

Pediatric End-of-life Care Barriers and Facilitators: Perception of Nursing Professionals in Jordan

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Abstract

Introduction: End-of-life care is a critical issue for pediatric population with terminal illness to ensure the best possible quality of care for them and their families. A survey was conducted to identify the barriers and facilitators to provide pediatric end-of-life care. **Methods:** A descriptive cross-sectional study was conducted at three tertiary centers providing end-of-life care in Jordan. Two hundred critical care nurses were surveyed (response rate 93%). **Results:** Nurses reported moderate level of experience in all areas of delivering pediatric end-of-life care. The highest scoring of barriers respectively were patients-families barriers having deal with angry family member; health-care professional barriers multiple physicians, involved with one patient, who differ in opinion about the direction care, and where plan of care should go; and organizational barriers not available support person for the family. The highest scoring of facilitators respectively were of patients families facilitators having family members accept that the patient is dying; health-care professional-facilitators having a physician agrees about the direction of care, and organizational facilitators providing family members adequate time to be alone with the pediatric after he or she has died. **Conclusion:** Nurses perceived that patient-family, health-care professionals, and organizational related barriers and facilitators were had the most influence in providing of pediatric end-of-life care. Findings highlighted the need for additional education and support for pediatric staff, across professions, in providing pediatric end-of-life care. A pediatric end-of-life care team should be developed to assist in improving patients' quality of care and increasing the awareness for the need for a standardized tool to evaluate the nursing competency level concerning pediatric end-of-life care.

Keywords: Barriers, end-of-life care, facilitators, pediatric

INTRODUCTION

Providing pediatric end-of-life care may be the most traumatic facet of nursing according to many researchers.^[1,2]

Pediatric end-of-life was defined by Contro *et al.*,^[3] as "the science and art of lessening physical, psychosocial, emotional, and existential suffering."^[3] Pediatric end-of-life care is a holistic care aiming at improving the quality of life in spite of prognosis. Nurses encounter many unpleasant and disturbing feelings and experiences that may hinder their abilities to provide satisfactory pediatric end-of-life care.^[2,4]

There are many barriers and facilitators for pediatric end-of-life care. Barriers to provide pediatric end-of-life care are categorized into patient-family-related factors, health-care professional-related factors, and organizational-related factors.^[4-7] Contro *et al.*,^[3] affirms that barriers may occur when health-care providers are prevented from acting

according to their professional standards. Determination of these barriers must be achieved to maintain appropriate patient care.^[8] When nurses feel they can no longer help the terminally ill recover, they begin to experience a deep sense of sadness, uncertainty, and helplessness and do not know how to cope with the dilemma of providing pediatric end-of-life care.^[9] Terminal pediatric patients can suffer from pain and other alarming symptoms because of inadequate symptom management, lack of education, poor communication, and an unspecialized environment because this care most of the

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time provided in Intensive Care Unit (ICU) which impact the quality of pediatric end-of-life care (Wolfe, Grier, Klar, Levin, and Jeffrey, 2000).^[9-11]

However, facilitators to pediatric end-of-life care were defined as “any supportive issue that advocates the delivery of optimal pediatric end-of-life care services.”^[12] These facilitators to improve pediatric end-of-life care include patient-family, health-care professional, and organization-related facilitators.^[4,6,7,13]

A number of specific interventions, programs, and resources have been suggested to improve care for pediatric end-of-life. In a national survey of ICU directors in the U.S more than 80% of respondents identified helpful strategies to improve end-of-life care in ICUs.^[14] These strategies included training of health professionals in end-of-life communication skills, role modeling, and supervision of trainees by clinicians experienced in end-of-life care, and regular meetings of a senior physician and nurse with the patient’s family to help reduce conflict about appropriate care goals.^[14] Furthermore, ICU directors also offered other strategies including access to consultants with expertise in palliative care, incorporation of end-of-life care within the ICU, hospital and health system quality monitoring programs, and bereavement services.^[14]

Other studies identified possible facilitators to provide pediatric end-of-life care and their families including providing a peaceful, dignified bedside environment for the family after a patient’s death, acceptance of the family toward the dying patient, and allowing the family adequate time alone with the patient.^[4,6,15] However, few of these strategies available in ICUs.^[4,6,15]

It is important to remember that the combination of pediatric end-of-life care with curative treatment is essential in providing the child and family with the most holistic nursing care possible. There is much to be done by nursing professionals to secure the future of pediatric end-of-life care programs. The first task is to increase the awareness of pediatric end-of-life care programs and the special needs of nurses who care for pediatric patients in the end-of-life stage. This study would involve clearly identifying the role of the nurses in pediatric end-of-life care specifically and pediatric palliative care in general.

Pediatric end-of-life care is deemed a necessary service in pediatric care units for several reasons. First, many pediatric patients have a significant risk of dying during ICUs admission. Second, a significant part of patient care before death involves extremely invasive and painful procedures. Third, the pediatric patients’ end-of-life care and their families inevitably confront crisis situations to a greater degree in ICUs than during admission to nonintensive pediatric care units.^[16,17] Yet, many children who survive with significant morbidity are often returned to ICUs and die later.^[8] Such situations encounter pediatric care health professionals to efficiently provide quality pediatric end-of-life care that addresses the physical, psychological, and spiritual needs of pediatric patients and their families.

In Jordan, limited evidence exists to identify the barriers that hinder providing end-of-life care, and facilitators that help in providing end-of-life care for pediatric patients in the intensive care setting. This study aimed to identify the barriers and facilitators to provide pediatric end-of-life care the Jordanian intensive care settings.

The research questions were addressed in this study as follows:

1. What are the greatest intense, and the greatest frequently occurring barriers that would hinder providing end-of-life care to pediatric patients as perceived by nurses in the ICUs?
2. What are the greatest intense and the greatest frequent facilitators that would help in providing end-of-life care to pediatric patients as perceived by nurses in the ICUs?

METHODS

Design

A descriptive cross-sectional design was used to identify the barriers and facilitators in providing pediatric end-of-care as perceived by critical care nurses.

Setting

The study was conducted from January 2016 to July 2016 in the ICUs of three tertiary care centers in Amman, the capital of Jordan: One as university center and two governmental centers. These centers provide specialized care services in ICUs for pediatric patients who are critically ill and have multiple complications and/or conditions that require continued hospitalization and advanced treatments.

Study population

Nurses who are providing pediatric end-of-life care in ICUs in Jordan were eligible to participate. Two hundred participants were required based on power = 0.80, alpha (α) = 0.05, and medium effect size = 0.25.^[18] All the nurses included in the study practiced end-of-life care in ICUs. Ethical approval was obtained, and standard code of ethics for nurses and the requirements of the Institutional Review Board were followed.

Survey questionnaire

Two questionnaires were used to collect data. The two surveys were conducted using a 5 point Likert scale. Initially, the selection of demographic variables for the proposed study was guided by literature reviewed. Age, gender, level of education, ICU experience, number of pediatric patients given end-of-life care, nurses positions, unit capacity, ICUs’ types were used to describe Jordanian nurses who are providing pediatric end-of-life care in ICUs. The first questionnaire was The Experience of Pediatric End of Life Care questionnaire^[3] designed to measure experience and competency of pediatrics end-of-life care in eight items. Experience scale reliability was (Cronbach’s α = 0.90). Second, Modified National Survey of Critical Care Nurses Regarding End-of-Life Care Questionnaire (Beckstrand, Kirchoff, 2008) was used to measure barriers and facilitators to provide pediatric end-of-life care. This questionnaire is comprised

53 items splitting into two subscales with thirty items for barrier subscale, and 23 items for the facilitator subscale. Participants were asked to indicate on a 5-point Likert scale point scale for intensity (0 = not an obstacle, 1 = extremely small, 2 = small barrier, 3 = medium, 4 = large, 5 = extremely large) and participants were asked to indicate on a 5-point Likert scale point scale for frequency (0 = never occurs, 1 = almost never occurs, 2 = sometimes occurs, 3 = fairly often occurs, 4 = very often occurs, 5 = always occurs). Barrier subscale reliability was (Cronbach's $\alpha = 0.92$). The facilitator subscale splits into a 5-point scale for intensity (0 = not a help, 1 = extremely small, 2 = small help, 3 = medium help, 4 = large help, 5 = extremely large) and 5-point scale for facilitator frequency (FF) (0 = never occurs, 1 = almost never occurs, 2 = sometimes occurs, 3 = fairly often occurs, 4 = very often occurs, 5 = always occurs). Facilitator subscale reliability was (Cronbach's $\alpha = 0.96$). The barriers and facilitators categorized into three categories: Patient-family category, healthcare-professional category, and organizational category. All questionnaires were translated from English to Arabic and back translated by a panel of three qualified academic doctoral-prepared experts in nursing pediatric care and served as content specialists selected from the Faculty of Nursing at the University of Jordan for content validity purpose.

Analysis

The data were coded numerically and subjected to descriptive and inferential statistical analysis using statistical software (Statistical Package for the Social Sciences (SPSS. 17). SPSS Inc. was a software house headquartered in Chicago and incorporated in Delaware, most noted for the proprietary software of the same name SPSS. The company was started in 1968 when Norman Nie, Dale Bent, and Hadlai "Tex" Hull developed and started selling the SPSS software. Statistical significance was set at $P < 0.05$. Means were computed from intensity and frequency ratings for each item on the Modified National Survey. An item score was computed for each of the thirty items of barrier subscale. Each item score was calculated by multiplying the mean of the barrier intensity ratings by the mean of the barrier frequency ratings for that item. The range of possible item scores was 0–25. The range of possible values for the barriers scores was 0–750. Similarly, an item score was computed for each of the 23 items of facilitator subscale. Each item score was calculated by multiplying the mean of the facilitator intensity ratings by the mean of the FF ratings for that item. The range of possible item scores was 0–25. The range of possible values for the barriers scores was 0–575.

The barriers and facilitators categorized into three categories: patient-family category, health-care professional category, and organizational category. The questionnaire items as follows represent patient-family-related barriers items: (2, 3, 4, 6, 7, 9, 10, 16, 22, 24), health-care professional-related barriers items are (1, 5, 13, 15, 17, 18, 23, 26, 27, 29), organizational-related barriers items are (8, 11, 12, 14, 19, 20, 21, 25, 28), patient-family-related facilitators items are (31, 37, 48, 50),

health-care professional related facilitators items are (32, 34, 36, 38, 40, 42, 44, 45, 46, 52, 53), organizational-related facilitators items are (33, 35, 39, 43, 47, 49, 51, 54).

RESULTS

Of the 200 questionnaires distributed, 186 were returned (response rate 93%). The majority of participant's age was ranged between 26 and 30 years 97 (52.2%). Participants were predominately female 160 (67.7%), two-third of them were educated at the baccalaureate level 127 (68.3%) and had 108 (58.1%) of the participants 2–5 years of nursing experience in critical care. The majority of participants 72 (38.2%) were

Table 1: Demographic characteristics of participants (n=186)

	n	%
Gender		
Male	60	32.3
Female	126	67.7
Age		
Less than 26	42	22.6
26-30 years	97	52.2
More than 30	47	25.3
Education Level		
Diploma Degree	50	26.9
Bachelors Degree	127	68.3
ICU Experiences		
Master Degree	9	4.8
Less than 2 years	21	11.3
2-5 years	111	59.7
More than 5 years	54	29
Number of patients have given immediate EOL care in ICU		
Less than 5 patients	29	15.6
5-10	33	17.7
11-20	71	38.2
More than 20 patients	53	28.5
Nurses positions		
Staff nurse	145	78
Charge nurse	41	22
Unit capacity		
Less than 10 beds	57	30.6
10-20 beds	123	66.1
More than 20 beds	6	3.2
ICU types		
Pediatric ICU	45	24.2
Intensive Care Unit	51	27.4
ER-ICU	16	8.6
Medical ICU	20	10.8
Nuro-nurosurgical ICU	3	1.6
CCU	13	7
Surgical ICU	21	11.3
Shock-Trauma Unit	1	0.5
Combined ICU-CCU	7	3.8
Cardio-surgical ICU	9	4.8
Respiratory ICU	0	0

dealt with more than twenty children during the period of dying and were predominately they hold staff nurses position 145 (78%) as shown in Table 1.

Nurses reporting moderate level of experience in all areas of delivering pediatric end-of-life care starting by coordinating care of dying patients, managing symptoms, pain management, discussing transitioning from curative treatment to end-of-life care, discussing Do Not Resuscitate status with patients and families, and ending by acting as mentor or role model to younger colleagues (scale anchors range from 1 to 4; mean ranged = 2.33 [0.79] to 2.57 [0.71]) indicating that nurses require further training in end-of-life care for pediatric patients.

Barriers to provide pediatric end-of-life care

Barriers were grouped into three main categories: Patient-family category, health-care professional category, and organizational category. Nurses reported that the greatest frequent and intense patient-family related barrier to provide pediatric end-of-life care was deal with angry family member situation (mean = 12.51) as shown in Table 2. As well, nurses reported that the greatest frequent and intense health-care professional related barrier to provide pediatric end-of-life care was multiple physicians, involved with one patient, who differ in opinion about the direction care, should go (mean = 10.05). Finally, nurses reported that the greatest frequent and intense organizational related barrier to provide pediatric end-of-life care was not available support person for the family such as

Table 2: Barriers as a perceived severity score (n=186)

Barriers category	Intensity Mean	Frequency Mean	Severity barrier score Mean
Patient-family related category			
Deal with angry family member	3.68	3.40	12.51
Family not understanding what life saving measures really mean	3.60	2.97	10.69
Family not accepting patient poor prognosis	3.57	2.95	10.53
Dealing with culture differences that families employ in grieving	3.36	3.02	10.15
Not enough time to provide quality end of life care	3.27	3.00	9.81
Deal with distraught family members while providing care	3.32	2.88	9.56
Patient have pain that is difficult to control	3.13	3.00	9.39
Intra-family fighting about whether to continue or stop life support	3.26	2.75	8.80
No designated family member for information	3.00	2.89	8.67
Poor design of units which not allow for privacy or grieving	2.77	2.45	6.79
Healthcare- professional related category			
Multiple physicians, involved with one patient, who differ in opinion about the direction care should go	3.55	2.83	10.05
Lack of nursing education and training regarding family grieving and quality end of life care	3.20	3.00	9.60
Physicians who are evasive and avoid having conversations with family members	3.6	2.62	9.43
When nurse opinion about the direction of patient care should go is not requested, not valued or not considered	3.32	2.57	8.53
Nurse knowing about the patient's poor prognosis before the family is told the prognosis	2.55	3.26	8.31
Continuing treatments for patient even though the treatments cause the patient pain or discomfort	2.94	2.75	8.10
The nurse not knowing the patient's wishes regarding continuing with treatments because of the inability to communicate due to a depressed neurological status	3.00	2.55	7.65
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	2.79	2.67	7.45
Physicians who are overly optimistic to the family about the patient surviving	2.51	2.45	6.15
Physicians who will not allow the patient to die from the disease process	2.64	2.30	6.10
Organizational related category			
Not available support person for the family such as a social worker or religious leader	3.32	2.72	9.03
Unit visiting hours too restrictive	3.10	2.88	8.93
The unavailability of an ethics board or committee to review difficult patient cases	3.10	2.67	8.3
The family, for whatever reason is not with the patient when he or she is dying	3.10	2.60	8.10
Employing life sustaining measures at the family's request even though the patient had signed advanced directives requesting no such treatment	3.00	2.67	8.01
Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients	2.86	2.74	7.84
Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital	2.93	2.66	7.79
Unit visiting hours that are too liberal	2.94	2.52	7.41

a social worker or religious leader (mean = 9.03) as shown in Table 2.

Facilitators to provide pediatric end-of-life care

Facilitators were grouped into three main categories including patient-family category, health-care professional category, and organizational category. Nurses reported that the greatest frequent and intense helpful patient-family-related facilitator to provide pediatric end-of-life care was having family members accept that the patient is dying (mean = 9.94) as shown in Table 3. The greatest frequent and intense helpful health-care professional-related facilitator to provide pediatric end-of-life care was having the physicians involved in the patients care agree about the direction care should go (mean = 11.10). Moreover, the greatest frequent and intense helpful organizational-related facilitator in providing end-of-life care to pediatric patients was allowing family

members adequate time to be alone with the patient after he or she has died (mean = 11.10) as shown in Table 3.

DISCUSSION

Providing end-of-life care for pediatric patients and their families can be stressful for nurses because they may be insufficiently trained to manage the process. The process of dying in an ICU can be complicated. Nurses who have chosen to work in ICU settings can find the confusion associated with death unpleasant. A better understanding of the greatest intense and the greatest frequently occurring barriers that restrict nurses from providing quality of pediatric end-of-life care could lead to increase the awareness and testing of interventions to lower both the intensity and the frequency of these barriers. Understanding the greatest intense and greatest frequent facilitators could

Table 3: Facilitators as perceived help score (n=186)

Facilitators category	Intensity Mean	Frequency Mean	Severity facilitator score Mean
Patient-family related category			
Having family members accept that the patient is dying	3.60	2.76	9.94
Having one family member to be the designated contact person for all other family members regarding patient information	3.51	2.76	9.69
Having family members thank you or in some other way show appreciation for your care of the patient who has died	3.41	2.66	9.10
Having the family physically help care for the dying patient	2.80	2.59	7.25
Healthcare-professional-related category			
Having the physicians involved in the patients care agree about the direction care should go	3.81	2.91	11.10
Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient condition will completely recover	3.80	2.87	10.91
Providing a peaceful, dignified bedside scene for family members once the patients has died	3.79	2.65	10.04
Teaching families how to act around the dying patient such as saying to them "she can still hear. it is OK to talk to her"	3.70	2.60	9.62
Having the physician meet in person with the family after the patient death to offer support and validate that all possible care was done	3.69	2.60	9.59
Having a fellow nurse tell you that "you did all you could for that patient," or other some words of support	3.66	2.56	9.37
The nurse drawing on his/her own previous experience with the critical illness or death of a family member	3.52	2.65	9.33
Having fellow nurses take care of your other patient (s) while you get away from the unit for a few moments after the death of your patient	3.44	2.70	9.29
Having enough time to prepare the family for the expected death of the patient	3.23	2.55	8.24
Talking with the patient about his or her feelings and thoughts about dying	2.69	2.43	6.54
Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient	2.69	2.27	6.12
Organizational related category			
Allowing family members adequate time to be alone with the pediatric after he or she has died	3.61	2.72	9.82
A unit designed so that the family has a place to go to grieve in private	3.52	2.73	9.61
Having a unit schedule that allows for continuity of care for the dying patient by the same nurses	3.41	2.75	9.38
Having a support person outside of the work setting who will listen to you after the death of your patient	3.50	2.67	9.35
Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later	3.51	2.54	8.92
Letting the social worker or religious leader take primary care of the grieving family	3.50	2.40	8.40
After the patient death, having support staff compile all the necessary paper work for you which must be signed by the family before they leave the unit	2.95	2.50	7.38
Having un-licensed personnel available to help care for dying patients	2.55	2.31	5.89

lead to the development of interventions to maintain the highly rated supportive behaviors and increase the lower rated supportive behaviors.^[15] The study aimed to identify barriers and facilitators to provide pediatric end-of-life care in ICUs in Jordan through surveying nurses' perceptions.

Nurses reported are moderately experienced, in average in all areas of delivering pediatric end-of-life care, from coordinating care of end-of-life for pediatric patients to acting as mentor or role model to younger colleagues. These results indicated that pediatric end-of-life care training might be primarily occurring informally (i.e., through personal and clinical experiences). As well, there is often a strong dependence on trial and error in learning to care for pediatric end-of-life care (Hinds, Oakes, Furman, Quargnenti, Olson, and Foppiano 2001).^[19] Moreover, hands-on training is inadequate and ineffective at improving their ability to provide pediatric end-of-life care during work.^[20] Together, these findings provide strong support for the need for formalized training in pediatric end-of-life care.

This study is consistent with Higginson *et al.*^[21] (2003) study in which the nurses reported inexperienced with regard pediatric end-of-life care, namely in pain and symptoms management, and felt particularly distressed when a pediatric patient appeared to be suffering.

Inexperienced in pediatric end-of-life care can cause nurses to feel less competent and often result in susceptibility to feelings of burnout, inadequacy, and discomfort.^[3] Consequently, despite the availability of guidelines regarding the need for instruction in caring for terminally ill pediatric patients during training, the majority of nurses never receive formal instruction in end-of-life care.^[2,6,22]

Perceived barriers

Barriers are the factors that hinder providing end-of-life care for pediatric.^[3] Barriers were grouped into three categories: patient-family-related category, health-care professional-related category, and organizational-related category.

The greatest barrier patient-family-related category was dealing with an angry family member; the finding was consistent with studies of^[6,13,23,24] that reported the highly rated barrier to provide pediatric end-of-life care was dealing with anxious family members. This status might be related to the time surrounding the death of pediatric is extremely tense and stressful for parents and family members. Further, parents reported they are increasing stress from seeing the child suffer and from fearing the death of the child, particularly because they are unable to protect their child, and they did not know much about the disease (Mularski *et al.* 2005).^[4,25,26] These stressors cause a sense of deep helplessness for parents, and they need compassionate support from caregivers; nurses are well-positioned to provide such support.^[4,10,27] Thus, nurses must make time to listen when family members need to express their feelings, to provide words of comfort and talk openly and honestly about grief.

Moreover, "multiple physicians involved in the care of one patient who differ in opinion about the direction of care" was rated as the greatest barrier related to health-care professionals. This finding is consistent with to studies.^[4,15] Pediatric patients who are critical ill mostly confronted compound diseases that needed involvement of several different specialties of physicians. Among these separate groups of specialties, there are frequent differences in opinion regarding the plan for a patient's treatment. These separate specialists often fail to communicate or collaborate effectively with each other, further fragmenting care.^[4,28]

ICU nurses confront stressful consequences of fragmented caregiving, including communication of inconsistent or conflicting information to patients and families, failure to achieve clarity about care goals.^[6,14] According to Beckstrand and Kirchhoff,^[15] communicating the pediatric end-of-life care decisions to the family is a challenge for nurses, because nurses feel poorly prepared to provide information about expected prognosis.

Finally, "no available support person for the family such as a social worker or religious leader" was ranked as the greatest organizational-related barrier. Jordanian intensive care nurses felt that lack of support personnel for the family was an important barrier standing against providing pediatric end-of-life care. Interdisciplinary team is a cornerstone to enhance the quality of pediatrics end-of-life care.^[29] The interdisciplinary team of pediatric end-of-life care is not well established in the selected centers. In addition, nursing shortage certainly increases the workload for intensive care nurses. They have to simultaneously deal with patients whose lives are being maintained and those whose lives are ending. The intensive care nurses may feel it is too much to tolerate these situations alone. Therefore, they need support and assistance from others such as social workers or religious leaders in moving through the pediatric end-of-life care process with their patients.

Perceived facilitators

Facilitators are the factors that may be helpful to facilitate the enhancement of end-of-life care services.^[3] Facilitators were grouped for three categories: patient-family-related category, health-care professional-related category, and organizational-related category.

The greatest patient-family-related facilitator that reported by nurses was: Having family members accept that the pediatric patient is dying. The finding of the present study consistent with studies reported earlier.^[4,7,13,24,30]

A family member who accepts the pediatric patient who is dying encourages other family members to accept end-of-life care earlier, leading to better quality of life and less suffering for the pediatric patient (Wolfe *et al.*, 2000).^[11] As well, family members who realize the valued time that they have to spend with their loved one^[4] are more likely to facilitate quality of pediatric end-of-life care.

Moreover, the greatest health-care professional-related facilitator reported by nurses was “having involved physicians agree about the direction of pediatric end-of-life care.” The finding of the present study consistent with studies reported earlier.^[4,13,23,24] The finding directed the need for physicians as a gatekeeper to stop aggressive treatment and to cooperate with the other health care providers to provide pediatric end-of-life care. In line with existing pediatric literature, collaboration among physicians should be the basis to provide quality of pediatric end-of-life care.^[4,7,31,32]

The advantages of collaboration are 2-fold: First, communication and sharing among experts allows treatment to proceed in the same direction leading to integrated care, and second, the consistency of information facilitates parental decision making.^[4,33] Nurses may deal with involved physicians who are not keeping the direction of care on the same pathway. As patient advocates, nurses need to encourage collaboration to ensure that the care that patients and families receive from different specialties is connected in a consistent way.

Finally, the greatest facilitating factor that relate to organization support was: Allowing family member’s adequate time to be alone with a pediatric patient after he or she has died. The finding reflects the nurses’ need for legislative and administrative support to provide psychological and spiritual therapy for pediatric and their families in end-of-life stage.

In line with this finding, studies were consistent.^[4,13,24,34] Prior evidence supports that psychological stress after the death of a child could seriously influence health outcomes of parents.^[4,35] Allowing adequate time alone after a child has died respects and preserves the parent-child relationship and allows parents to fulfill their roles as a caregiver and guardian for their child.^[4,34] Several studies document the essential need for parents to stay with their child’s body in a sad time.^[4,10,36] This could help parents to cope with their early grief and may positively shape long-term sadness.^[4]

CONCLUSION

The study concluded that the greatest barrier of patient-family-related category to provide pediatric end-of-life care as perceived by nurses was dealing with an angry family member. In addition, multiple physicians involved in the care of one patient who differ in opinion about the direction of care was rated as the greatest barrier related to health-care professionals to provide pediatric end-of-life care, and no available support person for the family such as a social worker or religious leader was rated as the greatest organizational-related barrier. Furthermore, having family members accept that the pediatric patient is dying care was rated as the greatest facilitator related to patient-family category to provide pediatric end-of-life care. As well, involved physicians agree about the direction of pediatric end-of-life care plan was rated as the greatest facilitator related to health-care professionals. Finally, the greatest facilitating factor dealing with organization support

was allowing family members adequate time to be alone with a pediatric patient after he or she has died.

Limitations of this study

Considering the importance of the issue studied. The limitations of this descriptive study must be considered in interpreting the results. The study involved a small sample of nurses from critical care unit only, and the findings may not be representative of the perceptions of pediatric end-of-life care among nurses in other settings. As well, this study was limited to three centers located in Amman the capital, which limits the external validity of the findings. Future research should include additional studies with a larger sample size recruited from other hospital settings. More descriptive studies are still needed to gain a comprehensive understanding of the quality of pediatric end-of-life care, barriers and facilitators to provide pediatric end-of-life care in Jordanian ICUs. This is an important step before moving to interventional studies. Polit and Beck^[37] advised that interventions often fail because they are designed without an adequate understanding of the problem and the relationship between variables.

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Conflicts of interest

There are no conflicts of interest.

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