Original article

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End-of-life care (EOLC) in Jordanian critical care units: Barriers and strategies for improving

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Abstract

***Background*: End-of-life care (EOLC) is a pivotal element of work in ICUs and for critical care nurses, thus, it is considered one of the top research priorities recently as number of admission ICUs increasing and high percentage of deaths also.**

***Objective*: This study was conducted to explore the obstacles of EOLC and strategies for improvement from nurses' perception.**

***Methods*: The questionnaire, that was developed by Beckstrand and Kirchhoff (2005), was used to collect data from 163 critical care nurses from different hospitals.**

***Results*: Two hundred questionnaires were distributed. One hundred and sixty-three questionnaires were completed and returned with response rate 81.5%. The majority of the participants were male nurse 104 (63.8%), with bachelor degree 153 (93.9%), working in adult ICU 105 (64.4%), as bedside nurse 141 (86.5%). The highest obstacles from the nurses' perception were family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information (mean=4.07). Furthermore, the highest three supportive behaviors from the nurses' perception were physicians agreeing about direction of patient care (mean=3.96), family members accept that patient is dying (mean=3.94), and family designating one family member as contact person for the rest of the family (mean=3.89).**

***Conclusion*: As the number of deaths is increasing in critical care units, the needs to understand how the EOLC is provided in these units. Identifying obstacles and supportive behaviours will assist the stakeholders and policymakers to set the action plans for improving the quality of EOLC.**

Key words: End-of-life care, obstacles, supportive, critical care units.

Introduction

Admission to the Intensive Care Units (ICUs) is considered a distress condition to the patients and families. Large number of patients die in the health settings and one of five patients die in critical care units. (1) Death is a fact. Around 80% of deaths in the United States happen in hospitals, more than 10% of the patients spend a week in ICUs before they die.

Reasons for ICU admission could be related to severe injuries, worsening in health status, and different types of trauma, thus, health professional has limited time to begin relationship with the patients or families. In addition, direct communication could be interpreted because of crowded environment, limited space, and patient's physical and emotional condition. (2)

End-of-life care (EOLC) is a pivotal element of work in ICUs and for critical care nurses, thus, it is considered one of the top research priorities recently as number of admission ICUs increasing and high percentage of deaths also. (3,4)

End-of-life care (EOLC) is known as the care and management of the terminally ill patients and their families. Several elements of quality of EOLC in critical care units have been addressed including patients/families involvement in decision making,

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professional communication between health professionals and patients/families, quality of care provided, types of support provided, illness and symptoms management, spirituality, and organizational support for ICUs professionals. (5)

In addition, working in ICUs environment is stressful and emotionally stressed for the health professionals such as nurses and physician. They experience wide range of distressed feelings such as helplessness, loss of power, sadness, and hopelessness especially when caring of patients at the end stage of their illness. (4)

Health professional focus mainly on symptom management, illness prognosis, treatment modalities, and physical side. In fact, caring in ICUs is universal and holistic model. Thus, previous research showed inadequate care provided to the patients and families at the end-of-life stage.

Nurses' experience of EOLC has been studied previously. (6-11) The previous work highlighted the importance of understanding the factors associated with the provision of EOLC in hospitals, especially in ICUs. Identifying the barriers, challenges, and strategic for improvement will be used as a baseline for developing structure care model for terminally ill patients and families at the end-of-life period. The results by Nelson and colleagues (2006) identified the important barrier to optimal EOLC including patients/families factors, unrealistic expectations, failure to discuss the treatment plan with patients, lack of advance directives, and other factors related to clinician including insufficient training, physician's limited time. In addition, institutional factors were identified including space for family and lack of palliative care service. (12,13 Moreover, factors related to patients/families, clinicians' opinions, cultural diversities, and language barrier were identified as key factors for having EOLC in ICUs among Saudi Arabia health professionals. (1)

Whilst the results of these studies enrich our understanding and information about the critical care nurses' behaviors and feelings in term of provision care at the EOLC, the ability of generalize these results in different countries and different cultural perspectives such as Arab countries is limited. Thus, this study responses to lack of knowledge and limited research in the Arab countries, particularly Jordan, addressing this important priority of research.

Methods

Sample

A multisite cross-sectional descriptive design was used. A sample of 163 critical care nurses from different governmental and private hospitals completed the self-reported questionnaire. A convenience sampling technique was used to recruit the participants in order to increase the generalizability of the results.

Data collection

The questionnaire, that was developed by Beckstrand and Kirchhoff (2005), was used to investigate the obstacles and supportive strategies toward having EOLC in critical care units. English version of the instrument was used, the scale valid and reliable with Cronbach's α 0.89 for the 29 obstacle items and 0.86 for the 24 supportive behavior items. (14) Critical care nurses were invited to participate in the current study. Convenience sampling approach was used as it exploratory and time convenience. Research authors were responsible for data collection. After obtaining the ethical permissions, the investigators explained the purpose and method of the study to the head nurses in critical care units. Potential participants were provided with a copy of the self-administered questionnaire, cover letter, and consent form. Questionnaire and open envelop were provided. Once the participant completed the questionnaire, it was returned in sealed envelope to the collection box, which was available in each unit. The research authors collected the questionnaire weekly. The data collection was finished in four weeks. Time to complete the questionnaires was 20 to 30 minutes.

Data analysis

SPSS version 23 was used to analyze the responses. Data cleaning and verification were performed and checked by two researchers. Descriptive analysis including frequencies, mean, and rank was undertaken.

Results

Two hundred questionnaire were distributed. One hundred and sixty-three questionnaires were completed and returned with response rate 81.5%. The majority of the participants were male nurse 104 (63.8%), with bachelor degree 153 (93.9 %), working in adult ICU 105 (64.4%), as bedside nurse 141 (86.5 %). The mean of the participants' age was 29.12 (SD=4.12). The results showed that the mean of their experience in critical care units was 4.3 years (SD=3.07). **Table 1** details these results.

Obstacles for EOLC

The highest obstacles from the nurses' perception were family and friends who continually call the nurse wanting an update on the patient's condi-

tion rather than calling the designated family member for information (mean=4.07), family members not understanding what 'life-saving measures' really mean (i.e., that multiple needle sticks cause pain and bruising, that an endotracheal [ET] tube will not allow the patient to talk, or that ribs may be broken during chest compression [mean=4.06]), and not enough time to provide quality end-of-life (mean=4.04). **Table 2** details the results.

Supportive behaviors

The highest three supportive behaviors from the nurses' perception were physicians agreeing about direction of patient care (mean=3.96), family members accept that patient is dying (mean=3.94), and family designating one family member as contact person for the rest of the family (mean=3.89). **Table 3** details these results.

Discussion

Critical care nurses that experience stressful moments when providing EOLC might be related to the lack of training in EOLC. This stressful environment might lead to poor quality of care, deteriorate job performance, and finally increase the staff turnover. This study was conducted to identify the obstacles and supportive strategies for EOLC in critical care units from the nurses' perception. These findings might be used to reframe the policy, providing educational program, and highlight the needs for better EOLC.

Perceived obstacles

The highest perceived obstacle was frequent call from the family and friends asking about patients' condition (mean=4.07). These results supporting the previous studies conducted in different culture and different health system. The problem of frequent calls is not new, for decades. It is considered one of the most causes of nurses' interruption in critical care units. Providing family with updated information is highly recognized and part of family-centered care approach, however, this should not lead to distract the nurses from their direct care for the patients.

The second most intense obstacle in the current study was family members not understanding what 'life-saving measures' really mean (mean=4.06). These results are not surprising as the family wants to do everything possible to save their patient's life. Family concerns on patient psychological status, cleaning, being comfortable beside the medical intervention.

The third obstacle was not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life (mean=4.04). These results disagree with the results of previous studies. The explanation of that might be related to nurse-patient ratio in critical care units in Jordan. The ratio is outstandard and can reach to 1:3. The nurses are extremely busy in providing the direct care for critically ill patients and they don't have time for EOLC.

Supportive behaviors

The highest supportive behaviors from the nurses' perception were physicians agreeing about direction of patient care (mean=3.96). These results supporting and consistent with the previous literature. (15) The current findings addressed the importance of professional's collaboration between the physician and other care providers to stop the aggressive treatment and starting EOLC. In the line with existing literature, collaboration and agreement among health professionals should be the first step for providing EOLC. (16)

The second supportive behavior is family acceptance that patient is dying. Family acceptance encourages other members in the family to accept EOLC. This leads to decrease suffering, psychosocial distress, and better quality of life, (17) and they can spend more time with beloved patient. (18)

Family designating one family member as contact person for the rest of the family was perceived as one of the top three supportive behaviors. Nurses perceived communication as important supportive EOLC behavior. Having one family member to communicate will save the nurses' time and workload. It is easier to explain patient's condition and EOLC with one person. This finding supports the previous results by Heaston. (19)

Conclusion

As the number of deaths is increasing in critical care units, there is the need to understand how the EOLC is provided in these units. Identifying obstacles and supportive behaviours will assist the stakeholders and policymakers to set the action plans for improving the quality of EOLC.

Declaration of interest

The authors declare that there is no conflict of interest.

Table 1. Demographics of sample (n=163)

Variable	Frequency (n)	Percentage (%)	Mean	Standard deviation
Gender				
- Male	104	63.8		
- Female	59	36.2		
Nurses' qualification				
- Diploma	2	1.20		
- Bachelor	153	93.9		
- Higher diploma	2	1.20		
- Master	6	3.70		
Types of critical care units				
- ICU/adult	105	64.4		
- CCU	42	25.8		
- Pediatric ICU	16	9.80		
Nurses' role				
- Bedside nurse	141	86.5		
- In charge nurse	19	11.7		
- Head nurse	3	1.80		
Age			29.13	4.12
Experience as Registered Nurse (year)			5.20	3.45
Experience in critical care units (year)			4.33	3.07
Hours worked per week			41.61	3.21

Legend: ICU=intensive care unit; CCU=coronary care unit.

Table 2. Mean and standard deviation for perceived obstacles in end-of-life care (n=163)

	Obstacle	Mean	Standard deviation
1	Families not accepting what the physician is telling them about the patient's poor prognosis	4.01	0.81
2	The nurse having to deal with angry family members	4.02	0.83
3	Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information	4.07	0.67
4	Family members not understanding what 'life-saving measures' really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube will not allow the patient to talk, or that ribs may be broken during chest compression	4.06	0.83
5	Multiple physicians, involved with one patient, differ in opinion about the direction care should go	4.00	0.83
6	The nurse having to deal with distraught family members while still providing care for the patient	3.96	0.89
7	Unit visiting hours that are too liberal	3.95	0.76
8	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family	3.94	0.78
9	Physicians who are evasive and avoid having conversations with family members	4.03	0.84
10	Continuing treatment for a dying patient even though the treatment causes the patient pain or discomfort	4.03	0.82
11	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation	3.95	0.82
12	Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life	4.04	0.79
13	When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered	4.00	0.84
14	Employing life-sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment	3.81	0.95
15	Intra-family fighting about whether to continue or stop life support	3.76	1.06
16	Physicians who are overly optimistic to the family about the patient surviving	3.73	1.09
17	Physicians who will not allow the patient to die from the disease process	3.72	1.01
18	The family, for whatever reason, is not with the patient when he or she is dying	3.64	1.01
19	Dealing with the cultural differences that families employ in grieving for their dying family member	3.75	1.02
20	The unavailability of an ethics board or committee to review difficult patient cases	3.85	0.87
21	Being called away from the patient and family because of the need to help with a new admission or to help another nurse care for his/her patients	3.91	0.88
22	The nurse knowing about the patient's poor prognosis before the family is told the prognosis	3.86	0.90
23	Continuing to provide advanced treatments for dying patients because of financial benefits to the hospital	3.81	0.88

24	Lack of nursing education and training regarding family grieving and quality end-of-life care	3.88	0.88
25	The patient having pain that is difficult to control or alleviate	3.88	0.88
26	Poor design of units which do not allow for privacy of dying patients or grieving family members	3.98	0.91
27	No available support person for the family such as a social worker or religious leader	3.89	0.96
28	Pressure to limit family grieving after the patient's death to accommodate a new admission to that room	3.87	0.91
29	Unit visiting hours that are too restrictive	3.80	0.87

Legend: ET=endotracheal.

Table 3. Mean and standard deviation for perceived supportive behavior in end-of-life care

	Supportive care/strategies for improvement	Mean	Standard deviation
1	Family members having adequate time to be alone with the patient after his/her death	3.76	1.07
2	Family members having a peaceful and dignified bedside scene	3.83	0.96
3	Families being taught how to act around dying patient	3.79	0.98
4	Family members show gratitude to nurse for care provided to patient who has died	3.76	1.04
5	Physicians agreeing about direction of patient care	3.96	1.05
6	Family members accept that patient is dying	3.94	1.06
7	Families having unlimited access to the dying patient	3.76	1.06
8	Nurse drawing on previous experience with the critical illness or death of a family member	3.75	1.02
9	Family designating one family member as contact person for the rest of the family	3.89	1.10
10	Nurses offer words of support to each other	3.70	1.08
11	Nurse having enough time to prepare the family for patient's death	3.64	1.03
12	Nurses scheduled so that patient receives continuity of care	3.69	1.06
13	Unit designed so family has a place to grieve in private	3.65	1.09
14	Staff compiles all paper work to be signed by the family before they leave the unit	3.73	1.09
15	Nurses offer supportive physical touch to each other	3.72	1.10
16	Physicians meet in person with the family after the patient's death	3.80	1.03
17	Nurses having a supportive person outside of the work setting to listen after the death of a patient	3.82	1.00
18	Physicians putting hope in tangible terms for family	3.76	1.00
19	Letting the social worker or religious leader take primary care of the grieving family	3.79	0.88
20	Nurse talking with patient about his or her feelings and thoughts about dying	3.85	0.93
21	Nurses take care of patients while affected nurse "gets away" for a moment after the death of a patient	3.85	0.93
22	Family physically helping to care for the dying patient	3.83	1.01
23	Having unlicensed personnel available to help care for dying patients	3.85	0.75
24	Ethics committee constantly involved in the unit, so they are involved from the beginning should an ethical situation arise later	3.84	0.75

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Appendix

Part A: Sociodemographic data

1	Gender	1. Male 2. Female
2	Qualification	1. Diploma degree 2. Bachelor degree 3. Higher Diploma 4. Master degree 5. Other: mention please……
3	Experience in critical care units	……year
	Experience as registered nurse	…….year
4	Types of critical care units	1. ICU/adult 2. Coronary care units 3. Pediatric ICU 4. Other: mention please……..
5	Your role	1. Bedside nurse/staff nurse 2. Charge nurse/staff nurse 3. Other: mention please……..
6	Age	…….year
7	Hours worked per week	…….hour

EOLC obstacles questionnaire

	Obstacle	1	2	3	4	5
1	Families not accepting what the physician is telling them about the patient's poor prognosis					
2	The nurse having to deal with angry family members					
3	Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the desig-nated family member for information					
4	Family members not understanding what 'life-saving measures' really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube will not allow the patient to talk, or that ribs may be broken during chest compression					
5	Multiple physicians, involved with one patient, who differ in opinion about the direction care should go					
6	The nurse having to deal with distraught family members while still providing care for the patient					
7	Unit visiting hours that are too liberal					
8	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family					
9	Physicians who are evasive and avoid having conversations with family members					
10	Continuing treatment for a dying patient even though the treatment causes the patient pain or discomfort					

11	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation					
12	Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life					
13	When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered					
14	Employing life-sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment					
15	Intra-family fighting about whether to continue or stop life support					
16	Physicians who are overly optimistic to the family about the patient surviving					
17	Physicians who will not allow the patient to die from the disease process					
18	The family, for whatever reason, is not with the patient when he or she is dying					
19	Dealing with the cultural differences that families employ in grieving for their dying family member					
20	The unavailability of an ethics board or committee to review difficult patient cases					
21	Being called away from the patient and family because of the need to help with a new admission or to help another nurse care for his/her patients					
22	The nurse knowing about the patient's poor prognosis before the family is told the prognosis					
23	Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital					
24	Lack of nursing education and training regarding family grieving and quality end-of-life care					
25	The patient having pain that is difficult to control or alleviate					
26	Poor design of units which do not allow for privacy of dying patients or grieving family members					
27	No available support person for the family such as a social worker or religious leader					
28	Pressure to limit family grieving after the patient's death to accommodate a new admission to that room					
29	Unit visiting hours that are too restrictive					

Strategies for improvement

	Supportive behaviors/improvement strategies	1	2	3	4	5
1	Family members having adequate time to be alone with the patient after his/her death					
2	Family members having a peaceful and dignified bedside scene					
3	Families being taught how to act around dying patient					
4	Family members show gratitude to nurse for care provided to patient who has died					
5	Physicians agreeing about direction of patient care					
6	Family members accept that patient is dying					
7	Families having unlimited access to the dying patient					
8	Nurse drawing on previous experience with the critical illness or death of a family member					
9	Family designating one family member as contact person for the rest of the family					
10	Nurses offer words of support to each other					
11	Nurse having enough time to prepare the family for patient's death					
12	Nurses scheduled so that patient receives continuity of care					
13	Unit designed so family has a place to grieve in private					
14	Staff compiles all paper work to be signed by the family before they leave the unit					
15	Nurses offer supportive physical touch to each other					
16	Physicians meet in person with the family after the patient's death					
17	Nurses having a supportive person outside of the work setting to listen after the death of a patient					
18	Physicians putting hope in tangible terms for family					
19	Letting the social worker or religious leader take primary care of the grieving family					
20	Nurse talking with patient about his or her feelings and thoughts about dying					
21	Nurses take care of patients while affected nurse "gets away" for a moment after the death of a patient					
22	Family physically helping to care for the dying patient					
23	Having unlicensed personnel available to help care for dying patients					
24	Ethics committee constantly involved in the unit, so they are involved from the beginning should an ethical situation arise later					
Choices were 0, not a support, to 5, extremely intense support						