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Quality of End of Life Care and Its Association with Nurse Practice Environments in U.S. Hospitals

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Stocks		x		x		x		x
Royalties		x		x		x		x
Expert Testimony		x		x		x		x
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Abstract

OBJECTIVES: The purpose of this study is two-fold: (1) to describe the quality of end of life care in U.S. hospitals from the perspective of hospital nurses and (2) to evaluate the relationship between the nurse practice environment and end of life care quality.

DESIGN: Cross-sectional analysis of multiple linked secondary data-sources.

PARTICIPANTS and SETTING: 12,870 direct care registered nurses in 491 acute-care hospitals.

MEASUREMENTS: Measures of end of life care quality and nurse practice environment were derived from the 2016 RN4CAST-US survey of nurses. Nurses reported on end of life care quality for patients for whom death within a year would not be surprising. Nurse practice environment was measured using the Practice Environment Scale of the Nursing Work Index (PES-NWI) – a National Quality Forum validated scale.

RESULTS: The majority of nurses gave their hospitals an unfavorable evaluation of end of life care overall (58%) and said patients often experience painful procedures that were unlikely to change their outcome (53%). The best predictor of poor quality was the nurse practice environment. Nurses in the best environments were 55% less likely than nurses in poor environments to rate their hospital's overall end of life care quality unfavorably (OR = 0.45, 95% CI = 0.39–0.52, $p < 0.001$).

CONCLUSION: Quality of end of life care in U.S. hospitals is imperfect, and significantly worse in hospitals with poor nurse practice environments than in hospitals with the best environments. This study reinforces the importance of nurses in providing high quality end of life care.

Keywords

end of life; quality; hospitals

INTRODUCTION

At the end of life, hospitalized older adults often experience high-cost and low-quality care that does not improve survival [1–5], quality of life [5–9], or satisfaction [10–12], and is often incongruent with patients' values [13–16]. For example, despite most older adults preferring to remain at home [13–16], 72% of elderly patients with advanced cancer experience aggressive medical treatments, such as mechanical ventilation and intensive care unit admissions, and 67% have two or more hospitalizations in the last month of life [12].

Action is needed to improve the care for patients who find themselves in hospitals near the end of life.

Nurses are ideally suited to improve patient and family care at the end of life. Their physical presence at the bedside and training in symptom management and palliation position them to directly attend to and oversee the care of dying patients [17, 18]. In fact, bereaved family members say their loved one's treatment preferences were respected and concerns listened to when nurses were involved in end of life care and decision-making [19]. Despite nurses' proximity to patients and their clinical skill set, they remain an untapped resource due to the constraints and demands of their practice environments.

A barrier to more fully engaging nurses in end of life care is that nurses are often stretched thin caring for acutely ill patients. Heavy workloads and under-resourced working conditions result in overburdened nurses who prioritize administering treatments and medications over more time-intensive care needs such as talking with, teaching, and developing plans of care with patients, families, and other clinical providers [20–22]. Additionally, while physicians agree that being more inclusive of nurses in care planning could improve end of life care [23, 24], nurses say their clinical judgment is under-utilized by physicians [25, 26]. Lack of communication between providers and undefined role responsibilities are problematic, particularly with regards to discussions about prognosis and care options [27]. Previous research suggests that when nurses practice in environments characterized by effective nurse-physician teamwork, where authority is devolved to nurses to act in their areas of expertise, where nurses have manageable workloads, and where nurses are highly engaged in hospital decision-making, patients experience better care of all kinds [20, 28–31].

The purpose of this study is two-fold: (1) to describe the quality of end of life care in U.S. hospitals and (2) to evaluate the relationship between the nurse practice environment and end of life care quality. We take advantage of the heterogeneity in hospitals' nurse practice environments to evaluate the relationship between practice environments and the quality of end of life care. We hypothesize that the quality of care provided to patients at the end of life will be better in hospitals which have better nurse practice environments; environments, that is, which are more supportive of nurses and more conducive to better nursing practice.

METHODS

Sample and Data Sources

We used data from the RN4CAST-US 2016 survey of registered nurses, which employed a modified Dillman method [32] to randomly sample registered nurses in four states (California, Florida, New Jersey, and Pennsylvania). The survey methodology is described in detail in the Supplementary Materials. In brief, nurses were identified through state boards of nursing licensure lists and selected to receive surveys mailed to their home address. Mailed and online response options were offered. Surveyed nurses were asked to provide information about their employing hospital, including the hospital name, which allowed each nurse respondent to be linked to a hospital, nurse responses to be aggregated within each hospital, and then linked to the American Hospital Association Annual Survey. The

Annual Survey provided information on hospital structural characteristics (i.e., size, teaching status, technology status, profit status).

The overall response rate of the RN4CAST-US 2016 was 26%. We describe in detail why the overall response rate is not a major limitation on this study in the Supplementary Materials. Briefly, this is a study of hospitals – not nurses – and the strength of our survey design is that it yields an unbiased sample of representative hospitals. Additionally, our sample of direct care hospital nurses represents only 35% of the RN4CAST-US sampling frame, so the true response rate of our sample is likely larger than the response rate to the RN4CAST-US. Finally, we conducted an intensive re-survey of non-respondents to empirically examine whether and to what extent nonresponse bias was present in the survey of nurses. Analyses reveal no significant differences between respondents and non-respondents on nurses' ratings of their practice environment and quality of care.

Our sample of hospitals included 491 nonfederal acute care hospitals in California, Florida, New Jersey, and Pennsylvania. Some 12,870 registered nurses providing direct patient care in the 491 study hospitals — an average of 48 nurses per hospital —, contributed information about the quality of end of life care in their hospitals.

Measures

End of Life Care Quality.—Nurses were asked to appraise their hospital's overall end of life care quality for patients for whom death within a year would not be surprising. The "surprise" question is a predictively validated tool for identifying individuals at the end of life [33]. Our global measure of overall end of life care quality was informed by the structure of the Agency for Healthcare Research and Quality's (AHRQ) overall patient safety grade and used a rating scale of A (excellent) through F (failing). Our second global measure of quality was derived from a 10-point scale on which nurses rated the care received at the end of life from *all providers for the last patient he/she cared for who died*. A rating of 10 indicated the "best possible care" and a rating of 0 indicated the "worst possible care." We define an unfavorable rating as less than a 9 out of 10, which has been validated in other work [34–36].

Specific quality measures were evaluated on a 4-point Likert scale. Nurses were asked to report what they observed in their clinical environments, whether or not it applied to them or their specific patients. The specific quality measures included whether: 1) patients often experience painful/uncomfortable procedures that are not likely to change their outcome, 2) nurses are discouraged from discussing care options with dying patients/families, 3) nurses and physicians often disagree about end of life care, 4) end of life decisions are made as a team, 5) advance directives are documented and accessible, and 6) patients die with dignity.

Nurse Practice Environment.—The nurse practice environment was measured using the Practice Environment Scale of the Nursing Work Index (PES-NWI) which is a National Quality Forum validated scale on which nurses report about various organizational features present in their practice environment [37]. Nurses used a 4-point Likert scale to indicate their agreement/disagreement with statements about their organization. The PES-NWI measures 5 concepts: 1) nurse participation in hospital affairs, 2) nursing foundation for

quality care, 3) nurse manager ability, leadership, and support, 4) staffing and resource adequacy, and 5) nurse-physician relations. Nurse responses were aggregated to the hospital-level by taking the average within each hospital. Hospitals were first grouped into quartiles based on the average nurse practice environment scores, and the four quartiles were then divided into three groups. Hospitals with the best environments are those ranked in the top quartile, hospitals with mixed environments are those in the middle two quartiles, and hospitals with poor environments are those in the bottom quartile.

Potential Confounding Variables.—To account for potentially confounding relationships between practice environments and nurse reports of end of life quality, we adjusted for nurse and hospital characteristics. Nurse characteristics included age, sex, years of experience, education, specialty certification, working in an intensive care unit (ICU), and the frequency of providing end of life care (i.e., routinely/occasionally or never/rarely). Hospital characteristics included size, teaching status, technology status, and profit status.

Analysis

We described nurse reports of end of life care quality using descriptive statistics and tested for differences in quality across hospitals using chi-square tests. Hospital-level measures of quality were constructed by aggregating nurse responses within hospitals. Multi-level logistic regression models were used to describe the effect of better practice environments on end of life quality, while accounting for nurse and hospital characteristics. Nurse practice environment is a hospital-level categorical variable scored linearly (0-poor; 1-mixed; 2-best). Statistical analyses were conducted in STATA.

RESULTS

Among all hospital nurses, nearly half gave their hospitals an unfavorable grade on overall end of life care (47.9%) and the majority (58.3%) gave their hospital an unfavorable rating (of less than 9 on a 10-point scale) for the care of last patient they were in contact with who died (Table 1). The most common specific quality problem reported by 52.6% nurses was that patients often experience painful procedures that are not likely to change their outcome. More than one-third (37.7%) of nurses reported that nurses in their hospital are discouraged from discussing care options with patients, and a similar percentage reported that nurses and physicians often disagreed about end of life care decisions. Roughly one in six nurses (16.5%) indicated that care decisions are not made as a team, about one in seven (15%) indicated the patient's end of life directives are not clearly documented and accessible, and one in eight (11.8%) reported that patients do not always die with dignity.

Table 1 shows that when nurse reports of end of life care quality were compared across hospitals with poor, mixed, and the best nurse practice environments, poorer end of life care quality was associated with poorer environments. For example, 60.2%, 48.1%, and 40.2% of nurses in hospitals with poor, mixed, and best environments, respectively, gave their hospital an unfavorable grade on end of life care. While differences across nurses in the three groups of hospitals are larger for some of the measures than others, all of the differences are statistically significant, and the pattern of the difference is similar in all cases. Nurses in hospitals with poor nurse practice environments report poorer end of life care quality than

those in hospitals with mixed environments, and nurses in hospitals with mixed environments report poorer quality than nurses in hospitals with the best environments. Figure 1 shows the average end of life grades for hospitals with different nurse practice environments. For example, 61% of hospitals with poor environments have an average grade of C, D, or F, compared with only 7.4% of hospitals with the best environments.

While there were no significant differences in quality between hospitals by teaching status, technology status, or size, for-profit hospitals had significantly higher percentages of nurses giving unfavorable grades and lower ratings on quality than not-for-profits and government nonfederal hospitals (Table 2). These differences between for-profit hospitals and other hospitals are insignificant however in multivariate models which take account of the differences in practice environments.

The bivariate results in Table 1 showed the differences in quality assessments for nurses in hospitals with poor, mixed, and the best practice environments to be monotonic and fairly linear. Thus, the odds ratios shown in Table 3 are from multi-level logistic regression models, which constrain the associations to be linear and estimate them before and after adjusting for other potentially confounding characteristics, including nurse and hospital characteristics. For both the unadjusted and adjusted models, the odds ratios in the first column indicate the differences in the odds on reporting unfavorable quality in hospitals with mixed vs. poor environments and in hospitals with the best vs. mixed environments. The squared odds ratios in the second column indicate the differences implied by the linear association between the best vs. poor environment hospitals. Before and after adjustment, nurses working in hospitals with the best vs. mixed environments, and in mixed vs. poor environments, had lower odds on giving their hospital an unfavorable grade on overall end of life care quality by a factor of 0.67 (or odds that were 33% lower). Nurses working in hospitals with the best vs. poor environments had lower odds on giving their hospital an unfavorable grade by a factor of $0.67^2 = 0.45$ (or odds that were 55% lower). Odds ratios related to the association of the practice environment with the other global measure and with the six specific quality measures are either similar in magnitude or only slightly larger, and all of the associations in the table are significant and sizable.

DISCUSSION

The majority of nurses say their hospital provides unsatisfactory end of life care. Hospitals with poor environments — those which afford limited clinical authority to nurses, maintain high nurse workloads, and unsuccessfully foster interprofessional teamwork — were more likely to have unfavorable end of life care quality ratings compared to hospitals with the best environments. Relationships between nurse practice environments and end of life care quality persisted, even after controlling for hospital and individual nurse characteristics.

Our main findings are consistent with other work which has linked hospital nursing and healthcare quality and safety among acutely ill patients expected to survive [35], but is only now being explored in the care of terminally ill patients. McHugh and Stimpfel (2012) demonstrated the validity of using nurses as informants of care quality by showing that hospital nurses' ratings were consistent with other widely-recognized quality measures,

including mortality and patient satisfaction [38]. Our study brings new contributions to the measurement of end of life care quality in hospitals, which has never before been described in a large representative sample of hospitals. Two-thirds of nurses in our study reported frequently caring for patients in the last year of life, which suggests hospital nurses have considerable experience from which to base their evaluations of quality. Nurses' assessments of care are developed over time through repeated encounters and direct observations of patient care. It is not surprising that nurses' ratings of hospitals are similar to patients' [35].

Nearly half of nurses gave their hospital an unfavorable overall grade on quality, and identified patients' experiencing painful procedures that were not likely to change their outcome as the most common quality problem. This observation is consistent with the mounting evidence about aggressive medical intervention during the final days of life, which the National Quality Forum and others have recognized as inappropriate for terminally ill individuals [15, 39–42]. Nurses practicing in hospitals with the best environments were significantly less likely to report that patients in their hospital experienced painful procedures, probably because those nurses were more likely to be included in team decision-making and empowered to discuss care options with patients and their families. When nurses work in hospitals that foster collegial relationships with physicians and devolve to nurses authority to make decisions commensurate with their expertise and their responsibilities for patients, research shows that patients experience more favorable outcomes [19, 20, 28, 31]. Indeed, a large literature points to a hierarchical hospital culture, including physicians undervaluing the clinical judgements of nurses, and inadequate resources such as unmanageable workloads, as common barriers nurses encounter in the provision of patient-centered end of life care [19, 25–27]. Our study lends credence to the hypothesis that when nurses have adequate time to spend with patients/families, establish rapport, and elicit patient/families understanding about prognosis and treatment options, *and* when nurses are involved in team decision-making as patient advocates and knowledgeable clinicians, patients/families experience better care.

Prior research has found that patients dying in large, for-profit, teaching hospitals are more likely to receive aggressive care; however, the variation in end of life care is significantly greater within hospital types than across, suggesting these hospital factors do not entirely explain the variation in end of life care quality [6, 43, 44]. In the present study, we found no differences in quality between hospitals by size, teaching status, or technology status, and only modest differences by profit status.

In this study, the large majority (85%) of nurses say that patients' advanced directives are clearly documented and accessible, which suggests that problems in hospital end of life care do not primarily result from inaccessible advanced directives or a lack of advanced care planning, as others have suggested [45]. Other initiatives to improve end of life care have included expanding access to palliative care, which has been associated with a range of outcomes including better management of symptom burden, improved quality of life, patient/family satisfaction [4, 46], greater hospice utilization, lower likelihood of in-hospital death, and greater likelihood of death at home [47]. However, palliative care continues to be a limited resource [48]. Only two-thirds of hospitals with fifty or more beds have palliative care teams [49], which are concentrated among large community hospitals and academic

medical centers [50]. The prevalence of palliative care teams has not kept pace with the demand, with estimates suggesting that as many as 2 million hospitalized patients have unmet palliative care needs [49]. In addition to growing the number of palliative care providers, our findings support mobilizing an already available resource of clinicians skilled in end of life care — nurses.

Limitations

This study has some limitations. Cross-sectional data limit our warrant for causality. While our models include a large number of potential confounders they may, as is often the case with non-experimental designs, be prone to bias resulting from omitted variables. For example, it is possible that nurses' disposition towards pessimism (or optimism) could confound relationships between nurse practice environments and their ratings of end of life care quality. Moreover, it is possible that the quality of the nurses' practice environment might bias the nurses' assessment of care quality, influencing nurses to over or under-state the quality of end of life care. We do not have independent reports from patients and/or bereaved family members, including measures of satisfaction, although previous research shows nurses to be accurate informants about patient outcomes [38]. Finally, while the response rate for nurses was not as high as it was for hospitals (i.e., 93% of hospitals with >250 beds and 64% of all hospitals, in the four states), we found no significant differences between nurse respondents and non-respondents on reports of care quality (see Supplementary Materials for more details).

CONCLUSION

Hospitals' quality of end of life care is uneven, with significantly worse quality in hospitals with poor nurse practice environments compared to hospitals with the best environments. Nurses working in hospitals today are more highly-qualified than ever before to care for dying patients – and may be an unleveraged resource in the provision of high quality care for individuals at the end of life.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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We certify that this work is novel research. The potential impact of this research on clinical care and health policy includes the following: (1) novel evidence about the quality of end of life care in a large representative sample of U.S. hospitals; (2) evidence that end of life care quality in hospitals might be enhanced through improvements to the practice environments of direct care nurses in hospitals.

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Figure 1.

End of life grades for hospitals with different nurse practice environments

Note. Grades are based on a rating scale of A (excellent) through F (failing).

Table 1.

Percentage of hospital nurses who agree with the following statements about end of life care quality in their hospitals

	All Hospitals (N = 491)	Nurse Practice Environment				p-value
		Poor (N = 123)		Mixed (N = 246)		Best (N = 122)
Global Quality Measures						
Unfavorable end of life grade overall (C, D or F)	47.9%	60.2%		48.1%		40.2%
Less than a 9 out of 10 end of life quality rating	58.3%	64.0%		59.3%		53.3%
Specific Quality Measures						
Patients near the end of life often experience painful or uncomfortable procedures that are not likely to change their outcome	52.6%	57.7%		52.5%		49.7%
Nurses are discouraged from discussing care options with patients	37.7%	41.1%		37.0%		36.5%
Nurses and physicians often disagree about end of life care	37.5%	41.9%		36.9%		35.9%
End of life care decisions are not made as a team with physicians, nurses, patients, families, and others	16.5%	24.7%		16.4%		11.9%
Patients' end of life directives are not clearly documented and accessible	15.0%	19.7%		15.5%		11.5%
Patients do not die with dignity	11.8%	16.4%		11.5%		9.6%

Notes. The numbers (Ns) in the column headings are the number of hospitals. The number of nurses reporting the 8 quality measures exceeded 8,620 in all cases, or more than 48 nurses per hospital, on average. Chi-square tests were used to test for differences between nurse practice environments.

Table 2.

Hospital variation in overall end of life quality, by hospital structural characteristics

	No. of Hospitals (N=491)	Percentage of nurses giving an unfavorable grade (C, D or F)	p-value	Percentage of nurses giving less than a 9/10 rating	p-value
Teaching status					
Non-teaching	248	47.3%	0.331	59.0%	0.362
Minor	204	48.7%		57.5%	
Major	39	47.2%		58.5%	
Size					
Small	22	44.7%	0.290	58.0%	0.496
Medium	203	48.9%		59.2%	
Large	266	47.6%		58.0%	
Technology status					
Low technology	253	48.1%	0.659	57.5%	0.196
High technology	238	47.7%		58.8%	
Profit Status					
For-profit	84	55.4%	<0.001	64.7%	<0.001
Not-for-profit	340	46.9%		57.9%	
Government nonfederal	49	47.7%		56.9%	

Notes. Chi-square tests were used to test for differences in quality measures by hospital structural characteristics.

Table 3.

Effect of nurse practice environment on end of life quality measures, before and after adjustments

	Nurse Practice Environment			
	Unadjusted		Fully adjusted	
	OR	OR ²	OR	OR ²
Global Quality Measures				
Unfavorable end of life grade overall (C, D or F)	0.67 ^{***} (0.63–0.71)	0.45 ^{***} (0.39–0.50)	0.67 ^{***} (0.63–0.72)	0.45 ^{***} (0.40–0.52)
Less than a 9 out of 10 end of life quality rating	0.79 ^{***} (0.75–0.84)	0.63 ^{***} (0.56–0.71)	0.78 ^{***} (0.73–0.83)	0.61 ^{***} (0.54–0.69)
Specific Quality Measures				
Patients near the end of life often experience painful or uncomfortable procedures that are not likely to change their outcome	0.84 ^{***} (0.79–0.89)	0.70 ^{***} (0.62–0.79)	0.84 ^{***} (0.79–0.90)	0.71 ^{***} (0.62–0.80)
Nurses are discouraged from discussing care options with patients	0.91 ^{**} (0.84–0.97)	0.82 ^{**} (0.71–0.94)	0.89 ^{**} (0.83–0.96)	0.80 ^{**} (0.69–0.93)
Nurses and physicians often disagree about end of life care	0.88 ^{***} (0.82–0.93)	0.77 ^{***} (0.68–0.87)	0.88 ^{***} (0.83–0.95)	0.78 ^{***} (0.68–0.89)
End of life care decisions are not made as a team with physicians, nurses, patients, families, and others	0.64 ^{***} (0.59–0.69)	0.40 ^{***} (0.35–0.47)	0.66 ^{***} (0.61–0.71)	0.43 ^{***} (0.37–0.51)
Patients' end-of-life directives are not clearly documented and accessible	0.72 ^{***} (0.65–0.79)	0.51 ^{***} (0.43–0.62)	0.70 ^{***} (0.64–0.77)	0.49 ^{***} (0.40–0.60)
Patients do not die with dignity	0.74 ^{***} (0.66–0.83)	0.55 ^{***} (0.44–0.69)	0.70 ^{***} (0.62–0.79)	0.49 ^{***} (0.39–0.62)

Notes.

**
p<0.01;

p<0.001. The nurses practice environment is a hospital-level categorical variable which is scored linearly (0-poor; 1-mixed; 2-best) to constrain the odds on the nurse-reported outcomes to change linearly across the three practice environment categories. Thus, odds ratios (OR) represent the differences in quality between hospitals with poor vs. mixed environments and with mixed vs. the best environments. OR² estimates the differences between the hospitals with poor vs. the best environments. The fully adjusted models include controls for nursing characteristics (i.e., age, sex, years of experience, education, specialty certification, working in an ICU) and hospital characteristics (i.e., teaching status, technology status, size, profit status).