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A M E R I C A N C O L L E G E O F
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Family Member Satisfaction With End-of-Life Decision Making in the ICU*

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Rationale: Families of ICU patients may be at risk for increased psychological morbidity due to end-of-life decision making. The identification of chart-based quality indicators of palliative care that predict family satisfaction with decision making may help to guide interventions to improve decision making and family outcomes.

Objective: To determine patient and family characteristics and chart the documentation of processes of care that are associated with increased family satisfaction with end-of-life decision making for ICU patients.

Methods: We conducted a cohort study of ICU patients dying in 10 medical centers in the Seattle-Tacoma area.

Measurement: Outcomes from family surveys included summary scores for family satisfaction with decision making and a single-item score that indicated feeling supported during decision making. Predictor variables were obtained from surveys and chart abstraction.

Main results: The survey response rate was 41% (442 of 1,074 families responded). Analyses were conducted of 356 families with questionnaire and chart abstraction data. Family satisfaction with decision making was associated with the withdrawal of life support, and chart documentation of physician recommendations to withdraw life support, discussions of patients' wishes, and discussions of families' spiritual needs. Feeling supported during decision making was associated with the withdrawal of life support, spiritual care involvement, and chart documentation of physician recommendations to withdraw life support, expressions of families' wishes to withdraw life support, and discussions of families' spiritual needs.

Conclusions: Increased family satisfaction with decision making is associated with withdrawing life support and the documentation of palliative care indicators including the following: physician recommendations to withdraw life support; expressions of patients' wishes; and discussions of families' spiritual needs. These findings provide direction for future studies to investigate approaches to improving family satisfaction in end-of-life decision making. In addition, because there were few nonwhites in this study, these results may not be generalizable to more diverse populations. Future studies should target diverse populations in order to test whether similar factors are similarly important for end-of-life decision making.

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Key words: decision making; end of life; family satisfaction; palliative care; posttraumatic stress disorder

Abbreviations: FS-ICU = Family Satisfaction in the ICU; FS-ICU Decision Making = satisfaction with decision making domain of Family Satisfaction in the ICU; FS-Support = "Did you feel supported during the decision-making process?" item; IQR = interquartile range; PTSD = posttraumatic stress disorder

Approximately 20% of all deaths in the United States occur in the ICU,¹ and the majority of ICU deaths involve decisions to withdraw life support.^{2,3} Because patients in the ICU are usually too ill or sedated to express their treatment preferences and values, a surrogate decision maker is often involved. The Study to Understand Prognoses and

Preferences for Outcomes and Risks of Treatment⁴ demonstrated that many physicians were unaware of their patients' preferences for end-of-life treatment and did not follow these preferences in the care that they delivered. Therefore, family members play an important role in decision making in the ICU setting.

There is growing recognition of the importance of developing a model that describes shared decision making in the ICU. However, there is considerable variability in the approaches used to accomplish this.⁵ Research^{6,7} has demonstrated that communication between physicians and surrogate decision makers is often poor. For example, one study⁷ found that 35% of surrogate decision makers did not understand the physician's explanation about the diagnosis or options for further care of the patient. Similarly, another study⁸ found that almost half of surrogate decision makers reported that physician-family communication was incomplete in the ICU.

Dissatisfaction with decision making among family members in the ICU may affect not only patient care, but also the psychological health of the decision makers. Pochard et al⁹ reported that 73% of surrogate decision makers experienced anxiety and 35% experienced depression during their loved one's ICU stay. Another study⁸ suggested that 33% of family members had a high burden of symptoms of post-traumatic stress disorder (PTSD) and that family members had a higher burden of PTSD symptoms if they were involved in end-of-life decision making. More recently, a randomized trial¹⁰ from France suggested that providing a bereavement packet and standardizing "end-of-life family conferences" to encourage family participation significantly decreased family symptoms of depression, anxiety, and PTSD 3 months after the patient's death. Therefore, understanding and improving the satisfaction of family members with decision making about end-of-life care in the ICU may be important not only for better patient-centered and family-centered care, but also as a way of reducing families' risks for developing symptoms of anxiety, depression, and PTSD after the death of a loved one in the ICU.

There is increasing interest in using the medical chart to identify indicators of high-quality palliative and end-of-life care in order to assess and improve the quality of care provided to patients and family members in the ICU. A 2006 expert consensus document¹¹ proposed 18 chart-based indicators, and

others¹² have proposed a "palliative care bundle" based on chart documentation of palliative care in the ICU. In this exploratory study, we used these palliative care indicators proposed by expert consensus to identify factors that may be associated with family members feeling more satisfied with and more supported during end-of-life decision making.

We hypothesize that there may be certain patient characteristics, family member characteristics, and end-of-life care processes that are associated with increased satisfaction in decision making, and that these may help to guide future research for developing interventions to improve shared decision making in the ICU. In addition, we believe that understanding approaches that may improve satisfaction with decision making in the ICU may be essential to identifying factors that may reduce the risk of psychological disease in family members of patients who die in the ICU.

MATERIALS AND METHODS

Design

We are currently performing a cluster randomized trial of an interdisciplinary, quality-improvement intervention to enhance palliative care in the ICUs of 15 hospitals in the Seattle-Tacoma, WA, area. For the current analyses, we used baseline survey and medical record abstraction data from 10 of these hospitals (data collected from August 9, 2003, to November 27, 2005). Hospitals included a university-affiliated county hospital (65 ICU beds), two community-based teaching hospitals (44 and 45 ICU beds), and seven community-based nonteaching hospitals (ranging in size from 15 to 45 ICU beds).

Questionnaires

The Family Satisfaction in the ICU (FS-ICU) survey is a valid and reliable instrument that is designed to measure family satisfaction with ICU care. Details of the original development and validation of the questionnaire have been presented elsewhere.^{13,14} Recently, Wall and colleagues¹⁵ developed a validated scoring method for the FS-ICU and empirically demonstrated the following two domains within the instrument: satisfaction with care; and satisfaction with decision making (FS-ICU Decision Making).

In the current study, our objective was to identify factors that have been previously suggested as indicators of high-quality palliative care by expert consensus documents^{11,12} and were associated with family satisfaction with decision making. Therefore, we used the FS-ICU Decision-Making subscale as our primary outcome variable. The subscale score was the mean of all valid responses on 10 relevant items and was transformed to range from 0 to 100, with higher scores indicating more satisfaction. Examples of the questionnaire items included the following questions: "Did you feel included in the decision-making process?" and "Did you receive an appropriate amount of information to participate in the decision-making process?" Total scores were calculated using a minimum of one valid response. Additionally, we included as a second outcome variable, the single item, "Did you feel supported

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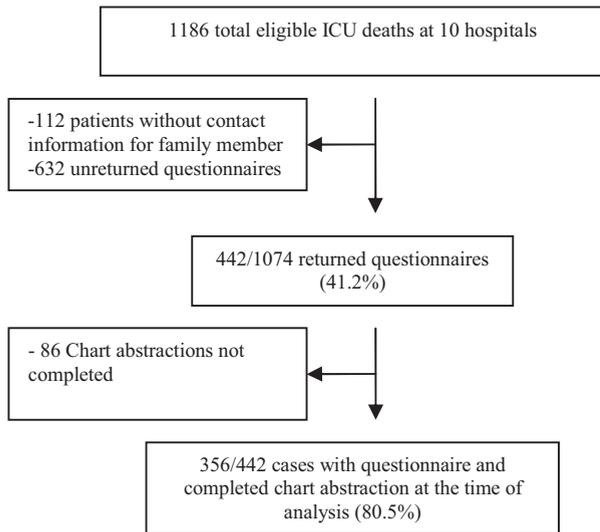


FIGURE 1. Identification of cases for analysis.

during the decision-making process?” (FS-Support). This item, which is included in the FS-ICU Decision-Making score, was also arithmetically transformed to a score of 0 to 100 from a scale of 1 to 5 to provide a score that is directly comparable to the FS-ICU Decision-Making subscale. This item was of interest because of its potential utility as a single-item outcome for measuring the effect of interventions designed to enhance the family’s decision-making experience.

Study Participants

Figure 1 shows the development of the sample of study subjects. Subjects included all patients dying in the ICU or within 24 h of transfer from the ICU and their family members. ICU decedents were identified using hospital admission, discharge, and transfer records. Patients who died within 24 h of being transferred from the ICU were included in order to capture patients who were transferred after life support withdrawal. Family members were identified using two approaches. At one site, the legal next of kin was identified from electronic medical records. At the other nine sites, the questionnaire was sent to the patient’s home and addressed to the “Family of [patient’s name].” All study procedures were approved by the institutional review boards of all participating hospitals.

Data Collection

Surveys along with \$10 incentives were mailed to the family member 1 to 2 months after the patient’s death, and included a cover letter expressing condolences and explaining the purpose of the study. An option was offered to the recipient to defer to another individual (family or friend) who was involved in the patient’s care, if they preferred. Family members could refuse participation by returning a self-addressed stamped refusal card, calling a toll free number, and leaving a message requesting no further mailings, or by returning a blank questionnaire. A reminder/thank-you card was mailed 1 week after the initial mailing. If the questionnaire packet was not received within the following 3 weeks, a final mailing with a second copy of the survey was sent. These methods were used to enhance response rates.¹⁶

Patients’ medical records were reviewed by trained chart abstractors using a standardized chart abstraction protocol. Chart

abstractor training included 80 to 120 h (2 to 3 weeks) of formal training. Training included instruction on the protocol, guided practice charts, and independent chart review with reconciliation with the research abstractor trainer. Abstractors were required to reach 90% agreement with the trainer before being able to code independently. After initial training, 5% of the charts were co-reviewed to ensure 95% agreement on the 440 abstracted data elements.

Statistical Analysis

Our primary goal was to identify predictors of family satisfaction with decision making when a loved one died in the ICU. We used two separate methods to assess family satisfaction with decision making. First, we used the 10-item FS-ICU Decision-Making subscale. Second, we examined a single FS-ICU item (FS-Support).

The predictor variables included patient characteristics (*eg*, age, race and ethnicity, and diagnosis), family member/friend characteristics (*eg*, age, race and ethnicity, education, and relationship to patient), and processes of care that were documented in the medical record (*eg*, withdrawing life support, use of spiritual care services, and documentation of discussions in family conferences) [Appendix]. Kruskal-Wallis tests were calculated for categorical predictor variables, and Mann-Whitney tests were performed for dichotomous predictor variables. Significance was reported at $p \leq 0.05$.

In order to assess whether respondents were significantly different from nonrespondents, we compared demographic characteristics including age, gender, race and ethnicity, insurance type, ICU admission diagnosis, comorbidities, and ICU length of stay. We used *t* tests for continuous variables that approximated a normal distribution, Mann-Whitney tests for nonnormally distributed continuous variables (*ie*, ICU length of stay), and χ^2 tests for categorical variables. All analyses were performed using a statistical software package (SPSS, version 13.0; SPSS; Chicago, IL).

RESULTS

After excluding patients for whom there was no contact information, survey packets were sent to 1,074 family members. Among the 442 family members who returned survey packets (response rate, 41.2%), chart abstraction data were available for 356 patients (Fig 1).

Baseline demographics of family members who returned questionnaires and patients, both with and without family questionnaires, are reported in Tables 1 and 2, respectively. Demographic characteristics for patients for whom questionnaires were not returned, compared to patients with returned questionnaires, did not vary significantly by age, gender, or insurance type. Patients with family member respondents were more likely to be white and to have had longer ICU stays. A lower proportion of patients with neurologic or psychiatric comorbidities had family members who responded to the survey.

The median FS-ICU Decision-Making score was 80 (interquartile range [IQR], 62.5 to 92.5).

Table 1—Demographics of Respondents (n = 356)*

Characteristics	Values
Age, yr	58.56 ± 14.54
Female gender	233 (65.4)
Race†	
White	305 (85.7)
Black	14 (3.9)
Asian	16 (4.5)
Pacific Islander	3 (0.8)
Native American	16 (4.5)
Hispanic	7 (2.0)
Other	8 (2.2)
Respondent relationship	
Spouse	153 (43.0)
Adult child	122 (34.3)
Sibling	23 (6.5)
Parent	17 (4.8)
Other	32 (9.0)
Unknown	9 (2.5)
Education	
Less than high school	11 (3.1)
High school	73 (20.5)
Some college or trade school	159 (44.7)
4-yr college degree	50 (14.0)
Graduate or professional school	52 (14.6)
Unknown	11 (3.1)

*Values are given as the mean ± SD or total No. (%).

†Respondents were allowed to enter more than one race/ethnicity.

No significant associations with the FS-ICU Decision-Making subscale score were found for a patient or family member demographic characteristics or for patient diagnoses (data not shown). Processes of care that were significantly associated with higher FS-ICU Decision-Making subscale scores included medical record documentation of the following: (1) having life support withdrawn ($p \leq 0.001$); (2) having a physician recommend withdrawal of life support therapies during a family conference ($p = 0.02$); (3) discussing the patient's end-of-life wishes during the family conference ($p = 0.01$); and (4) discussing spiritual needs during a family conference ($p = 0.05$). Lower scores were significantly associated with having documentation of family-physician discord during a family conference ($p < 0.001$) [Fig 2].

The median score for the single item FS-Support was 75 (IQR, 50 to 100). Significant associations with the single item FS-Support are shown in Figure 3. No patient or family demographic characteristics or patient diagnoses were associated with this item (data not shown). Medical record documentation of the following processes of care was associated with higher scores on this item: (1) having life support withdrawn ($p = 0.002$); (2) involvement of spiritual care services ($p = 0.02$); (3) having a physician recommend withdrawal of life support therapies during a family conference ($p = 0.04$); (4) having the family express wishes to withdraw

life support during a family conference ($p = 0.03$); and (5) having spiritual needs discussed at a family conference ($p = 0.002$). A lower FS-Support item score was associated with family-physician discord occurring during the family conference and documented in the chart ($p < 0.001$), and with the patient dying in the setting of full support ($p = 0.02$).

CONCLUSIONS

Our findings suggest that family members with a loved one dying in the ICU report more satisfaction with decision making and report feeling more supported during the decision-making process in situations where life support is withdrawn, when there is more complete chart documentation of communication during the family conference and in circumstances where there is chart documentation of an assessment of the spiritual care needs of family members. Of interest, family or patient demographics such as age, race and ethnicity, education level, gender, and number and type of patient comorbidities were not associated with family member satisfaction in end-of-life decision making in our study. Other studies^{17–19} have shown an association between satisfaction with care and demographics such as race, ethnicity, and education.

Family members who made a decision to withdraw life-sustaining efforts reported greater feelings of support during end-of-life decision making and higher satisfaction with end-of-life decision making. This finding suggests that being involved in this decision may be an important aspect of satisfaction with the decision-making process. These results could be related to the family accepting the inevitable, preparing for their loved one's death, and having some sort of control in this situation. For example, these findings are supported by a study²⁰ showing that most ICU family members do not want to keep their loved one "alive on life support when there is little hope for a meaningful recovery." Similarly, another study²¹ showed that family members of a dying patient needed adequate time to prepare for the death of their loved one. Cumulatively, these findings suggest that supporting family members through the decision to withdraw life support when survival is unlikely could be an important target for future studies to investigate in order to improve satisfaction with decision making in the ICU.

However, although supporting family members in their decision to withdraw life support may be an important intervention, it is important to note

Table 2—Demographics for Patients for Whom Family Members Responded to the Survey and Those Patients for Whom Family Members Did Not Respond*

Patient Characteristics	Patients With a Family Survey Returned (n = 356)	Patients Without a Family Survey Returned (n = 484)	p Value
Age, yr	70.1 ± 15.9	68.1 ± 16.2	0.072
Female gender	147 (41.3)	229 (47.3)	0.083
Race†			
White	278 (78.1)	288 (59.5)	< 0.001
Black	8 (2.2)	42 (8.7)	< 0.001
Asian	13 (3.7)	46 (9.5)	0.001
Pacific Islander	0 (0)	12 (2.5)	< 0.01
Native American	2 (0.6)	6 (1.2)	0.195
Hispanic	4 (1.1)	4 (0.8)	0.05
Other	1 (0.3)	5 (1.0)	0.148
Insurance type			0.514
Private/commercial	33 (9.3)	38 (7.9)	
Government/public	252 (70.8)	346 (71.5)	
None, unknown	71 (19.1)	100 (20.7)	
Hospital admission diagnosis†			0.02
Cardiovascular events, illness	69 (19.4)	69 (14.3)	
Trauma	41 (11.5)	29 (6.0)	
Sepsis	37 (10.4)	53 (11.0)	
Respiratory failure/pulmonary disease	33 (9.3)	65 (13.4)	
Pneumonia	27 (7.6)	30 (6.2)	
Comorbidities†			
Cardiovascular	145 (40.7)	191 (39.5)	0.152
Respiratory	99 (27.8)	149 (31.2)	0.293
Oncologic	94 (26.4)	110 (22.7)	0.057
Neurologic	56 (15.7)	86 (17.8)	< 0.001
Hepatic	29 (8.1)	44 (9.1)	0.137
Renal	22 (6.2)	44 (9.2)	0.109
Psychiatric	110 (30.9)	197 (40.7)	0.001
Length of ICU stay, d	2.79 (0.89–7.06)	2.38 (0.75–5.8)	0.0221

*Values are given as the mean ± SD, No. (%), or median (IQR), unless otherwise indicated.

†More than one response could be entered per patient.

that not all decisions to withdraw life support are under the control of ICU clinicians. First, family members may not be ready to withdraw life support even if death is inevitable because they have not come to terms with their loved one's illness and impending death.²² Second, the details and trajectory of the illness or injury may incorporate a high level of uncertainty about the outcome. Uncertainty about the outcome may result in unclear recommendations from the physician about end-of-life decisions^{23,24} and could also possibly lead to worse family satisfaction in decision making and feelings of support. In contrast, if the physician makes recommendations to withdraw life support when the outcome is uncertain, family members could lose trust in the physician or may feel as if they have to make the decision on their own.²⁵ These two situations might potentially be associated with family dissatisfaction with decision making and be difficult for clinicians to address. Nonetheless, since the majority of deaths are preceded by a decision to withdraw life-sustaining treatment, we believe that our findings suggest

that the process of supporting family members through a decision to withdraw life support when survival is unlikely may be an important area to investigate in future research.

In the past few years, several studies have suggested that reducing the number of days spent in the ICU prior to death by implementing proactive ethics consultation,²⁶ proactive palliative care consultation,^{27–29} and routine ICU family conferences³⁰ can lead to improved quality of care. Although these studies demonstrated a “reduction in the prolongation of dying” in the ICU, they did not examine family satisfaction with decision making or family outcomes such as symptoms of depression, anxiety, or PTSD. Our findings suggest that the proactive identification of circumstances in which the withdrawal of life support is indicated may also be associated with increased family satisfaction with decision making. Furthermore, a recent randomized trial¹⁰ found that an intervention including a standardized end-of-life family conference focused on supporting the involvement of family members, in addition to the administration of a bereavement

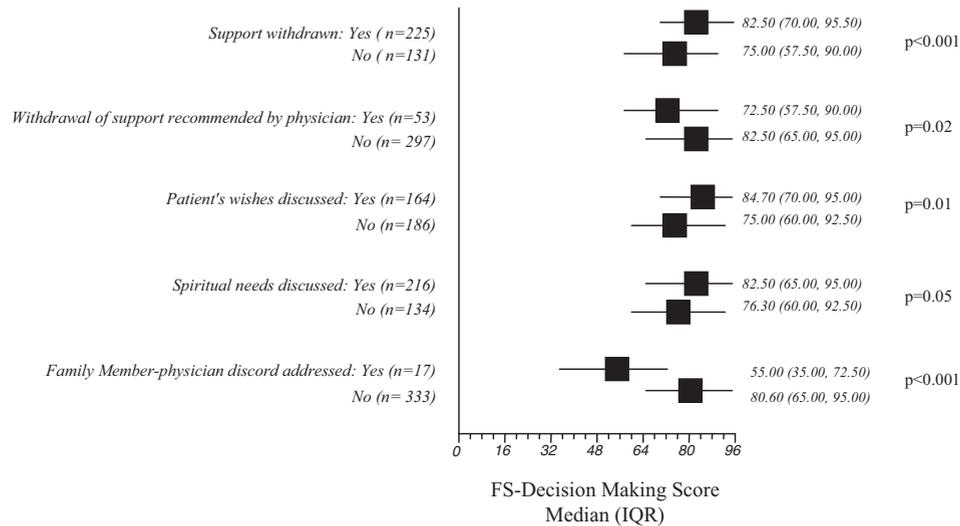


FIGURE 2. Significant associations between the FS-ICU Decision-Making subscale score and the processes of care variables.

pamphlet, resulted in a dramatic decrease in symptoms of depression, anxiety, and PTSD in family members. Our study provides specific suggestions for other components of care for family members that may be useful for interventions to improve satisfaction with decision-making and psychological outcomes. Future studies should examine the effect of improving communication and reducing the prolongation of dying in the ICU on family satisfaction with decision making.

Our results also suggest that family members felt more support and were more satisfied with the decision-making process when spirituality was addressed during a family conference. A previous report³¹ on the family members of pediatric patients similarly showed that families were more satisfied and felt more supported with their end-of-life decisions when spiritual care was offered. Spirituality may provide a platform for family members to express themselves and feel com-

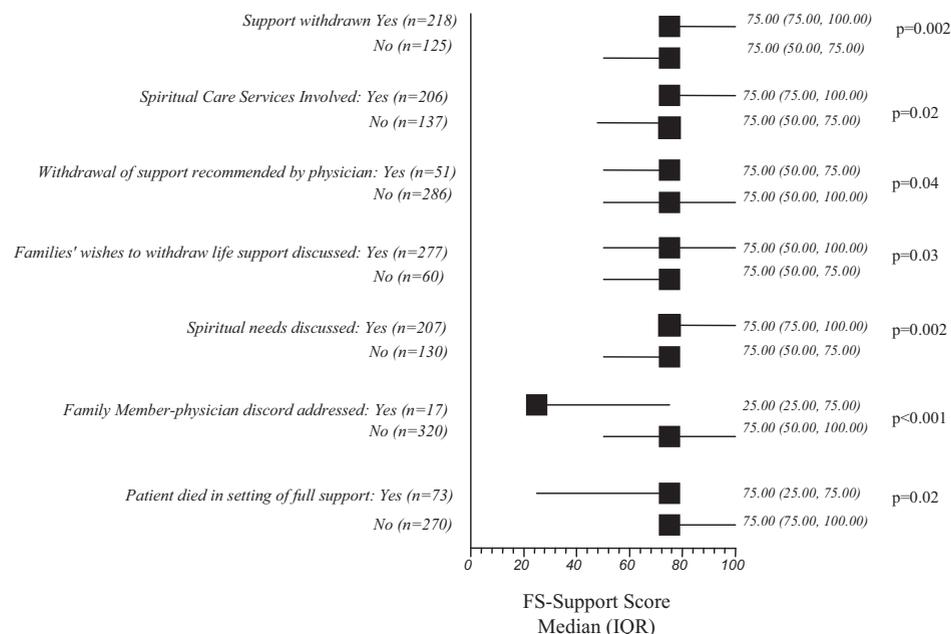


FIGURE 3. Significant associations between the FS-Support item score and the processes of care variables.

forted. Families may be able to use spiritual care to cope with death and the guilt of “letting their loved one go.”³² The association between the documentation of the discussion of spiritual needs and increased satisfaction with end-of-life decision making suggests that the involvement of spiritual care at the end of life is an important aspect for future investigation.

Our finding that family-physician disagreements are significantly associated with less family satisfaction with decision making and decreased feelings of support during the process suggests that effective communication and conflict resolution between the physician and family member are important. Although family-physician disagreement was documented in medical records in only 5% of the cases, other studies³³ have suggested that, when specifically asked about conflict, family members report family-physician conflict in 40% of the cases. Abbott and colleagues³³ reported that family-physician conflict was most commonly attributed to poor communication (33%) or the unprofessional behavior of the staff (15%). Therefore, we believe that improving communication strategies and reducing clinician-family discord may also be crucial to investigate in future studies that investigate improving family member satisfaction with decision making.

Our study has several limitations. First, although we designed this study as an exploratory analysis, multiple comparisons could have led to spurious associations. Therefore, our results should be considered hypothesis-generating, and additional research testing of these associations is needed. Second, our study had a relatively low response rate of 41%. This low response rate is typical in this type of survey research that contacts the families of patients who have died.^{14,34–36} Third, we found that patients of nonresponding family members were less likely to be white and had shorter ICU stays, suggesting that there may be some response bias. These results have been demonstrated elsewhere and suggest that further research is needed to improve the response rates of minorities.³⁷ However, it is important to note that there is no ethical alternative to allowing family members to opt out of participation. Because of this difference, these results may not be generalizable to nonwhite populations, and the further investigation of predictors that are associated with end-of-life decision making in minor-

ity patients should be specifically studied. Fourth, the validity of using chart documentation of processes of care as a surrogate marker for quality of care is limited by the comprehensiveness of the documentation in the medical record.³⁸ In addition, we did not survey the family members about their perceptions of family conferences, and it is unclear whether family perceptions would be a better predictor of satisfaction than chart documentation. Also, the physician who documents family conference discussions may have other characteristics or skills that may lead to higher family member satisfaction with decision making. Although the family conference documentation in the medical record is likely to be incomplete, the fact that we found positive associations between satisfaction with decision making and chart-assessed processes of care suggests that chart documentation of these aspects of care yields potential markers for improved family experience. Finally, this study took place in 10 hospitals in the Seattle-Tacoma area, and the findings may not generalize to other areas.

In order to develop or refine ICU-based strategies that may increase family member satisfaction with decision making and may lead to improved quality of end-of-life care in the ICU, we will need to fully understand the potential predictors associated with family member satisfaction with end-of-life decision making. Although our results may not be generalizable to nonwhite populations, our findings suggest that family members feel more satisfied and supported in the decision-making process in circumstances in which life support is withdrawn. They also report feeling more satisfied and supported in circumstances where there is chart documentation of family conference discussions about the patient's end-of-life wishes, physician recommendations for withdrawing life support, and attention to families' spiritual needs. A recent randomized trial¹⁰ demonstrated that a focus on communication can improve family outcomes, and our findings complement this prior study by providing some specific guidance for the development of future interventions to support families during decision making regarding end-of-life care. Future studies are warranted to evaluate end-of-life decision making in minority patients, and to further investigate novel interventions to improve communication about the withdrawal of life support and to increase the involvement of spiritual care services in all populations.

APPENDIX

Predictor Variables Assessed*

Patient
Demographics
Age at time of death
Gender
Race
Ethnicity
Insurance type
Consults
Palliative care consult
Social work consult
Spiritual care consult
Orders
DNR order in place
Died in the setting of full support
Support withdrawn
CPR was ordered/performed in the last hour of life
Status
On the ventilator in the last week of life
On noninvasive positive-pressure ventilator in the last week of life
Mental status in the last day of life
Comorbidities
Renal disease, arthritis, COPD, peptic ulcer, HIV, heart disease/hypertension/peripheral vascular disease, liver disease, stroke, drug/alcohol abuse, history of psychological disease, and history of trauma
Family member
Demographics
Age
Gender
Race
Ethnicity
Education status
Family relationship
Relationship to patient
Years that the family member knew the patient
Lived with patient
Family conference from first and last 72 h of ICU stay
Family conference occurred
Prognosis discussed
Withdrawal of support recommended by physician
Family wishes to withdraw life support discussed
Patient's wishes discussed
Spiritual care needs discussed
Family discord with other family member/doctor/nurses

*DNR = do not resuscitate; CPR = cardiopulmonary resuscitation.

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