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Beyond Pain: Nurses' Assessment of Patient Suffering, Dignity, and Dying in the Intensive Care Unit

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Abstract

Context—Deaths in the intensive care unit (ICU) are increasingly common in the U.S., yet little is known about patients' experiences at the end of life in the ICU.

Objectives—The objective of this study was to determine nurse assessment of symptoms experienced, and care received by ICU patients in their final week, and their associations with nurse-perceived suffering and dignity.

Methods—From September 2015 to March 2017, nurses who cared for 200 ICU patients who died were interviewed about physical and psychosocial dimensions of patients' experiences. Medical chart abstraction was used to document baseline patient characteristics and care.

Results—The patient sample was 61% males, 70.2% whites, and on average 66.9 (SD 15.1) years old. Nurses reported that 40.9% of patients suffered severely and 33.1% experienced severe loss of dignity. The most common symptoms perceived to contribute to suffering and loss of dignity included trouble breathing (44.0%), edema (41.9%), and loss of control of limbs (36.1%). Most ($n = 9$) remained significantly ($P < 0.05$) associated with suffering, after adjusting for physical pain, including fever/chills, fatigue, and edema. Most patients received vasopressors and mechanical ventilation. Renal replacement therapy was significantly (<0.05) associated with severe suffering (adjusted odds ratio [AOR] 2.53) and loss of dignity (AOR 3.15). Use of feeding tube was associated with severe loss of dignity (AOR 3.12).

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Disclosures

The authors declare no conflicts of interest.

Conclusion—Dying ICU patients are perceived by nurses to experience extreme indignities and suffer beyond physical pain. Attention to symptoms such as dyspnea and edema may improve the quality of death in the ICU.

Keywords

End-of-life care; intensive care unit; quality of death; suffering; dignity

Introduction

Death may be inevitable, but suffering and loss of dignity at the end of life (EoL) need not be. Approximately 500,000 people die in U.S. hospitals after intensive care unit (ICU) admissions per year,¹ and ICU stays in the last month of life are increasingly common.² Critical care at the EoL exacts a heavy toll on patients, family members, and clinicians.^{3–7} Research is needed to explore the experience of patients who die in the ICU and relate that experience to clinician-perceived patient suffering and dignity.

Approximately, a third of Medicare expenditures in the last year of life are spent on the patient's final month primarily for life-prolonging care received in the ICU.⁸ These procedures are inversely related to the quality of life in the patient's final week. As a result, investigators have used avoidance of ICU admission in the last month of life as an indicator of high-quality EoL care.⁹ Despite these concerns, ICUs, compared with other settings, are capable of reducing suffering at the EoL.¹⁰ They are staffed with highly trained clinicians who have access to restricted medications as well as multidisciplinary teams of clergy, therapists, and palliative care experts. Some studies have examined the specific impact of ICU procedures on pain,¹¹ whereas others have explored global evaluations of physical, psychological distress, and quality of death.^{5,12,13} To the best of our knowledge, none have examined the impact of symptoms and procedures on suffering and dignity among patients confronting death in the ICU.

In fact, the experience of dying in the ICU is poorly understood. Most research on symptom profiles of terminally ill patients has focused on patients who reside at home, in hospice, or in other long-term care facilities,^{14–17} and only a few have focused on patients in the ICU.^{13,18} Suffering experienced by patients dying in the ICU likely involves more than only physical pain and may be more akin to total pain, which refers to psychological, emotional, and physical distress.¹⁹ The effect of symptoms and care on dying patients' dignity is another outcome warranting clinical attention. Given that dying with dignity is considered by some to be the hallmark of a good death,^{20,21} preserving dignity should be a focus of high-quality EoL care in the ICU.²²

To advance understanding of the patient experience at the EoL in the ICU, we conducted a study of patients who died in ICUs at two large, urban, and academic medical centers. We expanded on previously validated quality of death tools²³ to develop an assessment that facilitates the evaluation of patient symptoms and care received as distinct factors and then related each specifically to nurse-perceived patient suffering and dignity. Nurses who cared for these patients were asked to assess the patients' experiences in their final week. We hypothesized that nurse assessments of common symptoms such as trouble breathing and

edema would be significantly associated with perceived suffering and loss of dignity and that these associations would persist even after controlling for physical pain. We also examined associations between life-sustaining interventions and patient suffering and dignity and expected these interventions to result in nurse-perceived patient suffering and loss of dignity.

Methods

Study Design

From September 2015 to March 2017, data were collected retrospectively from nurses and medical charts to assess the quality of life of 200 patients who died in the medical ICU (MICU) or cardiac care unit of New York Presbyterian Hospital/Weill Cornell Medical Center in New York City or the surgical ICU at the Brigham and Women's Hospital in Boston. Both are large, urban, academic, and quaternary care centers. Nurses have been shown to provide accurate assessments of patients' pain and symptom control at the EoL and have been used to assess patient quality of death in the ICU¹⁸ and predictions of in-hospital outcomes, particularly when compared with physicians and family members.^{9,24–27} Furthermore, because patients in the ICU often have difficulty communicating, and because nurse evaluations were more accessible than physician or family member evaluations, nurses were selected to be the primary assessors of patient experience in this study.

Selection of Subjects and Informed Consent

Each week, trained study staff screened consecutive patients who died in the MICU and cardiac care unit at New York Presbyterian Hospital/Weill Cornell ($n = 357$) or in the surgical ICU at Brigham and Women's Hospital ($n = 64$). Medical charts were reviewed to identify nurses who cared for patients for at least one 12-hour shift in the patient's last week. About 96% of the nurses approached (100 of 104) agreed to participate and completed written informed consent. About 49 nurses completed an assessment for more than one patient. Nurse participation occurring outside working hours was compensated with a \$20 gift card. Institutional review board approval was obtained from all participating study sites.

The most common reason that eligible patients were excluded was nurse scheduling conflicts, as we required that nurses be interviewed within three weeks of the patient's death. About 70 patients were excluded because they were in the ICU for less than 24 hours and did not have a nurse who took care of them for an entire shift. The 151 eligible patients without nurse assessments were older than those studied ($P = 0.03$) but did not differ on race, gender, or comorbidities. Nurses who completed assessments took care of patients for an average of 2.3 shifts, and 33.7% of nurse assessors were present at the time of death.

Data Collection

Trained staff conducted the structured clinical interview with the nurse. Medical charts were reviewed to obtain patient demographic information, diagnoses, and care received in the patient's last week. Use of life-sustaining therapies, including mechanical ventilation, renal replacement therapy, feeding tubes, and vasopressors, was documented.

Measures

We developed measures to assess the patient experience in the last week of life in the ICU by reviewing the relevant literature and data from our other EoL studies, using validated quality of life measures, and discussions with ICU physicians, nurses, and EoL specialists. After enrollment, nurses evaluated aspects of patient experiences on a scale from 1 to 10, where 1 was defined as best possible and 10 was defined as worst possible. Nurses were asked about patients' existential, emotional, physical, and overall suffering. They also were asked to evaluate the symptoms patients experienced that may have contributed to suffering. The assessment was built on the previously validated questions on patient quality of life in the last week of life (i.e., overall psychological distress, overall physical distress, and overall quality of death).⁹ In addition, nurses were asked about their perceptions of patient dignity.

The suffering and loss of dignity measures were associated with previously validated measures of psychological distress, physical distress, and overall quality of death, and peacefulness at the EoL,^{8,12,28–30} using Pearson correlation coefficients. Results demonstrated highly significant associations (all $P < 0.001$) in the expected direction with these measures. Patient suffering and loss of dignity were positively associated ($r = 0.66$; $P < 0.001$) (Supplemental Table 1), yet distinct experiences.

Data Analysis

We conducted a cluster analysis of patient symptoms, nominated by nurses, which contributed to patient suffering at the EoL; the cluster analysis identified five symptom clusters. Within each cluster, we estimated associations between each symptom and the validated loss of dignity and suffering measures. We also examined associations between symptoms and suffering after adjusting for physical pain to demonstrate the relationship between that symptom beyond physical pain.

We identified patients who were on life-sustaining therapies in the last week of life and determined how remaining on those life-sustaining therapies, and being withdrawn from them, over and above confounding conditions at intake, related to nurse-perceived patient suffering and loss of dignity.

Bivariate and multivariable generalized estimating equations with an exchangeable correlation structure and logit link for the binary outcome were used to measure the independent associations of patient baseline characteristics, symptoms, and care received with validated measures of suffering and loss of dignity. Generalized estimating equation methods are suited for the clustering of patients at the nurse level included in this analysis and account for correlations arising from repeated measurements by the same nurse by adjusting the standard error accordingly. Results are presented as odds ratios (OR).

Results

Patient Sample Characteristics

About 200 patients had nurse evaluations of the patient's experience during the last week of life. The sample was 61% males, 70.2% whites, and the mean age at death was 66.9 (SD

15.1) years (Table 1). About 72% of patients died in the MICU, and 80.6% of patients had do-not-resuscitate (DNR) orders. About 31% of patients were admitted to the ICU for respiratory failure, and 13.5% had sepsis or septic shock. About 38.0% of patients had a solid or hematologic malignancy (Table 2).

Dying Patients' Experience of Suffering and Loss of Dignity

Nurses perceived that 40.9% of the patients for whom they cared had severe (8 of 10) suffering and 33.1% severe (8 of 10) loss of dignity (Table 3).

Compared with patients admitted for respiratory failure, patients admitted for cardiac conditions other than cardiac arrest suffered less ($P < 0.05$); those admitted with sepsis suffered more ($P < 0.05$); and those who had an active hematologic malignancy experienced a greater loss of dignity ($P < 0.05$), as assessed by the nurses caring for them (Table 2).

Physical Signs and Symptoms

Using a threshold score of 8 of 10 to indicate severe suffering levels, the most prevalent symptoms perceived to contribute to severe suffering were trouble breathing (44.0%), edema (41.9%), and loss of control of limbs (36.1%). About nine symptoms were significantly ($P < 0.05$) associated with loss of dignity, including fecal incontinence (OR 5.58), loss of control of limbs (OR 5.10), and edema (OR 3.47). After adjusting for physical pain, nine symptoms remained significantly ($P < 0.05$) associated with suffering, including fever/chills, fatigue, edema, and trouble breathing (Table 3).

Medical Care Received in the Last Week of Life

Most patients received vasopressors (86.5%) and mechanical ventilation (82.0%). Use of feeding tube was common (63.0%); its sustained use was associated with perceived loss of dignity (AOR 3.12; $P < 0.05$). A substantial number of patients underwent renal replacement therapy (33.5%), and its sustained use was associated with suffering and loss of dignity (AOR 2.53 and 3.15, respectively; $P < 0.05$), as assessed by nurses (Table 4).

Discussion

We found that nurses perceived high rates of suffering in those who die in the ICU. According to nurse assessments, several signs and symptoms, such as trouble breathing and edema, contributed to this suffering and remained significant even after controlling for physical pain. Moreover, we identified medical procedures perceived to exacerbate patient suffering and loss of dignity. Notably, this suffering and loss of dignity were common despite a high prevalence of DNR orders.

The past studies of ICU care have focused on death, or the prevention of death, as the primary goal,^{31–33} whereas this report focuses on nurse assessments of the patient experience. With intensive staffing of specialized nurses and access to fast-acting medications, ICUs have the ability to minimize suffering and loss of dignity in those with severe symptoms. Despite this potential, we find that the experience of dying in the ICU is not good—with 41% of patients perceived to suffer severely and 33% to endure extreme loss

of dignity by the nurses who cared for them as they were dying. Suffering and loss of dignity were significantly but imperfectly associated with one another; their unique associations with diagnoses, symptoms, and care further demonstrate the distinction between these two measures. Our results suggest that suffering and loss of dignity in dying ICU patients might be reduced by efforts to manage symptoms beyond pain and to either limit or withdraw specific life-sustaining therapies.

Our study revealed the signs and symptoms that contributed significantly to nurse-perceived patient suffering and loss of dignity in their patients' final week. Although pain is often the most feared symptom among patients,³⁴ and pain management has become a benchmark of good care,^{4,35,36} pain was not the most distressing symptom in the studied sample. After accounting for physical pain scores, most of the identified symptoms were still significantly associated with suffering. In addition to pain, most of the other assessed symptoms, including broken skin and edema, were significantly associated with loss of dignity. Trouble breathing, although often underreported and difficult to measure and confirm in dying patients,³⁷ was the most common symptom perceived to contribute to suffering in our study and was also significantly associated with loss of dignity. Previous studies have documented patient symptoms at the EoL and their influence on quality of life,^{9,13} and several studies have explored the meaning and experience of dignity in the ICU.^{38,39} However, to the best of our knowledge, no other studies have directly examined the influence of patient symptoms on suffering and loss of dignity in patients dying in the ICU. These results reveal great potential for improving the patient experience by better detection and management of these common and distressing symptoms.

The association of renal replacement therapy with poor quality of life is well known,⁴⁰ its influence on ICU patients' suffering and dignity at the EoL is not. We found that receiving sustained renal replacement therapy was independently associated with significant suffering and loss of dignity. Studies have shown that feeding tube use in the last week of life is associated with worse quality of life,⁹ but to our knowledge, its use in the ICU and its influence on dignity has not been well studied. These results raise the question whether patients on renal replacement therapy and feeding tubes would suffer fewer indignities if these interventions were withdrawn before death.

Although our data do not differentiate between DNR orders that were completed early or late during the patient's ICU course, 80.6% of our patients had a DNR order completed at the time of death. Our results show that DNR order completion was not associated with severe suffering or loss of dignity at the EoL. Future studies are needed to examine timing of DNR order completion and its impact on patient care and experience.

These suggestions are offered within the context of the complexities of ICU care. We do appreciate that there are often trade-offs whereby removal of life support or treatment of one symptom may result in the onset of other distressing conditions. In addition, there is often uncertainty about whether the patient is dying and knowing if care is beneficial or inappropriate. Such clinical realities, no doubt, complicate effective symptom management of critically ill patients in the ICU.

Our findings should be considered in the context of both the study's strengths and its weaknesses. One limitation was the use of nurse assessments to evaluate patient symptoms, suffering, and dignity. Nurses were directly responsible for the care of the patients in their last week and may have felt responsible for patient suffering, potentially affecting their ratings. Because all the studied patients died, frustration over perceived futility may have led nurses to overestimation of suffering and loss of dignity. In addition, nurses potentially had different perspectives than patients on EoL care and treatment options, which may have further biased our results. In some circumstances, patient suffering may have been underreported. For example, patients on mechanical ventilation can have dyspnea and respiratory distress but be unable to communicate this suffering effectively to their nurses, thus leaving it undetected.⁴¹

Despite the potential limitations of nurse reports of the dying patient experience, there are also advantages. First, as much as patient reports of their experience would be the most direct, patients in the last week of life are typically not capable of doing so. Consistent with other studies,²¹ we found that most patients (64%) had extreme difficulty communicating in the ICU. Therefore, relying on patient reports would have necessitated the exclusion of most patients and would not have provided a representative reflection of patients' experience dying in the ICU. Furthermore, because it is difficult to predict the exact date of a patient's death, it would have been impractical if not unethical to prospectively interview patients about their experiences as they were dying. Previous studies have shown that nurses can accurately assess patients' quality of life,⁹ that nurses can more accurately predict in-hospital survival in ICU patients when compared with physicians,²⁴ and that if anything nurses provide conservative estimates of patient quality of death relative to ratings of their bereaved family members.¹³ About 96% of the nurses approached to participate agreed to do so suggesting minimal nurse rater selection bias. Furthermore, nurse assessors directly cared for patients for more than two shifts, on average, in the assessed week, and a third were physically present at the time of death. Nurse assessments were completed within three weeks of the patient's death to minimize recall bias. Although it would have been advantageous to have more complete information about nurse evaluator background, institutional review board concerns over maintaining nurse anonymity prevented us from collecting these data.

Another limitation is that we did not use previously validated assessment tools. Mularski et al.²³ have validated the Quality of Death and Dying tool, which combines an assessment of the patient experience with the care the patient received and preparation for death, to produce a composite assessment of the patient's overall quality of death among patients in the ICU. However, this tool neither does focus on the experience of care from the patient's perspective as distinct from the care the patient received near death nor does relate symptomatic experience to nurse-perceived patients' suffering and dignity, which was the focus of this study. For this reason, we expanded on existing tools to develop a more comprehensive psychometric assessment of the patient's experience from the perspective of the nurses who cared for them as they were dying in the ICU. By isolating the psychological symptoms of patients, and focusing on suffering and loss of dignity, we could then examine how physical symptoms and life-sustaining procedures would relate to the psychological experience of patients.

A strength of this study is that it was conducted in three different types of ICUs at two quaternary academic centers. Although hospitals were both in the Northeast, studies have shown that intensity of care at the EoL varies dramatically even in the same region.⁴² However, academic referral hospitals may have different patient, doctor, and nurse populations when compared with community-based hospitals and rural settings.⁴³ Another strength is that patients in this study were racially diverse, with a wide range of medical conditions.

Our data suggest that expanding our focus beyond pain alone to include assessment of other common symptoms, and withdrawal of burdensome life-sustaining therapies among those actively dying, may lead to improved quality of death in the ICU. Although not their preferred place to die,⁴⁴ many Americans spend their final days in the ICU. Intensive nursing and access to medications give ICUs the potential to minimize suffering and maintain dignity at the EoL. These data importantly identify potential targets for future interventions to improve patient care and experience and mitigate suffering and loss of dignity among the growing number of vulnerable patients who die in the ICU.

In conclusion, we found high rates of nurse-perceived suffering and loss of dignity in the patient's last week of life in the ICU. Nurse assessments of severe symptoms, such as trouble breathing and edema, were significantly associated with suffering even when controlling for physical pain.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Patient Sample Characteristics

Categorical Variables	<i>N</i>	<i>n</i>	%
Sex, male	200	122	61.0
Race	178		
White		125	70.2
African American		25	14.0
Asian American		23	12.9
More than one		5	2.8
Ethnicity, Latino	157	22	14.0
ICU	200		
SICU		30	15.0
CCU		26	13.0
MICU		144	72.0
DNR order completion	191	154	80.6
Continuous Variables	<i>N</i>	Mean	SD
Age (yrs)	200	66.9	15.1
Length of ICU stay (days)	200	9.6	10.4

ICU = intensive care unit; SICU = surgical ICU; CCU = cardiac care unit; MICU = medical ICU; DNR = do not resuscitate.

Table 2
 Patients' Conditions at ICU Intake and Associations With Suffering and Loss of Dignity

Categorical Variables	Full Sample (N = 200)			Association With Suffering (N = 193)		Association With Loss of Dignity (N = 175)	
	n	%	OR	P	OR	P	
Admission diagnosis							
Respiratory failure	62	31.0	1.00	Ref.	1.00	Ref.	
Cardiac arrest	23	11.5	0.45	0.095	0.38	0.101	
Other primary cardiac diagnosis	18	9.0	0.17	0.018	0.12	0.072	
Sepsis/septic shock	27	13.5	3.25	0.024	1.79	0.223	
Trauma	9	4.5	0.38	0.280	0.31	0.209	
Cancer	8	4.0	0.84	0.832	3.33	0.182	
Hemorrhage	21	10.5	0.94	0.914	1.22	0.748	
Neurological	10	5.0	0.84	0.819	0.86	0.862	
Other	22	11.0	0.58	0.179	0.56	0.309	
Medical conditions							
Active malignancy	76	38.0	1.51	0.164	1.16	0.628	
Hematologic malignancy	38	19.0	1.18	0.607	2.16	0.019	
COPD	16	8.0	2.13	0.166	1.32	0.651	
Kidney disease	42	21.0	0.82	0.547	0.92	0.817	
Liver disease	22	11.0	1.23	0.599	1.31	0.499	
Continuous Variables							
	Mean	SD	OR	P	OR	P	
Charlson Comorbidity Index	5.52	2.59	1.03	0.645	0.96	0.570	

ICU = intensive care unit; OR = odds ratio; Ref. = reference; COPD = chronic obstructive pulmonary disease.

Table 3

Patient Physical Signs and Symptoms of Patients in the ICU in the Last Week of Life

Cluster	Sign/Symptom	N	n	%	Association With Suffering			Adjusting for Pain			Association With Loss of Dignity		
					N	OR	P	N	AOR	P	N	OR	P
Cardiopulmonary and painful conditions	Trouble breathing	193	85	44.0	187	5.43	0.000	181	3.94	0.000	170	2.36	0.016
	Edema	191	80	41.9	185	5.31	0.000	179	4.07	0.000	168	3.47	0.000
Gastrointestinal-related conditions	Physical pain	190	63	33.2	185	3.89	0.000				168	3.40	0.001
	Painful broken skin	189	43	22.8	183	4.09	0.000	177	2.78	0.017	167	3.89	0.001
Incontinence-related conditions	Thirst	153	47	30.7	150	3.32	0.002	148	3.20	0.003	139	1.23	0.677
	Hunger	157	28	17.8	154	4.28	0.000	151	3.16	0.001	142	1.72	0.240
Muscular and temperature dysregulation	Nausea and/or vomiting	189	16	8.5	184	3.59	0.029	177	2.76	0.143	166	1.55	0.526
	Fecal incontinence	190	55	28.9	184	2.92	0.000	178	2.13	0.014	167	5.58	0.000
Sleep disturbance and exhaustion	Constipation and/or diarrhea	187	39	20.9	182	2.91	0.001	177	1.85	0.101	165	4.10	0.001
	Urinary incontinence	190	18	9.5	184	3.21	0.007	178	2.08	0.087	168	3.39	0.005
Indicators of severe symptoms, that is, rated 8, 9, or 10 on a 10-point scale.	Loss of control of limbs	183	66	36.1	177	3.41	0.000	172	3.35	0.001	161	5.10	0.000
	Fever or chills	187	29	15.5	182	4.30	0.001	177	4.33	0.002	164	2.34	0.019
ICU = intensive care unit; OR = odds ratio; AOR = adjusted odds ratio.	Fatigue	163	51	31.3	161	5.27	0.000	159	4.26	0.000	146	1.87	0.217
	Difficulty sleeping	172	31	18.0	168	2.49	0.040	165	2.17	0.091	155	0.83	0.735

ICU = intensive care unit; OR = odds ratio; AOR = adjusted odds ratio.

Indicators of severe symptoms, that is, rated 8, 9, or 10 on a 10-point scale.

Table 4

Effects of ICU Procedures on Patients' Suffering and Loss of Dignity

Treatment/Procedure	Full Sample (N = 200)			Association With Suffering (N = 193)			Association With Loss of Dignity (N = 175)		
	n	%	AOR	P	AOR	P	AOR	P	
Surgical procedure	27	13.5	0.81	0.664			1.25	0.626	
Cardiac resuscitation	63	31.5	1.43	0.221			1.76	0.121	
Vasopressors									
No	27	13.5	1.00	Ref.			1.00	Ref.	
Yes, then withdrawn	44	22.0	0.91	0.873			1.12	0.884	
Yes, then sustained	129	64.5	1.51	0.383			2.00	0.381	
Dialysis									
No	133	66.5	1.00	Ref.			1.00	Ref.	
Yes, then withdrawn	16	8.0	0.90	0.833			1.81	0.251	
Yes, then sustained	51	25.5	2.53	0.013			3.15	0.011	
Mechanical ventilation									
No	36	18.0	1.00	Ref.			1.00	Ref.	
Yes, then withdrawn	48	24.0	0.50	0.118			0.58	0.213	
Yes, then sustained	116	58.0	0.96	0.925			1.52	0.339	
Feeding tube									
No	74	37.0	1.00	Ref.			1.00	Ref.	
Yes, then withdrawn	32	16.0	0.48	0.090			0.68	0.408	
Yes, then sustained	94	47.0	1.17	0.691			3.12	0.011	

ICU = intensive care unit; AOR = adjusted odds ratio; Ref. = reference.

AOR adjusted for ICU admission diagnosis (sepsis vs. other primary cardiac vs. all others) and hematologic malignancy.