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Emergency Department Nurses' Suggestions
for Improving End of Life Care

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A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

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ABSTRACT

Emergency Department Nurses' Suggestions for Improving End of Life Care

Introduction: Death is not an uncommon outcome for patients who seek immediate care in an emergency department. Although death is common in the emergency department there is little literature regarding end-of-life care in the emergency department. The purpose of this research study is to determine what changes emergency nurses would suggest to improve end-of-life care for dying patients and their families in emergency departments.

Background: A national, geographically dispersed, random sample of 1000 emergency nurses were sent a questionnaire entitled, "Emergency Nurses' Perceptions of End-of-Life Care." Inclusion criteria included nurses who were members of the Emergency Nurses Association, could read English, worked in an emergency department, and had cared for at least one emergency patient at the end-of-life.

Results: There was an overwhelming consistency in recommended changes to improve care of the dying emergency department patient by the nurses participating in the study. Five major themes were identified: 1) increasing the amount of time emergency nurses have to care for dying patients and their families; 2) consistently allowing family presence during resuscitation; 3) providing a comfortable patient room; 4) providing for more privacy at the end-of-life; and 5) providing a family grief room.

Conclusion: The emergency department will continue to be the primary access point for dying patients to receive medical and nursing care. Implementing changes based on emergency nurse recommendations may dramatically improve the experience for the dying patient as well as their family members.

Keywords: emergency nursing, end-of-life care, emergency nurses, grieving, emergency department

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Table of Contents

TITLE PAGE.....	i
ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	iii
TABLE OF CONTENTS.....	iv
TABLE OF TABLES	v
Methodology.....	3
Results.....	3
Major Themes.....	4
Increased RN time with the patient and family	4
Family presence	5
Comfortable patient room.....	6
Providing for more privacy.....	6
Family grief room.....	7
Minor Themes.....	7
Increased ancillary service involvement.....	7
Managing pain and minimizing suffering.....	8
Family education.....	8
Upholding advance directives.....	9
Miscellaneous Responses.....	9
Discussion.....	9
Limitations	11
Conclusion	11
References.....	12

Table of Tables

Table 1	14
Table 2 Major and Minor Themes*	16

Emergency Department Nurses' Suggestions for Improving End-of-Life Care

Death is not an uncommon outcome for patients who seek immediate care in an emergency department (ED). In 2006, more than 249,000 patients died in the emergency department or were reported as being dead on arrival (DOA) to the emergency department.¹ Because of the high number of deaths in the emergency department, emergency nurses are often called upon to provide end-of-life (EOL) care for dying patients and their families. However, the emergency department is a difficult location for patients, family members, and clinicians to make EOL decisions and for healthcare providers to give appropriate EOL care. The ED environment makes EOL decisions increasingly difficult for all involved, due to time constraints, lack of patient and family privacy, communication challenges, lack of accessibility of patient information to health care providers, and societal expectations regarding emergency care.²

Emergency departments are becoming increasingly busy with 19.2 million visits reported annually across the United States. This high patient volume is further complicated by a decreasing number of emergency departments, as well as the fact that the emergency department is becoming the portal for inpatient admissions accounting for 50.2% of non-obstetric admissions nationally.¹ Many patients seeking ED care have advanced chronic illness requiring immediate aid for symptom distress, are experiencing acute change in their health status, or are brought to the emergency department by their caregivers who can no longer physically care for, or psychologically cope with them.³

As in many other critical care areas of the hospitals, heroic measures are often expected in the emergency department. Patient care plans that include only comfort measures or

withholding and, even, withdrawing medical treatments are viewed as traumatic decisions for most ED clinicians and require an enormous amount of effort to implement.⁴ Because emergency nurses provide most of the EOL care in emergency departments, nurses witness, on a daily basis, what obstacles inhibit EOL care and what helpful behaviors improve EOL care for dying patients and their families.^{5,6}

Although death is a common occurrence in the emergency department there is little literature regarding EOL care in the emergency department. McClain and Perkins⁷ gave an overview of EOL challenges that are commonly associated with caring for terminally ill ED patients including pain control, dyspnea, fatigue, delirium, and dehydration. Le Conte et al.⁸ completed a prospective study regarding the withholding and withdrawing of life-support therapy in an ED setting which demonstrated poor participation of both patients and nurses in the decision making process. Chan⁹ found that little is known regarding EOL ED care and that most EOL models are developed for more chronic disease processes in which the trajectory is known and predetermined. Therefore, these predetermined models do not fit sudden illness, injury, or acute exacerbation of a chronic illness as is often seen in emergency departments.

Li et al.¹⁰ reported the nursing actions that suddenly bereaved family members viewed as helpful included providing written information, enabling the family to view the deceased, respecting individual customs, and honoring religious procedures. Heaston⁶ used a national sample of 300 emergency nurses and identified perceptions of common obstacles and supportive behaviors emergency nurses encounter while providing EOL care. Beckstrand et al.⁵ sampled 700 emergency nurses, and then reported the size, frequency of occurrence data and magnitude of both obstacles and supportive behaviors in providing EOL care in EDs.

The purpose of this research study is to determine what changes emergency nurses would suggest to improve EOL care for dying patients and their families in emergency departments.

Methodology

A national, geographically dispersed, random sample of 1000 emergency nurses were sent a questionnaire entitled “Emergency Nurses’ Perceptions of End-of-Life Care.” Quantitative data from this research study have been previously published.^{4,5} Inclusion criteria included nurses who were members of the Emergency Nurses Association (ENA), could read English, worked in an emergency department, and had cared for at least one emergency patient at the EOL.

All responses were typed into a Word© database. Four different nurse experts, including a qualitative nurse researcher, a doctorally prepared critical care nurse researcher, an advanced practice nurse with many years of emergency nursing experience, and a graduate student who was an emergency nurse, individually reviewed and coded each returned response. Inter-rater reliability was >98% between all reviewers. Any differences in individual item coding were discussed until agreement was obtained.

Results

After three separate mailings, 441 survey responses were received. Of the 441 emergency room nurses across the United States who returned completed questionnaires, 230 (52%) offered one or more suggestions in response to the question, “If you had the ability to change just one aspect of the end-of-life care given to dying ED patients, what would it be?” While each of the 230 nurses was asked to report just one aspect of EOL care they would like to change, many nurses (n = 47) gave multiple suggestions for change resulting in 295 total suggestions.

The 230 respondents who provided suggestions for improving EOL care in the emergency department were age 23 to 71 years old (mean 46 years). A total of 86% were women. Respondents represented a variety of educational backgrounds including masters prepared nurses (20%), BSN (43%), ADN (24%), and diploma (11%). Respondents were employed as charge nurses (34%), direct care nurses (31%), clinical nurse specialists (2%), or in other roles such as managers or nurse educators (32%). Respondents had been registered nurses for a mean of 20.1 years with a mean of 14 years of experience in the emergency department. Respondents included 67% that were currently certified as emergency nurses with a mean of 9.8 years certified as an emergency nurse. Among the respondents, 74% had cared for more than 30 dying patients, with many having cared for between 21 and 30 dying patients (10%).

Major Themes

There was an overwhelming consistency in recommended changes to improve care of the dying ED patient by the nurses participating in the study. Five major themes were identified including, 1) increasing the amount of time and the availability emergency nurses have to care for dying patients and their families (n = 76); 2) consistently allowing family presence during resuscitation (n = 41); 3) providing a comfortable patient room (n = 34), 4) providing for more privacy at the EOL (n = 32); and, 5) providing a family grief room (n = 20).

Increased RN time with the patient and family

Emergency nurses recognized that effectively delivering EOL care requires time and a consistent presence. Subjects recognized the importance of nurses being present and available to help educate and support family members at this transitional time in a patient's life. Nurses described a desire to change the quality and consistency of this last family interaction by recommending, *"The ER RN [should] have the time to spend with the family of a dying patient,*

not a run in and run out type of care.” Several respondents echoed this nurse’s comment, recommending that nurses, *“Have more involvement with the family and [have the] opportunity to express condolences [and] give comfort in simple ways.”*

Emergency nurses also recognized that staffing limitations, plus the nursing needs of other patients, decreased their ability to provide optimal care to dying patients. Epitomizing this idea, one nurse said *“[There needs to be enough] staffing that allows me to do it right. I know what to do, too bad I’m not given the time.”* Several nurses recommended specifically that the nurse be able to give 1:1 nurse to patient care at the EOL in order to meet the many demands associated with this transition. One nurse responded, *“Free me of responsibility for other patients to facilitate my providing uninterrupted care for [the] dying patient and their family.”* One nurse hoped to *“Make EOL patients a 1:1 ratio to allow ample time to ease the patient to death’s door with dignity while supporting the family.”*

Family presence

Emergency nurses overwhelmingly recommended that they would improve ED EOL care by connecting patients with their family members rather than separating them at this critical time. Emergency nurses expressed a desire to have a hospital policy enabling family presence during EOL and that the policy be implemented on a consistent basis (n = 41). Family involvement in EOL care was also emphasized by one emergency nurse who stated, *“Make sure families are involved and informed of what is being done and what will be happening. You must include family, not exclude family, at these times.”* Another nurse further articulated the importance of family involvement by stating, *“I would bring family members in during resuscitative efforts so they could be part of the end of life team.”* One nurse who worked in a 76 bed emergency department recommended there be a *“Hospital policy regarding allowing family*

in the room during resuscitation efforts; instead of [family presence] being [implemented] haphazardly.” Finally, one respondent hoped to “Give [the patient] and their family a chance to see and hear and touch [each other] during their last moments; to know that [the family’s] presence was felt [by the dying patient].”

Comfortable patient room

Many respondents felt that creating a place of comfort should be the priority in providing EOL care in the emergency department (n = 34). One nurse wrote, *“Our ED rooms are so cold feeling; [the dying patient] need a peaceful place.”* Another nurse stated that a private area is needed, *“...so that the family can experience this part of the patients’ life with dignity, support, privacy and compassion.”* One nurse expressed a desire to, *“Have a special room for the patient with a room connected for the family connected, and have décor more like home, less institutional appearing.”* Another respondent requested a *“Better architecturally planned ED to allow for enhanced privacy and room for the dying patient and family.”*

Responses also addressed concern for patients that may be sharing space in close proximity to a dying patient, *“We do our best to provide as much privacy and support as we can, but often in a room for two patients [with] a curtain between them [it’s] very hard for [those on] the other side of the room.”*

Providing for more privacy

The recommendation for improved privacy for dying patients and their families was common (n = 32). In addition to providing a room for family members to grieve, nurses suggested changes to patient care rooms to improve the shared experience for both family and dying patient. One nurse responded, *“[That we need] better provisions for grieving, better rooms and rooms that are only [used] for this purpose.”* Several nurses recommended having areas that

were quieter with one nurse noting that in the emergency department, *“Even though they are in a separate room, everyone in the ED knows what is happening.”* Several nurses expressed their feeling that providing privacy may not be possible in a busy emergency department and recommended attempting to move the patient and family members to an area outside the department.

Family grief room

With the hectic pace and close quarters often present in an ED environment this can be an uncomfortable setting for grieving family members who are supporting a dying patient. Many respondents (n = 20) suggested access to a “grief room” in the emergency department might improve this difficult environmental problem. Their recommendations included, *“For our small ED it would be nice to have a room or private area for the family to use during this difficult time.”* Another nurse recommended, *“Provide an additional private, quiet environment for the family, physicians, clergy and other support personnel to communicate and make decisions.”*

Minor Themes

Four other themes were also identified, but each was mentioned by 16 or less emergency nurses. These four themes included increasing support from, and involvement of ancillary staff (n = 16); minimizing suffering by managing pain (n = 14); improving nursing education to the family regarding EOL care (n = 13); and upholding advanced directives and patient wishes (n = 11).

Increased ancillary service involvement

Suggested methods for providing improved EOL care to the patient and family included non-pharmaceutical interventions and increased involvement from ancillary services. One nurse recommended, *“[Having] ancillary staff at every facility (even small ones) [that] can contact*

people for families, pastoral care, social services etc.” Frustration was evident as this respondent recommended,

“More help to deal with the family so I can focus on the patient [and] not have to be a social worker. Chaplains and social workers are not always available and I do not have the time or inclination to care for family needs during [the] grieving process.”

Managing pain and minimizing suffering

Providing better pain control for dying patients was an emphasis for many nurses. A nurse with over 11 years in emergency nursing experience who works in a 60 bed emergency department recommended, *“Provide more comfort with decreased procedures and increased pain medication. Comfort medications should never be withheld due to side effects that may hasten death (hypotension, [decreased] respiration etc.).”* Another respondent stated, *“I wish we weren’t a society afraid of administering adequate doses of pain medications. We often fear we could suppress their respiratory effort when death is imminent anyway.”* Perhaps this respondent summarized the optimal goal best when saying, *“I would increase the amount and frequency of pain medications given to the dying patient to meet their actual needs regardless of outcome.”*

Family education

Respondents consistently emphasized the importance of educating patients and families regarding EOL care and expectations. A nurse with eight years of emergency experience suggested, *“Educate the family to the client’s illness before the client goes to the emergency room [and] also discuss what an advanced directive and DNR is before the situation happens, to make that decision easier on everyone.”* Another nurse hoped the following question would be

posed to family members, *“I would ask them, do you really feel your loved one would want to be kept alive this way?”*

Upholding advance directives

Nurses suggested that patient’s desires and wishes at the end-of-life be honored. One nurse hoped to, *“[Know] the patients’ wishes up front. We often do not have rapid access to documents when they exist, and many patients have no documentation of their wishes.”* Even with appropriate documentation available, supporting the patients’ EOL decisions can be difficult for family. Other respondents emphasize respecting the patient and their decision, *“Support the patients’ EOL wishes/decisions even though the family is [not] sure.”* One nurse encouraged, *“Let patients die with peace and dignity when it is their wish that no extreme measures be taken.”*

Miscellaneous Responses

While many themes emerged from the data, there were many responses categorized as miscellaneous (n = 39). Several nurses articulated the difficulty in choosing one specific aspect of ED EOL care to change. For example, one emergency nurse with over ten years of emergency experience said, *“Each situation is unique, it’s difficult to generalize [because] there are so many contributing factors, for example, staffing, how busy the department is, space, and how much time the dying patient has.”* Additional suggestions included improving physician communication with the patient and family, improving staff education regarding EOL care, providing a “good death”, and improving critical debriefings after a patient death.

Discussion

These results contribute to the body of knowledge that emergency nurses recognized as deficiencies in ED EOL care and supported changes to current practice. The high response rate to

this questionnaire, as well as the frequency of multiple recommendations from emergency nurses, indicated there were many components of EOL care that can potentially be improved. Study participants formed clearly defined recommendations for priority changes to improve the ED EOL care which should be targeted for quality improvement initiatives as well as future research.

Emergency nurses overwhelmingly placed the highest priority for change on increasing RN time with the dying patient and their loved ones. ENA's position statement regarding staffing and productivity in the ED, which was developed as early as 1987 and was revised as recently as 2011, recognizes emergency nurse workloads are often too high to adequately care for dying patients and their families.¹¹ Variables that affect the consumption of nursing time and resources, and staffing not based solely on nurse to patient ratios, are all important factors for consideration when caring for EOL patients in the emergency department.¹¹ The frequency of responses that recommended improvements in this aspect of ED EOL care suggests previous efforts have been ineffective and new strategies to improve RN availability to the dying patient and their loved ones must be implemented.

The frequency of suggestions regarding improved management of family presence at the EOL is congruent with previously published data, which indicates patients and family members desire to be together at the EOL even when CPR or invasive procedures may be in progress.¹²⁻¹⁴ The frequency of suggestions directed at improving this component of EOL care supports findings that 74% of emergency nurses requested written policies regarding family presence and 96% supported additional education to ED staff regarding benefits of family witnessed resuscitation.¹⁴ Family presence has been shown to facilitate a sense of patient and family

connectedness, as well as allowing family members to directly convey support and helps facilitate the grieving process.¹²

Emergency nurse responses support the need to improve the level of comfort provided to the patient and family in a private setting to appreciate this important part of life. Currently there are no ideal EOL or palliative care models for emergency nurses to guide their care.⁹ While making changes to the ED design and processes to facilitate improved care for dying patients may be possible in the future, an immediate modification to current practice may be early initiation of palliative care through improved staff training as well as early referral to palliative care professionals. A study, which evaluated an out-of-hospital setting that covered over 47 million people, showed fewer than 6% of the emergency medical systems had protocols for palliative care.¹⁵ An additional study showed over 68% of patients receiving palliative care would have liked to have this option offered earlier in their disease process, with no patients reporting a desire to delay palliative care until later in the disease process.¹⁶

Limitations

Responses were only obtained from nurses who were members of ENA. Some responses were not legible or did not make sense grammatically and, therefore, could not be coded into a specific theme. We also do not know what the emergency nurses in this sample who did not answer this question would have as their suggestions for improvement of EOL care.

Conclusion

The emergency department will continue to be the primary access point for dying patients to receive medical and nursing care. Implementing changes based on emergency nurse recommendations will dramatically improve the experience for the dying patient as well as their family members.

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Table 1
Demographics

Demographics of Nurses. N = 1000, 441 returned, n = 230 respondents (52%) to this item = 295 total suggestions.			
Characteristics			
Gender	<u>n</u>	<u>%</u>	
Female	196	(85.2)	
Male	34	(14.8)	
	<u>M</u>	<u>SD</u>	<u>Range</u>
Age	46	9.5	25 - 71
Years as RN	20.1	10.6	1 - 45
Years in ED	14.5	8.9	1 - 40
Hours worked/week	27.8	13.8	0 - 75
Number of beds in ED	27.1	14.7	0 - 76
Dying patients cared for:		<u>%</u>	
>30		74.6	
21 - 30		10.1	
11 - 20		10.8	
5 - 10		2.6	
<5		1.9	
Highest degree:		<u>%</u>	
Diploma		13.7	
Associate		26.1	
Bachelor		40.5	
Master		18.9	
Doctoral		.8	
Ever certified as CEN	<u>n</u>	<u>%</u>	
Yes	158	(68.6)	
No	72	(31.3)	
Currently CEN	<u>n</u>	<u>%</u>	
Yes	111	(66.9)	
No	55	(33.1)	
Years as CEN	9.8	6.7	.3 - 26
Practice area:		<u>%</u>	
Direct Care/Bedside Nurse		31.1	
Staff/Charge Nurse		34.1	
Clinical Nurse Specialist		2.2	

Other (Manager, Educator, etc.)	32.6	
Hospital type:	<u>%</u>	
Community, non-profit	65.7	
Community, profit	12.7	
County Hospital	4.9	
Other	16.4	

 Table 2 Major and Minor Themes*

Major Themes

1. Increase time and availability ED nurses have to care for dying patients and their families (*n* = 76)
2. Consistently allow family presence during resuscitation (*n* = 41)
3. Provide a comfortable patient room (*n* = 34)
4. Provide for more privacy at the EOL (*n* = 32)
5. Provide a family grief room (*n* = 20)

Minor Themes

1. Increase support and involvement from ancillary staff (*n* = 16)
2. Minimize patient suffering by managing pain (*n*=14)
3. Improve education to the family regarding EOL care (*n* = 13)
4. Uphold advance directives and follow the patient's wishes (*n* = 11)

*Major themes were themes that had more than 20 responses. Minor themes had ≤ 16 responses.