

Toward Shared Decision Making at the End of Life in Intensive Care Units

Opportunities for Improvement

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Background: In North America, families generally wish to be involved in end-of-life decisions when the patient cannot participate, yet little is known about the extent to which shared decision making occurs in intensive care units.

Methods: We audiotaped 51 physician-family conferences about major end-of-life treatment decisions at 4 hospitals from August 1, 2000, to July 31, 2002. We measured shared decision making using a previously validated instrument to assess the following 10 elements: discussing the nature of the decision, describing treatment alternatives, discussing the pros and cons of the choices, discussing uncertainty, assessing family understanding, eliciting patient values and preferences, discussing the family's role in decision making, assessing the need for input from others, exploring the context of the decision, and eliciting the family's opinion about the treatment decision. We used a mixed-effects regression model to determine predictors of shared decision making and to evaluate whether higher levels of shared decision making were associated with greater family satisfaction.

Results: Only 2% (1/51) of decisions met all 10 criteria for shared decision making. The most frequently addressed elements were the nature of the decision (100%) and the context of the decision to be made (92%). The least frequently addressed elements were the family's role in decision making (31%) and an assessment of the family's understanding of the decision (25%). In multivariate analysis, lower family educational level was associated with less shared decision making (partial correlation coefficient, 0.34; standardized β , .3; $P = .02$). Higher levels of shared decision making were associated with greater family satisfaction with communication (partial correlation coefficient, 0.15; standardized β , .09; $P = .03$).

Conclusions: Shared decision making about end-of-life treatment choices was often incomplete, especially among less educated families. Higher levels of shared decision making were associated with greater family satisfaction. Shared decision making may be an important area for quality improvement in intensive care units.

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IN THE UNITED STATES, 1 IN 5 deaths occurs in or shortly after discharge from an intensive care unit (ICU).¹ Most of these deaths are preceded by decisions to forgo life-sustaining treatment.^{2,3} Because most critically ill patients are unable to participate in end-of-life treatment decisions,^{2,3} family members are generally asked to speak for the patient and, to varying degrees, to participate in decision making.⁴ However, problems with end-of-life decision making are well documented in ICUs, including inadequate physician communication with surrogate decision makers,⁴ value conflicts,⁵ and physician-family disagreement about the care of patients who ultimately die.^{6,7}

In recent years, there have been calls to improve the quality of end-of-life decisions for incapacitated patients by fostering family involvement in these decisions.^{4,8,9} In 2004, North American and European critical care societies endorsed shared decision making between clini-

cians and family members for decisions to forgo life-sustaining treatment.^{10,11} This shared approach is supported by most critically ill patients^{4,12} and their family members; 81% of family members of ICU patients in a recent study¹³ wished to participate actively in treatment decisions.

What exactly is shared decision making? Many experts agree that shared decision making is a process of communication between clinicians and patients or surrogates that involves the following competencies: (1) discussing the nature of the decision to be made, (2) exchanging relevant medical information and information about a patient's values, (3) checking for understanding of information, (4) discussing preferred roles in decision making, and (5) achieving consensus about the treatment course most consistent with the patient's values and preferences.¹⁴ The shared approach to decision making is to be distinguished from paternalism, in which the physician makes the clinical decision with mere family assent, and from

Table 1. Relationship Between Coded Physician Behaviors and Shared Decision Making

Dimension of Shared Decision Making*	Coded Physician Behaviors
Providing medical information	(1) Discuss the nature of the decision. <i>What is the essential clinical issue we are addressing?</i> (2) Describe treatment alternatives. <i>What are the clinically reasonable choices?</i> (3) Discuss the pros and cons of the choices. <i>What are the pros and cons of the treatment choices?</i> (4) Discuss uncertainty. <i>What is the likelihood of success of treatment?</i> (5) Assess family understanding. <i>Is the family now an informed participant with a working understanding of the decision?</i>
Eliciting patient values and preferences	(6) Elicit patient values and preferences. <i>What is known about the patient's medical preferences or values?</i>
Exploring the family's preferred role in decision making	(7) Discuss the family's role in decision making. <i>What role should the family play in making the decision? Families should be offered a role in decision making even if some will decline, preferring to defer to the physician.</i> (8) Assess the need for input from others. <i>Is there anyone else the family would like to consult?</i>
Deliberation and decision making	(9) Explore the context of the decision. <i>How will the decision affect the patient's life?</i> (10) Elicit the family's opinion about the treatment decision. <i>What does the family think is the most appropriate decision for the patient?</i>

*Adapted from Charles et al.^{14,17}

informed choice, in which the physician only provides information and the family makes the final decision after receiving this information.¹⁵

Fully involving family members in shared decision making about major end-of-life decisions is a challenging task. Little training or research exists to guide physicians and other clinicians on how best to accomplish this. To date, no studies (to our knowledge) have evaluated the extent of shared decision making about major end-of-life decisions for critically ill patients. Moreover, little is known about whether characteristics of physicians or families predict the degree of shared decision making in ICUs. Therefore, we undertook this study to determine (1) the nature and extent of shared decision making about end-of-life treatment in ICUs, (2) what factors predict higher levels of shared decision making, and (3) whether there is an association between shared decision making and family satisfaction with communication.

METHODS

STUDY DESIGN, PATIENTS, AND SETTING

The study was conducted from August 1, 2000, to July 31, 2002, in 4 Seattle-area hospitals, including a county hospital serving an inner-city population, a university hospital, and 2 community hospitals. Through daily contact with charge nurses, we

identified eligible ICU family conferences meeting each of the following criteria: (1) they occurred on weekdays, (2) they included family members and physicians, and (3) all participants spoke English well enough not to require the use of an interpreter. To specifically identify conferences in which there would be deliberation about major end-of-life treatment decisions, we asked the patient's attending physician if he or she anticipated that there would be discussion of withholding or withdrawing life-sustaining treatment. Because conferences in which bad news is delivered often lead to discussion about limiting life support, we included conferences in which the physician anticipated discussing bad news. The conferences represent a consecutive sample of scheduled family conferences that occurred between 8 AM and 6 PM on weekdays. We excluded conferences in which the physician stated that these issues would not be discussed. We also excluded patients younger than 18 years. After talking with study staff and if all participants consented, the conference was audiotaped. Each hospital's institutional review board approved all procedures.

CODING AND ANALYSIS OF THE AUDIOTAPES

A medical transcriptionist transcribed the audiotaped conferences verbatim. These audiotapes and transcripts were then analyzed using a valid and reliable measure of shared decision making.¹⁶ The measure was developed to codify abstract principles of decision making into a practical model. Specific elements of the instrument translate into the kinds of questions that the clinician poses during the clinical encounter and represent the central aspects of shared decision making. **Table 1** lists the central aspects of shared decision making as conceptualized by Charles et al^{14,17} and the coding elements that assess these behaviors. Because obtaining information about the patient's values and treatment preferences from the family is an important part of shared decision making in ICUs and because it was not assessed on the original instrument, we added an element to assess this.

As described herein, coders were trained to evaluate the presence or absence of each of the 10 elements. An element was considered present if it was mentioned at all by a clinician or a family member, however briefly. Although the physician leading the conference usually addressed these elements, we included comments by any clinician present in the conference because these are often multidisciplinary conferences involving the expertise of nurses, social workers, and spiritual care providers. The 10 elements address the following clinician behaviors: (1) discussing the nature of the decision, (2) describing treatment alternatives, (3) discussing the pros and cons of the choices, (4) discussing uncertainty, (5) assessing family understanding, (6) eliciting patient values and preferences, (7) discussing the family's role in decision making, (8) assessing the need for input from others, (9) exploring the context of the decision, and (10) eliciting the family's opinion about the treatment decision.

CODER TRAINING

Two coders received intensive training on the shared decision-making coding, followed by extensive discussion with 3 of us (D.B.W., C.H.B., and S.B.). Afterward, the coders practiced coding skills in joint listening sessions in which initially the investigators highlighted specific examples of elements within the audiotaped conferences. The coders progressed through multiple iterations of joint listening and individual coding to accurately identify the presence or absence of each element.

INTERRATER RELIABILITY

Interrater reliability among the coders was calculated on a random sample of 20% of the audiotapes. The κ statistic for the 9 items originally part of the instrument was 0.69. The κ statistic for the item added to the original instrument (exploration of patient values and treatment preferences) was 0.91. In instances of discrepant coding, the 2 coders discussed and achieved consensus on those elements. The coders were blinded to the demographic and family satisfaction data on the questionnaires.

ASSESSMENT OF DEMOGRAPHICS AND CONFERENCE CHARACTERISTICS

Physicians and family members completed questionnaires addressing their demographic characteristics. We also asked the physician leading the conference to indicate how strongly he or she believed that life support should be withdrawn (10 [not at all] to 0 [very strongly]) and to rate his or her comfort discussing bad news with patients and family members (on a scale of 0 [not at all comfortable] to 10 [very uncomfortable]). After the conference, each family member completed a 6-item questionnaire about family satisfaction with communication (**Table 2**) adapted from a previously validated instrument.¹⁸ The internal consistency of the 6 items was high (Cronbach α , 0.92). The criterion validity of the instrument was supported by a strong correlation between the 6-item summary scores and subjects' responses to a single question assessing their satisfaction with the ICU conference ($r=0.76$, $P<.001$).

STATISTICAL ANALYSIS

We determined the summary shared decision-making score (range, 0 [least] to 10 [most]) for each conference and the frequency with which the individual elements were addressed in the conferences. We used a mixed-effects regression model to examine whether physician, family members, or patient characteristics were associated with the total shared decision-making score and to determine whether higher levels of shared decision making predicted greater family satisfaction with communication. A mixed-effects model permits appropriate analysis of clustered data. We initially analyzed each predictor in a univariate model, and we included all predictors with $P<.15$ in the final multivariate model. Regression assumptions (eg, influence, outliers, and nonconstant variance) were verified using graphical techniques, and all were met. We calculated partial correlation coefficients for both multivariate models. All analyses were performed using statistical software (STATA version 9.0; StataCorp LP, College Station, Tex). All reported P values are 2-sided. Statistical significance was set at $P<.05$.

RESULTS

Among 111 eligible family conferences identified, 51 were audiotaped (**Figure 1**). The proportion of all eligible conferences that were audiotaped was 46% (51/111).

CHARACTERISTICS OF THE PARTICIPANTS

Table 3 summarizes the demographic characteristics of the patients, the participating family members, and the physicians leading the conferences. The patients' in-hospital mortality was 80% (41/51). Sixty percent of family members were female, and 80.5% were of white race/ethnicity. The mean \pm SD age of family members was

Table 2. Questionnaire About Family Satisfaction With Communication*

Questionnaire

- How well did the doctor answer your questions about your loved one's illness and treatment?
- How well did the doctor listen to what you have to say?
- How well did the doctor ask about the kinds of treatments your loved one would want if she/he could speak for herself/himself?
- How well did the doctor help your family decide about the treatments your loved one would want?
- How well did this conference help you understand the choices and decisions that may need to be made?
- Overall, how would you rate the doctor's communication with you during the family conference?

*Adapted from McDonagh et al.¹⁸ The response choices comprise a scale ranging from 0 to 10, where 0 indicates "the very worst I could imagine" and 10 indicates "the very best I could imagine."

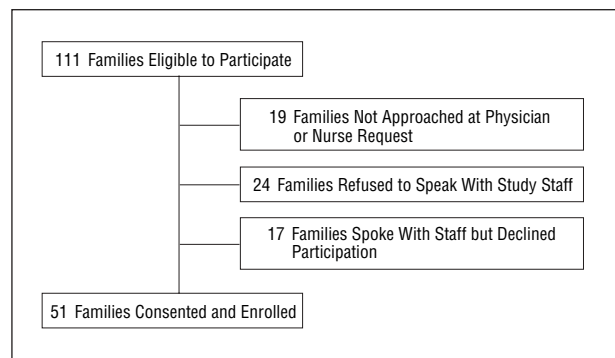


Figure 1. Flow diagram describing the enrollment of 51 family conferences.

48.0 \pm 15.8 years. Twenty-four physicians conducted a single conference, 7 conducted 2 conferences, 3 conducted 3 conferences, and 1 conducted 4 conferences. Fifty-seven percent of physicians leading the conferences were attending physicians, and 42.9% were residents or fellows under the direct supervision of an attending physician in all but 6 conferences. We do not have information about the amount of prior discussion and planning that occurred between attending physicians and trainees for the 6 conferences led by trainees without the attending physician present. Two hundred twenty-one clinicians participated, including the physicians leading the conferences, other physicians, nurses, social workers, and spiritual care providers. The number of clinicians in each conference ranged from 1 to 12, with a mean of 4.3.

CHARACTERISTICS OF THE CONFERENCES

In all but 2 conferences (96%), there was deliberation about whether to withdraw life support (44/51) or whether to write a do-not-resuscitate order (19/51). In the remaining 2 conferences, the main decisions were whether to perform a tracheostomy for prolonged ventilator dependence and whether to perform major abdominal surgery in the setting of prolonged multiple organ system dysfunction. The mean \pm SD duration of each conference was 32.0 \pm 14.8 minutes.

Table 3. Demographic Characteristics of Patients, Family Members, and Physicians*

Characteristic	Patients (n = 51)	Family Members Participating (n = 169)	Physicians Leading the Conferences (n = 35)
Sex			
Female	26 (51.0)	101 (59.8)	12 (34.3)
Male	25 (49.0)	68 (40.2)	23 (65.7)
Race/ethnicity†			
White	31 (60.8)	136 (80.5)	30 (85.7)
African American	7 (13.7)	14 (8.3)	0
Hispanic	2 (3.9)	6 (3.6)	2 (5.7)
Asian or Pacific Islander	1 (2.0)	5 (3.0)	4 (11.4)
Native American	1 (2.0)	10 (5.9)	0
Other or undocumented	9 (17.6)	0	1 (2.9)
Admission diagnosis			
Intracranial hemorrhage	9 (17.6)
End-stage liver disease or gastrointestinal tract bleeding	8 (15.7)
Trauma	8 (15.7)
Sepsis or infection	7 (13.7)
Respiratory failure	6 (11.8)
Cardiac failure or myocardial infarction	5 (9.8)
Other	8 (15.7)
Relationship to patient			
Spouse or partner	...	17 (10.1)	...
Child	...	35 (20.7)	...
Sibling	...	34 (20.1)	...
Parent	...	20 (11.8)	...
Friend	...	9 (5.3)	...
Other relative	...	52 (30.8)	...
Other	...	2 (1.2)	...
Staff position			
Attending physician	20 (57.1)
Resident or fellow	15 (42.9)
Specialty			
Internal medicine	26 (74.3)
Neurology	5 (14.3)
Surgery	3 (8.6)
Anesthesia	1 (2.9)
Age, y	60.0 ± 20.3	48.0 ± 15.8	38.0 ± 9.5
Years in practice	12.4 ± 9.7

*Data are given as the number (percentage) or as mean ± SD.

†Sum to more than 169 family members and more than 35 physicians because some individuals identified with more than 1 race/ethnicity.

ASSESSMENT OF SHARED DECISION MAKING

The mean ± SD shared decision-making score was 6.1 ± 1.8 (on a 10-point scale). **Figure 2A** shows the distribution of shared decision-making scores. Only 1 (2%) of 51 decisions met all 10 criteria for shared decision making. **Figure 2B** shows the proportion of conferences in which each element was addressed. There was substantial variation in the frequency with which individual elements of shared decision making occurred (range, 25%-100%). The most frequently addressed elements were the nature of the decision (element 1, 100%) and the context of the decision to be made (element 9, 92%). The least frequently discussed elements were the family's role in decision making (element 7, 31%) and an assessment

of the family's understanding of information relevant to the decision (element 5, 25%).

Six of the elements of shared decision making comprise an information-giving subscale (elements 1-4, 6, and 9) because these items predominantly assess whether salient information is exchanged about the patient and his or her illness (**Figure 2B**). The other 4 items comprise a process of decision-making subscale (elements 5, 7, 8, and 10) because these items primarily assess behaviors related to how the medical decision will be made. Physicians' mean ± SD scores were significantly higher on the information-giving subscale compared with the process of decision-making subscale (7.9 ± 2.0 vs 3.5 ± 2.5 on a normalized 10-point scale, $P < .001$).

FACTORS ASSOCIATED WITH SHARED DECISION MAKING

Table 4 summarizes the univariate relationships between predictors and the total shared decision-making score. Two factors were associated with higher shared-decision scores, including the strength of the physician's belief that life support should be withdrawn and higher family educational level. The physician's age, sex, race/ethnicity, specialty, and years in practice were not associated with the degree of shared decision making. There were also no differences in shared decision-making scores between conferences led by an attending physician and those led by a resident or fellow.

Table 5 lists the factors independently associated with the degree of shared decision making during the conferences. After adjusting for potential confounding and for clustering, there was a strong positive association between the strength of the physician's belief that life support should be withdrawn and the degree of shared decision making (partial correlation coefficient, 0.47; standardized β , .2; $P < .001$). The family educational level was strongly associated with the degree of shared decision making. For every 1-point increase in the family educational level on a 4-point scale, there was an absolute increase of 0.5 in the shared decision-making score (partial correlation coefficient, 0.34; standardized β , .3; $P = .02$).

ASSOCIATION BETWEEN SHARED DECISION MAKING AND FAMILY SATISFACTION

Eighty-two percent (175/214) of family members completed the 6-item questionnaire about family satisfaction with communication after the conference. The mean number of family members per conference who completed the questionnaire was 3.7 (range, 0-12). After accounting for clustering by conference and by physicians leading the conferences, there was a small but significant association between higher levels of shared decision making and greater family satisfaction with communication (partial correlation coefficient, 0.15; standardized β , .09; $P = .03$). The shared decision-making score explained only 3% of the variance in family satisfaction with communication.

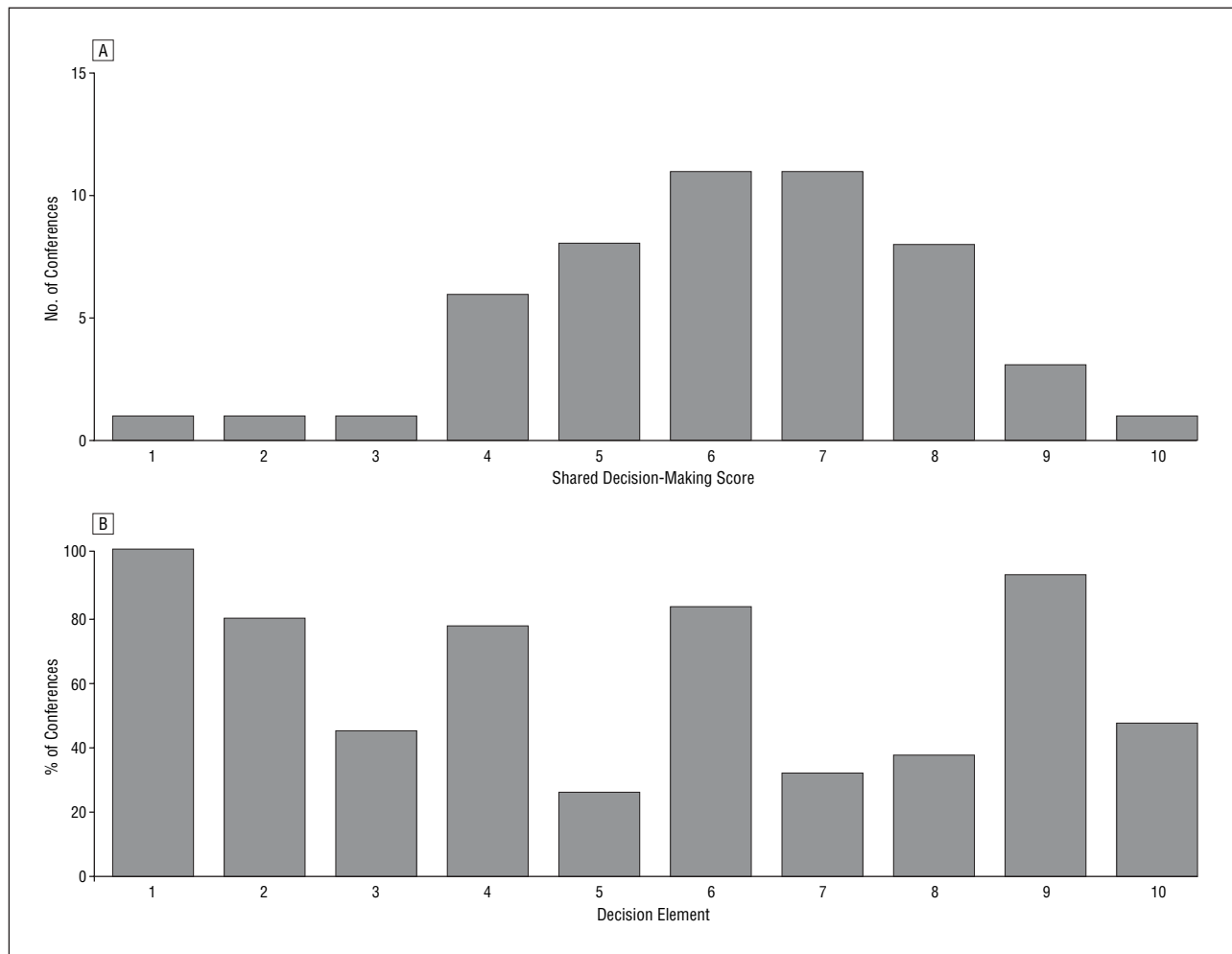


Figure 2. Shared decision making bar graphs. A, Distribution of shared decision-making scores on a scale of 0 (least) to 10 (most). The highest point on each bar indicates the number of conferences with that score. B, Frequency of elements of shared decision making. The bar graph shows the proportion of conferences in which the individual decision elements occurred, eg, decision element 5, assessing family understanding, occurred in 25% of the conferences. The 10 elements address the following clinician behaviors: (1) discussing the nature of the decision, (2) describing treatment alternatives, (3) discussing the pros and cons of the choices, (4) discussing uncertainty, (5) assessing family understanding, (6) eliciting patient values and preferences, (7) discussing the family's role in decision making, (8) assessing the need for input from others, (9) exploring the context of the decision, and (10) eliciting the family's opinion about the treatment decision.

COMMENT

We observed that shared decision making is often incomplete between clinicians and family members regarding end-of-life decisions for incapacitated ICU patients. Clinicians generally made efforts to understand patients' treatment preferences and to provide important medical information to families. However, clinicians rarely checked for family understanding of the information or elicited from the family members their preferred roles in decision making. We observed lower levels of shared decision making among less educated families compared with more educated families. We also observed higher levels of shared decision making the more the physician leading the conference believed that life support should be withdrawn.

Although our data suggest that clinicians actively strive to understand patients as individuals and to convey the medical information that families need to participate in treatment decisions, we identified several aspects of shared decision making that may be important targets for quality improvement efforts. Clinicians did not routinely check

that family members understood the information they were given. For families to participate in decision making, they need to understand the patient's condition and the likely outcomes of treatment.¹⁴ However, misunderstandings about prognosis are common between physicians and families of critically ill patients, even after physician-family conferences.^{4,19} Evidence from other disciplines in medicine suggest that patients better understand the treatment plan and have better outcomes when physicians explicitly check to make sure they have understood the information presented.²⁰ The relative infrequency of efforts to assure understanding raises the concern that family members may not be adequately informed to effectively participate in decision making.

We observed that clinicians generally did not inquire about families' preferred roles in decision making. There is wide variation among families' preferred roles in decision making, with approximately 15% of families preferring to leave decisions to the physician but with most preferring an active role in decision making.¹³ For some families, being asked to participate in end-of-life treat-

Table 4. Univariate Analysis of Factors Associated With Higher Levels of Shared Decision Making

Factor	Increase in Shared Decision-Making Score (95% Confidence Interval)	P Value
Physicians		
White race/ethnicity vs other	0.4 (-1.0 to 1.8)	.56
Male sex	-0.1 (-1.2 to 1.0)	.85
Age per 5-y increase	-0.1 (-0.4 to 0.2)	.38
Internal medicine specialty vs other Level of training	0.6 (-0.4 to 1.7)	.24
Attending physician vs resident or fellow	0.1 (-1.0 to 1.2)	.84
Years in practice per 1-y increase	0.0 (-0.1 to 0.1)	.62
Questionnaire responses		
Belief that life support should be withdrawn per 1-point increase*	0.2 (0.1 to 0.4)	.02
Physician-family conflict about withdrawing life support per 1-point increase†	-0.1 (-0.3 to 0.1)	.46
Comfort breaking bad news per 1-point increase	-0.1 (-1.0 to 0.7)	.76
Family Members		
White race/ethnicity vs other	-0.2 (-1.4 to 1.0)	.78
Educational level per 1-point increase in educational level‡	0.5 (-0.1 to 1.0)	.08
No. of family members at conference per 1-person increase	0.1 (-0.2 to 0.3)	.53
Patients		
White race/ethnicity vs other	-0.5 (-1.7 to 0.8)	.46
Male sex vs female	-0.2 (-1.2 to 0.9)	.73
Age per 5-y increase	0.0 (-0.1 to -0.2)	.79

*The response choices comprise a scale ranging from 0 to 10, where 0 indicates "not at all" and 10 indicates "extremely strongly."

†The response choices comprise a scale ranging from 0 to 10, where 0 indicates "no conflict" and 10 indicates "the worst situation I could imagine."

‡Highest educational level of any family member attending the conference, where 1 indicates high school or less; 2, some college; 3, college graduate; and 4, graduate school.

ment decisions will impose substantial emotional burdens.²¹ For others, it will provide an opportunity to honor the patient by ensuring that the treatment plan is consistent with the patient's values, even if those values are different from those of the family members.²² This variability in preferences suggests that explicit discussion of roles in decision making may be a crucial step in the process of achieving appropriate family involvement in decisions.¹⁰

Involvement in end-of-life treatment decisions may not be without risk for families of critically ill patients. In a study conducted in French ICUs, Pochard and colleagues⁴ reported that the strongest predictor of posttraumatic stress reaction in surrogate decision makers was if they reported inadequate receipt of information from the physician. They also noted that active participation in decisions was associated with more posttraumatic stress symptoms. Although this study assessed an individual's risk of posttraumatic stress reaction and not the actual diagnosis of posttraumatic stress disorder, it highlights the importance of providing families with adequate information and of inquiring about whether they want to be involved in decisions to limit life support. Our finding that physicians did not inquire about families' preferred roles

Table 5. Multivariate Analysis of Factors Associated With Higher Levels of Shared Decision Making*

Factor	Increase in Shared Decision-Making Score (95% Confidence Interval)	Standardized β Coefficient	P Value
Physicians			
Belief that life support should be withdrawn per 1-point increase†	0.3 (0.1 to 0.4)	.2	<.001
Family Members			
Educational level per 1-point increase in educational level‡	0.5 (0.1 to 0.9)	.3	.02

*The final multivariate model included 2 factors with $P < .15$ in the univariate analysis.

†The response choices comprise a scale ranging from 0 to 10, where 0 indicates "not at all" and 10 indicates "extremely strongly."

‡Highest educational level of any family member attending the conference, where 1 indicates high school or less; 2, some college; 3, college graduate; and 4, graduate school.

in decision making in more than two thirds of the conferences is concerning because it may result in families' actual roles in decision making differing from their preferred roles. Further research is needed to determine if tailoring family involvement in decisions to their preferred levels affects long-term psychological outcomes.

We observed higher levels of shared decision making among more educated families compared with less educated families. Although there is evidence that less educated individuals prefer a less active role in general medical decisions,²³ we are unaware of any evidence suggesting that subjects' educational levels are associated with their preferred roles in end-of-life decision making. Clinicians were no more likely to ask less educated families about their preferred roles in decision making. This suggests that the lower level of shared decision making observed in this population is not because of an explicit acknowledgment about decisional roles between clinicians and family members. Because we did not record information about families' preferred roles in decision making, we cannot exclude the possibility that clinicians were appropriately interpreting and acting on nonverbal cues about families' preferred roles in decision making. It is unclear why shared decision-making scores were lowest among the least educated families, but this finding warrants further investigation and may indicate an important target for quality improvement.

This study provides preliminary evidence that shared decision making about end-of-life treatment is associated with higher family satisfaction with communication. Although statistically significant, the amount of variance in family satisfaction explained by the shared decision-making score is small. Nevertheless, these results provide a measure of empirical support for the recent consensus statement from American and European critical care societies advocating shared decision making in ICUs.^{10,11} Randomized controlled trials are needed to determine the extent to which an intervention to foster shared decision making may improve family outcomes, including satisfac-

tion with decision making, and to evaluate the prevalence of complicated grief, posttraumatic stress disorder, and other psychological morbidity.

This study has several limitations. First, slightly less than 50% of eligible conferences were audiotaped. Our response rate reflects the known difficulty of enrolling families of patients near death in research studies.^{24,25} Because of privacy protections, we were unable to collect information from nonparticipants to determine if there were differences between physician-family pairs who agreed to audiotaping and those who did not. It is possible that the physician-family pairs who agreed to audiotaping were more comfortable with their shared relationship and that these conferences may represent better-than-average communication. Second, although participants were unaware of the specific study aims, knowledge that the conference was being audiotaped may have affected the clinicians' behavior. If being audiotaped influenced clinicians' communication about decision making, it would likely increase their performance, and our results may represent an overestimate of actual practice. Third, we audiotaped 1 conference per patient about end-of-life decision making. It is possible that for some patients there was more than 1 conversation about the decisions and that communication not audiotaped contained important elements of shared decision making not present in the audiotaped conference. Fourth, the instrument we used was originally designed to evaluate decision making in the outpatient setting and may not capture all the relevant aspects of shared decision making about limiting life support. However, the same ethical principles that apply to outpatient decision making apply to decision making at the end of life. Fifth, we used the shared decision-making score as a continuous measure with equal weighting for each element. Further research is needed to determine whether alternate ways of developing a score may provide a more valid and robust measure of shared decision making. Sixth, approximately 80% of family members and physicians in this study were of white race/ethnicity, and these findings may not generalize to ethnic groups underrepresented in the study sample.

End-of-life decisions in critically ill patients are complex from a medical perspective and from an emotional one. Shared decision making allows clinicians and family members to contribute their expertise to arrive at a medically sound treatment decision that is consonant with a patient's values and preferences. This study identifies aspects of shared decision making that may be important targets for future ICU quality improvement initiatives and provides preliminary evidence of an association between shared decision making and family satisfaction with end-of-life communication.

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REFERENCES

1. Angus DC, Barnato AE, Linde-Zwirble WT, et al. Use of intensive care at the end of life in the United States. *Crit Care Med*. 2004;32:638-643.
2. Prendergast TJ, Claessens MT, Luce JM. A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med*. 1998;158:1163-1167.
3. Cohen S, Sprung C, Sjøkvist P, et al. Communication of end-of-life decisions in European intensive care units. *Intensive Care Med*. 2005;31:1215-1221.
4. Pochard F, Darmon M, Fassier T, et al; FAMIREA Study Group. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death: a prospective multicenter study. *J Crit Care*. 2005;20:90-96.
5. Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. *Ann Intern Med*. 1990;(112):949-954.
6. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsy JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med*. 2001;29:197-201.
7. Breen CM, Abernethy AP, Abbott KH, Tulsy JA. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *J Gen Intern Med*. 2001;16:283-289.
8. Dowling J, Wang B. Impact on family satisfaction: the Critical Care Family Assistance Program. *Chest*. 2005;128(suppl):76S-80S.
9. Lederer MA, Goode T, Dowling J. Origins and development: the Critical Care Family Assistance Program. *Chest*. 2005;128(suppl):65S-75S.
10. Carlet J, Thijs LG, Antonelli M, et al. Challenges in end-of-life care in the ICU: statement of the Fifth International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. *Intensive Care Med*. 2004;30:770-784.
11. Thompson BT, Cox PN, Antonelli M, et al. Challenges in end-of-life care in the ICU: statement of the Fifth International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: executive summary. *Crit Care Med*. 2004;32:1781-1784.
12. Heyland DK, Tranmer J, O'Callaghan CJ, Gafni A. The seriously ill hospitalized patient: preferred role in end-of-life decision making? *J Crit Care*. 2003;18:3-10.
13. Heyland DK, Cook DJ, Rocker GM, et al. Decision-making in the ICU: perspectives of the substitute decision-maker. *Intensive Care Med*. 2003;29:75-82.
14. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med*. 1999;49:651-661.
15. Quill TE, Brody H. Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. *Ann Intern Med*. 1996;125:763-769.
16. Braddock CH III, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: time to get back to basics. *JAMA*. 1999;282:2313-2320.
17. Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment? *BMJ*. 1999;319:780-782.
18. 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;32:1484-1488.
19. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA*. 1998;279:1709-1714.
20. Schillinger D, Piette J, Grumbach K, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. *Arch Intern Med*. 2003;163:83-90.
21. Tilden VP, Tolle SW, Nelson CA, Fields J. Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nurs Res*. 2001;50:105-115.
22. Jacob DA. Family members' experience with decision making for incompetent patients in the ICU: a qualitative study. *Am J Crit Care*. 1998;7:30-36.
23. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making: a national study of public preferences. *J Gen Intern Med*. 2005;20:531-535.
24. Casarett DJ, Crowley R, Hirschman KB. Surveys to assess satisfaction with end-of-life care: does timing matter? *J Pain Symptom Manage*. 2003;25:128-132.
25. Krouse RS, Rosenfeld KE, Grant M, et al. Palliative care research: issues and opportunities. *Cancer Epidemiol Biomarkers Prev*. 2004;13:337-339.