

Difficulties Felt by Intensive Care Unit Nurses in Providing End-of-Life Care in Southeast Iran

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Introduction: Critical care deaths represent most hospital deaths. The difficulties felt by intensive care unit (ICU) nurses providing end-of-life care may cause nurses to experience negative attitudes toward caring for dying patients. This study was conducted to examine the difficulties felt by ICU nurses providing end-of-life care in Southeast Iran. Method: The study used a cross-sectional descriptive design and was conducted in 3 hospitals supervised by Kerman Medical University. Using DFINE (difficulties felt by ICU nurses providing end-of-life care), difficulties felt by critical care nurses providing end-of-life care were assessed. Results: The results indicated that the difficulties that were felt by critical care nurses were moderate (2.64 ± 0.65) . Among the categories and items, the most difficulties felt by critical care nurses belonged to the category of "converting from curative care to end-of-life care" (3.12 ± 0.93) and the item "life-sustaining treatment is often given excessively" (3.49 \pm 1.14). **Conclusions:** The study suggests that health care managers should organize systematic and dynamic policies and procedures in dealing with end-of-life care to assist ICU nurses.

KEY WORDS

difficulties, end-of-life care, ICU nurses

The primary purpose of intensive care is to fight off death and restore health. Despite technological advances, death in the intensive care unit (ICU) remains commonplace. 1 Critical care deaths represent most hospital deaths. It is estimated that as many as one in five patients dies in critical care.² According to Rocker et al,¹

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most developed countries have largely a "death denying society," and many patients die institutionalized and technologically supported, some as victims of the medicalization of the dying process, although patients with advanced, progressive, incurable illness require to live as well as possible until they die. End-of-life care (EoLC) enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual, and practical support.³ Expert nursing care in the ICU has the potential to greatly reduce the burden and distress of those facing EoLC and the ability to offer support for many physical, psychological, social, and spiritual needs of patients and their families. 4 However, ICUs are designed to care for acutely ill patients, not for dying patients and their families, and EoLC can be associated with considerable difficulties for ICU nurses. 5 Gielen et al, in their study of Indian nurses, claimed, "nurses are not knowledgeable about different aspects of the care they provide for dying patients." Cavaye and Watts⁶ found that Iranian nurses do not feel confident, adequate, and competent in the care of dying patients. According to Ryan and Seymour, ⁷ EoLC can be a major cause of stress and actual grief reactions, such as fear, guilt, anger, and sorrow in the ICU. These emotional reactions are mainly in relation to the discussions around life-prolonging therapies, managing the transition from curative care to EoLC and dealing with the distress of patients and families. In addition, disagreement and conflicts can occur between ICU nurses and physicians regarding the direction of patient care,8 and physicians may pay limited attention to nurses' input in end-of-life decision making.⁹

Review of the literature showed that there are various difficulties in providing EoLC by nurses in the ICU. Espinosa et al¹⁰ assessed ICU nurses' experiences in providing terminal care. They identified barriers to optimal care included lack of involvement in the plan of care, differences between the medical and nursing practice models, disagreement among physicians and other healthcare team members, perception of futile care and unnecessary suffering, unrealistic expectations of the family, and lack of experience and education of the nurse.

Attia et al¹¹ assessed critical care nurses' perception of barriers and supportive behaviors in EoLC. They concluded

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that most intense obstacles to providing EoLC were related to intensive care environment, family members, nurses' knowledge and skills, physicians' attitudes, and treatment policy.¹¹

Zomorodi and Lynn¹² found personal, environmental, and relational factors that hinder critical care nurses' ability to provide quality end of life. They indicated that nurses' moral distress and learning through trial and error from their experiences was a personal barrier to providing quality EoLC in the ICU. Lack of time and the noise and technology in the ICU were identified as environmental barriers to providing quality EoLC. Ambiguity, along with the inability to obtain knowledgeable information about the patient and family; fragmentation of care and frustration with physicians; and communication problems between physicians, nurses, patients, and families were listed as top relational barriers to providing quality EoLC.

According to Peters et al, ¹³ the emotional effects of caring for dying patients and their relatives on a regular basis can make nurses, especially novice nurses, more negative about EoLC, which has an effect on their ability to provide quality care for dying patients. ⁹

The difficulties felt by ICU nurses providing EoLC may cause nurses to experience negative attitudes toward caring for dying patients. Perhaps, one of the best ways to improve quality of EoLC in the ICU is to clarify the perspective of nurses on existing difficulties. Nurses spend more time with patients and families facing the end of life than do any other health professionals, and their perspective incorporates the experience of many ICU deaths. ¹

The authors are aware of few studies that have assessed difficulties felt by Iranian nurses in providing EoLC. There are wide variations between and within countries and between individual ICUs. ¹⁴ Hence, this study was conducted to examine the difficulties felt by ICU nurses providing EoLC in Southeast Iran.

METHODS

Design and Ethical Considerations

The study used a cross-sectional descriptive design. The internal review board of Kerman University of Medical Sciences approved the study before data collection began. This study was also approved by the ethics committee of the Kerman University of Medical Sciences.

Project approval was obtained from both Kerman University of Medical Science and the heads of the 3 hospitals (Shahid Bahonar, Afzalipour, and Shafa Hospitals); the university supervises before the collection of any data.

Instrument

A demographic questionnaire was developed based on 4 categories: personal characteristics such as sex, age, marital status, and educational level; professional characteristics

such as years of nursing experience, years of experience in the ICU, and years of experience of caring for dying patients; and religious characteristics, consisting of intrinsic religiosity (belief in God) and extrinsic religiosity (attendance at religious services and activities).

A translated version of the DFINE (difficulties felt by ICU nurses providing EoLC) was used to examine difficulties felt by critical care nurses providing EoLC. This questionnaire was designed by Kinoshita and Miyashita¹⁵ and consists of 28 questions categorized in five subscales including as follows: (1) the purpose of the ICU is recovery and survival (4 items, 1-4), (2) nursing system and model nurse for EoLC (6 items, 5-10), (3) building confidence in EoLC (7 items, 11-17), (4) caring for patients and families at end of life (7 items, 18-24), and (5) converting from curative care to EoLC (4 items, 25-28). Answers were presented on a 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree), with higher points indicating greater experience of difficulty providing EoLC.

For translation of DFINE questionnaires from English into Farsi, the standard forward-backward procedure was applied. ¹⁶ Translation of the items and the response categories was independently performed by two professional translators. Afterward, they were back-translated into English, and, after a careful cultural adjustment, the final versions were provided. Translated questionnaires went through pilot testing. Suggestions by nurses were combined into the final questionnaire versions.

Validity and Reliability

According to Kinoshita and Miyashita, ¹⁵ for each subscale of DFINE ranged from 0.61 to 0.8, and in terms of test-retest reliability, interclass correlations for each factor ranged from 0.62 to 0.72. In Iran, no study was found that assessed the reliability and validity of this scale; therefore, the validity and reliability of the scale were rechecked. The validity of the scale was assessed through a content validity. Ten faculty members at the Nursing and Midwifery School reviewed the content of the scales from cultural and religious perspectives. They agreed that DFINE was a culturally appropriate questionnaire to be used in the research context.

Data Collection and Analysis

The study was based on a sample of all critical care nurses in hospitals supervised by Kerman University of Medical Science. The data were collected from 9 ICUs in 3 hospitals. These ICUs were composed of 4 trauma ICUs in Shahid Bahonar Hospital; a general ICU and a surgical ICU in Afzalipour Hospital; and a general ICU, an open heart ICU, a neuro-ICU in Shafa Hospital. Nurses were required to have more than 6 months of experience of working in the ICU because it was assumed that experienced nurses are more likely to be involved with caring for dying patients. Accompanied by a letter including some information

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about the aim of the study, the questionnaires were handed out by the fourth author to 145 nurses who were introduced by the head of each ICU at work during 2 months (April/May 2014). Nurses were orally informed about the aim of the study and the procedure. Participation in the study was voluntary and anonymous. Confidentiality was secured, and no personal information appeared on the questionnaires. The response rate was 89%.

Data from the questionnaires were analyzed using the Statistical Package for Social Sciences (SPSS 20). A Kolmogorov-Smirnov test indicated that the data were sampled from a population with a normal distribution. Descriptive statistics were computed for the study variables. A Pearson correlation was used to determine the correlation between some demographic information including nurses' age; their experience in nursing, experience in the ICU, and experience in caring for dying people; and the difficulties they felt in caring for dying patients. The comparison between other measured demographic factors was done using an independent *t* test or 1-way analysis of variance. *P* level was set at .05.

RESULTS

Participants

The participants mean (SD) age was 31.20 (5.58) years and were mainly women (93.1%) and married (70%) (Table 1). Most had Bachelor of Science in Nursing degrees (90.8%), and 44.6% of nurses had 1 to 5 years of nursing experience. Most respondents had between 1 and 5 years of experience of working in ICUs (64.6%) and between 1 and 5 years of experience of caring for dying people (65.4%). Thirteen had experience of caring for a dying family member. The overwhelming majority of participants were Muslim and Shia (96.9%). Furthermore, 70.8% stated that they always experience the existence of God in their daily living. Only 6.2% of participants mentioned that they never attend religious services, and 3.8% stated that they never attend to Quran reading and praying (Table 1).

Descriptive Findings

Descriptive analysis indicated that the difficulties felt by critical care nurses were moderate (2.64 ± 0.65) . Among the categories and items, the most difficulties belonged to the category of "converting from curative care to EoLC" (3.12 ± 0.93) , and the item "life-sustaining treatment is often given excessively" (3.49 ± 1.14) . The fewest difficulties felt by critical care nurses belonged to the category of "nursing system and model nurse for end-of-life care" (2.42 ± 0.84) . The lowest score belonged to the item "more nurses are needed for providing end-of-life care" (1.89 ± 1.08) (Table 2).

TABLE 1 Background Characteristics of Sample				
Variable	n	%		
Age, y				
20-30	66	50.8		
31-40	54	41.5		
41-50	8	6.2		
Sex				
Female	121	93.1		
Male	9	6.9		
Marital status				
Married	91	70		
Single	39	30		
Educational level				
Associate of science	12	9.2		
Bachelor of science	118	90.8		
Years of nursing experience				
1-5	58	44.6		
6-10	41	31.5		
>11	26	20		
Years of experience in ICU				
1-5	84	64.6		
6-10	29	22.3		
>11	9	6.9		
Years of experience of caring for dying persons				
1-5	85	65.4		
6-10	28	21.5		
>11	10	7.7		
Religion				
Shia	126	96.9		
Others	4	3.1		
Personal experience of god existence				
Always	92	70.8		
Often	32	24.6		

(continues)



TABLE 1 Background Characteristics of Sample, Continued					
Variable	n	%			
Sometimes		3.1			
Never	2	1.5			
Attendance to the religious services					
Always	11	8.5			
Often	64	49.2			
Sometimes		36.2			
Never	8	6.2			
Attendance to Quran reading and praying					
Always	7	5.4			
Often	51	39.2			
Sometimes	67	51.5			
Never	5	3.8			

Correlations

Pearson correlation analysis indicated that participants who were older (P = .04) and had more nursing experience (P = .01), more experience in the ICU (P = .002), and more experience of caring for dying persons (P = .007) felt more difficulties in the category of "converting from curative care to EoLC." Nurses who had more experience in the ICU also felt more difficulties in the category of "the purpose of ICU is recovery and survival" and in the total score of questionnaire. Respondents who had more experience of caring for dying people also mentioned more difficulties in the category of "nursing system and model nurse for end-of-life care" (Table 3).

DISCUSSION

This study explored difficulties felt by South East Iranian nurses in providing EoLC. Results indicated that the most difficulties felt by critical care nurses belonged to the category of "converting from curative care to EoLC" and the item "life-sustaining treatment is often given excessively."

Life-sustaining treatments such as ventilator support, dialysis, and cardiopulmonary resuscitation may prolong life but may also greatly diminish quality of death. Extending a patient's life in a severely compromised state may be associated with unnecessary pain and suffering for patient and family. When ICU professionals are of the opinion that the proposed treatment will not have the desired outcome or the adverse effects of the treatment will outweigh the benefits, curative cares should be replaced with palliative cares.

Most participants were Muslim and Shia (96.9%). Like most Iranians, most of the nurses considered themselves

religious.²⁰ The overwhelming majority of participants stated that they experience the existence of God in their daily living and perform religious activities. For Muslims, everything possible must be done to prevent premature death, but when medical experts believe that death is inevitable and it is determined that treatment will not improve the patient's condition or quality of life, withdrawal or withholding treatment is acceptable.²¹ Withholding life-sustaining treatment is accepted by most Muslims based on the "do no harm" principle, and they believe that they are obligated to do whatever is in their power to treat a life-threatening illness.²²

Nurses' experience of difficulties in the category of "converting from curative care to EoLC" and the item "life-sustaining treatment is often given excessively" may be due to some external factors preventing them from doing what is best for the patients and feeling that they have no control over specific situations. According to Shorideh et al²³ in Iran, it is not legal for physicians to withhold life-sustaining treatments such as cardiopulmonary resuscitation (including endotracheal intubation, cardiac massage, cardiac defibrillation, resuscitative drugs, pacemakers, and mechanical ventilation). Thus, they cannot write "do not resuscitate" in their orders. They state that the differences between moral and legal rules cause nurses to feel difficulties such as moral distress.²³ When clinicians feel forced to provide medically inappropriate or futile care to terminally ill patients, they experience moral distress and emotional exhaustion with subsequent burnout.²⁴

Another possible reason for the participants' distress sensation regarding the category of "converting from curative care to EoLC" might be due to their inadequate knowledge and competency. Iranmanesh et al²⁵ found that nurses in Iran had insufficient knowledge about palliative care. In Iran, the Bachelor of Science in Nursing curriculum contains only 2 to 4 hours of theoretical education about death and caring after death. Recently, part of a credit unit about palliative care was added to the curriculum of the master's in critical care nursing. Shorideh et al²³ indicated that, in Iran, there have been no published guidelines, position papers, legislation, or official statements concerning EoLC. According to Weinzimmer et al, 26 nurses' lack of knowledge can be a source of moral distress as when nurses who are not up-to-date on managing pain in terminally ill patients become morally distressed when caring for such patients.

On the basis of the findings, participants who were older and had more nursing experience, more experience in the ICU, and more experience of caring for dying persons felt more difficulties in the category of "converting from curative care to EoLC." In a previous study of critical care nurses, Beckstrand et al²⁷ stated that highly experienced critical care nurses perceived EoLC



TABLE 2 The DFINE Cate	·	Mann (CD)		
Categories The purpose of ICU is recovery	1. ICU is not an appropriate place to die.	Mean (SD) 2.59 (1.29)		
and survival, 2.78 (0.97)		2.46 (1.26)		
	2. Patients cannot approach peaceful death in the ICU.			
	3. Patients do not want to die in the ICU, I suppose.			
	4. When death is unavoidable, the patient had better leave the ICU quickly.			
Nursing system and model nurse for end-of-life care, 2.42 (0.84)	5. No time to care for dying patient.			
	6. Nursing system for end-of-life care is not established.	2.67 (1.27)		
	7. No time to discuss among nurses about end-of-life care.			
	8. More nurses are needed for providing end-of-life care.			
	9. There are no nurses to consult about end-of-life care.	2.60 (1.28)		
	10. There are no model nurses in providing for end-of-life care.	2.76 (1.24)		
Building confidence in end-of-life	11. I am frightened to tell the family that a patient's condition is worsening.	2.76 (1.30)		
care, 2.46 (0.73)	12. I often feel a pang of guilt when I face patient death.	2.26 (1.17)		
	13. I want to avoid the family when a patient's condition is worsening.	2.73 (1.23)		
	14. I often feel that it is my responsibility when a patient's condition is worsening.	2.48 (1.19)		
	15. No confidence to provide end-of-life care.	1.97 (1.08)		
	16. I would like to avoid care for dying patients, if possible.	2.42 (1.32)		
	17. No knowledge and skills to provide end-of-life care.			
Caring for patients and families at end of life, 2.74 (0.84)	18. Not enough contact with families.	2.50 (1.06)		
	19. It is difficult to provide care for families in the ICU.	2.92 (1.31)		
	20. It is difficult to fulfill patients' wishes of end of life.			
	21. No wish to develop a relationship with the family.	2.27 (1.17)		
	22. It is difficult to provide care for dying patients in the ICU.	2.62 (1.25)		
	23. Family has difficulty accepting death in the ICU.	2.66 (1.17)		
	24. It is difficult to fulfill family's wishes.			
Converting from curative care to	25. Doctors are too late in deciding that treatment is ineffective, I feel.	2.97 (1.24)		
end-of-life care, 3.12 (0.93)	26. It is difficult to attend to the family when a patient is dying.	3.05 (1.15)		
	27. Life-sustaining treatment is often given excessively.	3.49 (1.14)		
	28. Even in the end-of-life phase, limits on visiting hours and people are unavoidable.			
Total score				



TABLE 3 Correlation Between Demographic Information and the Difficulties Felt by ICU Nurses in Caring for Dying Patients

Difficulties Felt by Nurses	Age, y	Years of Nursing Experience	Years of Experience in ICU	Years of Experience of Caring for Dying Persons	
The purpose of ICU is recovery and survival	r = 0.09	r = 0.21	r = 0.23	r = 0.07	
	P = .37	P = .18	P = .009	P = .40	
Nursing system and model nurse for end-of-life care	r = 0.10	r = 0.07	r = 0.16	r = 0.18	
	P = .35	P = .40	P = .07	P = .04	
Building confidence in end-of-life care	r = 0.09	r = 0.05	r = 0.09	r = 0.02	
	P = .40	P = .53	P = .28	P = .75	
Caring for patients and families at end of life	r = 0.16	r = 0.03	r = 0.15	r = 0.10	
	P = .13	P = .72	P = .11	P = .24	
Converting from curative care to end-of-life care	r = 0.21	r = 0.22	r = 0.27	r = 0.24	
	P = .04	P = .01	P = .002	P = .007	
Total score	r = 0.15	r = 0.12	r = 0.24	r = 0.16	
	P = .15	P = .17	P = .00	P = .06	
Abbreviation: ICLL intensive care unit					

Abbreviation: ICU, intensive care unit.

obstacles as being more intense because they cared for the sickest ICU patients, who are more often at the end of life. Browning reported that moral distress intensity was high in critical care nurses who are caring for dying patients and positively correlated with age progression and years in critical care and nursing practice.

In contrast, Zomorodi and Lynn¹² found that the more expert nurses indicated an ability to adapt and change to specific situations because EoLC in the ICU became more comfortable with each exposure.¹²

Results indicated that the fewest difficulties felt by critical care nurses belonged to the category of "nursing system and model nurse for EoLC." The lowest score belonged to the item "more nurses are needed for providing EoLC."

Mesukko²⁹ identified the shortage of nurses that contributes to a lack of time to care for dying patients as a barrier to providing a good death in ICUs. Espinosa et al¹⁰ found the difference between the medical and nursing practice models as one of the barriers to optimal care. They state that approaches to EoLC come from two related but philosophically different care perspectives: the medical model and the nursing model. The medical educational model is based on the symptom or organ of dysfunction, whereas the holistic or nursing model is based on the entire person. The physician trained in the medical model focuses on the illness of organ of dysfunction. In contrast, nurses trained in a ho-

listic model look at all aspects of the patient. Inherent tension between these 2 models presents a barrier to nurses asked to implement physicians' directives. This tension can be very frustrating for nurses, particularly during EoLC. 10 Therefore, EoLC is multidisciplinary. Nurses may want to assert themselves in designing a model of interdisciplinary practice that will promote the best possible care for dying patients and their families.³⁰ It could be achieved by team working. Crawford and Price³¹ believed that EoLC teams may include doctors, nurses, social workers, allied health practitioners, and also a multitude of other caregivers. Medical science has come to new understandings about the interplay of the physical, functional, emotional, psychological, social, and spiritual aspects of caring and more recently have supported the development of multidisciplinary approaches.³¹

CONCLUSIONS

On the basis of the results, it seemed that nurses had moderate problems with EoLC. The role of palliative care at the end of life is to relieve the suffering of patients and their families by the comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms that patients experience. Nurses should participate in continuing educational programs regarding this area and

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also encounter this situation during their educational courses. In addition, health care managers should organize systematic and dynamic policies and procedures in dealing with EoLC to assist ICU nurses.

IMPLICATIONS FOR PRACTICE

Results of this study can be used by critical care nurses who care for patients at the end of life. With the increasing emphasis on quality care at the end of life, identifying the difficulties felt by ICU nurses will become increasingly important. The increasing number of chronically ill patients who die in the ICU setting certainly warrants further examination of this topic. Because one of the best ways to improve quality of EoLC in the ICU settings is to clarify the perspective of nurses on existing difficulties, therefore, understanding the difficulties felt by ICU nurses in providing EoLC is the first step to determine the interventions needed to improve this care in the future.

One of the possible causes of difficulties felt by ICU nurses was lack of EoLC education in Iran. Thus, developing EoL education may enhance nurses' knowledge/skill to face EoLC difficulties. Thus, it requires incorporation of EoLC into undergraduate nursing studies to emphasize that the process of dying is an important stage of life.

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