosis and the patient's values.(40) Elicitation is essential to strengthen this link and focus treatment on the patient as a person. Insufficient elicitation may also contribute to surrogates' psychological burdens related to decision-making.(41) Although surrogates generally believe the patient's preferences and values are important in decision-making,(42–44) difficulty perceiving the link between prognosis and the patient's values may lead to more internal conflict. To address these problems, interventions are needed to ensure patients' values and preferences are integrated into end-of-life decisions in ICUs, and to examine the impact of such efforts on patient, family and societal outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.
Percent distribution of discussion about the patient's preferences and values

Table 1

Demographic characteristics

	Patients (n=71) N(%) or mean (SD)	Surrogates (n=159) N(%) or mean (SD)	Physicians (n=54) N(%) or mean (SD)
Male	41 (58)	63 (39)	32 (59)
Race/ethnicity			
Non-Hispanic white	34 (48)	58 (37)	37 (68.5)
Non-Hispanic black	10 (14)	26 (16)	0 (0)
Hispanic	14 (20)	36 (23)	2 (3.75)
Asian/Pacific islander	12 (17)	23 (14)	14 (26)
Native American	1 (1)	5 (3)	0 (0)
Other/undocumented	0 (0)	11 (7)	1 (1.75)
Age (years)	62 (17)	46 (15)	37 (9)
Admission diagnosis			
Neurologic failure	26 (37)	-	-
Gastrointestinal failure	1 (1)	-	-
Cardiac failure or shock (including sepsis)	19 (27)	-	-
Hepatic failure	4 (6)	-	-
Metastatic cancer	3 (4)	-	-
Respiratory failure	12 (17)	-	-
Renal failure	1 (1)	-	-
Other/Multiple	5 (7)	-	-
APACHE II score on the day of meeting	29 (6)	-	-
Number of ICU days prior to meeting	10 (10)	-	-
Died during this hospitalization	52 (73)	-	-
Relationship to patient			
Spouse/partner	-	19 (12)	-
Child	-	64 (40)	-

	Patients (n=71) N(%) or mean (SD)	Surrogates (n=159) N(%) or mean (SD)	Physicians (n=54) N(%) or mean (SD)
Sibling	-	27 (17)	-
Parent	-	15 (10)	-
Other	-	34 (21)	-
Education			
Some high school	-	49 (31)	-
Some or all college	-	81 (51)	-
Graduate or professional school	-	29 (18)	-
Staff position			
Attending physician	-	-	36 (67)
Resident or fellow	-	-	18 (33)
Medical specialty			
Neurology	-	-	8 (15)
Surgery	-	-	6 (11)
Internal medicine	-	-	40 (74)
Cardiology	-	-	2
Hematology/Oncology	-	-	4
Hepatology	-	-	1
Pulmonology	-	-	3
Palliative care	-	-	2
Years in practice	-	-	7 (9)

Examples of clinician and surrogate statements for talking about incapacitated patients' treatment preferences and values

Topic	Clinician elicitation and incorporation	Surrogate discussion
Treatment preferences	<ul style="list-style-type: none"> Did she talk to anybody about what her wishes would be, in the event of some kind of disabling event like this? Has he ever made any requests in the past? Or, you know, signed any paperwork, or discussed with his doctor... saying that, 'If it got to that point, I wouldn't want that'? 	<ul style="list-style-type: none"> We've talked about it... He doesn't want to be hooked up like this, any longer than he has to be... But he wants to make sure... that obviously there's not a chance of him, you know, coming out of it. He doesn't want to... be in a bed with a tube and the whole thing, just to keep him alive. He's already said that to us, already. He doesn't want to be kept on life support.
Values	<ul style="list-style-type: none"> Direct exploration of health-related values: <i>How do you think she would feel, you know, because at this point, if there was a possibility for her to recover, it would take a very long time. And she might go from the hospital and have to go ... she ... Well, undoubtedly would have to go to like a skilled nursing facility, like a nursing home, and rehab and ... How do you think she would feel, if she couldn't take care of her son?</i> Asking for a substituted judgment: <i>If she wasn't to wake up, what do you think she would want?</i> Does she want to stay on these medicines indefinitely? Or does she want to see that she's tried and if it doesn't work, it doesn't work? 	<ul style="list-style-type: none"> Direct discussion of health-related values: <i>My father's really strong, but he's also a very independent person. So you know, of course he wants to fight to continue, but at the same time, he doesn't like to be in the situation he is... if this is gonna be a longer, length process, I'm sure he won't put any effort in it.</i> Making a substituted judgment: <i>Dad, she wouldn't want to be like that... She would not want to be like this.</i> I think she would probably accept that, just like, when you have a heart attack and you pass away in your sleep, ok?... I'm trying to put myself in her mind, it would be something she would be ok with... not having CPR.
How treatment preferences and values relate to treatment options	<ul style="list-style-type: none"> I think, you know, what we kind of felt like was... even though we read the directive, we felt like saying, you know, we feel like it's been ten days of trying and trying and that, based on his directive and talking to you, that we really would feel really comfortable transitioning to focusing on comfort, but to do that, then say, 'Ok, we have to stop doing CAT scans. We don't want to put a breathing tube in'... and all that stuff. And I think... it's a clear decision not to pursue that other workup type things we would do. There may be a situation, tomorrow, or the day after, where she may show a little bit of return to function, but she didn't have the miraculous recovery that we were holding out for. In which case, I think it's still, because of her wishes, we would want to back off. 	N/A

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Table 3
How often did clinicians and surrogates discuss various domains of health-related values?

	N (%) of 71 conferences
Longevity	23 (32)
Maintaining bodily integrity	12 (17)
Symptom palliation	12 (17)
Autonomy & independence	8 (11)
Emotional well-being & relationships	8 (11)
Maintaining physical function	8 (11)
Maintaining cognitive function	6 (8)
Adhering to religious or spiritual beliefs	1 (1)
Other	20 (28)