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Rural Emergency Nurses' Suggestions for
Improving End-of-Life Care Obstacles

Kelly Elizabeth Smith

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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June 2015

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ABSTRACT

Rural Emergency Nurses' Suggestions for Improving End-of-Life Care Obstacles

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Introduction: In 2010, of the 129 million visits to the emergency department (ED), 240,000 resulted in the patient dying or being pronounced dead on arrival. This number is likely to continue to increase as a significant portion of the American population ages and seeks care in the ED. Though care in the ED is focused on saving lives, death cannot always be prevented. Consequently, nurses face many barriers to providing quality end-of-life (EOL) care in the ED when death occurs. The purpose of this study was to identify suggestions emergency nurses have to improve EOL care specifically in rural ED's.

Methods: A 57-item questionnaire was sent to 52 rural hospitals in the Intermountain West and Alaska. One of the 57 questions asked nurses to identify the one aspect of EOL care they would change for dying patients in the ED. Each qualitative response was individually reviewed by a research team and then coded into a theme.

Results: Four major themes and three minor themes were identified. The major themes were providing greater privacy during EOL care for patients and family members, increasing availability of support services, additional staffing, and improved staff and community education.

Discussion: Providing adequate privacy for patients and family members is a major barrier to providing EOL care in the ED. This is largely due to poor department design, especially in rural ED's where space is limited. Lack of support services such as religious leaders, social workers, and additional staffing are also barriers to providing quality EOL care in rural ED's. Consequently, rural nurses are commonly pulled away from EOL care to perform ancillary duties because additional support personnel are lacking.

Conclusion: Providing EOL care in the ED is an extremely challenging and demanding task. It is especially difficult in rural ED's where staffing and resources are limited. Consequently, it is imperative that supportive behaviors are acknowledged and barriers are identified to improve EOL care provided to patients and family members in rural ED's. Due to the current lack of research in rural EOL care, further research is justified regarding this topic.

Keywords: end-of-life care, rural, emergency department

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Rural Emergency Nurses' Suggestions for Improving End-of-Life Care Obstacles

Death is a part of life that can neither be avoided nor predicted. In 2010, of the 129 million visits to the emergency department (ED), 240,000 resulted in the patient dying or being pronounced dead on arrival.¹ Though care in the ED is focused on saving lives and returning patients to a healthy state, death cannot always be prevented.²

As the population of the United States (U.S.) continues to age, ED visits of the aging population also continue to rise.¹ It is estimated that one in five persons will be age 65 and older by the year 2030.³ Consequently, the number of patients who are at the end-of-life (EOL) or dying will increase, further taxing the already limited resources available to provide EOL care in the ED. Thus, it is imperative that obstacles, as well as helpful or supportive behaviors to providing EOL care in the ED be identified.

Providing care to dying patients and their family members is a responsibility that all emergency nurses assume at some point in their career. However, since emergency nurses are primarily trained to save lives, emergency nurses often encounter obstacles to providing EOL care to dying patients, especially in rural settings where staffing and resources are limited.²

Background

EOL research in the ED from the nurses' perspective has generally focused on three primary aspects: issues regarding nurse workload while care for dying patients, care of family members in addition to care of dying patients, and difficulties in providing quality EOL care in ED's with poor department design have been reported.

Workload

A lack of adequate time to spend with dying patients and their family members was a significant obstacle that prevented emergency nurses from providing high quality EOL care. In two previous studies, randomly selected nurses who were members of the Emergency Nurses' Association reported that their assigned workloads were too high to provide quality EOL care.^{4,5} Additionally, nurses reported being pulled away from EOL care to assist with other patients and department obligations, resulting in disjointed care for the dying patient.^{2,6} In order to improve and provide optimal EOL care nurses suggested increasing the amount of time available to spend with dying patients, recommending one-to-one nursing care for EOL patients.⁶

Family Demands

Another emergency nurses' responsibility, which removed nurses from the bedside during EOL care was functioning as a liaison between the patient and family. In a study of 236 nurses working in rural ED's, emergency nurses reported frequent calls from both family members and friends seeking patient condition updates as a major obstacle to providing EOL care.² Additionally, as a liaison, nurses often intercepted distraught and angry family members,⁴ preventing nurses from spending valuable time with the patient. This lack of intermediary staff was especially evident in rural facilities where the presence of family support services such as social workers and religious leaders were limited.²

Department Design

ED layouts have been reported as an environmental factor preventing optimal EOL care. Nurses from rural and urban ED's reported that ED designs did not allow for adequate privacy for dying patients and grieving family members.^{2,4} When asked how to improve EOL care, a

national random sample of 230 emergency nurses suggested greater privacy for patients and family, including the need for a separate family grief room.⁶ These nurses suggested a designated grief room that would allow family members to grieve privately, away from the noise and distraction of a busy ED.

Summary

Given the ever-increasing aged population and the rate of death that occurs in ED's nationally, it is imperative that obstacles, as well as supportive behaviors to providing EOL care be identified. Obstacles identified in previous studies included limited time to provide care to dying patients due to a demanding workload, balancing patient needs and family demands, and lack of privacy due to poor ED designs. Specifically, because research regarding EOL care in rural ED's was limited, the purpose of this study was to identify suggestions emergency nurses might have to improve EOL care in rural ED's. Therefore, the research question for this study was, "If you had the ability to change just one aspect of the end-of-life care given to dying ED patients in a rural setting, what would it be?"

Methods

Study Design

A cross-sectional survey research design was used for this study.

Instrument

The *Rural Emergency Nurse's Perception of End-of-Life Care* questionnaire was utilized to assess nurses' perceptions of size and frequency for a set of listed obstacles to providing EOL care in rural ED's.² The questionnaire was modified from questionnaires used in previous ED EOL care studies and was then adapted to focus specifically on emergency care in rural settings.⁵

This 57-item questionnaire included 39 Likert-type items, 15 demographic questions, and 3 open-ended questions. The questionnaire was pre-tested by 15 nurses in two rural ED's in the Intermountain West. Feedback concerning content, questions, and completion time was obtained from the ED nurses. The questionnaire took approximately 25 minutes to complete. Findings for the quantitative data were published previously.² Participants were also asked to answer three open-ended questions for qualitative purposes.

Sample inclusion criteria included nurses who worked in rural ED, could read English, and had cared for at least one dying patient in an ED setting. Responses to the qualitative questions were entered into a word database. Each qualitative response was individually reviewed and coded by four different nurse experts. The coders included an experienced researcher, an advance practice nurse researcher, a qualitative researcher, and a graduate student with 5 years of ED experience. After review, responses were coded into themes.

Setting and Study Procedures

Five states were selected to participate in the study based upon the number of Critical Access Hospitals (CAHs) available in each of the states (see Figure 1).⁷ CAHs are hospitals certified under a set of Medicare Conditions of Participation located in rural areas of the country.⁸ The five states selected were Utah, Idaho, Nevada, Wyoming, and Alaska.

After Institutional Review Board approval was obtained, ED managers in 72 selected CAHs were contacted by phone. Phone messages were left for managers who were unavailable at the time of contact. Contact was attempted as many as four times. Managers who agreed to participate in the study were mailed study packets to be distributed among emergency nurses. Each packet contained a cover letter, a questionnaire, a self-addressed stamped return envelope,

and a one-dollar bill as compensation for completing the questionnaire. The packets were distributed to nursing staff for completion. Nurses were not obligated to participate or complete the questionnaire. Consent to participate was assumed upon return of the questionnaire.

Results

Of the 72 CAHs contacted, 56 ED managers returned our calls of inquiry. Of those 56 managers, ninety-six percent ($n = 52$) of the managers consented to distribute the questionnaire packets to ED nurses. Of the 508 questionnaires sent out, 46.4% ($n = 236$) were returned. Of those returned, 132 nurses responded to this specified item. Although nurses were asked to report just one aspect of EOL care they would like to change, 29 nurses provided multiples suggestions.

Of the 132 nurses who provided suggestions for improving EOL care in the ED, 88.6% ($n = 117$) were female and 11.4% ($n = 15$) were male. The average age of participating nurses was 47. The average years of experience of RN's who responded to the specific item was 15, with an average of 11.5 years of ED specific experience. Other demographic data are shown in Table 1.

Major Themes

After reviewing rural emergency nurses' suggestions to improve EOL care, four major themes were identified: (1) providing greater privacy during EOL care for patients and family members; (2) increasing availability of support services; (3) additional staffing; and (4) improved staff and community education. A theme was identified as a major theme if it had 23 or more suggestions. Table 2 summarizes the major and minor themes.

Providing greater privacy during EOL care. Emergency nurses overwhelmingly identified privacy as the top priority when providing EOL care in the ED ($n = 52$). One nurse described the current situation in regards to privacy in the ED stating, “privacy in the ED does not exist. This needs to be changed.” Three other nurses echoed this sentiment by suggesting the following in order to improve EOL care in the ED: “privacy,” “more privacy,” and “better privacy.”

Emergency nurses suggestions for improved privacy was not limited to patients alone, but included greater privacy for family as well. One nurse simply stated, “more privacy, especially for the family.” Several nurses identified the need for a separate family consultation room or specified area dedicated for family members. One nurse suggested, “I wish we had a separate family meeting room for the family to wait in and have the doctor meet with them. We only have an ER waiting room.” Another nurse recommended, “having a separate area for families to gather and receive information away from public areas.”

In addition to providing a separate family room, rural emergency nurses suggested changes in department design to ensure privacy and improve EOL care. One nurse stated, “I think if we had a private room designed and designated specifically for EOL patients that would be ideal.” Similarly, several nurses recommended designing single occupancy rooms in order to preserve privacy, especially in a rural setting. One nurse requested, “[a] better ED for privacy issues, separate rooms, not just pull curtains. This creates a lot of issues in a small town. Hearsay, rumors, etc.” Another respondent agreed, saying:

Get a new hospital so the ED can have private rooms instead of curtains to separate the beds. The other patients don't have to listen to what is going on or making them wait in to lobby until end of life care is done.

Increasing availability of support services. Many emergency nurses expressed the need for support services in order to provide quality EOL care to dying patients and their family members ($n = 32$). One nurse suggested, “more readily available family support, whether from social work, chaplains, or just another nurse to be able to focus on the family needs.” Similarly, another nurse suggested “[the presence of a] social worker. [Support staff] help the family and friends so much to deal with the loss.” Desperation was evident as one respondent requested, “more (any?) support staff – i.e. clergy; social worker; etc.” Interestingly, another nurse identified a possible limitation that prevents the presence of support services in rural facilities stating, “rural hospitals being able to afford to pay for social workers.”

Additional staffing. Nurses also reported that staffing ratios decreased their ability to provide optimal EOL care in the ED ($n = 26$). One nurse said, “I would like to be able to devote more time to my dying patient and their family. Unfortunately, staffing does not allow for this all the time.” Another nurse indicated that, “staffing is a skeleton crew. Quality time is a premium if the RN or LPN are free to give 1 on 1 care. [This] doesn’t always happen. It would be nice to give all the time to the EOL patient.” Nurses also expressed the desire to be able to provide one-to-one care at the EOL and be relieved of other patient assignments and department duties. One nurse wished, “that staffing would allow for one nurse, experienced in EOL care, to provide uninterrupted complete nursing care to the patient and family members throughout the patient’s stay in the ER.” Another nurse suggested:

I would think that if we could get a nurse assigned to take care of just that particular patient instead of being assigned to several different patients and have several duties to get done, the nurse assigned to just that one EOL patient could spend the quality time with the patient and family that is much need[ed] at that point in time.

Education – staff and community. Providing education to staff, as well as to the rural community members was the fourth most recommended theme to improve EOL care in the ED ($n = 23$). A participating nurse stated, “ER training does not really prepare you for end of life care.” In order to improve EOL care, a nurse suggested receiving, “more training on how to communicate with families who have lost or are losing loved ones.” Another experienced nurse recommended:

Some form of training on how to deal with dying patients that are either friends or family. In a rural setting, there is a high probability that the patient will be known to you As we keep getting newer, younger nurses, few of them have the life experience that teach them how to keep “performing” when faced with this.

Nurses also emphasized the importance of education for the community, including patients and family members. A nurse expressed:

I wish families had some way to gain knowledge on DNR, CPR, etc. so they would know informed choices at the end of their loved ones life. It is really hard to have a patient dying of cancer and the family wants CPR and everything done.

Another nurse recommended:

More education so that patient and family members have a realistic idea or understanding about the fact that the patient is going to die regardless of what we do.

People need help getting past the denial stage and on to the acceptance stage.

Minor Themes

Three minor themes were also identified to improve EOL care in the ED. The minor themes had eight or fewer respondents. The three minor themes included futility, pain control, and knowing the patient personally.

Futility. Inflicting unnecessary pain by performing ineffective or futile procedures are behaviors that nurses identified as detrimental during EOL care. A nurse recommended that, “we should let more people die with dignity instead of torturing them with multiple procedures that will not improve quality of life.” One nurse expressed a desire to put, “less focus on ‘SAVE HIM’ and more focus on being at [the] bedside and supporting [the] patient and family.” Another nurse wrote, “I would change treating EOL patients with anything but making them comfortable. When a 99-year-old patient is asking to die and nothing to be done. I wish family members could just let them go.”

Pain control. Managing and controlling pain during EOL care was a focus for many ED nurses. When asked what one aspect of EOL care would you change, a nurse expressed to have the “patient to be pain free.” Another nurse expressed concern that pain medications are sometimes withheld in order to ensure the patient remains hemodynamically stable despite being at the EOL stating, “often we will withhold pain meds and anxiety meds because B/P is low.” In order to prevent unnecessary pain one respondent desired to, “have a specific end of life, comfort-measure-only policy in force.”

Knowing the patient personally. Several emergency nurses emphasized the challenges and difficulties in providing EOL care to patients they know personally. Working in a rural community presents a unique challenge as one nurse describes, “with our community being small, most people know each other which is more often a problem at that time rather than a benefit.” Another nurse articulated her desire stating, “that we wouldn’t know the patient personally.” Similarly, another respondent describes the following challenge:

Family will be looking to you as their friend, to be constantly available for them

while somehow trying to care for the patient at the same time. This is compounded when the patient is your own family and because of staffing, you are the only nurse in the ER.

Miscellaneous Responses

Aside from the major and minor themes, there were ten responses that were categorized as miscellaneous items. Several of the items were associated with the family. For example, providing the family with a patient memento, more family involvement, and developing family care protocols. Additional suggestions included providing follow-up and feedback when patients are transferred, not knowing the patient's wishes, providing community hospice services, and overcoming language and cultural barriers.

Discussion

The necessity to provide privacy to dying patients and grieving family members during EOL care is consistent with previously published data that indicates privacy is a priority when providing EOL care in the ED.⁶ Lack of privacy for dying patients and grieving family members related to poor department design was found to be the second⁵ and third⁴ greatest obstacle in providing EOL care in the ED in previous studies. Similarly, based upon the published quantitative results of this study, rural emergency nurses also identified poor design as the third most significant barrier to providing EOL care in the ED.² It is evident that poor department design is a barrier in preserving privacy during EOL care. This obstacle is especially burdensome in rural departments, which commonly lack the accommodations necessary to ensure privacy during death and grieving due to space and design constraints.

The lack of available support services in rural ED's is a major barrier to providing quality EOL care to patients and family members. However, lack of support services appears to be a

unique obstacle that affects rural ED's.² In a previously published qualitative study, lack of support services was identified as only a minor theme affecting EOL care.⁶ Similarly, limited availability of support personnel also ranked low in two other ED studies that surveyed nurses nationwide.^{4,5} Nevertheless, the availability of support services greatly reduces the responsibility emergency nurses are expected to assume during EOL care. As social workers or chaplains assume part of the workload, nurses are able to focus their attention on the patient, thus maximizing the quality of care given to the patient. It is likely that rural emergency nurses identified this a larger barrier compared to other ED's because the number of resources available in rural hospital tends to be more limited when compared with urban settings.

Emergency nurses responses regarding staffing necessitate reconsideration of current staffing practices in rural ED's. The Emergency Nurses Association position statement regarding staffing and productivity indicates that staffing should be assessed routinely to assure safe and efficient care.⁹ Similar to the results of this study, staffing limitations was identified as a major obstacle in providing EOL care in two previous ED focused studies.^{5,6} These similarities confirm the necessity to re-evaluate staffing practices and to ensure nurses are assigned manageable workloads.

Limitations

A limitation of this study is that it was a convenience sample of nurses rather than a random sample due to the necessity to obtain rural emergency nurses from CAH's. Though the sample was not randomized, the response rate was high at 47%. This study was also limited geographically to the Intermountain West region, as well as to CAH's. Therefore, these results are not representative of other regions or non-CAH hospitals. A second limitation was that not all CAH ED's in this sample were contacted. Rural emergency nurses who were in these

hospitals may have provided different suggestions for improving EOL care. Additionally, three responses from the study could not be coded into a specific theme because a suggestion for improvement was not provided in the response.

Conclusion

Patient deaths are a common occurrence in ED's nationwide and providing care to dying patients is a demanding task that requires a significant number of resources. Providing this service is especially difficult in rural settings, where resources and staffing are limited. However, by identifying and implementing supportive behaviors and acknowledging the obstacles that rural ED nurses encounter during EOL care, changes can be made to improve the treatment they provide to patients and family members during this trying time. Due to the current lack of research in rural ED settings, further research is justified in the area of rural EOL nursing care.

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Figure 1

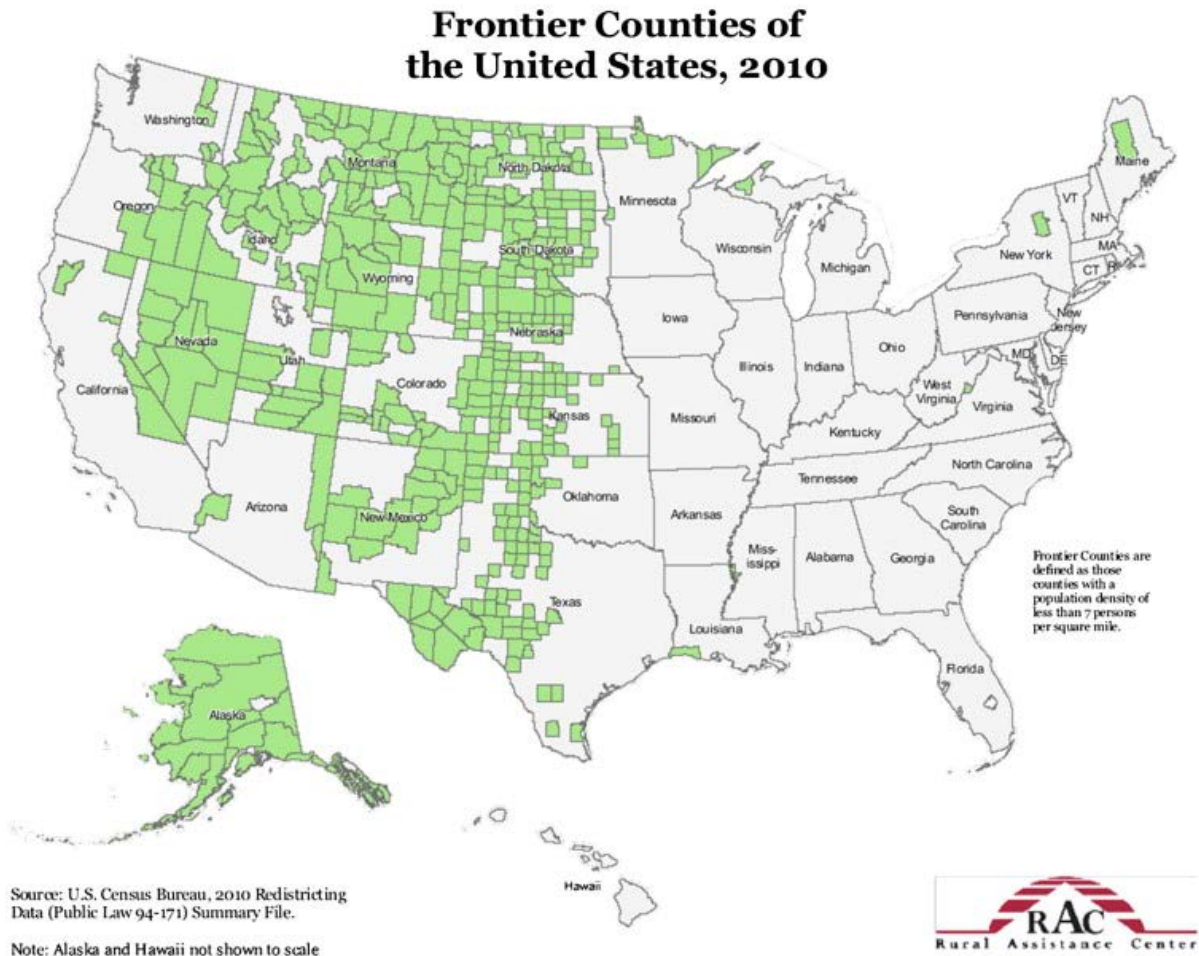


Table 1

Demographics of Nurses. N = 132.			
Characteristics			
Sex	<u>n</u>	<u>%</u>	
Female	117	(88.6)	
Male	15	(11.4)	
	<u>M</u>	<u>SD</u>	<u>Range</u>
Age	47	10.2	25 – 67
Years as RN	15.0	11.3	0 – 41
Years in ED	11.5	10.2	<1 – 41
Years in Rural Nursing	11.0	10.1	<1 – 41
Hours worked/week	32.0	12.4	0 – 80
Number of beds in ED	6.2	4.1	2 – 25
Dying patients cared for:		<u>%</u>	
>30		37.6	
21 – 30		12.8	
11 – 20		14.4	
5 – 10		19.2	
<5		14.4	
Other (no response)		1.6	
Highest degree:		<u>%</u>	
Diploma		5.5	
Associate		56.0	
Bachelor		31.1	
Master		3.0	
Other		1.5	
Ever certified as CEN	<u>n</u>	<u>%</u>	
Yes	21	(16.8)	
No	103	(82.4)	
Currently CEN	<u>n</u>	<u>%</u>	
Yes	17	(80.1)	
Years as CEN	5.8	6.2	0 – 20
Practice area:		<u>%</u>	
Direct Care/Bedside Nurse		36.2	
Staff/Charge Nurse		47.2	
Manager or Other		16.5	
Hospital type:		<u>%</u>	
Community, non-profit		64.3	
Community, profit		10.3	
County Hospital		23.8	
Other		1.6	

Table 2

Major and minor themes^a

Major themes	Minor themes
1. Providing Greater Privacy During EOL Care (n = 52) for Patients and Family Members	1. Futility (n = 8)
2. Increasing Availability of Support Services (n = 32)	2. Pain Control (n = 5)
3. Additional Staffing (n = 26) Personally (n = 4)	3. Knowing the Patient
4. Education – staff and community (n = 23)	

^aMajor themes had more than 23 responses. Minor themes had <8 responses