Identifying Elements of ICU Care That Families Report as Important But Unsatisfactory

Decision-Making, Control, and ICU Atmosphere

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Background: One in five deaths in the United States occurs in the ICU, and many of these deaths are experienced as less than optimal by families of dying people. The current study investigated the relationship between family satisfaction with ICU care and overall ratings of the quality of dying as a means of identifying targets for improving end-of-life experiences for patients and families.

Methods: This multisite cross-sectional study surveyed families of patients who died in the ICU in one of 15 hospitals in western Washington State. Measures included the Family Satisfaction in the ICU (FS-ICU) and the Single-Item Quality of Dying (QOD-1) questionnaires. Associations between FS-ICU items and the QOD-1 were examined using multivariate linear regression controlling for patient and family demographics and hospital site.

Results: Questionnaires were returned for 1,290 of 2,850 decedents (45%). Higher QOD-1 scores were significantly associated (all $P < .05$) with (1) perceived nursing skill and competence ($\beta = 0.15$), (2) support for family as decision-makers ($\beta = 0.10$), (3) family control over the patient's care ($\beta = 0.18$), and (4) ICU atmosphere ($\beta = 0.12$). FS-ICU items that received low ratings and correlated with higher QOD-1 scores (ie, important items with room for improvement) were (1) support of family as decision-maker, (2) family control over patient's care, and (3) ICU atmosphere.

Conclusions: Increased support for families as decision-makers and for their desired level of control over patient care along with improvements in the ICU atmosphere were identified as aspects of the ICU experience that may be important targets for quality improvement.

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Abbreviations: FS-ICU = Family Satisfaction in the ICU; IQR = interquartile range; QOD-1 = Single-Item Quality of Dying and Death; QODD = Quality of Dying and Death

Despite efforts over the past several decades, there is a continuing need to improve the quality of the end-of-life experiences for individuals undergoing treatment within the US health-care system.¹ Because one in five deaths in the United States occurs in the ICU, the ICU is an important focus for improving these end-of-life experiences.² Direct assessment of the patient's perception of the quality of dying often is not possible, especially within the ICU setting.^{3,4} Researchers, therefore, rely on family members and clinicians to assess the quality of the dying experience.⁵ Several tools, such as the Quality of

Dying and Death (QODD) questionnaire and the Family Satisfaction in the ICU (FS-ICU) survey, have been used as surrogate-completed measures of the quality of the end-of-life experience.⁶⁻¹² Both tools provide validated data that may be useful in understanding and improving patient and family experiences at the end of life. Unfortunately, these questionnaires contain a large number of questions and, therefore, implementing quality improvement measures directed at all aspects identified by these tools can be cumbersome.¹³⁻¹⁵ Further, it is unclear which, if any, of the individual aspects of satisfaction with care are most

predictive of the overall quality of dying and, thus, represent important items to target for quality improvement measures. A recent randomized trial that implemented a general quality improvement intervention for palliative and end-of-life care showed no benefit, suggesting the need for interventions that focus on specific aspects of care at the end of life that are documented to contribute to a good death from patient and family perspectives.¹³

In this study, we evaluated the association of specific items of the FS-ICU survey with family-reported scores on the single summary item from the QODD questionnaire that evaluates the overall quality of dying (Single-Item Quality of Dying and Death [QOD-1]) for patients who died in or shortly after a stay in the ICU. We used an approach that enabled us to identify aspects of care from the FS-ICU survey that were significantly correlated with increased satisfaction with the quality of dying and had relatively low satisfaction ratings, suggesting room for improvement.^{16,17} Such items, if identified, could potentially be targets for successful quality improvement interventions for end-of-life care in the ICU.

MATERIALS AND METHODS

Design Overview

Data were collected as part of a cluster randomized trial at 15 western Washington State hospitals to evaluate an interdisciplinary intervention to improve the quality of care for patients who die in the ICU.¹³⁻¹⁵ Because the primary outcome for the randomized trial was not significant, we pooled data from both control and intervention periods. All patients who died in the ICU or within 30 h of transfer out of the ICU were identified. Because medical records at these sites did not provide locator information for patients' families, questionnaires were sent to patients' homes 4 to 6 weeks after their deaths addressed to "the family of," requesting a response from the person most knowledgeable about the patient's end-of-life experience. To enhance response rates, we used survey methods suggested by Dillman,¹⁸ including a \$10 monetary incentive, reminder and thank-you postcards 3 weeks after the initial questionnaire distribution, and a second

set of materials to nonrespondents after 5 weeks. All procedures were approved by the institutional review boards at all institutions (e-Appendix 1).

Measures

The QODD questionnaire allows families or clinicians to retrospectively evaluate a patient's experiences at the end of life. Two versions have been developed: one for deaths occurring in community settings (31 items) and one for deaths occurring in the hospital or ICU (22 items).^{9,11,19} The QODD questionnaire has demonstrated good internal consistency and construct validity, correlating significantly with other measures of quality of care.^{9,12} Both QODD versions contain the following summary item: "Overall, how would you rate the quality of your loved one's dying?" This item, the QOD-1, is of interest because of its potential utility as a succinct measure of the effect of interventions on the quality of dying. It uses a rating scale of 0 to 10 and has previously been associated with indicators of palliative care in the ICU.²⁰

The FS-ICU survey is a reliable and valid 34-item questionnaire that measures family satisfaction with ICU care.^{6,7} A validated scoring method has been developed for a 24-item version and includes the following three scores ranging from 0 to 100: a total satisfaction score (24 items), a satisfaction with care domain score (14 items), and a satisfaction with decision-making domain score (10 items).⁸

Data Analysis

We used a three-step analytic approach to describe associations between FS-ICU items and the QOD-1. Initially, we explored the associations between each item of the FS-ICU survey and the QOD-1 using multivariate linear regression models with robust estimators and controlling for patient characteristics (age, sex, minority status), family member characteristics (age, sex, minority status, level of education, and relationship to patient), and hospital site. For this first step, we used pairwise deletion, allowing all available data to be used. We then ran a second model in which all FS-ICU items were included. The purpose of this second model was to control for correlations between FS-ICU items. This step required the use of only those subjects with complete data on all variables. Finally, we generated a performance-importance grid plotting the β coefficients for specific FS-ICU questions from the first step against the proportion of respondents rating that particular FS-ICU question as excellent (or best possible rating). Thus, the components of the FS-ICU survey that had the strongest association with the QOD-1 (largest β coefficient) yet received the lowest satisfaction ratings are located in the upper left quadrant of the grid.¹⁶ Significance for all analyses was $P \leq .05$.

RESULTS

Sample Characteristics

Of the 3,400 eligible patients who died during the study period (August 2003-February 2008), 2,850 had patient contact information. We received completed survey packets from 1,290 family members for a response rate of 45% (Fig 1). Demographic characteristics of the patients and their family members completing the surveys are presented in Table 1.

Measure Characteristics

The mean $\pm$ SD QOD-1 score was 6.96 ± 3.08 (range, 0-10), the median was 8.0 (interquartile range

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[IQR], 5-9), and the distribution was slightly skewed (-1.00). The mean FS-ICU score was 76.6 ± 20.6 (range, 2.5-100), the median was 81.3 (IQR, 66.7-92.7), and the distribution also deviated from a normal distribution (skew, -1.22). The satisfaction with care and decision-making subscales of the FS-ICU survey had means of 77.7 ± 20.6 and 75.2 ± 22.6 , medians of 83.9 (IQR, 67.9-94.0) and 80.0 (IQR, 62.5-92.5), and skews of -1.25 and -1.11 , respectively.

Components of Family Satisfaction That Predict Family-Assessed Quality of Dying

In the first analytic step, all the FS-ICU variables were significantly associated with the QOD-1 score ($P \leq .05$), with β coefficients ranging from 0.49 for atmosphere of the ICU and management of agitation to 0.29 and 0.27 for atmosphere of the waiting room and perceived level of inclusion in the decision-making process, respectively (Table 2). The second analytic step, in which we controlled for all FS-ICU items, included questionnaire data from 729 family members who had complete data on all items and covariates (Table 3). The following four items from the FS-ICU survey retained their significance when tested using this model: the family members' perception of the skill and competence of the nurses ($P = .01$), the atmosphere of the ICU ($P = .03$), the perceived level of support during the decision-making process ($P = .03$), and the families' perceived control of patient care ($P < .01$). The first two items are from the care domain of the FS-ICU survey, and the latter two items are from the decision-making domain.

Family Satisfaction Items With Low Performance and Correlation With Quality of Dying

The results of the third analytic step are presented in Figure 2: the performance-importance grid. The β coefficients from the first analysis are plotted against the proportion of respondents rating a survey item as excellent (or highest rating). All items from the FS-ICU survey are included and represented by one of the 24 data points. The three items that were most strongly associated with the QOD-1 yet received low satisfaction ratings are found in the upper left quadrant of the grid and were the atmosphere of the ICU, the level of support given for decision-making, and the amount of control over care.

DISCUSSION

The study suggests that specific aspects of ICU care identified from items in the FS-ICU survey are associated with families' assessments of the overall quality of dying as measured by the QOD-1 and, importantly, that some of these areas might be targets for particularly fruitful interventions to improve end-of-life care and family satisfaction with that care. Support for decision-making was one area that was strongly associated with family ratings of the overall quality of dying but received relatively low ratings of family satisfaction. A previous study using similar methods and the same FS-ICU items but focusing on family satisfaction among patients who predominantly survived critical illness also reported low ratings for support for decision-making.¹⁷ However, in that study's performance grid analysis in which the authors compared FS-ICU items with total satisfaction scores based on all FS-ICU items rather than on the quality of dying, the support for decision-making item was not significantly associated with lower overall satisfaction ratings. These discrepant findings may be due to regional differences (family experiences in German-Swiss ICUs) or to differences between family satisfaction for patients who survived compared with those who died in the ICU, as in the present study. We have previously shown that families of patients who died in the ICU rated their satisfaction with communication as higher than that by families of patients who survived, suggesting that patient outcome is likely to modify family expectations and assessments.²¹

Despite these study differences, families' low ratings for support for decision-making suggest opportunities for improvement in care. For example, because significant variability has been documented in family members' preferred role in decision-making and their views on how physicians should approach decision making,²²⁻²⁴ clinicians may need to consider how to approach and modify shared decision-making to better

FIGURE 1. Exclusion criteria and identification of 1,211 cases for analysis. QOD-1 = Single-Item Quality of Dying and Death.

Table 1—Characteristics of Patients Dying in the ICU and Their Family Respondents

Characteristic	Families (n = 1,290)		Patients (n = 1,290)	
	No.	Value	No.	Value
Age, y	1,260	58.0 ± 14.5	1,264	69.9 ± 15
Female sex	1,261	862 (68.4)	1,290	528 (40.9)
Nonwhite/Hispanic	1,249	181 (14.5)	1,290	176 (13.6)
Level of education	1,252		1,277	
Eighth grade or less		14 (1.1)		88 (6.9)
Some high school		36 (2.9)		101 (7.9)
High school diploma or GED		222 (17.7)		476 (37.3)
Some college or trade school		533 (42.6)		331 (25.9)
Four-year college degree		249 (19.9)		201 (15.7)
Graduate or professional school		198 (15.8)		80 (6.3)
Relationship to patient	1,264		...	
Spouse or partner		577 (45.6)		...
Adult child		444 (35.1)		...
Sibling, parent, other relative or friend		243 (19.1)		...
Presence of a living will at ICU admission	...	...	1,218	524 (43.0)

Data are presented as mean ± SD or No. (%), unless otherwise indicated. GED = general equivalency degree.

meet the needs of each patient and family, assessing with the family members what their preferences are for hearing prognostic information and receiving recommendations.²⁵⁻²⁷ Further, explicit clinician statements of support for decisions made during family conferences have been shown to be associated with

higher family satisfaction with clinician communication²⁸ as have empathic responses to family concerns expressed during these conferences; this may represent another avenue for enhancing families' perception of support for decision-making.²⁹ Finally, one cause for dissatisfaction with decision-making may be

Table 2—Associations Between Individual FS-ICU Items and QOD-1 Score

FS-ICU Item	No.	β	P Value
Care domain			
The courtesy, respect, and compassion your family member was given	1,176	0.44	< .001
How well the ICU staff treated your family member's pain	1,098	0.44	< .001
How well the ICU staff treated your family member's breathlessness	1,062	0.47	< .001
How well the ICU staff treated your family member's agitation	968	0.49	< .001
How well the ICU staff showed interest in your needs	1,178	0.44	< .001
How well the ICU staff provided emotional support	1,169	0.44	< .001
The teamwork of the ICU staff who took care of your family member	1,176	0.48	< .001
The courtesy, respect, and compassion you were given	1,176	0.48	< .001
How well the nurses cared for your family member	1,179	0.44	< .001
How often the nurses communicated about your family member's condition	1,179	0.40	< .001
How well the doctors cared for your family member	1,165	0.47	< .001
The atmosphere of ICU	1,173	0.49	< .001
The atmosphere in the ICU waiting room	1,086	0.28	< .001
How satisfied you were with the level or amount of care your family member received in the ICU	1,180	0.46	< .001
Decision-making domain			
How often doctors communicated with you about your family member's condition	1,171	0.41	< .001
Willingness of ICU staff to answer your questions	1,191	0.46	< .001
How well the ICU staff provided you with explanations that you understood	1,193	0.46	< .001
The honesty of information provided to you about your family member's condition	1,192	0.47	< .001
How well the ICU staff informed you of what was happening to your family member and why things were being done	1,193	0.48	< .001
The consistency of information provided to you about your family member's condition	1,179	0.45	< .001
Did you feel included in the decision-making process?	1,195	0.27	< .001
Did you feel supported in the decision-making process?	1,170	0.43	< .001
Did you feel you had control over the care of your family member?	1,180	0.41	< .001
When making decisions, did you have adequate time to have your concerns addressed and questions answered?	1,160	0.35	< .001

Associations were derived from linear regression using robust estimators, controlling for hospital site and patient and family member age, sex, and minority status. FS-ICU = Family Satisfaction in the ICU; QOD-1 = Single-Item Quality of Dying and Death.

Table 3—Associations Between FS-ICU Items and the QOD-1 Score, Adjusting for All Items and Selected Demographics (n = 729)

FS-ICU Item	β	t	P Value
Care domain			
The courtesy, respect, and compassion your family member was given	−0.10	−1.59	.11
How well the ICU staff treated your family member's pain	0.12	1.81	.07
How well the ICU staff treated your family member's breathlessness	0.04	0.56	.57
How well the ICU staff treated your family member's agitation	0.09	1.53	.13
How well the ICU staff showed interest in your needs	0.00	0.05	.96
How well the ICU staff provided emotional support	−0.10	−1.53	.13
The teamwork of the ICU staff who took care of your family member	0.00	0.04	.97
The courtesy, respect, and compassion you were given	0.08	1.19	.24
How well the nurses cared for your family member ^a	0.15	2.51	.01
How often the nurses communicated about your family member's condition	−0.09	−1.51	.13
How well the doctors cared for your family member	0.03	0.60	.55
The atmosphere of ICU ^a	0.12	2.22	.03
The atmosphere in the ICU waiting room	0.02	0.54	.59
How satisfied you were with the level or amount of care your family member received in the ICU	0.07	1.64	.10
Decision-making domain			
How often doctors communicated with you about your family member's condition	0.04	0.82	.42
Willingness of ICU staff to answer your questions	0.01	0.11	.92
How well the ICU staff provided you with explanations that you understood	−0.07	−0.76	.45
The honesty of information provided to you about your family member's condition	0.07	0.85	.40
How well the ICU staff informed you what was happening to your family member and why things were being done	0.03	0.31	.76
The consistency of information provided to you about your family member's condition	−0.03	−0.55	.58
Did you feel included in the decision-making process?	0.01	0.31	.76
Did you feel supported in the decision-making process? ^a	0.10	2.20	.03
Did you feel you had control over the care of your family member? ^a	0.18	3.91	< .01
When making decisions, did you have adequate time to have your concerns addressed and questions answered?	0.05	1.19	.23

Associations were derived from linear regression using robust estimators, controlling for all FS-ICU items; hospital site; and patient and family member age, sex, and minority status. Patient sex was the only covariate to affect the QOD-1 score ($\beta = 0.07$, $t = 2.31$, $P = .02$). See Table 2 legend for expansion of abbreviations.

^aSignificant at $P \leq .05$.

related to the appropriateness of the patient's ICU admission; that is, was the patient likely to benefit from the care provided? Families of patients unlikely to benefit from critical care may have unrealistic and unfulfilled expectations for their loved ones. These expectations may lead to dissatisfaction with the decision-making in which they were involved. Although we were not able to examine this issue in the analyses, it is an important factor to consider when designing interventions to improve care and family experiences of that care in the ICU.

The atmosphere of the ICU was also identified in this study as having potential for improving family ratings of quality of dying; it received low ratings of satisfaction from families but was significantly associated with higher family ratings of the quality of dying. One of the challenges in addressing this item is that it is not clear exactly what factors family members considered when they rated this item. Factors could have included the physical plant of the ICU, the efforts made to make the family feel comfortable in the ICU, visiting hour policies, and the degree to which the ICU felt foreign or intimidating to the

family. It is also unclear whether efforts to change the physical atmosphere, such as improving the noise level, lighting, art, and space, might improve family ratings. Understanding exactly what this means to family members and how it can be modified may be a fruitful area for future qualitative and quantitative research.

Notably, there are several items from the FS-ICU survey that measure communication with physicians and nurses, and although these items were significant in the bivariate analyses, they were not significantly associated with the overall quality of dying in the multivariate analyses. This was an unexpected finding because there has been widespread recognition of and focus on the importance of communication during end-of-life care in the ICU. The present analyses may have failed to show these relationships because of significant ($P < .01$) intercorrelations between items within the FS-ICU scales, which when including all items, make it more difficult to identify unique associations. A randomized trial from France that used enhanced communication techniques, including proactive family conferences using the VALUE

Family Satisfaction Survey: Care Domain Items

- 1 The courtesy, respect and compassion your family member was given
- 2 How well the ICU staff treated your family member's pain
- 3 How well the ICU staff treated your family member's breathlessness
- 4 How well the ICU staff treated your family member's agitation
- 5 How well the ICU staff showed interest in your needs
- 6 How well the ICU staff provided emotional support
- 7 The teamwork of the ICU staff who took care of your family member
- 8 The courtesy, respect and compassion you were given
- 9 How well the nurses cared for your family member
- 10 How often the nurses communicated about your family member's condition
- 11 How well the doctors cared for your family member
- 12 The atmosphere of ICU**
- 13 The atmosphere in the ICU waiting room
- 14 How satisfied were you with the level or amount of care your family member received in the ICU

Family Satisfaction Survey: Decision-making Domain Items

- 15 How often doctors communicated with you about your family member's condition
- 16 Willingness of ICU staff to answer your questions
- 17 How well the ICU staff provided you with explanations that you understood
- 18 The honesty of information provided to you about your family member's condition
- 19 How well the ICU staff informed you what was happening to your family member and why things were done
- 20 The consistency of information provided to you about your family member's condition
- 21 Did you feel included in the decision-making process
- 22 Did you feel supported in the decision-making process
- 23 Did you feel you had control over the care of your family member
- 24 When making decisions, did you have adequate time to have your concerns addressed and questions answered

FIGURE 2. Performance-importance grid plotting the proportion of excellent (or highest) ratings for a Family Satisfaction in the ICU (FS-ICU) item against the β coefficients from the analyses, adjusting for patient and family characteristics and hospital site but not for other FS-ICU items. (Bolded items represent those significant in analyses adjusting for all other FS-ICU items.)

(value family statements, acknowledge family emotions, listen to the family, understand patient as a person, elicit family questions) strategy and standardized bereavement pamphlets, demonstrated a significant decrease in depression, anxiety, and post-traumatic stress symptoms among family members 3 months after the patient's death.³⁰ Although we did not find significant associations between the items assessing physician or nurse communication and the quality of dying, it is likely that optimal communication

is important and failures in communication may contribute to respondents' impressions that the level of support for decision-making and the level of control over the care of their loved ones are less than optimal.

Finally, we found an independent correlation between family members' satisfaction with the skill and competence demonstrated by nurses and their ratings of the overall quality of dying. This finding highlights the importance of ICU nurses from family

members' perspectives and supports prior research highlighting the important roles and responsibilities of critical care nurses in end-of-life care in the ICU.³¹⁻³³ A recent study examined nurses' perspectives on important, yet underused palliative care skills, showing symptom management, communication skills, and patient-centered care as key areas of focus.³⁴ The current study supports the importance of investing in palliative care competencies for critical care nurses.

There are several important limitations of this study. First, despite having relied on proven questionnaire methods to enhance response rates, including monetary incentives and reminder mailings,¹⁸ the response rate was 45%. This response rate may be explained in part by not having access to family addresses. By addressing the questionnaires "to family of" the deceased patient, it is likely that many of the questionnaires did not reach appropriate respondents. Further, although this kind of response rate is common in after-death surveys and interviews of family respondents,³⁵⁻³⁷ caution must be exercised in generalizing the results. In analyses using the same database, we found differences in both the characteristics and the care of decedents for patients who had a family member who responded compared with those who did not. Patients without responding family members were more often of minority race and received fewer indicators of palliative care.³⁸ Furthermore, the respondent group was primarily white (85%), and because prior research has shown significant variability in cultural approaches to dying and death,^{39,40} the findings may be different from those derived from racially and ethnically diverse samples. Second, we completed a number of analyses and used an exploratory approach to these analyses; therefore, the findings should be considered as hypothesis generating, and further research is needed to explore causal and explanatory pathways. Third, the potential for overlap among the FS-ICU item ratings exists such that respondents' perceptions of ratings for one (or more) survey items may affect their perceptions and, thus, ratings of other items. In previous work refining the FS-ICU survey, however, redundancy (item scale Cronbach $\alpha > 0.8$) was a criterion for item reduction, which may reduce this concern somewhat.⁵ Finally, the questionnaire items require families to provide general, overall ratings. These items do not include details that would allow us to identify either the objective criteria or the personal meanings families have assigned to their assessments. Future research using qualitative as well as quantitative measures may help to describe more closely the criteria that families use to determine their satisfaction with care.

The present study identifies four items rating family satisfaction with the quality of end-of-life care that are independently correlated with higher family ratings

on a single summary item evaluating the overall quality of dying. One item (the perceived skill and competence of the nurses) was rated relatively highly, and three items (the atmosphere of the ICU, feeling of support in the decision-making process, and feeling of control over the care of their loved one) were rated relatively poorly. The elements that contribute to relatively poor ratings of the atmosphere of the ICU are unclear, and it will be important to describe these elements to better understand their relative contributions to these ratings. The other two items rated relatively poorly come from the decision-making domain of the FS-ICU survey and, thus, are important items to consider in the development of methods for shared decision-making about end-of-life care in the ICU. These relatively poorly rated items may represent practical targets for quality improvement interventions aimed at improving the quality of the dying experience for families of patients dying in the ICU.

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Dr Osborn: contributed to the interpretation and analysis of the data, preparation of the manuscript, and review and approval of the final manuscript.

Dr Curtis: contributed to the study design; data collection, analysis, and interpretation; preparation of the manuscript; and review and approval of the final manuscript.

Ms Nielsen: contributed to the study design; data collection, analysis, and interpretation; preparation of the manuscript; and review and approval of the final manuscript.

Dr Back: contributed to the study design and implementation and review and approval of the final manuscript.

Dr Shannon: contributed to the study design and implementation and review and approval of the final manuscript.

Dr Engelberg: contributed to the study design; data collection, analysis, and interpretation; preparation of the manuscript; and review and approval of the final manuscript.

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Additional information: The e-Appendix can be found in the "Supplemental Materials" area of the online article.

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