Measuring Family Satisfaction with Care and Quality of Dying in the Intensive Care Unit: Does Patient Age Matter?

Mithya Lewis-Newby, M.D., M.P.H.,¹ J. Randall Curtis, M.D., M.P.H.,²
Diane P. Martin, Ph.D., M.A.,³ and Ruth A. Engelberg, Ph.D.²

Abstract

Rationale: Few studies have examined the role of patient age on family experiences of end-of-life care.

Objectives: To assess measurement characteristics of two family-assessed questionnaires across three patient age groups.

Methods: Four hundred and ninety-six patients who died in an intensive care unit (ICU) at a single hospital were identified and one family member per patient was sent two questionnaires: 1) Family Satisfaction in the ICU (FS-ICU); and 2) Quality of Dying and Death (QODD). Two hundred and seventy-five surveys were returned (55.4%). We analyzed three age groups: <35, 35–64, and ≥65 years. Differences were evaluated using χ^2 tests to evaluate ceiling, floor, and missing responses; Kruskal-Wallis tests to compare median scores on items and total scores; and linear regression controlling for patient sex, race, diagnosis, and family-member sex, race, education, and relationship to provide adjusted comparisons of total and subscale scores.

Results: Measurement characteristics varied by age groups for both questionnaires. Missing values and floor endorsements were more common for the younger age groups for six items and one overall rating score. Ceiling endorsements were more common for the older group for 11 items. Fifteen items and four total scores were significantly higher in the older group.

Conclusions: The FS-ICU and QODD questionnaires performed differently across patient age groups. Assessments of family satisfaction and quality of dying and death were higher in the oldest group, particularly in the area of clinician-family communication. Studies of the dying experience of older adults may not generalize to patients of other ages, and study instruments should be validated among different age groups.

Introduction

APPROXIMATELY 20% OF DEATHS in the United States occur in an intensive care unit (ICU).¹ Despite the frequency of occurrence, many studies suggest that end-of-life care in the ICU is inadequate.^{2,3,4} As a result, there has been an increasing focus on measuring and understanding the experience of dying patients and their families in critical care settings^{5,6,7,8} and on developing interventions to improve the quality of such care.^{9,10,11,12,13,14} Most tools that are available to assess end-of-life care have been developed and used for older participants.^{15,16} It is unclear whether results from these studies can be generalized to younger patients whose life and

illness experiences may be quite different. Only a few studies have evaluated the association of patient age at the time of death with family assessments of end-of-life experiences.^{17,18}

To compare differences in families' experiences of patients' deaths that may be attributed to patient age, we examined the measurement characteristics of two questionnaires, the Family Satisfaction in the Intensive Care Unit (FS-ICU) and the Quality of Dying and Death (QODD), by patient age. We asked two specific questions: 1) did the questionnaires display similar characteristics across three patient age groups as measured by ceiling, floor, and missing responses; and 2) did scores on the questionnaires vary by patient age group, suggesting that patient age differentially affected families' experiences?

¹Seattle Children's Hospital and Regional Medical Center, Division of Pediatric Critical Care Medicine, Department of Pediatrics, ²Harborview Medical Center, Division of Pulmonary and Critical Care, Department of Medicine, ³Department of Health Services, School of Public Health, University of Washington, Seattle, Washington.

Accepted July 18, 2011.

Materials and Methods

Population and setting

Data for this study come from a prospective study that evaluated a palliative care intervention for ICU patients and their families.¹⁹ Study participants were recruited between July 2003 through October 2005 from Harborview Medical Center, a level 1 trauma hospital that had 65 critical care beds during the study. Eligible patients died in the ICU or within 30 hours of ICU discharge and had a minimum ICU stay of 6 hours. The University of Washington's institutional review board approved the study.

Measures and data collection

Survey packets were mailed to the family's home 4 to 6 weeks after the patient's death and included the FS-ICU and QODD questionnaires (see Appendices 1 and 2), and demographic questions about the patient and respondent. The

FS-ICU is a reliable and valid self-report questionnaire measuring family satisfaction with ICU care.^{15,20,21} It includes a total satisfaction score (24 items) and two subscale scores: satisfaction with care (14 items) and satisfaction with decision making (10 items).²² The QODD allows families to evaluate an adult patient's experiences at the end of life.^{16,23,24} A 22-item version has been used to evaluate the quality of ICU deaths.^{17,19,24,25,26,27,28} It also contains a single question assessing the overall quality of dying (QOD) that is scored separately. Higher scores on both questionnaires indicate better outcomes.

Statistical analysis

To test our hypothesis that differences would most likely be found between the youngest and oldest age groups, patients were stratified into three groups using Centers for Disease Control and Prevention death and mortality data to identify cutoffs²⁹: <35, 35–64, and ≥65 years-old. Descriptive information was assessed using analysis of variance (ANOVA) for

TABLE 1. CHARACTERISTICS OF STUDY POPULATION

	Age <35 (n=26)	Age 35–64 (n=113)	Age ≥65 (n=136)	P value
Patient characteristics				
Age, years, mean (SD)	25.38 (5.8)	53.6 (6.8)	76.9 (7.0)	
Female, no. (%)	5 (19.2)	46 (40.7)	48 (35.3)	0.117*
Nonwhite, no. (%)	5 (20.0) ^a	11 (10.2) ^b	22 (17.1) ^c	0.233*
LOS, days, median (IQR)	5.0 (2.0, 8.8)	5.0 (2.0, 12.0)	5.0 (2.0, 12.0)	0.815**
ICU LOS, days, median (IQR)	3.9 (2.2, 6.9)	4.8 (1.8, 9.7)	3.2 (1.5, 9.9)	0.563**
Diagnosis, no. (%)				<0.001*
Cardiovascular	0	9 (8.0)	9 (6.6)	
Infectious	2 (7.7)	18 (16.1)	6 (4.4)	
Respiratory	0	4 (3.6)	12 (8.8)	
Gastrointestinal and hepatic	1 (3.8)	13 (11.6)	7 (5.1)	
Neurologic	4 (15.4)	34 (30.4)	65 (47.8)	
Trauma	14 (53.8)	20 (17.9)	27 (19.9)	
Cancer	0	3 (2.7)	1 (0.7)	
Miscellaneous	5 (19.2)	11 (9.8)	9 (6.6)	
Service, no. (%)				0.045*
Medical ICU	5 (19.2)	40 (35.4)	36 (26.5)	
Cardiac care	0	7 (6.2)	7 (5.1)	
Neurology	1 (3.8)	11 (9.7)	21 (15.4)	
Neurosurgery	7 (26.9)	30 (26.5)	41 (30.1)	
General surgery/Trauma	12 (46.2)	20 (17.7)	28 (20.6)	
Burns/Plastics/Peds	1 (3.8)	5 (4.4)	1 (0.7)	
Other	0	0	2 (1.5)	
Family characteristics				
Age, years, mean (SD)	49.0 (10.1)	52.5 (12.8) ^d	61.22 (13.6) ^e	<0.001***
Female, no. (%)	20 (76.9)	71 (63.4) ^f	88 (65.7) ^g	0.423*
Nonwhite, no. (%)	7 (26.9)	16 (14.2)	26 (19.7)	0.249*
Level of education, no. (%)			^h	0.776*
High school or Less	6 (23.1)	29 (25.7)	35 (26.1)	
Some college	11 (42.3)	51 (45.1)	58 (43.3)	
4-Year college degree	4 (15.4)	16 (14.2)	27 (20.1)	
Graduate or Professional	5 (19.2)	17 (15.0)	14 (10.4)	
Relationship to patient, no. (%)			ⁱ	<0.001*
Parent	20 (76.9)	11 (9.7)	0	
Spouse/Partner	2 (7.7)	55 (48.7)	64 (47.4)	
Child	0	18 (15.9)	55 (40.7)	
Sibling/Other relative/Friend	4 (15.4)	29 (25.7)	16 (11.9)	

IQR, interquartile range; SD, standard deviation; ICU, intensive care unit; LOS, length of stay.

a–i: response (*n*) differs from total (*N*): a=25, b=108, c=129, d=112, e=134, f=112, g=134, h=134, i=135.

* χ^2 , **Kruskal-Wallis, ***ANOVA. P values set in bold are those P values that reach significance ($p < 0.05$).

normally distributed variables (family respondent age), Kruskal-Wallis tests for nonnormally distributed variables (length of stay), and χ^2 tests for categorical variables (patient sex, race/ethnicity, diagnosis, and service, as well as family-member sex, race/ethnicity, education, and relationship to patient). To evaluate questionnaire characteristics, we examined total, subscale, and item scores for percent missing, percent ceiling (highest), and percent floor (lowest) scores using χ^2 tests. To evaluate whether patient age was associated with different family assessments of end-of-life care, we completed unad-

justed and adjusted analyses. For the unadjusted analyses, we used Kruskal-Wallis tests to accommodate the nonnormally distributed responses. For the adjusted analyses, we used linear regression with robust standard errors, comparing FS-ICU and QODD total and subscores across the age groups adjusting for patient sex, patient race (white versus nonwhite), diagnosis (trauma versus neurologic versus all others), family-member sex, family-member race (white versus nonwhite), family-member education, and family-member relationship to the patient (parent, spouse, or other relationship). Because we

TABLE 2. MEASUREMENT CHARACTERISTICS FOR FS-ICU, QODD TOTAL/SUBSCALE SCORES, AND INDIVIDUAL ITEMS THAT SIGNIFICANTLY DIFFER BY AGE

	Age < 35 (n=26)	Age 35–64 (n=113)	Age ≥ 65 (n=136)	P value*
Total and subscale scores				
Missing % (n)				
FS-ICU total	3.8 (1)	2.7 (3)	1.5 (2)	0.678
FS-ICU care	3.8 (1)	2.7 (3)	1.5 (2)	0.678
FS-ICU DM	3.8 (1)	1.8 (2)	1.5 (2)	0.707
QODD	7.7 (2)	2.7 (3)	0.7 (1)	0.076
QOD	11.5 (3)	4.4 (5)	4.4 (6)	0.291
Floor % (n)				
FS-ICU total	0 (0)	0 (0)	0 (0)	–
FS-ICU care	0 (0)	0 (0)	0 (0)	–
FS-ICU DM	0 (0)	0 (0)	0 (0)	–
QODD	4.2 (1)	2.7 (3)	0.7 (1)	0.353
QOD	13.0 (3)	7.4 (8)	1.5 (2)	0.021
Ceiling % (n)				
FS-ICU total	4.0 (1)	2.7 (3)	4.5 (6)	0.770
FS-ICU care	8.0 (2)	7.3 (8)	14.9 (20)	0.146
FS-ICU DM	20.0 (5)	6.3 (7)	17.2 (23)	0.023
QODD	8.3 (2)	5.5 (6)	7.4 (10)	0.795
QOD	17.4 (4)	25.0 (27)	36.2 (47)	0.068
Individual items				
FS-ICU missing % (n)				
None				
FS-ICU floor % (n)				
ICU staff care of patient	7.7 (2)	0.0 (0)	0.0 (0)	< 0.001
Time for questions	4.0 (1)	22.4 (24)	3.8 (5)	< 0.001
FS-ICU ceiling % (n)				
Teamwork of ICU staff	48.0 (12)	55.6 (60)	70.1 (94)	0.021
RN communication	76.9 (20)	61.3 (68)	77.0 (104)	0.020
Competence of ICU MD	65.4 (17)	51.4 (57)	70.5 (93)	0.009
MD communication	36.0 (9)	35.1 (39)	53.7 (72)	0.010
Completeness of information	52.0 (13)	46.4 (52)	63.9 (85)	0.022
Time for questions	96.0 (24)	77.6 (83)	96.2 (125)	< 0.001
QODD missing % (n)				
Peace with dying	65.4 (17)	48.7 (55)	37.5 (51)	0.018
Fear of dying	61.5 (16)	54.0 (61)	39.0 (53)	0.019
Funeral arrangements	30.8 (8)	22.1 (25)	12.5 (17)	0.032
QODD Floor % (n)				
Funeral arrangements	27.8 (5)	15.9 (14)	7.6 (9)	0.024
QODD Ceiling % (n)				
Time spent with family	28.6 (6)	27.4 (26)	44.0 (51)	0.034
Costs taken care of	20.0 (3)	26.4 (19)	45.7 (43)	0.015
Use of dialysis	35.7 (5)	15.1 (8)	41.9 (31)	0.005
Funeral arrangements	5.6 (1)	13.6 (12)	30.3 (36)	0.004
Discussion of end-of-life care with MD	6.3 (1)	14.7 (11)	35.3 (36)	0.001

FS-ICU, Family Satisfaction in the Intensive Care Unit; QODD, Quality of Dying and Death; Care, Satisfaction with Care Subscale; DM, Satisfaction with Decision Making Subscale; QOD, Quality of Dying single item score. For complete phrasing of individual questions, please see Appendices 1 and 2.

* χ^2 tests: missing vs. all others; floor vs. all others; ceiling vs. all others. P values set in bold are those P values that reach significance ($p < 0.05$).

viewed this examination as hypothesis generating, we chose a liberal significance level and set $p \leq 0.05$ for all tests despite the large number of comparisons.

Results

Four hundred and ninety-six families received mailed questionnaires and returned surveys for 275 patients (55.4%). Response rate did not vary by age group. Patients' demographic characteristics differed across age groups (Table 1). A larger proportion of the youngest group had trauma diagnoses, whereas the oldest group had more neurologic diagnoses. Family respondents for the youngest group were younger and more likely to be the patients' parents.

Several significant differences were found in the characteristics of the FS-ICU by patient age (Table 2). The middle age group endorsed fewer ceiling scores for the decision-making subscale. The youngest group endorsed more floor scores for the item, "ICU staff care of patient" and the middle age group endorsed more floor scores for the item, "time for questions." The oldest group endorsed more ceiling scores on five items. The youngest and oldest groups endorsed more ceiling scores for "time for questions" than the middle group.

Significant differences were also found for the characteristics of the QODD (Table 2). For the single-item QOD the oldest group endorsed fewer floor scores. For the individual QODD questions, three items differed by missing responses (all fewer

in the oldest group), one item differed by floor scores (fewer in the oldest group), and five items differed by ceiling scores (all more in the oldest group).

In the unadjusted analyses of questionnaire items, nine of the FS-ICU items and six of the QODD items differed by age group with the highest scores associated with the oldest group. For the total and subscale scores, the FS-ICU total and decision-making subscale scores were higher for the oldest group. Similarly, the QODD total and the QOD-single-item scores were higher for the oldest group. These findings for the total and subscale scores were supported in the adjusted analyses except for the QODD total score. Additionally, in the adjusted analyses, the FS-ICU satisfaction with care subscale score was higher for the oldest group (Table 3).

Discussion

In this study, we found that both of these questionnaires, whether measuring satisfaction with end-of-life care or quality of dying and death, performed differently depending on patient age. First, a number of measurement characteristics that are important for construct validity³⁰ varied by age. In general, the oldest group had fewer missing responses, fewer percent floor responses, and more percent ceiling responses.

Second, families of patients from different age groups provided significantly different assessments of end-of-life experiences. Families of the oldest patients reported higher levels of

TABLE 3. DESCRIPTIVE STATISTICS FOR FS-ICU, QODD TOTAL/SUBSCALE SCORES, AND INDIVIDUAL ITEMS THAT SIGNIFICANTLY DIFFER BY AGE

	Age < 35 (n = 26)	Age 35–64 (n = 113)	Age ≥ 65 (n = 136)	Unadjusted P value*	Adjusted P value**
Median (IQR)					
FS-ICU total	83.3 (74.5, 94.7)	83.9 (69.4, 93.8)	88.0 (77.4, 94.8)	0.031	0.006
FS-ICU care	87.5 (74.1, 96.3)	87.5 (69.6, 94.6)	89.3 (80.4, 96.2)	0.070	0.010
FS-ICU DM	80.0 (71.3, 96.3)	80.0 (62.5, 95.0)	87.5 (75.0, 97.3)	0.010	0.001
QODD	57.6 (50.8, 78.8)	65.6 (45.2, 82.7)	72.9 (54.8, 89.5)	0.049	0.075
QOD	8 (5, 9)	8 (5, 9.75)	9 (7, 10)	0.019	0.004
FS-ICU %excellent (n)					
Teamwork of ICU staff	48.0 (12)	55.6 (60)	70.1 (94)	0.009	
ICU staff care of family	61.5 (16)	63.6 (68)	76.1 (102)	0.032	
RN communication	76.9 (20)	61.3 (68)	77.0 (104)	0.018	
Competence of ICU MD	65.4 (17)	51.4 (57)	70.5 (93)	0.008	
ICU waiting room	12.0 (3)	8.7 (9)	18.8 (24)	0.031	
MD communication	36.0 (9)	35.1 (39)	53.7 (72)	0.001	
Completeness of information	52.0 (13)	46.4 (52)	63.9 (85)	0.026	
Consistency of information	38.5 (10)	44.5 (49)	57.5 (77)	0.017	
Time for questions	96.0 (24)	77.6 (83)	96.2 (125)	<0.001	
QODD median (IQR)					
Time spent with family	8.0 (6.5, 10)	8.0 (3, 10)	9.0 (6, 10)	0.020	
Costs taken care of	7.0 (2, 9)	8.0 (4, 10)	9.0 (7, 10)	0.003	
Goodbye to loved ones	2.0 (0, 6.5)	1.0 (0, 5)	5.0 (0, 9)	0.050	
Use of dialysis	6.5 (5, 10)	5.0 (5, 9)	8.5 (5, 10)	0.030	
Funeral arrangements	4.0 (0, 5.5)	5.0 (2, 8)	8.0 (5, 10)	<0.001	
Discussion of end-of-life care with MD	5.0 (1, 8)	5.0 (3, 8)	8.5 (4.75, 10)	<0.001	

FSICU, Family Satisfaction in the Intensive Care Unit; QODD, Quality of Dying and Death; Care, Satisfaction with Care Subscale; DM, Satisfaction with Decision Making Subscale; QOD, Quality of Dying single item score; IQR, interquartile range; SD, standard deviation; LOS, length of stay. For complete phrasing of individual questions, please see Appendix 1 and 2.

*Kruskal-Wallis analysis.

**Scores are adjusted for patient sex, patient race (white vs. nonwhite), patient diagnosis (trauma vs. neurologic vs. all others), family-member sex, family-member race (white vs. nonwhite), family-member education, and family-member relationship to patient (parent vs. all others, spouse vs. all others) using linear regression with robust estimators.

P values set in bold are those P values that reach significance ($p < 0.05$).

overall satisfaction with the ICU care and they also perceived that their loved one had a higher-quality dying and death experience. These results persisted after adjusting for patient sex, race, and diagnosis as well as the family-member's sex, race, education, and relationship to the patient. The nine FS-ICU items that were rated as higher in the oldest group suggest that families of the oldest patients were more satisfied with diverse aspects of ICU care but especially those related to clinician-family communication. The six QODD items that were rated significantly higher in the oldest group fall into the domains of preparation and connectedness.³¹ Both of these domains are focused on communication (clinician-family, patient-family, or intra-family). No items differed by age in the domains of symptom control or transcendence.

This study has several important limitations. First, many patients had a trauma diagnosis; their experiences may be different from those of patients dying from other causes. Second, the small sample size of the youngest group ($n=26$) may reduce the study's power to find differences among age groups. Third, it is possible that patient age is a proxy for other important factors that covary with patient age (e.g., parental roles and experiences and clinician communication style) and which we have not accounted for in these analyses. Finally, this study cannot differentiate true differences in quality of care from questionnaire performance. Our findings should be regarded as hypothesis generating, requiring future studies to further explore these questions.

Most studies aimed at measuring family satisfaction with ICU care and family perceptions of their loved one's dying and death experience use questionnaires developed with older patients and enroll patients who would fall into our oldest group. Our study suggests that such questionnaires may not measure the patient and family end-of-life experiences equivalently across a range of adult patient ages, and further research is needed to improve these measures. Additionally, end-of-life experiences may differ by patient age; therefore, findings in previous studies may not generalize to younger patient age groups. Our study suggests a central role of communication in explaining many differences associated with patient age. Younger patients and their families may need more support around end-of-life preparation and discussion of treatment preferences. Finally, if satisfaction with care and quality of dying is lower for younger patients and their families, they may be at higher risk for stress disorders.^{18,32} Improving our understanding of the areas in which we provide lower-quality end-of-life care, such as for younger patients, may help us tailor our interventions and improve our care of patients and their families.

Acknowledgments

This project was funded by a grant from the National Institute of Nursing Research (R01NR05226) and a grant from the Robert Wood Johnson Foundation.

Author Disclosure Statement

No competing financial interests exist.

References

1. Angus DC, Barnato AE, Linde-Zwirble WT, Weissfeld LA, Watson RS, Rickert T, Rubenfeld GD; Robert Wood Johnson Foundation ICU End-Of-Life Peer Group: Use of intensive care at the end of life in the United States: An epidemiologic study. *Crit Care Med* 2004;32:638–643.
2. The SUPPORT Principal Investigators: A controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA* 1995;274:1591–1598.
3. Nelson JE, Meier D, Oei EJ, Nierman DM, Sensel RS, Manfredi PL, Davis SM, Morrison RS: Self-reported symptom experience of critically ill cancer patients receiving intensive care. *Crit Care Med* 2001;29:277–282.
4. Tilden VP, Tolle SW, Garland MJ, Nelson CA: Decisions about life-sustaining treatment: Impact of physicians' behaviors on the family. *Arch Intern Med* 1995;155:633–638.
5. Cook DJ: Health professional decision-making in the ICU: A review of the evidence. *New Horiz* 1997;5:15–19.
6. Johnson N, Cook D, Giacomini M, Willms D: Towards a "good" death: End-of-life narratives constructed in an intensive care unit. *Cult Med Psychiatry* 2000;24:275–295.
7. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulskey JA: Families looking back: One year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med* 2001;29:197–201.
8. McDonagh JR, Elliott TB, Engelberg RA, Treece PD, Shannon SE, Rubenfeld GD, Patrick DL, Curtis JR: 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.
9. Danis M: Improving end-of-life care in the intensive care unit: What's to be learned from outcomes research? *New Horiz* 1998;6:110–118.
10. Danis M, Federman D, Fins JJ, Fox E, Kastenbaum B, Lanken PN, Long K, Lowenstein E, Lynn J, Rouse F, Tulskey J: Incorporating palliative care into critical care education: Principles, challenges, and opportunities. *Crit Care Med* 1999;27:2005–2013.
11. Mularski RA, Bascom P, Osborne ML: Educational agendas for interdisciplinary end-of-life curricula. *Crit Care Med* 2001;29(2 Suppl):N16–N23.
12. Curtis JR, Patrick DL, Shannon SE, Treece PD, Engelberg RA, Rubenfeld GD: The family conference as a focus to improve communication about end-of-life care in the intensive care unit: Opportunities for improvement. *Crit Care Med* 2001;29(2 Suppl):N26–N33.
13. Campbell ML, Guzman JA: Impact of a proactive approach to improve end-of-life care in a medical ICU. *Chest* 2003;123:266–271.
14. Hall RI, Rocker GM, Murray D: Simple changes can improve conduct of end-of-life care in the intensive care unit. *Can J Anaesth* 2004;51(6):631–636.
15. Heyland DK, Tranmer JE: Measuring family satisfaction with care in the intensive care unit: The development of a questionnaire and preliminary results. *J Crit Care* 2001;16:142–149.
16. Mularski RA, Heine CE, Osborne ML, Ganzini L, Curtis JR: Quality of dying in the ICU: Ratings by family members. *Chest* 2005;128:280–287.
17. Glavan BJ, Engelberg RA, Downey L, Curtis JR: Using the medical record to evaluate the quality of end-of-life care in the intensive care unit. *Crit Care Med* 2008;36:1138–1146.
18. Greis CJ, Engelberg RA, Kross EK, Zatzick D, Nielsen EL, Downey L, Curtis JR: Predictors of symptoms of posttraumatic

- stress and depression in family members after patient death in the ICU. *Chest* 2010;137:280–7.
19. Treece PD, Engelberg RA, Shannon SE, Nielsen EL, Braungardt T, Rubenfeld GD, Steinberg KP, Curtis JR: Integrating palliative and critical care: Description of an intervention. *Crit Care Med* 2006;34(11 Suppl):S380–S387.
 20. Heyland DK, Rocker GM, Dodek PM, Kutsogiannis DJ, Konopad E, Cook DJ, Peters S, Tranmer JE, O'Callaghan CJ: Family satisfaction with care in the intensive care unit: Results of a multiple center study. *Crit Care Med* 2002;30:1413–1418.
 21. Family Satisfaction in the Intensive Care Unit (FS-ICU) Survey. www.criticalcareconnections.com [Last accessed June 1, 2010.]
 22. Wall RJ, Engelberg RA, Downey L, Heyland DK, Curtis JR: Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. *Crit Care Med* 2007;35:271–9.
 23. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I: A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manage* 2002;24:17–31.
 24. Mularski R, Curtis JR, Osborne M, Engelberg RA, Ganzini L: Agreement among family members in their assessment of the Quality of Dying and Death. *J Pain Symptom Manage* 2004;28:306–315.
 25. Levy CR, Ely EW, Payne K, Engelberg RA, Patrick DL, Curtis JR: Quality of dying and death in two medical ICUs: Perceptions of family and clinicians. *Chest* 2005;127:1775–1783.
 26. Curtis JR, Treece PD, Nielsen EL, Downey L, Shannon SE, Braungardt T, Owens D, Steinberg KP, Engelberg RA: Integrating palliative and critical care: Evaluation of a quality-improvement intervention. *Am J Respir Crit Care Med* 2008;178:269–275.
 27. Curtis JR, Nielsen EL, Treece PD, Downey L, Dotolo D, Shannon SE, Back AL, Rubenfeld GD, Engelberg RA: Effect of a Quality-Improvement Intervention on End-of-Life Care in the Intensive Care Unit: A Randomized Trial. *Am J Respir Crit Care Med*. 2011;183:348–355.
 28. Quality of Dying and Death (QODD) Survey. <http://depts.washington.edu/eolcare/instruments/index.html> [Last accessed June 1, 2010.]
 29. Centers for Disease Control and Prevention: National Vital Statistics System, Mortality Tables. http://www.cdc.gov/nchs/nvss/mortality_tables.htm [Last accessed June 1, 2010.]
 30. Stewart AL, Ware JE: *Measuring Functioning and Well Being: The Medical Outcomes Study Approach*. Durham, NC: Duke University Press, 1992.
 31. Downey L, Curtis JR, Lafferty WE, Herting JR, Engelberg RA: The quality of dying and death questionnaire (QODD): Empirical domains and theoretical perspectives. *J Pain Symptom Manage* 2010;39:9–22.
 32. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, Annane D, Bleichner G, Bollaert PE, Darmon M, Fassier T, Galliot R, Garrouste-Orgeas M, Goulenok C, Goldgran-Toledano D, Hayon J, Jourdain M, Kaidomar M, Laplace C, Larché J, Liotier J, Papazian L, Poisson C, Reignier J, Saidi F, Schlemmer B: Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med* 2005;171:987–994.

Address correspondence to:
 Mithya Lewis-Newby, M.D., M.P.H.
 Pediatric Critical Care Medicine
 Seattle Children's Hospital
 4800 Sand Point Way NE
 Mailstop W-8866
 Seattle, WA 98105

E-mail: mithya.lewis-newby@seattlechildrens.org

APPENDIX 1. ITEMS IN THE FAMILY SATISFACTION
IN THE ICU (FS-ICU) SURVEY

Item

- 1 Care: courtesy, respect, and compassion by staff toward patient
- 2 Care: management of pain
- 3 Care: management of breathlessness
- 4 Care: management of agitation
- 5 Care: how well staff considered family needs
- 6 Care: how well staff provided emotional support toward family
- 7 Care: coordination and teamwork by staff
- 8 Care: courtesy, respect, and compassion by staff toward family
- 9 Care: skill and competence of nurses
- 10 Care: communication by nurses
- 11 Care: skill and competence of doctors
- 12 Care: atmosphere of the ICU
- 13 Care: atmosphere of the ICU waiting room
- 14 Care: satisfaction with level or amount of care patient received
- 15 Decision making: frequency of communication by doctors
- 16 Decision making: willingness of staff to answer questions
- 17 Decision making: staff provided understandable explanations
- 18 Decision making: honesty of information provided about patient's condition
- 19 Decision making: completeness of information about what was happening
- 20 Decision making: consistency of information about patient's condition
- 21 Decision making: feel included in the decision-making process
- 22 Decision making: feel supported during the decision-making process
- 23 Decision making: feel control over the care of the patient
- 24 Decision making: adequate time to address concerns and answer questions

APPENDIX 2. ITEMS IN THE QUALITY OF DYING
AND DEATH (QODD) SURVEY

Item

- 1 How would you rate your loved one's pain control?
- 2 How would you rate loved one's control over what was going on around him/her?
- 3 How would you rate your loved one's ability to feed her/himself?
- 4 How would you rate your loved one's comfort with breathing?
- 5 How would you rate your loved one's peace with dying?
- 6 How would you rate your loved one's fear of dying?
- 7 How would you rate how often your loved one laughed and smiled?
- 8 How would you rate your loved one's ability to keep his/her dignity and self-respect?
- 9 How would you rate your loved one's time spent with family or friends?
- 10 How would you rate your loved one's time spent alone?
- 11 How would you rate your loved one's experience of being touched or hugged by his/her loved ones?
- 12 How would you rate your loved one's health care costs being taken care of?
- 13 How would you rate your loved one's chance to say goodbye to loved ones?
- 14 How would you rate your loved one's chance to clear up any bad feelings with others?
- 15 How would you rate your loved one's opportunity for visits from a religious or spiritual advisor?
- 16 How would you rate your loved one's opportunity for a spiritual service or ceremony before his/her death?
- 17 How would you rate your loved one's use or non-use of a mechanical ventilator to breath for him/her?
- 18 How would you rate your loved one's use or non-use of dialysis for his/her kidneys?
- 19 How would you rate your loved one's opportunity to have his/her funeral arrangements in order?
- 20 How would you rate your loved one's opportunity to discuss his/ her wishes for end-of -life care?
- 21 How would you rate the opportunity for someone to be present at the moment of your loved one's death?
- 22 How would you rate your loved one's state of consciousness at the moment of death?
- 23 Overall, how would you rate the quality of your loved one's dying?