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Rural Emergency Nurses' End-of-Life Care Obstacles  
Experiences: Stories from the Last Frontier

Jonathan D. Rohwer

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

### Rural Emergency Nurses' End-of-Life Care Obstacles Experiences: Stories from the Last Frontier

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**Introduction:** Rural emergency nurses face unique obstacles to providing quality end-of-life (EOL) care. Stories provided by emergency nurses embody their most difficult EOL care obstacles.

**Methods:** A questionnaire was sent to 53 rural hospitals. Respondents were asked to share stories that epitomized the obstacles faced while providing EOL care in the rural emergency setting.

**Results:** The lack of an ideal death (nurse personally knows the patient, issues with family members, and unknown patient wishes) was the top obstacle. Other reported obstacles were insufficient ED staff and power struggles between nurses and physicians.

**Discussion:** Rural emergency nurses often provide EOL care to friends and family members, while their urban counterparts are likely to transfer care to nurses with no relation to the dying patient. Not only does caring for patients that the nurse knows or is related to cause great distress to rural emergency nurses, this unfortunately common situation may also prevent patients from receiving the highest quality of EOL care.

**Conclusion:** Emergency nurses often face obstacles that hinder their ability to provide high quality EOL care to patients. These obstacles are compounded by a unique set of challenges faced by nurses working in rural emergency departments. Stories from rural emergency nurses revealed that being unable to provide optimal care at the EOL, having difficulties with family members, or not knowing the patient's wishes for EOL care were the most common obstacles. Additional obstacles included stories about the impact of low or unavailable staff and feeling powerless in some EOL situations.

**Keywords:** emergency, end-of-life, obstacles, emergency nurse, rural, rural nursing

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## Rural Emergency Nurses' End-of-Life Care Obstacles

### Experiences: Stories from the Last Frontier

When a patient dies in the emergency department (ED), emergency nurses play a significant role in providing bedside end-of-life (EOL) care. Administering EOL care in a compassionate and professional manner can be one of the most stressful and difficult facets of nursing care.<sup>1</sup> While maintaining the highest level of comfort possible for the patient and family can be difficult under the best conditions, providing comfort becomes even more complicated in the chaotic environment of the emergency department, where quality EOL care is often overshadowed by resuscitation efforts and emergency procedures.

Based upon data from the 2010 National Hospital Ambulatory Medical Care Survey (NHAMCS), 240,000 patients died in emergency departments in the United States, representing a seventy-two percent increase in the amount of ED deaths reported in 2007.<sup>2</sup> The increased rate of fatalities were due to traumatic as well as chronic causes.<sup>3</sup> An increase in ED deaths of this magnitude stands to place even more burden on already strained emergency nurses.

In the past decade there have been considerable efforts to understand the obstacles that prevented emergency nurses from providing high quality EOL care. Emergency nurses have reported many obstacles to providing optimal EOL care including poor ED design, lack of adequate privacy, inadequate palliative care training, and family issues.<sup>4-6</sup> While these reports have played an important role in understanding the barriers to providing EOL care in emergency departments, all have been national random samples and thus have focused primarily on urban populations without specifically considering rural ED counterparts.

Rural populations can present unique complications in all aspects of health care. In order to understand the specific EOL care obstacles faced by rural emergency nurses, a literature search was conducted. Search terms were "rural," "emergency department," and "end-of-life." CINAHL, MEDLINE, and PsychINFO were the databases included in the query. The search returned a single article on the obstacles noted in caring for dying rural ED patients.<sup>7</sup>

A separate search of the databases for emergency nurses' EOL stories returned no pertinent results. The minimal published research on rural emergency nursing demonstrates a need for increased understanding of the barriers to EOL care in rural emergency departments. This study will report the first-person experiences or stories of rural emergency nurses who have cared for dying patients and the obstacles they have encountered while attempting to provide EOL care.

This report presents the qualitative data gathered as one part of a larger, previously published study.<sup>7</sup> Emergency nurses were asked to respond to the following open-ended question, "Can you share with us an experience you have had, caring for a dying patient in a rural setting, which epitomizes the obstacles to providing EOL care in this setting?"

## **Methods**

### **Study Design**

This study was conducted as a cross-sectional mailed survey sent to rural emergency departments randomly selected from a convenience sample of five states with high proportions of designated rural areas as defined by the presence of critical access hospitals (CAH).

### **Data Collection Instrument**

Data for this research were part of a larger study by Beckstrand and Giles et al.<sup>7</sup> using the *Rural Emergency Nurses' Perception of End-of-Life Care* questionnaire. The questionnaire was adapted from a previous EOL questionnaire used to conduct research with a national random sample of emergency nurses.<sup>8</sup> The instrument was adapted for use specifically with rural emergency nurses by using previous rural EOL research and recommendations from experts in the field. The questionnaire was designed to measure emergency nurses' perceptions of the size and frequency of EOL care obstacles and to allow nurses to share personal experiences and recommendations in a free response format.<sup>8-9</sup>

The questionnaire was composed of 39 Likert-type questions, 3 open-ended questions, and 15 demographic questions. The instrument was pre-tested by 15 rural emergency nurses

from Utah. Nurses asked to complete the pre-test assessed the content of the questionnaire as well as the completion time. Average completion time was 25 minutes. Quantitative data from the original study was published previously.<sup>7</sup>

### **Sample and Setting**

Critical access hospital emergency departments provide emergency service to rural communities; therefore, emergency nurses working in the emergency departments of CAHs were identified as being appropriate to provide information regarding rural emergency EOL care. Figure 1 shows the 2010 United States Census information regarding rural population density distribution.<sup>10</sup> Based on areas of rural population and CAH availability, four states in the Intermountain West plus Alaska were chosen to participate.

### **Study Procedures**

After obtaining IRB approval, ED managers were contacted by phone. Seventy emergency departments were selected from CAHs in Utah, Idaho, Nevada, Wyoming, and Alaska. If the managers were unavailable or did not answer, detailed messages were left requesting study participation. Contact was attempted up to 4 times. If the manager agreed to distribute the study questionnaires, he or she was sent the appropriate number of questionnaire packets each containing an explanation of the study in the form of a cover letter, a questionnaire, a self-addressed stamped return envelope, and a 1 dollar bill attached to each questionnaire to thank the nurse for participating in the study. Managers were asked to distribute questionnaire packets to emergency nurses in their departments with no obligation to participate. The return of a completed questionnaire was considered consent to participate.

Contact was successfully made with 56 of the 70 CAH ED managers and 94.6% (n = 53) of those contacted agreed to participate in the study (see Table 1 for return by state). Five hundred and eight questionnaire packets were mailed. Completed and returned questionnaires for the larger study totaled 246 for a response rate of 46.4%. The respondents were primarily

registered nurses but also included 5 licensed practical nurses and 3 paramedics. Responses of non-registered nurses were not included in this data analysis.

Subjects were nurses who worked in rural emergency departments. Inclusion criteria incorporated the ability to read English, work in a rural emergency department, with a history of providing care for at least one dying ED patient. All responses were entered into a word database. Five nursing experts including an experienced researcher, a qualitative researcher, an advance practice nurse researcher, an advance practice nurse with 11 years of ED experience, and a graduate student individually reviewed and coded each response. During the first round of analysis all data were coded individually for themes. The second round of analysis involved the research team collectively identifying the themes and story arcs of all eligible data.

### **Data Analysis**

Of the 246 questionnaires returned, 107 nurses responded to this item. Those responses were initially reviewed to determine if the responses fit the criteria to be considered an experience or story. For this study, a story was defined as a sequence of events described in chronological order. Twenty-eight of the 107 responses to this item qualified as stories and were analyzed and coded for content themes. Responses not meeting the aforementioned criteria were generally suggestions or lists where specific details regarding EOL care obstacles were missing.

### **Results**

Twenty-seven (25.2%) nurses responded in an appropriate format for consideration as an EOL obstacle story. One participant responded with two distinct EOL obstacle stories for a total of twenty-eight story responses. Of the total respondents, 24 (88.9%) were women and 3 (11.1%) were men. The average age of the participants was 46 (SD = 9.5) years. Participants had an average of 15.4 (SD = 10.6) years of RN experience and 11.6 (SD = 8.1) years of experience in a rural emergency department. Other demographic data are displayed in Table 2.

Content analysis revealed three predominant themes with each theme representing an obstacle to providing quality EOL care that was present in the rural emergency nurses' stories. The most common obstacle themes were: 1) the lack of an ideal death for the patient, 2) insufficient ED staff to provide quality EOL care, and 3) power struggles between emergency nurses, physicians, and patients' families. Various other obstacle themes were also represented; however, less frequently (see Table 3).

### **Lack of an Ideal Death**

The most commonly identified obstacle theme (n = 13, 46.4%) was the absence of what the nurse considered to be an "ideal" or good death for the patient and the patient's family. Each nurse's story, specific to this theme, demonstrated different obstacles ranging from caring for dying patients or family members known to the nurse, to difficulties with family involvement, or not knowing the patient's EOL care wishes.

**Emergency nurses provided EOL care for people they know.** One particularly striking story related by a nurse, told of the hardship of caring for a trauma victim who was also her friend.

"[A] Co-worker (nurse) was involved in [a head injury] trauma. I did not know who the patient was until I saw the ring on her finger (wedding ring) and recognized it belonged to my friend. I then looked up and saw her husband sitting in a chair covered with blood. He had been doing CPR prior to [the] ambulance arrival. We coded her for an hour. The first half hour of her ER time I was unaware [that] this was my friend. [When] I did recognize her ring and her husband, I had a hard time refocusing. [There was] no time to call in clergy prior to death, [and] no social worker on staff at our hospital."

Another rural emergency nurse contributed this graphic story about providing EOL care to the dying family member of a coworker.

"We had a victim of a trauma brought in by his distraught family, one of which was his sister-in-law [who was] one of our emergency nurses. There was a ton of family there

and we didn't have the heart to ask them to leave. One brother became very anxious and had to also be seen by the MD and given a sedative. It was very chaotic. All efforts were made to save this young man but it was futile. I felt I was suctioning parts of his brain out through his mouth because it filled up as fast as I suctioned him but still all these heroic efforts were continued till he was warm and dead."

As these two stories shared by rural emergency nurses demonstrate, providing EOL care for known patients or families can be a tremendous obstacle. Families can also be an obstacle even when they are not known to the emergency nurse.

**Families as obstacles to providing rural EOL care.** Regarding the obstacle of difficulties with families, one rural emergency nurse shared the following story about how family issues impeded her attempt to provide quality EOL care.

"[A] mother was dying – She had 10 children. Living will and advanced directives [were] in place. The patient is showing true signs and symptoms of shutting down. The eldest siblings are okay with following Mom's advance directives, but not some of the younger...they proceeded to take their verbal disagreement out in the hospital halls, yelling loudly. Physician was notified, but didn't want to come in, left it to me to tell family that he will not change current care until all family members agreed...".

An additional rural emergency nurse told this story about the emotional difficulty of providing EOL care in the presence of grieving family members, "We let family come into the trauma room and having her lay across the patient yelling at him to not die, 'don't leave me,' was very hard on everyone."

Issues with families were important obstacles to providing EOL care in rural emergency departments. Another obstacle impeding good EOL care was when the patient's wishes for care were unknown.

**EOL care when patient wishes are unknown.** An emergency nurse shared the following story about obstacles faced when trying to provide an elderly patient with a peaceful or good death.

“[An] elderly woman came in with a quick response unit as a full code. We worked on the patient for approximately 45 minutes before the doctor called it. [Then] the patient started to breath agonally and the doctor stated not to resume CPR. [We] put the patient behind curtains and had pain meds on hands. It was [then] discovered that the patient was do not resuscitate (DNR). It took several minutes for the patient to die and we were unable to get ahold of any family.”

While these five stories provided examples of rural emergency nurses being unable to provide dying patients with a good death due to issues with knowing the patient, family difficulties, or unknown patient wishes, stories of obstacles related to insufficient staff were also frequently reported.

### **Insufficient ED Staff**

The second most commonly identified theme by the rural emergency nurses was the lack of sufficient staff (n = 9, 32.1%). One rural emergency nurse shared this story about a rural emergency department/hospital where a patient died unattended without immediately being noticed by the nursing staff,

“Pt. [at] EOL on [unit] with family visiting. ER full, nurse in ER, family left, new family member on their way down the hall. X-ray tech noticed pt. deceased, notified nurse. Nurse made it to the room [just] prior to the family member.”

This story highlights staffing issues and the dual responsibilities of rural emergency nurses who may be required to care for admitted patients in addition to patients entering through the emergency department. Not only did this patient face his or her last moments alone, but there was also no nurse present to ensure that EOL care, pain, and comfort goals were being met as the patient died.

Another nurse reported how a busy and understaffed emergency department also led to poor EOL care.

“A patient was in a very bad accident. We treated an aunt; grandmother; and the semi-truck driver... It was hard to give [them] EOL care. We also had a patient at the same time that wrecked a motorcycle with a broken ankle and no pedal pulses. We were so busy. The floor also had 5 inpatients. There was too much for three nurses to handle. The dying aunt and grandmother’s EOL cares [were] neglected. The niece who was traveling with them needed a lot of emotional support that we didn’t have time to give her.”

While staffing concerns did include a shortage of nurses, the concerns also embodied a deficit of help from social support staff in this critical situation.

Another rural emergency nurse shared this story about her trying attempt to provide EOL care for an infant without the help of support staff,

“[There was an] 18 month old SIDS [sudden infant death syndrome] patient brought to hospital by ambulance. Family was pretty much left alone for some time with child to say goodbye. We did not have any type of social service, counseling, or religious assistance. As the nurse, I did my best to check on them and provide emotional support, but I had no training or previous experience with a dying child.”

In addition to inadequate staffing and EOL training, the final major theme reflecting rural EOL care obstacles encompassed issues of nurses feeling powerless to help dying patients.

### **Power Struggles**

Disagreements between members of the healthcare team, as well as disagreements between the team and a patient’s family, were common occurrences in many rural emergency departments. One nurse related an account of how a power struggle between a physician, nurse, and patient’s family led to poor EOL care for an especially vulnerable patient.

“[A patient] was middle-aged and profoundly retarded. [Patient] had pacer discontinued two days prior to admission and sole parent had executed DNR. [The] patient went into arrest. Parent came to ER and provider persuaded parent that a chance of resuscitation was good. Pt. had been down greater than 30 minutes. Provider [then] used patient as practice for intubation, central line, and defibrillation.”

Sadly, this experience represents an example of unethical medical behavior toward a vulnerable dying patient where the nurse felt powerless to intercede. Unfortunately, current medical hierarchy often prevents nurses from having the opportunity to speak up and be a part of the decision making process at the end of life.

### **Other Obstacles**

In addition to the aforementioned themes, other stories also demonstrated several additional obstacle themes ranging from lack of EOL care training to problems with ED design; mostly regarding the lack of privacy for the dying patient and their grieving family. Rural emergency nurses also expressed concern over the sense of futility they felt while caring for dying patients. While these obstacles occurred less frequently, they did represent momentous hurdles to the provision of quality EOL care as well as areas of stress and concern for the rural emergency nurses.

### **Discussion**

Not being able to provide a good or ideal death was identified as the most significant obstacle theme. For this major theme, three subheadings emerged: 1) emergency nurses providing care to known patients, 2) families as obstacles to EOL care, and 3) unknown EOL care wishes. The inability to overcome these obstacles and provide the patient with an ideal death frequently appeared to be a cause of stress and regret for rural emergency nurses.

Rural emergency nurses are often required to provide EOL care to friends and family members, while their urban counterparts are more likely to have the option to transfer care to nurses with no relation to the dying patient. Not only does caring for patients that the nurse

knows or is related to cause great distress to rural emergency nurses, this unfortunately common situation may also prevent patients from receiving the highest quality of EOL care.

The 2010 study by Beckstrand and Giles et al. ranked “knowing the patient or family members personally” as the second-largest obstacle faced by rural emergency nurses in their provision of quality EOL care.<sup>7</sup> Previous studies that have not specifically examined rural emergency departments do not list knowing the patient as an obstacle to providing EOL care in the emergency department.<sup>5, 8-9</sup> This previous research supports the idea that knowing the patient is an obstacle that is largely unique to rural emergency nurses.

In concert with knowing the patient, problems with the patient’s family often prevented an ideal or good death. The problems with families included both too much and too little involvement in EOL care. One nurse was forced to become a mediator during a heated family dispute while another was unable to obtain information she needed to provide EOL care because the patient’s family left the emergency department suddenly. The previous study on rural emergency department EOL care obstacles included problems with families as five of the top ten obstacles. These problems ranged from “families who continually call” to “dealing with angry family members.”<sup>7</sup> Problems caused by family members also rank highly as obstacles to EOL care in non-rural emergency departments.<sup>8-9</sup>

The final minor theme in this area involved the nurse being unable to ascertain if the patient had specific EOL care wishes. One story highlighted the challenges faced by emergency nurses when an elderly patient entered the emergency department with no family and minimal accompanying information, thus preventing staff from verifying the patient’s code status or contacting family members before the patient died. While this obstacle played an important role in rural emergency nurses’ stories, they ranked it as the thirteenth most significant obstacle to EOL care in the previous study.<sup>7</sup>

### **Insufficient ED Staff**

Rural emergency nurses identified insufficient ED staff as another significant obstacle to providing quality EOL care. The nurses' stories epitomized the difficult task faced by nurses in rural emergency departments as staffing concerns compelled them to take on roles outside their level of training and experience in an attempt to afford comfort to dying patients and their families. Previous studies rated similar obstacles very highly. The authors of a 2010 study by Beckstrand and Giles et al. reported, "Patient care being fragmented in the rural emergency department because the nurse is required to fill many roles other than nursing," and "The nurse having too high a workload" as the fifth and fourteenth highest obstacles respectively.<sup>7</sup>

### **Power Struggles**

Power struggles between physicians and nurses have been an ongoing theme in hospital based health care. These struggles often lead to nurses being unsatisfied with the level of input they are afforded and feeling devalued.<sup>11</sup> It is no surprise that rural emergency nurses also experienced nurse-physician power struggles and felt that it was an important obstacle to providing good EOL care in their setting. In the chaotic environment of the emergency department, such disagreements have the potential to degrade the quality of the EOL care being provided by the ED staff. In addition to power struggles with physicians, rural emergency nurses also shared stories about disagreements with patient family members. Family members requesting that staff ignore patient wishes or continue heroic measures against advice were represented multiple times in the rural emergency nurses' stories.

There are few studies that specifically examine the obstacles faced by rural emergency nurses in their provision of EOL care. Many of the obstacles identified here in the nurses' stories were also represented in the previous quantitative study with similar levels of frequency.<sup>7</sup> Results of this study also correspond closely with the obstacles identified in other quantitative non-rural ED studies of the same nature.<sup>8-9</sup> No studies examining nurses' EOL care experiences in story format were available for comparison.

In contrast with previous reports on rural EOL care,<sup>7</sup> the current nurses' stories displayed some different obstacle themes. Inability to provide the patient with what the nurse considered to be an ideal death is a subject that has not been discussed in previous research. It also appears to be an area of significant distress for many nurses and represents the culmination of several other smaller obstacles.

This portion of the *Rural Emergency Nurses' Perception of End-of-Life Care* was designed to allow nurses a forum to express their experiences and the difficulties they face when caring for dying patients. The results show that rural emergency nurses' experiences with death are multifaceted and are often far from what might be considered ideal. The obstacles they face have lasting consequences not only for patients and families, but for the nurses as well.

### **Limitations**

This study is limited by a convenience sample of states with high proportions of CAHs instead of a randomly selected sample; however, the CAHs in the five states were randomly selected. Nurses' stories were personal and may not be representative of all rural emergency nurses' experiences.

### **Implications**

Understanding the experiences of rural emergency nurses in their battle to provide quality EOL care will lay the ground work for further research and may help provide the basis for systemic changes that remove the EOL care obstacles faced by nurses on the frontier of emergency health care. Rural hospitals and emergency department administration should be attentive to the needs of rural emergency nurses as they care for dying patients and their families.

### **Conclusion**

Nurses in the emergency department care for dying patients daily. Emergency nurses often face obstacles that hinder their ability to provide high quality EOL care to patients. These

obstacles are frequently compounded by the unique set of challenges faced by nurses working in rural emergency departments. Stories from rural emergency nurses revealed that being unable to provide optimal care at the EOL, having difficulties with family members, or not knowing the patient's wishes for EOL care were the most common obstacles. Additional obstacles included stories about the impact of low or unavailable staff and feeling powerless in some EOL situations. It is clear that rural emergency nursing remains a frontier area for health care and warrants continued research. A greater understanding of the obstacles faced by rural emergency nurses may allow for changes to be implemented that can improve the quality of EOL care for patients, as well as improve nurses' quality of life and job satisfaction.

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Table 1

*Questionnaires returned by state*

State	Questionnaires returned n (%)
Idaho	113 (47.5)
Wyoming	57 (23.9)
Utah	29 (12.2)
Nevada	21 (8.8)
Alaska	18 (7.6)
Total	238 (100)

Table 2

*Demographics of Nurses<sup>a</sup>*

Characteristic	n	%	M	SD	Range
Sex					
Female	24	88.9			
Male	3	11.1			
Age (y)			46	9.5	63 - 27
Years as registered nurse			15.4	10.6	2 - 39
Years in emergency department			11.8	8.1	1.5 - 36
Years in rural nursing			11.6	8.1	2 - 36
Beds in emergency department			5.3	2.8	
No. of dying patients cared for					
>30		30			
21-30		14.8			
11-20		30			
5-10		14.8			
<5		0.0			
Highest degree					
Diploma		0.04			
Associate		70.4			
Bachelor		18.5			
Master		0.04			
Other		0			
Ever certified as CEN					
Yes	4	16			
No	20	80			
Currently CEN					
Yes	3	11.5			
No	3	11.5			
Years as CEN			9.8	6.7	0.3 - 26
Practice area					
Direct care/bedside nurse		24			
Staff/charge nurse		68			
Clinical nurse specialist		0			

Other (manager, educator, etc)	8
Hospital type	
Community, non-profit	73.1
Community, profit	0
County hospital	25.9
Other	0

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CEN, Certified emergency nurse.

<sup>a</sup>n = 27

Table 3

*Frequency of perceived obstacles to providing end-of-life care*

<b>Obstacle Themes</b>	<b>Frequency rank</b>	<b>n</b>
Lack of ideal death	1	13
Insufficient staffing	2	9
Power struggles	3	9
Chaotic/overwhelming environment	4	8
Staff relationship to patient	5	5
Ignoring patient's wishes	6	4
Lack of family involvement	7	3
ED design	8	2
Futility of efforts	9	1

Figure 1

