

Clinician-Family Communication About Patients' Values and Preferences in Intensive Care Units

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IMPORTANCE Little is known about whether clinicians and surrogate decision makers follow recommended strategies for shared decision making by incorporating intensive care unit (ICU) patients' values and preferences into treatment decisions.

OBJECTIVES To determine how often clinicians and surrogates exchange information about patients' previously expressed values and preferences and deliberate and plan treatment based on these factors during conferences about prognosis and goals of care for incapacitated ICU patients.

DESIGN, SETTING, AND PARTICIPANTS A secondary analysis of a prospective, multicenter cohort study of audiorecorded clinician-family conferences between surrogates and clinicians of 249 incapacitated, critically ill adults was conducted. The study was performed between October 8, 2009, and October 23, 2012. Data analysis was performed between July 2, 2014, and April 20, 2015. Patient eligibility criteria included lack of decision-making capacity, a diagnosis of acute respiratory distress syndrome, and predicted in-hospital mortality of 50% or more. In addition to the patients, 451 surrogates and 144 clinicians at 13 ICUs at 6 US academic and community medical centers were included.

MAIN OUTCOMES AND MEASURES Two coders analyzed transcripts of audiorecorded conversations for statements in which clinicians and surrogates exchanged information about patients' treatment preferences and health-related values and applied them in deliberation and treatment planning.

RESULTS Of the 249 patients, 134 (54.9%) were men; mean (SD) age was 58.2 (16.5) years. Among the 244 conferences that addressed a decision about goals of care, 63 (25.8%; 95% CI, 20.3%-31.3%) contained no information exchange or deliberation about patients' values and preferences. Clinicians and surrogates exchanged information about patients' values and preferences in 167 (68.4%) (95% CI, 62.6%-74.3%) of the conferences and specifically deliberated about how the patients' values applied to the decision in 108 (44.3%; 95% CI, 38.0%-50.5%). Important end-of-life considerations, such as physical, cognitive, and social functioning or spirituality were each discussed in 87 (35.7%) or less of the conferences; surrogates provided a substituted judgment in 33 (13.5%); and clinicians made treatment recommendations based on patients' values and preferences in 20 conferences (8.2%).

CONCLUSIONS AND RELEVANCE Most clinician-family conferences about prognosis and goals of care for critically ill patients appear to lack important elements of communication about values and preferences, with robust deliberation being particularly deficient. Interventions may be needed to better prepare surrogates for these conversations and improve clinicians' communication skills for eliciting and incorporating patients' values and preferences into treatment decisions.

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Critical care medicine's rapidly advancing technology can help seriously ill patients sustain a life that they value at all costs, recover to a meaningful quality of life, or prolong their functional impairment at the end of life.¹⁻⁵ This range of outcomes is possible because what constitutes a meaningful life, a good death, or intolerable suffering is personal. Because most critically ill patients are incapacitated and unable to communicate these values, their families and friends typically represent them as surrogate decision makers. International critical care societies recommend that clinicians and surrogates make health care decisions together using a process of shared decision making.⁶ Shared decision making consists of 3 elements: (1) information exchange about both clinical (ie, diagnosis, prognosis, and treatment options) and personal (ie, patients' values and preferences) topics, (2) deliberation about how to apply patients' values to the clinical situation, and (3) development of a treatment plan that respects patients' preferences. Identifying and discussing patients' values (ie, what is important to them) and preferences (ie, what treatment they want) are essential to shared, patient-centered decision making.

Previous research suggests that clinicians and surrogates do not follow existing recommendations for incorporating patients' values and preferences in 12% to 50% of intensive care unit (ICU) family conferences about goals of care.⁷⁻¹² These studies have several limitations. First, most were conducted with relatively small sample sizes in single regions of the United States. Second, some were conducted in simulation rather than actual practice. Third, these analyses provided limited insight about the extent to which clinicians and families incorporate information about patients' values and preferences into deliberations and treatment planning.

We conducted a secondary analysis of a multicenter study of audiorecorded ICU family conferences to quantify the frequency and scope of information exchange, deliberation, and treatment planning related to the values and preferences of incapacitated patients at high risk of death.

Methods

Description of Parent Study

This secondary analysis evaluated data originally collected in a prospective cohort study designed to identify effective strategies for disclosing prognosis to surrogate decision makers of incapacitated, critically ill patients. Data collection occurred in 13 ICUs at 6 US academic and community medical centers between October 8, 2009, and October 23, 2012. Data analysis was performed between July 2, 2014, and April 20, 2015. Institutional review boards at University of California at San Francisco, Fresno; University of Washington; University of California, San Francisco; University of North Carolina at Chapel Hill; University of Pittsburgh; and Baystate Medical Center approved the study protocol. All participants or their surrogates provided written informed consent. Both participants and health care professionals received financial compensation.

A full description of study methods has been published.¹³⁻¹⁵ To be eligible, patients (1) lacked decision-making capacity, as

Key Points

Question To what extent do clinicians and surrogates in intensive care units incorporate critically ill patients' values and preferences into treatment decisions?

Findings In this secondary analysis of a cohort study, 249 clinician-family intensive care unit conferences were analyzed for statements that exchanged information about incapacitated patients' treatment preferences and health-related values and applied them to deliberation and treatment planning. Most conferences lacked adequate communication, particularly in terms of deliberating about patients' values and preferences and applying them to treatment decisions.

Meaning Interventions are needed to better prepare surrogates for these difficult conversations and to improve clinicians' communication skills.

judged by the patient's attending physician; (2) met conventional diagnostic criteria for acute respiratory distress syndrome; (3) had Acute Physiology Assessment and Chronic Health Evaluation II scores higher than 25, predicting 50% or greater in-hospital mortality; and (4) had 1 or more available family member or friend to represent them as a surrogate decision maker (hereafter termed family or surrogate). We included clinician-family conferences that took place on a weekday and were conducted in English.

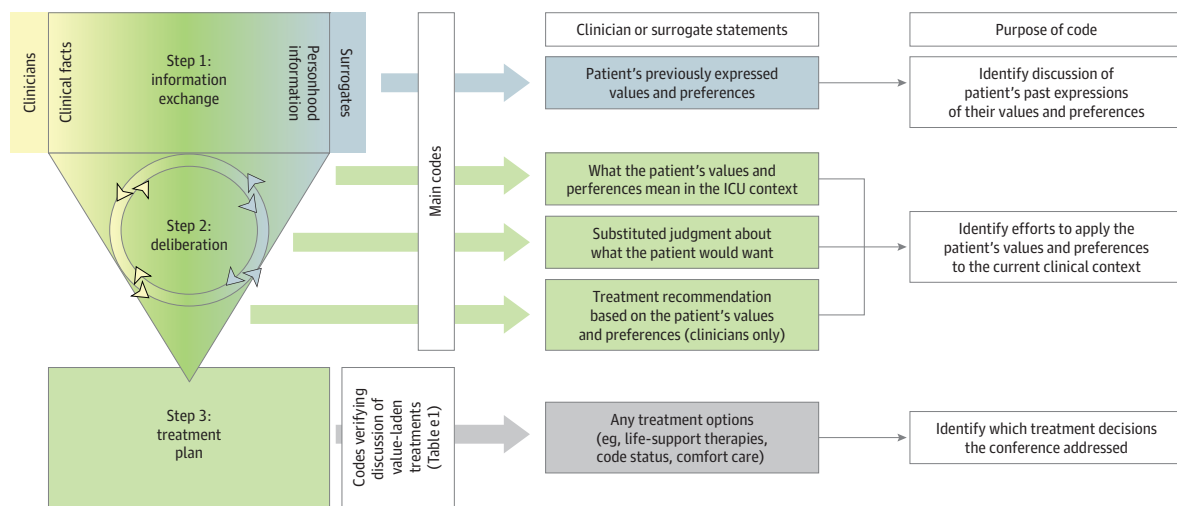
Researchers recorded clinician-family conferences in which clinicians anticipated discussing patients' prognosis and experienced medical transcriptionists transcribed the conversations. To ensure that conferences contained decision making about goals of care, we coded for evidence of decision making about resuscitation, life-support therapies, and treatment limitations; clinicians and surrogates discussed such treatment options in 98.0% of the recorded conferences (eTable in the Supplement). Trained study personnel abstracted patients' demographic and clinical data from medical records. Clinicians and surrogates completed questionnaires providing their demographic data.

Measurements

We developed a quantitative coding scheme following Crabtree and Miller's template method¹⁶ and a published framework for discussing incapacitated patients' values and preferences with surrogate decision makers¹⁷ (Figure 1). Using this framework allowed us to describe the extent to which clinicians and surrogates explicitly followed recommended practices. A priori, we decided to code for maximal inclusiveness regarding whether patients' values and preferences were discussed. Therefore, values were broadly defined as a patient's lifestyle, activities, attitudes, beliefs, and feelings about what makes life worth living, including prior vocation, family ties, substance use, hobbies, functional status, and personality traits. Preferences refer to a patient's previously stated wishes about life-extending treatments (ie, oral or written advance directives).¹⁸

A statement was any length of speech by an interlocutor that addressed a single idea. Therefore, an individual speech turn could receive multiple codes. To describe information exchange, we coded clinicians' and surrogates' statements about

Figure 1. Main Coding Scheme and the Elements of Shared Decision Making



The left-hand side shows the process of shared decision making. During information exchange, clinicians share clinical facts (ie, diagnosis, prognosis, treatment options [yellow]) and surrogates share personhood information (ie, values and preferences [blue]). During deliberation, they discuss how to apply the information to the decisions at hand, blending clinical and personhood

information (green). The goal of this process is a patient-centered treatment plan (green). The center shows the main coding scheme, which focuses on communication about the patient's values and preferences (blue and green), as well as secondary codes to verify that value-laden treatments were discussed. The right-hand column describes the purpose of each code.

patients' health-related values and past expressions of treatment preferences. To describe deliberation and treatment planning, we coded statements in which clinicians or surrogates attempted to apply patients' values and preferences to the current clinical context. The 3 deliberative strategies included attempts to interpret how the patient might feel about the prognosis and treatment options based on his values and preferences (eg, "He would hate being attached to machines."); statements about what treatment the patient might choose based on their values and preferences (ie, the surrogate's substituted judgment, eg, "He would want us to stop life support and let him go."); and clinicians' treatment recommendations based on patients' values and preferences (eg, "Based on what you're telling me about how independent he is and how hard it's been for him to accept help at home, I'm afraid we're not going to get him back to a quality of life that's acceptable to him. Perhaps we should consider making him comfortable.") We did not develop separate codes for deliberation vs treatment planning because they were operationally indistinguishable in these conferences. **Table 1** provides sample statements for each code.

We subcoded for discussion of 7 categories of values, developed a priori based on the literature about what many patients near the end of life judge to be important (**Figure 2**).¹⁹⁻²³ Statements received multiple codes if they addressed several values.

Coder Training and Coding Procedures

We used Atlas.ti, version 6.2 (Atlas.ti), for transcript data management. Two trained coders (L.P.S. and N.C.E.) initially coded a subset of 5 transcripts line by line, resolving any differences by discussion. We then used a bank of coded statements⁸ to test interrater reliability both before beginning to code (summary $\kappa = 0.92$) and midway through coding to assess for coder

drift (summary $\kappa = 0.89$). The individual κ values for each of the main codes in Figure 1 were 0.78 or higher.

All transcripts were coded once. The 2 coders then reviewed all statements, discussed any differences, and resolved discrepancies by consensus.

Statistical Analysis

We used Stata, version 13.0 (StataCorp), to conduct all descriptive and inferential analyses. Proportions and 95% CIs were calculated based on whether the code was present vs absent at the conference level. We then computed means (SDs), medians, and interquartile ranges (IQRs) for the number of coded statements per conference. We used the Wilcoxon rank-sum test to test for associations between the number of deliberative statements in the conference and the presence of a treatment recommendation based on the patient's values and preferences. Testing was 2-tailed, with a *P* value < .05 considered significant.

Results

Table 2 describes the study population. Overall, 275 of 405 (67.9%) eligible patients were enrolled in the parent study; 130 patients were not included because 21 clinicians and 109 surrogates declined to participate. Of 275 enrolled patients, 249 had an audiorecorded clinician-family conversation, which involved 450 surrogates and 141 clinicians.

Mean (SD) patient age was 58.2 (16.5) years; 134 patients (54.9%) were men, and 182 (74.6%) were non-Hispanic white. A total of 130 patients (53.3%) were admitted from home. One hundred eight patients (44.3%) died in the hospital. Mean age of the surrogate decision makers was 49.4 (13.9) years; 155 (34.4%) were men; and 261 (57.9%) were spouses or children

Table 1. Sample Statements

Element of Shared Decision Making	Sample Statements	
	Clinician	Surrogate
Information exchange about values and preferences	<p>And physically, was he fairly active? Does he do everything for himself at home?</p> <p>Prior to coming into the hospital, what was her life like? What was her quality of life like?</p> <p>I guess I kind of want to get a sense as to what ... what she was like.</p>	<p>He always told me, "Don't ever put me in a nursing home."</p> <p>I heard him say he wouldn't want to be a vegetable. He wouldn't want to be dependent on a machine.</p> <p>He said, "Do all you can. I have it on my directives ... I want you to do anything possible to bring me back to my kids. But if I'm not gonna ... I don't want to be here for a month ... trying to live for no reason."</p>
Deliberation about values and preferences		
Strategy 1: Interpreting how the patient might feel about the prognosis and treatment options	<p>What's the minimal outcome that would be acceptable to her? Because even with recovery, she's probably If she medically can get through this, she's probably looking at long-term care in skilled facilities, uh, or similar types of facilities, uh, over the next 3 months to a year or longer.</p> <p>Do you have any sense of how he'd feel about living like this?</p> <p>My concern is, you sort of said like, if he made it through this that he'd be mad at you.</p>	<p>I don't think he's gonna live a quality life like he wants. And what he told me, before, I couldn't ... I wouldn't have the heart to put him in a nursing home and to live on machines. That's no life.</p> <p>See, that would destroy her more.</p> <p>We just know our mother and she would not want anybody else to take care of her. Now the medical part of this, she would be all for doing whatever it would take to be okay.</p>
Strategy 2: Asking for/providing a substituted judgment about what treatment the patient might choose	<p>Knowing what I've just told all of you, would she want to keep going? And if so, how long?</p> <p>Do any of you have a sense of what she'd want to do in this spot?</p> <p>Is that what he would want?</p>	<p>I don't think she'd want that.</p> <p>If I looked at him and said, "If you had to make a choice, right now, between life and death, what would you take?" I cannot imagine my dad saying, "Death." As I couldn't imagine most people saying that. You know what I'm saying?</p> <p>I can't answer that right now.</p> <p>I don't know.</p>
Strategy 3: Making a treatment recommendation based on patient values and preferences	<p>She's been a fighter, she would want to keep fighting this right now. And we're going to do what we can to help her We know that's going to be tough going for her ... but, well how it impacts us today and tomorrow and the next day, is let's keep supporting her and do everything we can for her. And then give her the chance to prove us wrong.</p> <p>You know, especially, you're telling me he wouldn't want to go through a lot of really burdensome medical treatments for really not any likelihood of Right now, he wouldn't even approve of what's getting done to him right now. And I think it's absolutely the right thing not to put him through treatments that he wouldn't want. That's a really loving decision.</p>	<p>NA^a</p>

Abbreviation: NA, not applicable.

^a Applies to clinicians only.

of the patient. A total of 214 surrogates (47.6%) had at least some college education, and 350 (77.6%) described themselves as religious or very religious. Clinicians included attendings (72 [51.1%]), trainees (67 [47.5%]), and nurse practitioners (2 [1.4%]), of whom 86 (61.0%) were from nonsurgical specialties. Conferences occurred on ICU day 5.

Five of 249 (2.0%) conferences did not contain any discussion of goals of care (eTable in the Supplement). Thus, the reported statistics describe the 244 conferences in which goals of care were discussed. Among these 244 conferences, 63 (25.8%; 95% CI, 20.3%-31.3%) contained no information exchange or deliberation about patients' values and preferences.

Information Exchange About Patients' Values and Preferences

In 167 (68.4%; 95% CI, 62.6%-74.3%) conferences, clinicians and surrogates exchanged information about the patient's values and preferences. Within these conferences, clinicians asked a mean of 2.3 (median 1; interquartile range [IQR], 0-3) questions about patients' values and preferences, and surrogates made a mean of 5.2 (median, 4; IQR, 2-7) statements reporting them. Further data are reported in Table 3.

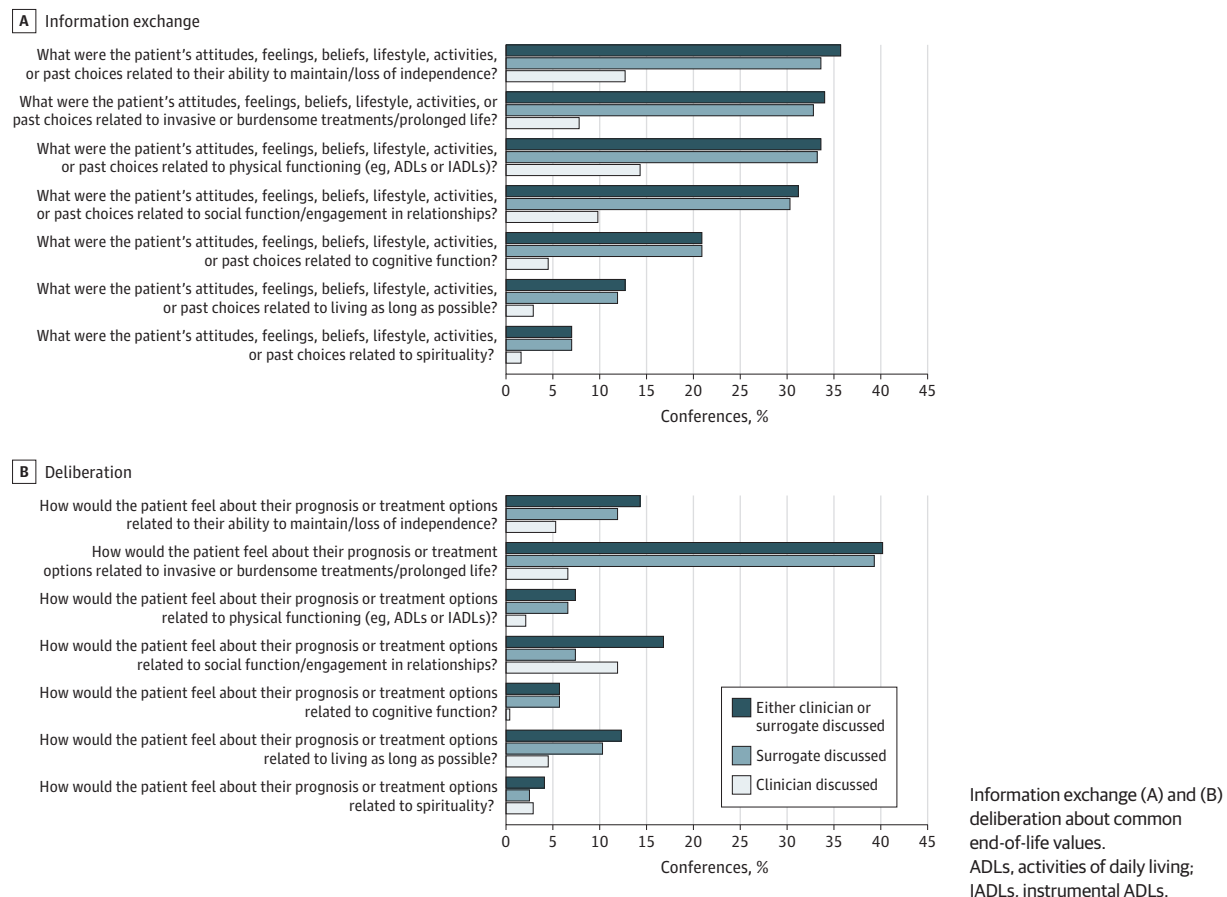
The most commonly discussed values were independence, including willingness to live in a nursing home (87

[35.7%]), and avoiding burdensome treatments, including prolonged life support (83 [34.0%]) (Figure 2A). Many statements were general; for example, some families talked about patients' level of functioning prior to hospitalization, saying things such as, "It's been years [since she was healthy] ... It's always been something that's been preventing her from being active," without explicitly addressing how patients felt about or coped with impaired functioning or reduced independence. In 20 (8.2%) conferences, the discussion was so general that it did not fit any of the 7 value categories. In these cases, conversation most typically centered on quality of life without specifying what constituted quality of life for that patient. For example, clinicians often asked questions such as, "[So] life was rich and full for her?" without exploring what made it that way.

Applying Values and Preferences to Decisions

In 136 (55.7%; 95% CI, 49.5%-62.0%) conferences, there was no deliberation about how to apply patients' values and preferences in the current clinical situation. Among the 108 (44.3%; 95% CI, 38.0%-50.5%) conferences with some deliberation, clinicians made a mean of 1.6 (median, 1; IQR, 0-2) statements and surrogates made a mean of 2.1 (median, 1; IQR 1-3) statements about applying patients' values and preferences to the

Figure 2. Frequency of Information Exchange and Deliberation in Clinician-Family Conferences (n = 244)



current situation. Among these 108 conferences containing deliberation, clinicians used 1 of the 3 deliberative strategies in 37 (34.3%), 2 strategies in 24 (22.2%), and all 3 in 6 (5.6%) conferences, and surrogates offered deliberations without clinician facilitation in 41 (38.0%).

The most commonly used deliberative strategy was discussing how to interpret patients' values and preferences in the current clinical situation (91 [37.3%] conferences). In 21 (8.6%) conferences, deliberations were generally about whether the likely outcome represented an acceptable quality of life, without specifying what would be acceptable or unacceptable about it. Of the 7 categories of values commonly important to patients near the end of life, discussions most often addressed how patients would feel about dying or being on prolonged life support (Figure 2B). Only 18 (7.4%) and 14 (5.7%) of the conferences, respectively, contained discussion of how patients would feel about living with prolonged physical or cognitive/emotional impairment.

Clinicians asked surrogates to make a substituted judgment about what treatment patients would choose 64 times within 40 (16.4%) conferences. In 2 of these conferences, the clinician was clarifying a substituted judgment the surrogate had already provided. In an additional 12 conferences, surrogates answered with a substituted judgment. In the remaining 26 conferences, the conversation turned to a different subject without the surrogate providing a substituted judgment.

In 20 (8.2%) conferences, clinicians provided a treatment recommendation based on surrogates' statements about patients' values and preferences. These 20 conferences contained significantly more deliberative statements than those with deliberation but no treatment recommendation (mean, 6.3 [median, 6, IQR, 3-8] vs mean, 3.1 [median, 2, IQR, 1-4], $P = .001$, using Wilcoxon rank-sum test), indicating a strong association between more extensive deliberation and a patient-centered treatment recommendation. Of these, 3 included a reference to a prior conversation about the patient's values and preferences, 1 responded directly to the values and preferences from information exchange, 5 occurred after deliberation about how to interpret the patient's values and preferences, and 11 occurred after both deliberation about interpreting the patient's values and preferences as well as discussion of a substituted judgment.

Discussion

In this large, multicenter study, there was no discussion of patients' values and preferences in 63 (25.8%) clinician-family conferences about prognosis and goals of care. Furthermore, when discussion was present, it was often limited, especially in regard to deliberations: the median number of deliberative statements by clinicians was 1.6 and surrogates was 2.1;

Table 2. Patient, Surrogate, and Clinician Characteristics

Characteristic	No. (%)		
	Patient (n = 249)	Surrogate (n = 450) ^a	Clinician (n = 141) ^b
Male	134 (54.9)	155 (34.4)	97 (68.8)
Race/ethnicity			
Non-Hispanic white	182 (74.6)	340 (75.6)	99 (70.2)
Non-Hispanic black	29 (11.9)	46 (10.2)	5 (3.6)
Hispanic	21 (8.6)	42 (9.3)	7 (5.0)
Asian/Pacific Islander	8 (3.3)	14 (3.1)	25 (17.7)
Native American	1 (0.4)	1 (0.2)	0
Other/undocumented	3 (1.2)	7 (1.6)	5 (3.5)
Age, mean (SD), y	58.2 (16.5)	49.4 (13.9)	5 (3.5)
Admission source			
Home	130 (53.3)	NA	NA
Acute care facility	96 (39.3)	NA	NA
Nursing facility	11 (4.5)	NA	NA
Other	4 (1.6)	NA	NA
Admission diagnosis			
Cardiovascular or cardiovascular surgery	87 (35.7)	NA	NA
Gastrointestinal or gastrointestinal surgery	12 (4.9)	NA	NA
Genitourinary	3 (1.2)	NA	NA
Hematologic	1 (0.4)	NA	NA
Metabolic	2 (0.8)	NA	NA
Neurologic or neurologic surgery	11 (4.5)	NA	NA
Respiratory	103 (42.2)	NA	NA
Trauma	23 (9.4)	NA	NA
Other	2 (0.8)	NA	NA
APACHE II score on day of conference, mean (SD)	26.7 (6.7)	NA	NA
No. of ICU days at the time of conference, mean (SD)	6.1 (3.3)	NA	NA
Died during this hospitalization	108 (44.3)	NA	NA
Surrogate relationship to patient			
Spouse/partner	NA	99 (22.0)	NA
Child	NA	162 (36.0)	NA
Sibling	NA	55 (12.2)	NA
Parent	NA	64 (14.2)	NA
Other relative	NA	58 (12.9)	NA
Other relationship	NA	11 (2.4)	NA
Not answered	NA	1 (0.2)	NA
Surrogate educational level			
Less than high school diploma	NA	40 (8.9)	NA
High school diploma	NA	113 (25.1)	NA
Some or all college	NA	214 (47.6)	NA
Graduate or professional school	NA	82 (18.2)	NA
Not answered	NA	1 (0.2)	NA
Religiosity			
Not religious	NA	33 (7.3)	31 (22.0)
Somewhat religious	NA	65 (14.4)	42 (29.8)
Religious	NA	140 (31.1)	43 (30.5)
Very religious	NA	210 (46.7)	24 (17.0)
Not answered	NA	2 (0.4)	1 (0.7)

(continued)

Table 2. Patient, Surrogate, and Clinician Characteristics (continued)

Characteristic	No. (%)		
	Patient (n = 249)	Surrogate (n = 450) ^a	Clinician (n = 141) ^b
Clinician staff position			
Attending physician	NA	NA	72 (51.1)
Fellow	NA	NA	40 (28.4)
Resident	NA	NA	27 (19.2)
Nurse practitioner	NA	NA	2 (1.4)
Clinician medical specialty ^c			
Anesthesia	NA	NA	6 (5.4)
Neurology	NA	NA	1 (0.8)
Surgery	NA	NA	23 (20.5)
Internal medicine	NA	NA	74 (66.1)
Internal medicine and anesthesia	NA	NA	3 (2.7)
Internal medicine and pediatrics	NA	NA	2 (1.8)
None/not answered	NA	NA	4 (3.6)
Clinician years in practice, mean (SD)	NA	NA	8.6 (9.6)

Abbreviations: APACHE, Acute Physiology Assessment and Chronic Health Evaluation; ICU, intensive care unit.

^a A total of 456 surrogates of 244 patients participated in the audiorecorded conferences, but 6 did not complete the baseline questionnaire, leaving 450.

^b A total of 142 unique clinicians of 244 patients participated in the audiorecorded conferences, but 1 did not complete the baseline questionnaire, leaving 141.

^c Applicable only if the clinician was an attending or fellow (n = 112).

discussion of common end-of-life values was not systematic, with the patient's values related to physical, cognitive, and social functioning each discussed in 35.7% or less of the conferences; and only 8.2% resulted in clinicians explicitly basing a treatment recommendation on patients' values and preferences. These results suggest that clinicians and surrogates do not talk about patients' values and preferences, making shared decision making impossible.

These findings expand on previous research showing that a significant proportion of clinician-family conferences about life-support decisions lack adequate communication about incapacitated, critically ill patients' values and preferences.⁷⁻¹² First, the size and diversity of our multicenter sample increased the likelihood that the results are generalizable to other institutions and populations across the country. Second, although prior research has focused on the presence or absence of discussion about patients' values and preferences, our study delved deeper into the structure and content of those discussions.

Structurally, we found that information exchange about patients' values and preferences occurred more often than explicit deliberation about how to apply them in the current clinical situation. Although deliberations tended to be brief, conferences that contained lengthier deliberations about how to interpret patients' values and preferences in the current clinical context were more likely to result in clinicians making a patient-centered treatment recommendation. Overall, this finding suggests that explicit discussion about how to interpret patients' values and preferences in light of the clinical situation may be an important deliberative strategy for generating

Table 3. Frequency of Information Exchange and Deliberation About Patients' Values and Preferences by Clinicians and Surrogates

Element of Shared Decision Making	Clinicians	Surrogates	Overall
Exchanged information About Patients' Values and Preferences			
Conferences, No. (%)	106 (43.4)	165 (67.6)	167 (68.4)
Statements per conference among conferences with discussion, mean (SD)	2.3 (3.6)	5.2 (4.8)	7.5 (7.8)
Deliberated About Patients' Values and Preferences			
Interpreted how patient might feel about the prognosis and treatment options			
Conferences, No. (%)	43 (17.6)	79 (32.4)	91 (37.3)
Statements per conference among conferences with discussion, mean (SD)	0.7 (1.3)	1.6 (1.6)	2.3 (2.4)
Asked for/provided a substituted judgment about what treatment the patient might choose			
Conferences, No. (%)	40 (16.4)	33 (13.5)	50 (20.5)
Statements per conference among conferences with discussion, mean (SD)	0.6 (1.1)	0.5 (1.0)	1.1 (1.8)
Made a recommendation based on patient values and preferences			
Conferences, No. (%)	20 (8.2)	NA ^a	NA ^a
Statements per conference among conferences with discussion, mean (SD)	0.3 (0.6)	NA ^a	NA ^a

Abbreviation: NA, not applicable.

^a Making a treatment recommendation applies to clinicians only.

a patient-centered treatment plan. Further research is needed to assess association between questions such as, “How would your dad feel about having to go through a prolonged course of rehabilitation, probably in a nursing facility?” with the quality of shared decision making.²⁴

In terms of content, we found that conversations frequently omitted considerations important to patients at high risk of death, especially those related to an acceptable level of functioning and quality of life. Without this information, clinicians cannot make patient-centered recommendations and surrogates cannot understand how treatments may reflect important patient values.²⁵ One possible reason clinicians do not discuss these levels is that they are not explicitly thinking about the relationship between prognosis or treatment options and values and preferences. Starting to do so may help clinicians facilitate more patient-centered conversations. Engaging surrogates in robust deliberation that connects patients' end-of-life values with a treatment plan may help clinicians feel more comfortable that surrogates understand the quality-of-life implications of their decisions. Including the surrogates may also mitigate many of their barriers to decision making, such as accepting a poor prognosis, understanding the risks and benefits of treatments, and agreeing on goals of care.²⁶

There are several research and clinical implications of our findings. First, interventions should be developed to better prepare surrogates for these difficult conversations—a major focus of advance care planning research.²⁷ Second, interventions are needed to teach clinicians communication skills for eliciting patients' values and preferences and then incorporating them into a treatment plan. Third, increased awareness that patients' values and preferences tend to be a blind spot in these conversations may prompt clinicians to discuss them. Until evidence from more definitive studies is available, we suggest that clinicians use 3 techniques: (1) asking what was important to patients about their previous functioning and quality of life, (2) asking how patients would feel about their expected level of function and lifestyle if they survive critical illness, and (3) providing (with surrogates' permission) a treatment recommendation that draws on preceding conversa-

tion about patients' values and preferences. This approach is supported by literature showing that palliative care clinicians help families understand prognostic information in light of patients' values,²⁸ family satisfaction is higher when the family talks more,²⁹ and empowering patients and families is essential for shared decision making.³⁰⁻³² A number of models are available to teach clinicians how to have these conversations.³³

Limitations

Our study has several limitations. First, only 1 clinician-family conference was recorded for each patient, and it is possible that prior or subsequent family conferences contained richer discussion of patients' values and preferences. Research is needed to describe how clinician-surrogate communication evolves over time. However, since 98% of the conferences contained discussion of treatment options, patients' values and preferences should have been relevant for the included conferences. Second, the Hawthorne effect may have affected these conferences by prompting clinicians' best efforts, meaning that our results may overestimate communication and underestimate the problem. Third, our results describe the context of acute critical illness and may not apply to other contexts of surrogate decision making, such as longstanding cognitive impairment (eg, dementia). Fourth, to our knowledge, no validated measures exist to assess the quality of communication about patients' values and preferences. Therefore, we cannot definitively judge whether what we observed was sufficient. However, our analyses were based on the central elements of shared decision making, according to which we found quantitative gaps in communication. Moreover, our inclusive approach to coding statements about the patient as a person may mean our results underestimate the scope of problems related to incorporating patients' values and preferences into treatment decisions.

Fifth, the parent study did not collect long-term outcomes data, so we were unable to investigate associations between communication about patients' values and preferences and eventual patient and family outcomes. Sixth, this study did not address other important dimensions of shared

decision making, relationships between them (eg, how discussion of treatment options and discussion of values and preferences affect each other), or why clinicians and surrogates struggle to discuss patients' values and preferences. These topics are important areas for further study. Seventh, because these conversations are culturally embedded, populations with different cultural norms require separate study.

Conclusions

Intensive care unit family conferences about goals of care appear to rarely follow recommended practices for shared decision making based on patients' values and preferences.

The biggest gaps noted in our study occurred in deliberating how patients would feel facing the current situation, particularly regarding their expected level of functioning if they survive critical illness. Without a shared understanding of patients' values and preferences in these areas, clinicians and families are likely to struggle to agree on a patient-centered treatment strategy. This situation merits development of interventions to better prepare surrogates to represent patients' values and preferences in ICU family conferences and train clinicians to facilitate these conversations. For now, we recommend that clinicians should ask questions and recommend treatment based on their best understanding of how patients would feel about their expected lifestyle and functioning after critical illness.

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REFERENCES

- Dowdy DW, Eid MP, Sedrakyan A, et al. Quality of life in adult survivors of critical illness: a systematic review of the literature. *Intensive Care Med*. 2005;31(5):611-620. doi:10.1007/s00134-005-2592-6
- Pandharipande PP, Girard TD, Jackson JC, et al; BRAIN-ICU Study Investigators. Long-term cognitive impairment after critical illness. *N Engl J Med*. 2013;369(14):1306-1316. doi:10.1056/NEJMoa1301372
- Herridge MS, Tansey CM, Matté A, et al; Canadian Critical Care Trials Group. Functional disability 5 years after acute respiratory distress syndrome. *N Engl J Med*. 2011;364(14):1293-1304. doi:10.1056/NEJMoa1011802
- Sacanella E, Pérez-Castejón JM, Nicolás JM, et al. Functional status and quality of life 12 months after discharge from a medical ICU in healthy elderly patients: a prospective observational study. *Crit Care*. 2011;15(2):R105. doi:10.1186/cc10121
- Guentner K, Hoffman LA, Happ MB, et al. Preferences for mechanical ventilation among survivors of prolonged mechanical ventilation and tracheostomy. *Am J Crit Care*. 2006;15(1):65-77.
- Kon AA, Davidson JE, Morrison W, Danis M, White DB; American College of Critical Care Medicine; American Thoracic Society. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society policy statement. *Crit Care Med*. 2016;44(1):188-201. doi:10.1097/CCM.0000000000001396
- White DB, Braddock CH III, Berecknyei S, Curtis JR. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. *Arch Intern Med*. 2007;167(5):461-467. doi:10.1001/archinte.167.5.461
- Scheunemann LP, Cunningham TV, Arnold RM, Buddadhumarak P, White DB. How clinicians discuss critically ill patients' preferences and values with surrogates: an empirical analysis. *Crit Care Med*. 2015;43(4):757-764. doi:10.1097/CCM.0000000000000772
- Mohan D, Alexander SC, Garrigues SK, Arnold RM, Barnato AE. Communication practices in physician decision-making for an unstable critically ill patient with end-stage cancer. *J Palliat Med*. 2010;13(8):949-956. doi:10.1089/jpm.2010.0053
- Uy J, White DB, Mohan D, Arnold RM, Barnato AE. Physicians' decision-making roles for an acutely unstable critically and terminally ill patient. *Crit Care Med*. 2013;41(6):1511-1517. doi:10.1097/CCM.0b013e318287f0dd
- Douglas SL, Daly BJ, Lipson AR. Neglect of quality-of-life considerations in intensive care unit family meetings for long-stay intensive care unit patients. *Crit Care Med*. 2012;40(2):461-467. doi:10.1097/CCM.0b013e31823d8c4
- Curtis JR, Engelberg RA, Wenrich MD, Shannon SE, Treece PD, Rubenfeld GD. Missed opportunities during family conferences about end-of-life care in the intensive care unit. *Am J Respir Crit Care Med*. 2005;171(8):844-849. doi:10.1164/rccm.200409-1267OC
- Chiarchiaro J, Buddadhumarak P, Arnold RM, White DB. Quality of communication in the ICU and surrogate's understanding of prognosis. *Crit Care Med*. 2015;43(3):542-548. doi:10.1097/CCM.0000000000000719
- Ernecoff NC, Curlin FA, Buddadhumarak P, White DB. Health care professionals' responses to religious or spiritual statements by surrogate decision makers during goals-of-care discussions. *JAMA Intern Med*. 2015;175(10):1662-1669. doi:10.1001/jamainternmed.2015.4124

15. Chiarchiaro J, Buddadhumaruk P, Arnold RM, White DB. Prior advance care planning is associated with less decisional conflict among surrogates for critically ill patients. *Ann Am Thorac Soc*. 2015;12(10):1528-1533. doi:10.1513/AnnalsATS.201504-253OC
16. Crabtree BF, Miller WL, eds. *Doing Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage Publications, Inc; 1999.
17. Scheunemann LP, Arnold RM, White DB. The facilitated values history: helping surrogates make authentic decisions for incapacitated patients with advanced illness. *Am J Respir Crit Care Med*. 2012;186(6):480-486. doi:10.1164/rccm.201204-0710CP
18. Llewellyn-Thomas HA, Crump RT. Decision support for patients: values clarification and preference elicitation. *Med Care Res Rev*. 2013;70(1)(suppl):50S-79S. doi:10.1177/1077558712461182
19. Fried TR, Bradley EH, Towle VR, Allore H. Understanding the treatment preferences of seriously ill patients. *N Engl J Med*. 2002;346(14):1061-1066. doi:10.1056/NEJMsa012528
20. Karel MJ, Moye J, Bank A, Azar AR. Three methods of assessing values for advance care planning: comparing persons with and without dementia. *J Aging Health*. 2007;19(1):123-151. doi:10.1177/0898264306296394
21. Ditto PH, Druley JA, Moore KA, Danks JH, Smucker WD. Fates worse than death: the role of valued life activities in health-state evaluations. *Health Psychol*. 1996;15(5):332-343. doi:10.1037/0278-6133.15.5.332
22. Hawkins NA, Ditto PH, Danks JH, Smucker WD. Micromanaging death: process preferences, values, and goals in end-of-life medical decision making. *Gerontologist*. 2005;45(1):107-117. doi:10.1093/geront/45.1.107
23. Patrick DL, Starks HE, Cain KC, Uhlmann RF, Pearlman RA. Measuring preferences for health states worse than death. *Med Decis Making*. 1994;14(1):9-18. doi:10.1177/0272989X9401400102
24. Schwarze ML, Campbell TC, Cunningham TV, White DB, Arnold RM. You can't get what you want: innovation for end-of-life communication in the intensive care unit. *Am J Respir Crit Care Med*. 2016;193(1):14-16. doi:10.1164/rccm.201508-1592OE
25. Volandes AE, Barry MJ, Wood F, Elwyn G. Audio-video decision support for patients: the documentary genre as a basis for decision aids. *Health Expect*. 2013;16(3):e80-e88. doi:10.1111/j.1369-7625.2011.00727.x
26. You JJ, Downar J, Fowler RA, et al; Canadian Researchers at the End of Life Network. Barriers to goals of care discussions with seriously ill hospitalized patients and their families: a multicenter survey of clinicians. *JAMA Intern Med*. 2015;175(4):549-556. doi:10.1001/jamainternmed.2014.7732
27. Sudore RL, Fried TR. Redefining the "planning" in advance care planning: preparing for end-of-life decision making. *Ann Intern Med*. 2010;153(4):256-261. doi:10.7326/0003-4819-153-4-201008170-00008
28. Norton SA, Metzger M, DeLuca J, Alexander SC, Quill TE, Gramling R. Palliative care communication: linking patients' prognoses, values, and goals of care. *Res Nurs Health*. 2013;36(6):582-590. doi:10.1002/nur.21563
29. McDonagh JR, Elliott TB, Engelberg RA, et al. Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. *Crit Care Med*. 2004;32(7):1484-1488. doi:10.1097/O1.CCM.0000127262.16690.65
30. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns*. 2014;94(3):291-309. doi:10.1016/j.pec.2013.10.031
31. Barratt A. Evidence based medicine and shared decision making: the challenge of getting both evidence and preferences into health care. *Patient Educ Couns*. 2008;73(3):407-412. doi:10.1016/j.pec.2008.07.054
32. Légaré F, Ratté S, Stacey D, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev*. 2010;(5):CD006732.
33. Arnold RM, Back AL, Barnato AE, et al. The Critical Care Communication project: improving fellows' communication skills. *J Crit Care*. 2015;30(2):250-254. doi:10.1016/j.jccr.2014.11.016

Invited Commentary

Communication About Treatment Options and Shared Decision Making in the Intensive Care Unit

Terri R. Fried, MD

The intensive care unit (ICU) is a site for frequent and complex medical decision making characterized by considerations to forgo or withdraw life-sustaining therapies. Shared decision making (SDM) is supported by critical care organizations as central to ensuring that care plans reflect patients' values. Surrogates are called upon to provide information about these values for the many patients who lack decisional capacity. A policy statement by the American College of Critical Care Medicine and American Thoracic Society defined SDM as "a collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals, and preferences."^{1(p2)}

The study by Scheunemann et al² in this issue of *JAMA Internal Medicine* provides an invaluable window into the extent to which the principles and practices of SDM are present in the ICU. The analysis used a unique resource of audio-recorded family conferences from multiple ICUs and methodically examined these recordings for the key elements of SDM involving surrogate decision makers. The authors defined SDM as information exchange and deliberation about values and

preferences, with deliberation consisting of interpretation of how patients would feel about their prognosis and treatment options, clinician solicitation of and surrogate provision of substituted judgment, and clinician treatment recommendation based on values and preferences.

Although there have been other examinations of SDM in the ICU, this study is notable for analyzing actual (rather than simulated) decisions involving 249 patients and 451 surrogates in a geographically diverse set of ICUs. The study demonstrated that 25.8% of the conferences included no information exchange and, even when this exchange occurred, it frequently involved general statements about the patient's health status prior to hospitalization without explicit consideration of what that status meant to the patient. There was even less deliberation about values and preferences, occurring in fewer than one-half of family meetings. When deliberation occurred, it was of limited scope, with discussions most often involving patients' attitudes toward dying and/or receiving prolonged life support and only rarely considering other outcomes of intensive care, such as physical and cognitive impairment.

The article by Scheunemann et al² confirms a body of research establishing that clinician-family decision making for critically ill patients who lack capacity is infrequently cen-