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Hospital Variation and Temporal Trends in Palliative and End-of-Life Care in the ICU

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Abstract

Objectives—Although studies have shown regional and interhospital variability in the intensity of end-of-life care, few data are available assessing variability in specific aspects of palliative care in the ICU across hospitals or interhospital variability in family and nurse ratings of this care. Recently, relatively high family satisfaction with ICU end-of-life care has prompted speculation that ICU palliative care has improved over time, but temporal trends have not been documented.

Design/Setting—Retrospective cohort study of consecutive patients dying in the ICU in 13 Seattle-Tacoma-area hospitals between 2003 and 2008.

Measurements—We examined variability over time and among hospitals in satisfaction and quality of dying assessed by family, quality of dying assessed by nurses, and chart-based indicators of palliative care. We used regression analyses adjusting for patient, family, and nurse characteristics.

Main Results—Medical charts were abstracted for 3,065 of 3,246 eligible patients over a 55-month period. There were significant differences between hospitals for all chart-based indicators ($p < 0.001$), family satisfaction ($p < 0.001$), family-rated quality of dying ($p = 0.03$), and nurse-rated quality of dying ($p = 0.003$). There were few significant changes in these measures over time, although we found a significant increase in pain assessments in the last 24 hours of life ($p < 0.001$) as well as decreased documentation of family conferences ($p < 0.001$) and discussion of prognosis ($p = 0.020$) in the first 72 hours in the ICU.

Conclusions—We found significant interhospital variation in ratings and delivery of palliative care, consistent with prior studies showing variation in intensity of care at the end of life. We did not find evidence of temporal changes in most aspects of palliative care, family satisfaction, or nurse/family ratings of the quality of dying. With the possible exception of pain assessment, there is little evidence that the quality of palliative care has improved over the time period studied.

Keywords

critical care; death; dying; end-of-life care; intensive care; palliative care; withdrawing life support

A growing body of evidence demonstrates the importance of end-of-life care in the ICU. The ICU is a common place of death, as approximately one fifth of all deaths in the United States occur during or soon after a stay in the ICU (1). Many studies have documented regional and interhospital variability in the intensity of treatment at the end of life, but variability in family assessments, nurse assessments, and specific quality markers for palliative and end-of-life care in the ICU has not been as thoroughly examined (2–4).

The Study to Understand Prognosis, Preferences, and Risks of Treatment (SUPPORT) showed that the quality of end-of-life care for seriously ill hospitalized patients was poor between 1989 and 1994 with a high burden of pain and other symptoms, and many patients receiving treatments they would not choose (5). SUPPORT also found that, for 50% of the patients, physicians were unaware of preferences for intensity of care at the end of life (5–7). Two recent trends raise the possibility that palliative and end-of-life care in the ICU may have improved over time: 1) the increasing emphasis on providing palliative care to patients in critical care settings (8–11) and 2) findings from recent studies reporting relatively high levels of family satisfaction with care in the ICU (12–14). Despite these important trends (15), there are few studies examining improvement in the delivery of palliative and end-of-life care in the ICU over time.

We were interested in examining interhospital variability and temporal trends in the quality of palliative and end-of-life care in the ICU. We used data from a recent cluster-randomized trial of a quality-improvement intervention designed to improve palliative and end-of-life care in the ICU (16) to ask two questions: 1) Is there significant variability across individual hospitals in the quality of end-of-life care in the ICU, as defined by family and nurse ratings and by chart-based indicators of palliative care? and 2) Is there evidence that this quality of care has improved over time within institutions? Based on the prior literature, we hypothesized significant differences between individual hospitals and improved quality of end-of-life care in the ICU over time.

METHODS

Population and Setting

Hospitals in the Seattle/Tacoma region were eligible if they had enough ICU deaths to meet sample size requirements (16, 17). Of 16 eligible hospitals, 15 agreed to participate (94%) in a study of a systems-level quality improvement intervention designed to improve palliative care in the ICU. We excluded two hospitals from these analyses because outcome data were

collected for less than 2 years (12 and 14 months, respectively), making it difficult to detect changes over time. The remaining 13 hospitals had a median of 42 months in the study (inter-quartile range, 36.6–47.5; range, 26.5–50.5). Study deaths spanned August 2003 to February 2008. Hospitals included two university-affiliated teaching hospitals, three community-based teaching hospitals, and eight community-based, non-teaching hospitals. The number of ICU beds ranged from 10 to 65 with a median of 24 (interquartile range, 16–38). There were no significant differences in quality of care attributed to the intervention (16), and we therefore combined all patients into a single sample for this analysis.

Patients were identified using ICU admission and discharge logs for deaths. As our goal was to examine end-of-life care in the ICU, eligible patients were those who had died in the ICU after a minimum ICU stay of 6 hours or within 30 hours after being transferred to another hospital location. These time restrictions allowed ICU clinicians sufficient opportunity to affect end-of-life care (16). All study procedures were approved by institutional review boards at all hospitals (UW HSC#23503).

Data Collection

Collection of survey data has been described in detail previously (16–18) and is summarized here. In brief, study materials were sent to patients' homes 4–6 weeks after the patient's death, addressed to the family of the patient, requesting response by the person most knowledgeable about the patient's end-of-life experiences. Nurse questionnaires were distributed to up to two nurses for each patient; these nurses were identified as a) the nurse who had primary responsibility for the patient's care during the shift when death occurred and b) for patients whose ICU stay was longer than one nursing shift, the nurse who had primary responsibility for the patient's care during the shift prior to the shift when death occurred. In order to facilitate accurate recall, we distributed questionnaires to nurses' mailboxes within 72 hrs of the patient's death.

Questionnaire materials included an incentive (\$10 to family, coffee card to nurses), postage-paid return envelope, and questionnaire booklet. We used standard methods to enhance response rates (19) that included follow-up mailings with reminder/thank-you postcards 3 weeks after initial distribution followed by a second set of materials to nonrespondents after 5 weeks. Medical records were abstracted by trained chart abstractors using a standardized abstraction protocol. Abstraction training included 80 hours of formal training with instruction on the protocol, guided practice charts, and independent chart review followed by reconciliation with the research-abstractor trainer (20, 21). After initial training, 5% of the charts were coreviewed to ensure greater than 95% agreement on the 440 abstracted elements. Death certificates were obtained from Washington State and included identifiers that allowed us to link the death certificate data with the patient sample.

Predictor and Outcome Variables

Hospital—In order to identify variation across the 13 hospitals, individual hospitals were represented in regression models as 12 dummy indicators.

Time—To examine trends over time, time in years was the predictor variable. Time was computed as the elapsed time for each patient, in decimal years, between the earliest patient death in the study and that individual patient's death.

Covariates—For tests of differences between hospitals, we included patient and family characteristics as covariates for family outcomes and patient and nurse characteristics as covariates for nurse outcomes. Patient characteristics were drawn from the medical record and death certificate (age, sex, race, ethnicity, and cause of death), family characteristics from the family surveys (age, sex, race, and ethnicity), and nurse characteristics from the nurse survey (age). For tests of trends over time, we included these same covariates, plus the 12 dummy indicators for hospital.

Outcome Variables—Family- and nurse-assessed outcomes were described previously (16–18). Briefly, families completed the Family Satisfaction in the ICU (FS-ICU) survey and both families and nurses completed the Quality of Dying and Death (QODD) questionnaire. The FS-ICU is a validated 24-item survey divided into two domains which represent satisfaction with care and satisfaction with decision making and also provides a total score (FS-ICU). Each of the three FS-ICU scores has a potential range from 0 to 100, with 100 representing the highest satisfaction (12, 22, 23). The QODD questionnaire contains a single item rating the quality of dying (QOD-1) that is scored from 0 to 10, with 0 indicating “terrible” and 10 indicating “almost perfect”; this item has demonstrated construct validity correlating with other markers of the quality of palliative and end-of-life care (17, 20).

Chart-based outcomes were obtained from chart abstraction and included documentation of 11 unique processes of care within five domains: 1) use or nonuse of life-sustaining therapies (presence of a do-not-resuscitate [DNR] order prior to death, no cardiopulmonary resuscitation in the last 24 hours, and withdrawal of life support prior to death); 2) symptom management (assessment of pain in the last 24 hr of life); 3) communication about end-of-life care (occurrence of a family conference during the first 72 hr of a patient's ICU stay, occurrence of a prognostic discussion between family and physician in the first 72 hr of a patient's ICU stay); 4) use of support services (separately assessing palliative care, social work, or spiritual care consultation); and 5) length of stay (days in the ICU and days from ICU admission to ventilator withdrawal). All outcomes were dichotomously categorized as present or absent except for days in the ICU and days from ICU admission to ventilator withdrawal. In four of the 13 hospitals, palliative care consultation was not available at the time of this study, and these hospitals were excluded for the evaluation of palliative care consultation.

Analyses

All tests are based on regression models. Tests of differences between hospitals used probabilities associated with likelihood ratio tests for significant reduction in deviance, comparing a model in which dummy indicators for hospitals were included as predictors, with a model in which each hospital's effect was constrained to 0. Tests for temporal trend used probabilities associated with elapsed decimal years between the earliest death in the

study and each individual patient's death, treated as a linear predictor. Robust linear regression was used for the family and nurse outcomes, Cox models for days in the ICU and days to ventilator withdrawal, and logistic regression for all other chart outcomes. Because some nurses evaluated multiple patients, clustered regression was used for nurse outcomes. Statistical significance for all tests was set at $p < 0.05$.

RESULTS

Patient, Family, and Nurse Characteristics

There were 3,246 eligible patients who died in the ICU or within 30 hrs of transfer from the ICU for the 13 hospitals during the study period. We were able to abstract medical records for 3,065 patients (94%), as medical records for 181 patients were unavailable or incomplete. The mean patient age was 69 (SD, 16). Forty-one percent of patients were female and 21% were of minority race/ethnicity (nonwhite or Hispanic). The majority of patients (81%) had a DNR in place prior to death and 73% had life-sustaining therapy withdrawn. About 73% of patients had chart documentation of a family conference during the first 72 hours after admission, while only about 38% had documentation that prognosis was discussed with the family in the first 72 hours. Eighty-two percent of patients had documentation that their pain was assessed in the last 24 hours of life (Table 1).

Questionnaires were returned by a family regarding 1,215 patients. We identified usable addresses for 2,717 patients resulting in a response rate of 45% (1,215 of 2,717). The mean age of family respondents was 58 years (SD, 15) and 69% of respondents were female (Table 1).

We identified one or more nurses for 2,028 patients and received one or more usable responses for 1,207 patients, giving a patient-based response rate of 60% (1,207 of 2,028). We selected a single nurse questionnaire for each patient by choosing the most complete survey or randomly selecting among equally complete surveys, producing a sample of 575 nurses, with each nurse returning, on average, 2.1 questionnaires (median, 1; range, 1–11). Based on returned nurse surveys, the mean age for nurses was 42 and 86% of respondents were female (Table 1).

Associations Between Hospital and End-of-Life Care Outcomes of Interest

Hospitals, taken as a group, accounted for a significant amount of variance in all outcomes. For survey data, the family QOD-1 ($p = 0.031$) and all FS-ICU scores ($p < 0.001$) were significantly different among hospitals, as was the nurse QOD-1 ($p = 0.003$). For chart data, all of the chart indicators of palliative care varied significantly among hospitals ($p < 0.001$).

Figure 1 shows the performance of each hospital on four of the chart-based indicators of palliative care. Because a single graph with all 13 hospitals is difficult to interpret, we divided the hospitals into smaller sites ($n = 7$; ICU deaths per hospital = 92–238) and larger sites ($n = 6$; ICU deaths per hospital = 247–590). This enabled examining whether the larger sites, with potentially more stable estimates, displayed noticeably different patterns than those for smaller sites. Figure 1, A and B, suggests that although the variability across hospitals was significant, it could not be attributed to particular hospitals performing at

uniformly high or low levels on these indicators of palliative care in the ICU. There was no evidence that differential performance was due to hospital size.

Examination of Temporal Trends in Quality of Palliative and End-of-Life Care

We found no significant temporal trends over study years in the family QOD-1 or the FS-ICU scores, controlling for hospital, patient, and family characteristics. Similarly, nurse QOD-1 scores failed to provide evidence of a temporal trend, controlling for hospital, patient, and nurse characteristics. When evaluating chart indicators of palliative care for temporal trends, we found that over time patients were more likely to have documentation of pain assessment in their last 24 hours of life ($p < 0.001$), but less likely in their first 72 hours in the ICU to have documentation of a family conference ($p < 0.001$) or discussion of prognosis ($p = 0.020$). All other chart indicators of palliative care showed no significant change with time (Table 2).

Figure 2A, illustrates the change in the expected percentage of documented pain assessment over time for each individual hospital and for the combined hospital average. Similarly, Figure 2B shows the change in the expected percentage of documented family conferences over time. Each hospital-specific line represents the probability that a patient with characteristics matching those of an “average patient” from the combined hospitals would have pain assessment (or a family conference) if that average patient were cared for in the hospital of interest.

DISCUSSION

By focusing on the variability in family and nurse ratings of quality, as well as specific components of the delivery of palliative care in the ICU, our study adds to the current literature on regional and interhospital variability. Prior studies have documented regional and interhospital differences in the intensity of care at the end of life and the proportion of patients who die in the ICU, yet efforts to explain this variability have had limited success (2–4, 24, 25). Barnato et al (4) found that variability in intensity of care at the end of life was not explained by variability in patient preferences and that patient preferences for end-of-life care did not vary across different regions among Medicare beneficiaries. There is some evidence that regional variation in end-of-life care and expenditures are partially explained by physician, hospital, and ICU bed supply (26). However, Lin et al (3) explored these system-level factors in detail by examining organizational determinants (ICU programs, policies, and practices) in 124 Pennsylvania hospitals and found little additional explanatory power for the variation in end-of-life treatment intensity. Our results add to this literature, showing significant interhospital variability in family satisfaction with end-of-life care in the ICU, as well as in family and nurse ratings of the QOD-1. We also show significant interhospital variability in the palliative care delivered in the ICU at the end of life, as identified by chart-based indicators of palliative care.

One possible explanation for interhospital variability may be attributed to differential emphasis by hospitals on incorporating palliative and end-of-life care in the ICU. If this were the case, we would expect some hospitals would show higher quality on all or multiple measures. With only 13 hospitals, we could not use multilevel modeling techniques, which

would have allowed investigating the association of hospital characteristics with the outcomes of interest (27, 28). Nonetheless, our results do not support the hypothesis that some hospitals performed better than others on all measures. Instead, it appears that individual hospitals demonstrated higher performance on some measures but not others. The data for this report were from a randomized trial of an unsuccessful intervention to improve palliative and end-of-life care (16). It is possible that such interventions would be more successful if they better targeted the specific areas where improvement was needed at each site rather than having similar targets across all sites. Although the randomized trial did attempt to identify hospital-specific barriers to palliative care and address those barriers, the quality measures and targets were the same in each institution (16, 18). Further study is needed to understand the source of the variability in palliative and end-of-life care across hospitals and, more importantly, the best way to improve palliative and end-of-life care at each hospital.

With the current focus on the importance of providing palliative and end-of-life care to critically ill patients and their families (8, 10, 11), it seemed possible that this care might have been improving over time and that problems previously documented had declined or disappeared (5). We are unaware of any evidence suggesting temporal improvement in specific measures of quality of end-of-life care, and we found little evidence that the quality of end-of-life care in the ICU improved over the 55-month time period of our study. One area that showed some evidence of improvement was documented assessment of pain in the last 24 hrs of life. Assessment and treatment of pain have been a focus of quality improvement with campaigns to consider pain as “the fifth vital sign.” This may help explain some of the improvement we observed (29–31). Surprisingly, we saw a decrease in documented family conferences and discussion of prognosis over time. Several studies suggest that focusing on proactive family conferences earlier in the ICU course than our standard care can reduce psychological distress among family members and reduce the prolongation of dying in the ICU (32, 33). It is not clear why early conferences and prognosis discussions would decrease over time in our study. These findings are limited by the completeness of documentation which may be particularly problematic for prognostic discussions (34), although it seems unlikely that documentation decreased if the occurrence of these communication events remained steady or increased over time. Importantly, our failure to identify a consistent temporal trend in palliative care may be limited by the relatively short time span, encompassing deaths over 55 months. Data collected over a longer period of time may have shown significant improvement, especially when compared to the 1990s when the SUPPORT trial was published, documenting poor quality of end-of-life care (5).

Our study has several additional limitations. First, we conducted multiple comparisons and some of the significant findings may have occurred by chance. Therefore, these results should be considered hypothesis generating. Second, the data presented are from 13 hospitals in the Seattle-Tacoma area and may not generalize to other regions. Finally, our goal was to study end-of-life care delivered to patients who died in the ICU or shortly after a stay in the ICU and may not generalize to all patients at risk of dying in the ICU (35).

In summary, this study shows significant variability among hospitals in both the delivery and subsequent family and nurse ratings of palliative and end-of-life care in the ICU. Our findings expand on previous studies describing interhospital variability in the intensity of care at the end of life (2–4, 24, 25) and suggest that this variability may not be explained as much by some hospitals that do this well and others that do it poorly, but rather by variability in the individual processes of palliative and end-of-life care. Our findings also suggest that there is little evidence that the quality of palliative and end-of-life care improved significantly between 2003 and 2008, despite important advances in our understanding and increased emphasis on palliative and end-of-life care in the ICU. Future research should examine temporal trends over a longer period and develop a better understanding of the specific areas still in most need of improvement.

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Figure 1.

Variability in chart-based outcomes among hospitals. This figure shows the performance of each hospital on four of the chart-based indicators of palliative care (two covering the last 24 hr of life: no cardiopulmonary resuscitation (CPR), pain assessments; and two covering the first 72 hr in the ICU: family conferences and prognostic discussions). For the purposes of illustration, the hospitals were divided into those with a smaller number of deaths (**A**; $n = 7$) and those with a larger number of deaths (**B**; $n = 6$). Each hospital is represented by a different line showing that hospitals vary in their relative position compared to other hospitals.

Figure 2.

Outcome measures by hospital over time. This figure shows the change in the expected percentage of pain assessments in the last 24 hr of life (**A**) and family conferences in the first 72 hr in the ICU (**B**) over time for each individual hospital and for the total sample average. On average, pain assessments significantly increased over the study period ($p < 0.001$), while family conferences significantly decreased ($p < 0.001$). The within-hospital lines are adjusted for patient characteristics; the summary line (average [AVG]) is adjusted for patient characteristics and for hospital.

TABLE 1
Description of Samples From 13 Hospitals That Participated in Study More Than 24 Months

	Patients		Families		Nurses	
	Valid <i>n</i>	Statistics	Valid <i>n</i>	Statistics	Valid <i>n</i>	Statistics
Age, mean (SD)	3,065	69.1 (15.7)	1,187	58.2 (14.5)	1,196	42.1 (9.9)
Female, %	3,065	41.4	1,188	68.5	1,206	85.8
Minority, %	3,065	21.3	1,177	14.6	1,202	18.1
Cause of death, %	3,065					
Cancer		14.2				
Trauma		10.0				
Other cause		75.8				
Palliative consultation, %	3,061	8.4				
Social worker consultation, %	3,059	43.1				
Spiritual care consultation, %	3,060	46.5				
Do not resuscitate in place, %	3,048	81.4				
Withdraw/withhold life-sustaining therapy, %	3,048	72.6				
Pain assessed in the last 24 hr, %	3,062	81.9				
No cardiopulmonary resuscitation in the last 24 hr, %	3,062	83.3				
Family conference in the first 72 hr, %	3,063	73.1				
Prognosis discussed in the first 72 hr, %	3,062	37.8				
Days in ICU, mean (SD)	3,063	5.7 (9.0)				
Days to ventilator withdrawal, mean (SD)	1,549	6.2 (9.6)				
Quality of death rating, mean (SD), [range] ^a			1,139	7.0 (3.1) [0–10]	1,100	7.2 (2.8) [0–10]

	Patients		Families		Nurses	
	Valid <i>n</i>	Statistics	Valid <i>n</i>	Statistics	Valid <i>n</i>	Statistics
Family satisfaction with care, mean (SD), {range} ^b	1,167		77.8 (20.3)	{0–100}		
Family satisfaction with decision making, mean (SD), {range} ^b	1,192		75.4 (22.1)	{0–100}		
Total family satisfaction, mean (SD) {range} ^b	1,171		76.7 (20.2)	{2.5–100}		

^a Potential range = 0–10.

^b Potential range = 0–100.

TABLE 2

Associations^a Between Patient-Specific Outcomes of Interest and Elapsed Time in Years From Start of the Study to Patient Death, Adjusted for Covariates^b

Outcome	Beta for Elapsed Time	<i>p</i>
Family ratings		
Quality of dying (QOD-1)	0.162	0.054
Family satisfaction with care	0.874	0.118
Family satisfaction with decision making	0.584	0.338
Family satisfaction with ICU (total)	0.752	0.182
Nurse ratings		
Quality of dying (QOD-1)	0.002	0.982
Chart indicators		
Do-not-resuscitate order in place	−0.054	0.198
No cardiopulmonary resuscitation in the last 24 hr	0.000	0.995
Withdraw/withhold life-sustaining therapy	0.031	0.411
Pain assessed in the last 24 hr	0.222	<0.001 ^c
Family conference in the first 72 hr	−0.180	<0.001
Prognosis discussed in the first 72 hr	−0.081	0.020
Palliative care consultation	0.082	0.211
Social worker	0.016	0.688
Spiritual care	−0.024	0.521
Days in ICU	0.002	0.885
Days to ventilator withdrawal	0.020	0.375

^a Associations are based on regression models, in which the predictor of interest, computed for each patient, was the elapsed time in decimal years between the earliest death in the study and that patient's death.

^b Models for all outcomes were adjusted for hospital site, patient age, gender, racial-ethnic minority status, and cause of death. Models for family outcomes were also adjusted for the family respondent's age, gender, and racial-ethnic minority status. The nurse-outcome model was also adjusted for the nurse respondent's age, with clustering by nurse.

^c Bold text indicates $p < 0.05$.