

Palliative care indicators associated with nurse-rated quality of dying
in the intensive care unit

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Abstract

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Background: Palliative care is important in the intensive care unit (ICU) but specific indicators of quality palliative care are not yet well understood.

Objective: To identify palliative care quality indicators that are associated with nurse-ratings of the quality of dying for patients who die in the ICU.

Design: Cohort study using data from a multi-center trial of a hospital-based palliative care intervention.

Setting/Subjects: The study sample included patients who died in 14 Seattle-Tacoma ICUs from 2003-2008.

Measurements: The primary outcome was the single-item nurse rating of quality of dying (QOD-1). Palliative care quality indicators were: involvement of a social worker, involvement of

a spiritual care provider, do not resuscitate (DNR) orders in place at time of death, life-sustaining treatment withheld/withdrawn, pain assessment in the last 24 hours of life, CPR avoided in last hour of life, family conference in first 72 hours of ICU admission, and prognosis discussion in first 72 hours of ICU admission.

Results: Higher nurse QOD-1 was associated with having DNR orders in place at time of death, withdrawing/withholding life-sustaining treatment, avoiding CPR in the last hour of life, and occurrence of a family conference in the first 72 hours of ICU admission (all $p < 0.001$).

Conclusions: As rated by nurses, patients who had a family conference and avoided aggressive end of life procedures had a better dying experience. Improving end of life treatment planning may be important for increased quality of care for patients who die in the ICU.

Introduction

Research indicates that many patients die in physical or emotional discomfort.¹⁻³ Additionally, aggressive treatments are often deployed at the end of life without thorough assessment and consideration of the patient's wishes and with potentially negative impacts for the family. Palliative care aims to improve quality of life for the seriously ill through improved continuity of care, symptom management, addressing emotional needs, addressing spiritual needs, and eliciting and respecting patient values, goals and preferences.⁴ In the process of doing so, palliative care may reduce utilization of intensive, burdensome, and costly interventions.^{5,6}

Palliative care plays an important role in the intensive care unit (ICU), where approximately 33% of patients spend time in the final months of life and where an estimated 22% of patients die.^{7,8} While palliative care has been shown to improve quality of care and decrease utilization in the ICU,⁹⁻¹¹ the specific elements of palliative care that contribute to this improvement are not well understood. The Robert Wood Johnson Foundation Critical Care Workgroup has proposed palliative care quality indicators for use in critical care.¹² These indicators fit within seven domains: patient and family-centered decision making; communication; continuity of care; emotional and practical support; symptom management and comfort care; spiritual support; and emotional and organization support for ICU clinicians. Identifying a relationship between key palliative care indicators and improved end of life outcomes is valuable because it can identify potentially useful palliative care practices that could be targeted in future studies and quality improvement efforts.

Evidence suggests that some palliative care indicators are associated with family ratings of the quality of death and dying.¹³ While family ratings of a patient's experiences at the end of life are important, most families provide overwhelmingly positive ratings with ICU care so

alternative perspectives of a patient's death can be informative.¹⁴ Nurse ratings may provide an additional perspective, gained from attending to many patients who die; nurses are able to draw upon broad and diverse experiences to evaluate patients' end-of-life experiences. Hodde et al. demonstrated that nurse ratings of the quality of dying and death are feasible as an outcome measure to evaluate end of life ICU care.¹⁵ Nurses may also be more critical than families or physicians in evaluating patients' experiences at the end of life.¹⁶ Therefore, nurse ratings of the quality of dying may provide an important outcome for measuring and identifying potential targets for quality improvement.

Using data from hospitals involved in a multi-center trial of patients who died in the ICU, this study examined whether palliative care indicators extracted from medical charts were associated with better end of life outcomes, as assessed by nurse ratings of the quality of dying.

Methods

Study Data

Study data came from a trial of a multifaceted hospital-based intervention to improve the quality of end of life care in the ICU. Fourteen hospitals in the Seattle-Tacoma area participated in the study from August 2003 to February 2008. The study sample consisted of patients who died in the ICU (or within 30 hours of transfer from the ICU). This analysis further limits the study sample to those patients for whom a nurse completed the quality of dying and death questionnaire. The intervention did not show an overall effect, so all patients are included in this analysis regardless of whether they died before or after the intervention. Detailed description of the trial design, intervention, and main findings have been published previously.^{17,18}

Quality of Dying and Death Questionnaire

The Quality of Dying and Death (QODD) questionnaire was developed using published after-death reports; interviews and focus groups with patients; findings from prior qualitative research; and a review of pre-existing measures.¹⁹ The original family-rated version demonstrated good reliability and validity,²⁰ as has a revised version for hospital or ICU clinicians.¹⁵ The main outcome measure for this analysis was the nurse-rated, single-item Quality of Dying (QOD-1) summary measure of the QODD. This item asks nurses, “Overall, how would you rate the quality of your patient’s dying?” Response options range from 0 (“Terrible”) to 10 (“Almost Perfect”). An advantage of using the single-item summary measure is that it is easier to interpret, whereas there is some question of the dimensionality and interpretation of the multi-item QODD total score.²¹ It also avoids the pitfall of missing items, which has been an issue in prior studies.¹⁵

Data collection

When a patient died in the ICU, a study team member identified both the nurse who cared for the patient at the time of death or discharge from the ICU, and the nurse who worked the prior shift. Questionnaires were sent to the nurses within 72 hours of their patient’s death. To encourage participation, nurse questionnaire packets included an incentive (coffee card) and postage-paid return envelope. Reminders were sent three weeks later and, after five weeks, a second questionnaire package was sent to non-respondents.

Chart-Abstracted Palliative Care Indicators

Trained chart abstractors used a standardized protocol to review medical records of patients who died in the ICU. A 5% sample of all charts was reviewed by two abstractors to ensure greater than 95% agreement on abstracted data. Eight medical record data elements, consistent with the principles of palliative care, were used for this study:

- Involvement of a social worker
- Involvement of a spiritual care provider
- Do Not Resuscitate (DNR) orders in place at the time of death
- Withholding or withdrawing life support
- Pain assessment in the last 24 hours of life
- Avoidance of cardio-pulmonary resuscitation (CPR) in the last hour of life
- Occurrence of a family conference within 72 hours of ICU admission
- Documented discussion of the patient's prognosis during a family conference in the first 72 hours of ICU admission

Statistical Analyses

Bivariate analyses of the nurse QOD-1 by palliative care indicator were conducted using Mann-Whitney tests because the QOD-1 was not normally distributed. Tobit regression models were used for multivariate analyses to account for the censored distribution of the nurse QOD-1; approximately 20% of the nurses responded with the highest response option of 10 (indicating an "Almost Perfect" experience). Because some nurses completed questionnaires for multiple patients, models were clustered within nurses.

Regression models for each of the eight palliative care indicators were adjusted for any confounders that changed the coefficient by 20% or more. Potential confounders were: cause of

death, patient age, patient sex, patient race/ethnicity, patient education, patient marital status, patient comorbidities, nurse age, nurse sex, nurse race/ethnicity, nurse time in critical care nursing, hospital, and pre/post intervention status. All analyses were conducted using Stata version 12.

Results

Sample Characteristics

Of 3400 patients included in the original trial, 1185 patients (34.9%) had a nurse QOD-1 questionnaire available, representing 606 unique nurses. Patient and nurse characteristics are presented in Table 1.

Patients with a nurse questionnaire were an average of 66 years old, 39% female, 21% nonwhite, and 42% had at least some college education. The median length of ICU stay was 3 days (interquartile range=7). Compared to those without a nurse survey, patients with a nurse QOD-1 were significantly younger; more likely to be male; had a longer ICU stay; and were more likely to die of trauma and less likely to die of cancer. Patients with a nurse QOD-1 were less likely to have cancer, immunosuppressive state, cerebrovascular disease, congestive heart failure, dementia and chronic renal disease; and were more likely to have drug use/abuse and alcohol abuse.

Nurses were an average age of 41 years, with few men (15%) and few minorities (17%) responding. Nurses were experienced in providing critical care nursing, with an average of 11 years of experience. Nurses completed an average of 2 QOD-1 questionnaires with a range of 1-10.

Documentation of Palliative Care Indicators

Table 2 demonstrates the percentage of patients for whom each palliative care indicator was documented. Most patients had DNR orders in place at time of death (84%), had pain assessed in the last 24 hours of life (86%), and were not administered CPR in the last hour of life (91%). Fewer patients had documentation of spiritual care (56%), social work support (53%), or a discussion of their prognosis in the first 72 hours of ICU admission (41%).

Bivariate Analyses

Bivariate analyses demonstrate the difference in nurse QOD-1 score between patients who did and did not have documentation of each palliative care indicator (Table 3). Nurse QOD-1 scores were significantly different for five palliative care indicators: involvement of a social worker, having DNR orders in place at the time of death, withdrawing or withholding life-support, avoidance of CPR in the last hour of life, and occurrence of a family conference within 72 hours of ICU admission. Nurse QOD-1 scores were not significantly different for involvement of a spiritual care provider, pain assessment in the last 24 hours of life, and discussion of prognosis during a family conference in the first 72 hours of ICU admission.

Multivariate Analyses

Multivariate analyses identified four palliative care indicators that were significantly associated with improved nurse QOD-1 scores (Table 4). Having DNR orders in place at the time of death was associated with a 2.0-point higher nurse QOD-1 score ($p < 0.001$). Withdrawing or withholding life-sustaining treatment was associated with a 2.5-point higher nurse QOD-1 score ($p < 0.001$). Avoiding CPR in the last hour of life was associated with a 3.7-point higher nurse

QOD-1 score ($p < 0.001$). The occurrence of a family conference in the first 72 hours of ICU admission was associated with a 1.0-point higher nurse QOD-1 score. The other palliative care indicators were not significantly associated with nurse QOD-1.

Discussion

In this analysis, four palliative care indicators were independently associated with a better nurse-rated dying experience. The three indicators that were most strongly associated with better nurse QOD-1 scores were all related to avoiding high intensity procedures at the end of life. This is in line with prior research and end-of-life treatment recommendations.^{15,13,22}

Four indicators, recommended in the field of palliative care,²³ were not associated with better nurse QOD-1 in this sample. This lack of association might have arisen in part from the short period that patients spent in the ICU; in order for spiritual support, social worker support, pain assessment, and discussion of prognosis to have a positive impact, these aspects of care may need to occur earlier, before the patient is so near to death. Additionally, these aspects of care may produce benefits that are intrinsic to the patient but not as readily perceived by nurses.

In this sample, the indicators that were significantly associated with nurse QOD-1 were received by 75% or more of patients. This result suggests that the most influential indicators in this study are being delivered fairly consistently in the study hospitals, but room for improvement still exists. In other health systems, occurrence of these indicators in the ICU is highly variable and greater attention to these indicators may be warranted.^{24,25}

Limitations

A limitation of this study was the low response rate, with a QOD-1 available for only 35% of the entire trial sample. These results may therefore not generalize to all patients who die in the ICU. We used a targeted list of palliative care indicators, but it should be noted that we examined documentation of these indicators in the medical record rather than actual occurrence and that there might be other indicators that are important but were not included in this study. Finally, since this is an observational study, we cannot assume causal relationships between palliative care indicators and QOD-1 ratings, but rather only associations. Indicators such as provision of social work or spiritual care may be affected by indication bias with these services more likely to be provided in situations where conflict arises or distress is higher.

Conclusion

Our study found that a family conference in the first 72 hours in the ICU and avoiding life-sustaining treatments at the end of life, particularly CPR in the hour before death, were significantly associated with better nurse ratings of patients' end-of-life experiences in the ICU. This result underscores the importance of patient-centered treatment planning in end of life care. Further research linking palliative care indicators to additional end-of-life outcomes is needed to improve the quality of palliative care in the ICU.

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Table 1. Patient and Nurse Characteristics

	Patients with Nurse QOD-1		Patients Without Nurse QOD-1		<i>p</i> ^a
	N	Mean or %	N	Mean or %	
Patients					
Age, mean (SD)	1185	65.8 (16.2)	2215	70.7 (14.9)	<0.001
Female, %	1185	39.0	2215	43.0	0.024
Nonwhite race/ethnicity, %	1185	21.4	2215	20.9	0.737
Education, %	1143		2172		0.081
8 th grade or less		7.9		7.3	
Some high school		10.8		8.3	
High school graduate/GED		39.2		40.2	
Some college		24.7		23.6	
4-year college degree		11.7		14.3	
Post-college study		5.8		6.3	
ICU LOS, median (IQR)^b	1160	3.1 (6.6)	2067	2.6 (5.3)	<0.001
Cause of death, %	1185		2215		<0.001
Trauma		17.1		5.6	
Cancer		10.6		16.9	
Other		72.3		77.4	
Comorbidities^c, %					
Malignancy	1122	22.5	2014	28.8	<0.001
Psychiatric disorder	1122	24.1	2014	23.1	0.557
Immunosuppressive state	1122	5.4	2014	7.4	0.035
Cerebrovascular disease	1122	12.3	2014	15.9	0.006
Liver disease	1122	7.5	2014	5.9	0.085
Respiratory disease	1122	28.4	2014	30.7	0.177
Drug use/abuse	1122	8.7	2014	4.2	<0.001
Alcohol abuse	1122	18.0	2014	13.5	0.001
Congestive heart failure	1122	21.0	2014	24.7	0.021
Dementia	1122	8.5	2014	11.1	0.021
HIV/AIDS	1122	1.3	2014	1.2	0.725
Chronic renal disease	1122	6.6	2014	10.0	0.001
Diabetes	1122	29.8	2014	31.3	0.379
Nurses					
Age, mean (SD)	599	41.4 (10.0)	--	--	
Female, %	605	85.0	--	--	
Nonwhite race/ethnicity, %	601	17.1	--	--	
Estimated years in critical care nursing, mean (SD)	603	10.5 (9.0)	--	--	
Number of QOD-1s completed, mean (range)	606	1.96 (1-10)			

a. P-values were generated from t-tests or Mann-Whitney tests for continuous variables and chi-squared tests for categorical variables.

b. ICU = Intensive Care Unit, LOS = Length of Stay, IQR = Interquartile Range.

c. Each patient could have more than one comorbidity.

Table 2. Percentage of Patients With Documentation of Each Palliative Care Indicator

Palliative Care Indicator	N	%
Social work support provided	1119	52.6
Spiritual support provided	1120	56.3
DNR in place at time of death	1114	84.0
Life-sustaining treatment withheld/withdrawn	1112	75.3
Pain assessment in the last 24 hours of life	1120	85.5
CPR avoided in last hour of life	1108	90.6
Family conference in first 72 hours in ICU	1107	74.5
Prognosis discussed in first 72 hours in ICU	1105	40.5

Table 3. Mean Nurse QOD-1 by Palliative Care Indicator

Palliative Care Indicator	n	Mean QOD-1	<i>p</i> ^a
Social work (N=1119)			
Social work support provided	588	7.00	0.011
Social work support not provided	531	7.34	
Spiritual care (N=1120)			
Spiritual support provided	630	7.32	0.110
Spiritual support not provided	490	6.97	
DNR orders (N=1114)			
DNR orders in place at time of death	936	7.45	<0.001
DNR orders not in place at time of death	178	5.68	
Life-sustaining treatment (N=1112)			
Life support withdrawn/withheld	837	7.69	<0.001
Died in setting of full life support	275	5.52	
Pain assessment (N=1120)			
Pain assessed in last 24 hours of life	958	7.18	0.737
Pain not assessed in last 24 hours of life	162	7.05	
CPR in last hour of life (N=1108)			
CPR avoided in last hour of life	1004	7.49	<0.001
CPR administered in last hour of life	104	4.19	
Family conference (N=1107)			
Family conference within 72 hours of ICU admission	825	7.40	<0.001
No family conference within 72 hours of ICU admission	282	6.56	
Discussion of prognosis with family (N=1105)			
Prognosis discussed in first 72 hours of ICU admission	447	7.33	0.174
Prognosis not discussed in first 72 hours of ICU admission	658	7.09	

a. P-values were generated from Mann-Whitney tests.

Table 4. Multivariate Tobit Regression Models with Nurse QOD-1 as the Outcome

Outcome	Palliative Care Indicator	N	b	p	95% CI
QOD-1 Score ^a	Social work support provided ^b	1103	-0.224	0.279	-0.629, 0.182
	Spiritual support provided	1120	0.363	0.086	-0.052, 0.778
	DNR in place at time of death	1114	1.995	<0.001	1.442, 2.549
	Life-sustaining treatment withheld/withdrawn	1112	2.461	<0.001	1.967, 2.956
	Pain assessment in the last 24 hours of life ^c	1115	0.302	0.317	-0.289, 0.892
	CPR avoided in last hour of life ^d	1103	3.720	<0.001	3.047, 4.392
	Family conference in first 72 hours in ICU	1107	1.029	<0.001	0.541, 1.517
	Prognosis discussed in first 72 hours in ICU	1105	0.276	0.155	-0.105, 0.656

a. Nurse QOD-1 score ranges from 0 indicating a “terrible” experience to 10 indicating an “almost perfect” experience.

b. Model adjusted for patient age and marital status.

c. Model adjusted for current/history of drug use/abuse, hospital, and nurse race/ethnicity.

d. Model adjusted for nurse race/ethnicity.