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Nurses' perception of obstacles and supportive behaviors in providing end of life care to critically ill pediatric patients

Gehan EL Nabawy Ahmed Moawad (PhD)
Lecturer of Pediatric Nursing, Faculty of Nursing
Mansoura University, Egypt

Abstract

Pediatric critical care nurses care for dying children daily. The process of dying in an intensive care unit is complicated, and research on specific obstacles that impede delivery of end-of-life care and/or supportive behaviors that help in delivery of end-of-life care in pediatric intensive care units is limited. So, this descriptive research design aimed to describe pediatric critical care nurses' perceptions of obstacles to provide end-of-life care and supportive behaviors that help in providing end-of life care in the intensive care units. The study concluded that the most supportive behaviors in providing end- of- life care to critically ill pediatric patients that perceived by nurses were, nurses scheduled so that child receives continuity of care and physicians agreeing about direction of child care while the most obstacles behaviors in providing end- of- life care were, child having pain that is difficult to control or alleviate, nurse too busy offering life saving measures to provide quality end of life care and family continually calls the nurse for update rather than the designated contact person. The study recommended that future researches are needed to identify and implement ways to decrease highly perceived obstacles and to continue to support highly perceived supportive behaviors. Furthermore, differences between ICU and non-ICU staff members' perceptions of end-of-life care are needed to be studied.

Key Wards: Perception, obstacles, supportive behaviors, end of life care, critically ill, children

Nurses are challenged in their efforts to provide end-of-life (EOL) care in critical care settings that emphasize curative and aggressive lifesaving treatment. Transitioning patients from cure to EOL care can be unclear or awkward and contribute to stress experienced by critical care nurses. Nurses believe they have important advocacy roles in assisting patients in this transition but may be uncomfortable with their skills to do so (Badger, 2005 & Saundra, Marjorie & Evie, 2010). Nurses perceive a good death as one that includes freedom from pain, provision of comfort, and respect for the dignity of the patient, meeting family needs for EOL rituals, and enough time for family members to say goodbye. Nurses also viewed consensus between the family, patient, nurse, and physician as contributing to quality EOL care experience and a good death. For family members, desired components of EOL care include adequate pain control, feeling at peace with the dying process, dignity and self-respect for the patient, having some control of the dying process, and clear communication (Mularski &et al, 2006). Attaining a balance in caring for dying patients is a major challenge to nurses: it concerns not only their interactions with patients and their families, but also their perceptions of themselves and their actions in end-of-life care. In end-of-life care, it is important for nurses to be able to change the focus of their care when the patient's condition is diagnosed as irreversible. They also need to be well equipped to maintain a balance, thereby preparing themselves for the patient's forthcoming death (Zargham-Boroujeni, 2009)

In a survey of members of the American Association of Critical-Care Nurses, subjects identified barriers to good EOL care as lack of staff time, staff shortages, lack of clear communication between health care team members, and treatment decisions that were not based on patient needs and preferences. Nurses expressed frustration about having a limited role in contributing to EOL care decisions when they have unique knowledge and understanding of the patients' experiences and wishes (Beckstrand, Callister & Kirchhoff, 2006). Furthermore, nurses working in intensive care units may lack knowledge and skills in end-of-life care, find caring for dying patients and the patients' families stressful, and lack support to provide this care. Nurses who work in intensive care units (ICUs) have traditionally received little education and training in care of dying patients and the patients' families, even though death often occurs in ICUs. However, education is not the only need of critical care nurses. Other factors that may be as important for providing end-of-life care include a work environment with strong communication and collaboration between nurses and physicians, use of palliative care services, ready availability of ethics consultations, and adequate support of patients, patients' families and staff (Malloy&et al , 2006).

Many aspects of critical care nurses' work environment present obstacles to providing quality end of- life care. For example, disagreement and conflicts can occur between nurses and physicians regarding different views on end-of-life issues, physicians' disregard of patients' wishes for care, avoidance of patients' families, giving false hope, not providing adequate orders for pain relief, and level of aggressiveness of treatments. Other areas known to influence quality end-of-life care are communication between nurses and physicians and the different levels of professions in the hospital hierarchy that result in physicians' paying limited attention to nurses' input in end-of-life decision making. Furthermore, ICUs are designed to care for acutely ill patients, not for dying patients and their families, and the highly technical and curative focus of the ICU may make fostering quality end-of life care more difficult (Norton & et al, 2003).Azoulay & et al, (2005) added that, investigators who explored critical care nurses' perceptions of the end-of-life care that nurses provide to patients and patients' families found that management of patients' physical signs and symptoms is done systematically and efficiently, whereas less attention is given to providing psychological support to patients and patients' families. Essential psychological support includes providing ongoing information, support, and bereavement care for families of patients who die in ICUs.

Emotional and organizational supports for critical care nurses are considered a supportive behavior to provide end- of- life care. This domain may include support during the time staff provide care to dying patients and the patients' families before and after the patients' death and may include formal and informal mechanisms such as having a staff counselor, team meetings, debriefing sessions, peer support, and in-service sessions related to end of-life care, loss, and grief. Provision of ongoing emotional and critical feedback to colleagues who are caring for dying patients and the patients' families when the feedback is needed, rather than at specific scheduled meetings, is important to critical care nurses. However, formal scheduled debriefing sessions are also a need, particularly after life support has been withdrawn from patients (Price, 2004).

Issues related to end-of-life care and decision making have led critical care nurses to describe feelings such as stress, frustration, anger, sadness, helplessness, and moral distress. Moral distress is associated with an inability of nurses to influence end-of-life decisions and decision-making processes, aggressive care provided to patients who are not benefiting from such care and conflicts within patients' families and the families' indecisiveness about terminating treatments. Moral distress also has been associated with nurses' inability to take the correct course of action because of institutional constraints (Robichaux & Clark, 2006). Moral distress is a serious problem for nurses who practice in ICUs, not just when providing end of- life care to patients and patients' families, but in general. Such distress may lead to burnout, job dissatisfaction, and leaving the work environment. In one study, critical care nurses reported that moral distress affected their job satisfaction, physical and psychological well- being, self-image, spirituality, and decisions about their own health (Meltzer & Huckabay, 2004).

An evaluation of the environment for EOL care and the identification of knowledge needed for effective EOL care can contribute to strategies for improving care and outcomes for patients and families. Potential benefits for patients, families, health care staff, and the organization include : increased satisfaction of patients and their families with the process that surrounds transitioning from curative to EOL care and through the dying process, establishment of standardized approaches to EOL care in the critical care environment, development of unit based nursing expertise in EOL care, increased nursing knowledge about strategies to help patients transition from curative to EOL care, and improved interdisciplinary communication among health care personnel (National Institute of Nursing Research, 2009 & Lissi et al , 2009).

The American Academy of Pediatrics has called for the writing of policies and clinical standards that support children who are living with terminal conditions. The goal of care for these sick children is providing equitable, effective help to cure, prolong life, or provide palliative care. Integrating palliative with curative care, beginning at diagnosis, may be difficult in the treatment of children. The success of medicine in improving survival rates among certain children with serious illnesses (eg, cancer, prematurity, congenital heart disease) may have had the unintended consequence of offering false hope to parents that death of their child can always be averted. The uncertain prognosis of a seriously ill child makes it difficult to predict the progression of the child's disease. Physicians may be reluctant to communicate to a child's family that the child is dying (Dussel & et al, 2009). Finally, palliative care is best delivered by an interdisciplinary team that considers the 8 domains defined by the National Consensus Project Clinical Guidelines for Quality Palliative Care: structure and process of care; physical aspects; psychological and psychiatric aspects; social aspects; spiritual, religious, and existential aspects; cultural aspects; care of the imminently dying patient; and ethical and legal aspects(National Consensus Project for Quality Palliative Care, 2009 & Lentz, 2009).

2. Significance

Pediatric critical care nurses care for dying children daily. The process of dying in intensive care units is complicated, and research on specific obstacles that impede delivery of end-of-life care and/or supportive behaviors that help in delivery of end-of-life care is limited. Despite adequate documentation of the difficulties and inadequacies of providing end-of-life care to children, research from the perspective of pediatric critical care nurses on obstacles and/or supportive behaviors that either restrict or promote good care of dying children is limited. More ever, published material specifically addresses both common barriers and supportive behaviors as perceived by pediatric nurses in end-of-life care are limited. In addition, relatively few researchers have addressed the perspectives of nurses who direct the development of end-of-life care programs, although nurses bear the major responsibility for implementing those programs.

3. Aim of the study:

To describe pediatric critical care nurses' perceptions of (1) obstacles to provide end-of-life care and (2) supportive behaviors that help in providing end-of life care in the intensive care units.

4. Research questions:

- What are the most obstacles to provide end-of-life care as perceived by pediatric critical care nurses in the intensive care units?
- What are the most supportive behaviors that help in providing end-of-life care as perceived by pediatric critical care nurses in the intensive care units?
- What is the most helpful that pediatric critical care nurses think to improve end of life care in their units?

5. Methodology

5.1 Research design:

The current research design was a descriptive design aimed to describe pediatric critical care nurses' perceptions of (1) obstacles to provide end-of-life care and (2) supportive behaviors that help in providing end-of life care in the intensive care units.

5.2 Setting:

The study was conducted at Pediatric Intensive Care Unit (PICU) and Neonatal Intensive Care Unit (NICU) of Children's University Hospital in Mansoura, Egypt.

5.3 Subjects:

The study involved 94nurses; 51nurses from Pediatric Intensive Care Unit (PICU) and 43 nurses from Neonatal Intensive Care Unit (NICU).The total number of nurses in both units were 110 nurse .16 nurses were refused to participate in the study without explain the cause. The data collected during one month at the end of 2012.

5.4 Instrument:

The data was collected using the following tools:-

(A) -The structured questionnaire sheet was developed by the researcher. It was written in simple Arabic language. The questionnaire was concerned with gathering data related to:

1- Nurses' demographic characteristics that include age, qualification, years of experience, unit, number of beds, number of working hours per week, if they have dealt with a child during the period of dying?, how many children they have dealt with them during the period of dying?, how old was the average age?, and if they are taken any previous educational programs about death, dying or about how to take care of dying children?.

2- An open-ended question was added to ask the nurses about what they think that is helpful to improve end of life care in their units (a written protocol for nursing management of pain, dyspnea, and comfort measurements, use of a palliative care team, greater emphasis on spiritual care, better communication among nurses, physicians, and children' families, training and education of physicians, nurses, and family about death, dying, and caring of dying children, education in ethical and legal issues, greater family involvement)

(B) - Nurses' perception of obstacles and supportive behaviors in providing end of life care to critically ill pediatric patients was assessed using National Survey of Critical-Care Nurses Regarding End-of-Life Care .It was developed, pretested, and administered in 1998 (Kirchhoff & Beckstrand, 2000). In (2005) they were adapted the questionnaire by adding 5 new obstacles and a single support item as suggested by the nurses in the original study. The total items became 53 items: 29 obstacle items, 24 supportive behaviors (1 = never occurs and 5=always occurs).

For this study; the final questionnaire contained 48 items: 26 obstacle items, 22 supportive behaviors. 2 items from supportive behaviors and 3 items of obstacles were deleted due to some of these items is repeated or not understood when translated to Arabic or not corresponded with the pediatric age group and some are not correlated to our culture. Responses were revised, coded, tabulated and analyzed by using SPSS software version 17.0 (SPSS Inc., Chicago, IL, USA). Descriptive statistics were used to analyze the demographic data. Categorical data were described with frequencies and percentages, while numerical data were described with mean and standard deviation, depending on variable distribution.

6. Results

Frequencies and percentages of the demographic variables will be presented. Descriptive statistics will be reported on nurses' perception of obstacles and supportive behaviors in providing end of life care to critically ill pediatric patients, as well as the results of the open-ended question.

Table 1 shows that, the highest percent (44.7%) of studied nurses, their age were ranged from 30 years to less than 35 years and about two third (60.6%) of them had bachelor degree in nursing. In relation to their unit, more than half (54.3%) of them were working in pediatric intensive care unit and (46.8%) of them had experience ranged from 5 to less than 10 years in their units. As regards number of working hours per week, the majority (70.2%) of them was working from 30 to less than 40 years per week. All the studied nurses were dealt with a child during the period of dying and the majority (94.7%) of them was dealt with more than 10 children during the period of dying. More than two third (62.8%) of them they didn't take any previous educational programs about death, dying or about how to take care of dying children.

Table 2 indicates that, the most supportive behaviors in providing end- of- life care to critically ill pediatric patients that perceived by nurses were, staff compiles all paper work to be signed by the family before they leave the unit (mean=4.62), nurses scheduled so that child receives continuity of care (mean=4.17), physicians agreeing about direction of child care (mean=4.05) and nurses offer supportive physical touch to each other (mean=4.09). Table 3 illustrates that, the most obstacles behaviors in providing end- of- life care to critically ill pediatric patients that perceived by nurses were, child having pain that is difficult to control or alleviate (mean=4.14), nurse too busy offering life saving measures to provide quality end of life care (mean=4.05) and family continually calls the nurse for update rather than the designated contact person (mean= 4.01).

Table 4 it is observed from this table that, the most of nurses (41.5%) reported that training and education of physicians, nurses, and family about death, dying, and caring of dying children is the most helpful to improve end of life care in their units followed by a written protocol for nursing management of pain, dyspnea, and comfort measurements (21.3%) and the least helpful (2.1%) is the greater family involvement in caring of their dying children.

7. Discussion:

Nurses are the largest group of the treatment team who are responsible for taking care of the dying patients. This duty also includes the nurses working at infants and children wards. Since children are quantitatively and qualitatively a substantial portion of community, and are the central elements of the social structure, they form the most sensitive and vulnerable social group. There has been a high constant attention to the mortality rate of infants so that it is one the most important health indicators in the society which not only indicates the health condition of children, but the health of all people and the socio-economical conditions of their lives as well. Fortunately, in recent years, there has been an appropriate attention to the requirements of children who have an incurable disease. Similarly, the number of these children has increased alongside the developments in technology and medicinal treatments. In case a nurse is willing to take care of this kind of patients, any event would bother them and affect their emotions severely because this care is not similar to any other life experiences for them. All nurses who are engaged with taking care of dying patients need to reflectively ponder over their feelings toward death as it is crystal clear that our attitudes are related to our behavior and performance and the nurses' attitudes toward death and dying affect their nursing care (Zargham-Boroujeni, et al , 2011).

Dying children and their families require comprehensive, compassionate, and developmentally appropriate palliative care. Palliative care is active involvement, not passive withdrawal. Palliative care is a relatively new health care discipline. It is defined as health services with a focus on relieving both the physical and the mental suffering of terminally ill patients and the patients' families. Palliative care is described as a way to meet the physical, mental, and spiritual needs of people who are chronically ill and dying. It is considered appropriate for ill children with many different medical conditions, even when cure for a child remains a distinct possibility (Sedigheh & et al, 2010).

Providing end-of-life care for patients and their families can be stressful for nurses because the nurses may be insufficiently trained to manage the process. Job stress associated with working in ICUs may lead to burnout or a state of emotional and physical exhaustion. As working conditions decline, job performance may deteriorate, the quality of care may diminish, and employee turnover may increase. The process of dying in an ICU can be messy, noisy, and complicated. Healthcare personnel who have chosen to work in an ICU environment can find the chaos associated with death unpleasant. A better understanding of the most intense and the most frequently occurring obstacles that restrict nurses from providing quality end-of-life care could lead to the development and testing of interventions to lower both the intensity and the frequency of these obstacles, thus lessening the burden of care. An understanding of the most intense and most frequent supportive behaviors could lead to the development of interventions to maintain the highly rated supportive behaviors and increase the lower rated supportive behaviors (Beckstrand & Kirchhoff, 2005).The aims of this study were to describe pediatric critical care nurses' perceptions of obstacles to provide end-of-life care and supportive behaviors that help in providing end-of life care in the intensive care units.

The results of this study showed that, the most supportive behaviors in providing end- of- life care to critically ill pediatric patients that perceived by nurses were, staff compiles all paper work to be signed by the family before they leave the unit (mean=4.62), nurses scheduled so that child receives continuity of care (mean=4.17), physicians agreeing about direction of child care (mean=4.05) and nurses offer supportive physical touch to each other (mean=4.09). The lowest perceived supportive behaviors were, ethics committee constantly involved in the unit, so they are involved from the beginning should an ethical situation arise later(mean=1.25), family physically helping to care for the dying child(mean=1.44) and letting the social worker or religious leader take primary care of the grieving family(mean=1.46). These results supported by Beckstrand & et al, (2010) who conducted a study to describe pediatric nurses' perceptions of obstacles and supportive behaviors in end-of-life care, found that, the items with the highest mean scores were agreement among physicians about the direction a patient's care should go, family members' acceptance that a patient was dying, and designation of a single family member as the contact person for all the other family members about information on the patient. Supportive behaviors that occurred least frequently were having members of the ethics committee routinely attend unit rounds and having unlicensed personnel available to help care for dying patients .Items with the lowest perceived supportive behaviors scores included having members of the ethics committee routinely attend unit rounds, using unlicensed personnel to help care for dying patients, and having a patient's family members physically help care for the patient.

Also, these findings may be related to, when the nurses collect all papers that needed to be signed by the family before they leave the unit and scheduled their nursing management so that child receives continuity of care, all these will save more time for nurses to provide end of life care.

As regarding obstacles behaviors, the findings of the present study illustrated that, the most obstacles behaviors in providing end- of- life care to critically ill pediatric patients that perceived by nurses were, child having pain that is difficult to control or alleviate (mean=4.14), nurse too busy offering life saving measures to provide quality end of life care (mean=4.05) and family continually calls the nurse for update rather than the designated contact person (mean= 4.01).The lowest perceived obstacles were, physicians overly optimistic to family about the child surviving (mean=2.22), nurse not trained regarding family grieving and quality end of life care (mean=2.15) and nurse not being able to communicate with the child to learn of his / her wishes regarding treatment due to sedation or depressed neurological status or because of his/her younger age (mean=2.26).These findings are in agreement with Beckstrand & Kirchhoff, (2005) who conducted a study to measure critical care nurses' perceptions of the intensity and frequency of occurrence of obstacles to providing end-of-life care and supportive behaviors that help in providing end-of life care in the intensive care unit, they found that, the three items perceived as the most intense obstacles to provide end-of-life care were having multiple physicians who differed in opinion about the direction of a patient's care, patients' family members and friends who continually called a nurse for an update on the patients' condition rather than calling the designated contact person, and physicians who were evasive and avoided conversations with patients' family members.

Similarly, these results may be attributed to, child' family members continually call a nurse for updates on the child' condition is considered an intense obstacle because frequent telephone calls directly stop nurses from providing care.

In addition, critically ill child cannot communicate on their own and therefore require another person, a nurse or a significant other, to become the gatekeeper of information about their condition. For child' family, however, the same technology that is used to monitor a child's current condition and allows rapid interventions is also the most sensitive to electrical interference; therefore, few types of cell phones can be used in ICUs and so contacting child' family members from outside the hospital is difficult. This protective ICU environment isolates child' family so that the family needs to remain close to their ill loved ones competes with trying to communicate with others outside the hospital. A child's family members can make calls from the waiting room telephone, but incoming calls to the family members must almost always be routed through the unit to the child's nurse.

Furthermore, these findings may be explained as, from nurses' point of view and from their psychological and emotional aspects, the child must never suffer from pain though the nurses are continuously concerned with alleviating and controlling pain although this pain is difficult to control and the nurses are too busy in offering life saving measures so they don't have time to provide quality end of life care.

The results of the present study showed that, the most of nurses (41.5%) reported that training and education of physicians, nurses, and family about death, dying, and caring of dying children is the most helpful to improve end of life care in their units followed by a written protocol for nursing management of pain, dyspnea, and comfort measurements (21.3%). This result supported by Curtis & Rubenfeld,(2005) who stated that, despite efforts are being made to improve educational curricula and continuing professional education, practicing nurses still lack knowledge in providing end-of-life care and have variable opportunities for continuing education to improve end-of life care. Critical care nurses not only lack knowledge about palliative care in general and management of signs and symptoms in particular, but also lack knowledge about the process of withdrawing or withholding life-sustaining treatments, providing support to and communicating with patients and patients' families, cultural influences in the care of dying patients and patients' families from ethnic minority groups, and the spiritual needs of patients and patients' families. Finally, caring for dying children involves unique barriers. Conflicts arise when futile efforts are continued to save what society has determined should not be lost. In a study of pediatric palliative health care providers, a total of 446 staff members and physicians were asked about their comfort and expertise in providing end-of-life care to children. Staff members felt inexperienced in communicating about end-of-life issues with children and children' families. Staff members also reported feeling unprepared to deal with pain and symptom management, and a majority (54%) felt personally unsupported as they cared for dying children (Contro & et al, 2004). In another study, barriers included uncertain prognosis, unwillingness of patients' family members to acknowledge incurable conditions, language barriers, and time constraints (Davies & et al, 2008).

8. Conclusion

The present study concluded that, the most supportive behaviors in providing end- of- life care to critically ill pediatric patients that perceived by nurses were, staff compiles all paper work to be signed by the family before they leave the unit and nurses scheduled so that child receives continuity of care. While the lowest perceived supportive behaviors were, ethics committee constantly involved in the unit. In addition, the most obstacles behaviors in providing end- of- life care to critically ill pediatric patients that perceived by nurses were, child having pain that is difficult to control or alleviate and nurse too busy offering life saving measures to provide quality end of life care. The lowest perceived obstacles were physicians overly optimistic to family about the child surviving and nurse not trained regarding family grieving and quality end of life care. Furthermore, the most of nurses reported that training and education of physicians, nurses, and family about death, dying, and caring of dying children is the most helpful to improve end of life care in their units followed by a written protocol for nursing management of pain, dyspnea, and comfort measurements and the least helpful is the greater family involvement in caring of their dying children.

9. Recommendations

In the light of findings of the current study, the following recommendations are suggested:

- Explore new ways of disseminating information about child to the child' family members on a regular basis to diminish the number of incoming calls handled by nurses.
- Educate physicians and nurses about the wishes of child' family members for direct, clear, and honest information on child.
- Educate and encourage physicians to communicate directly, in a more open manner, with each other and with child' family.

Future researches are needed to identify and implement ways to decrease highly perceived obstacles and to continue to support highly perceived supportive behaviors. In addition, researches may be indicated to differentiate neonatal nurses' perceptions of barriers and supportive behaviors from those of pediatric nurses. Furthermore, differences between ICU and non-ICU staff members' perceptions of end-of-life care are needed to be studied.

9. Limitations

The study did not distinguish between neonatal and PICU nurses in their perception regarding obstacles and supportive behaviors that help in providing end-of life care in their units. The sample consisted of nurses from only a single setting, Children's University Hospital in Mansoura, how nurses from other exclusively pediatric organizations perceive end-of-life care is not known. Future research on these nurses' perceptions is planned.

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Tables:

Table 1: Percentage distribution of nurses according to their characteristics.

Demographic variables	***Frequency***	***Percent***
Age From 20 to less than 25 years	6	6.4
From 25 years to less than 30 years	38	40.4
From 30 years to less than 35 years	42	44.7
From 35 years to less than 40 years	6	6.4
More than 40 years	2	2.1
X ± SD	2.5745 ± 0.79635	
Qualification Diploma	34	36.2
Technical institute of nursing	2	2.1
Bachelor	57	60.6
Master	1	1.1
Unit Pediatric intensive care unit	51	54.3
Neonatal intensive care unit	43	45.7
Years of experience Less than 5 years	14	14.9
From 5 to less than 10 years	44	46.8
More than 10 years	36	38.3
X ± SD	2.2340 ± 0.69446	
Number of working hours per week Less than 30 hours per week	3	3.2
From 30 hours to less than 40 hours per week	66	70.2
More than 40 hours per week	25	26.6
X ± SD	2.2340 ± 0.49569	
Do you have dealt with a child during the period of dying? Yes	94	100.0

No	0	0.0
Number of children who have dealt with them during the period of dying Less than 10 children	5	5.3
More than 10 children	89	94.7
X ± SD	1.9468 ±	0.22562
Are you taken any previous educational programs about death, dying or about how to take care of dying children? yes	35	37.2
No	59	62.8
Total	**94**	**100.0**

Table 2: Nurses' perception of supportive behaviors in providing end- of- life care to critically ill pediatric patients

Statement	Mean	Std. Deviation
1- Family members having adequate time to be alone with the child after his/ her death.	2.09	.939
2- Family members having a peaceful and dignified bedside scene.	2.56	.922
3- Families being taught how to act around dying child.	2.08	1.35
4- Family members show gratitude to nurse for care provided to child who has died.	2.68	1.41
5- Physicians agreeing about direction of child care.	**4.05**	.943
6- Family members accept that child is dying.	2.96	.994
7-Families having unlimited access to the dying child.	2.95	1.35
8- Nurse drawing on previous experience with the critical illness or death of a family member	2.71	1.59
9-Family designating one family member as contact person for the rest of the family.	3.24	1.39
10- Nurses offer words of support to each other	3.50	1.25
11- Nurse having enough time to prepare the family for child's death.	2.92	1.34
12- Nurses scheduled so that child receives continuity of care.	**4.17**	1.09
13- Unit designed so family has a place to grieve in private.	1.66	1.09
14- Staff compiles all paper work to be signed by the family before they leave the unit.	**4.62**	.831
15- Nurses offer supportive physical touch to each other.	**4.09**	.917
16- Physicians meet in person with the family after the child's death	3.97	1.15
17- Physicians putting hope in tangible terms for family.	3.40	1.13
18- Letting the social worker or religious leader take primary care of the grieving family.	**1.46**	.958

19- Nurses take care of children while affected nurse "gets away" for a moment after the death of a child.	3.14	1.46
20- Family physically helping to care for the dying child.	**1.44**	.922
21- Having unlicensed personnel available to help care for dying children.	1.84	1.16
22- Ethics committee constantly involved in the unit, so they are involved from the beginning should an ethical situation arise later.	**1.25**	.900

Table 3: Nurses' perception of obstacles behaviors in providing end- of- life care to critically ill pediatric patients

Statement	Mean	Std. Deviation
1- Family continually calls the nurse for update rather than the designated contact person.	**4.01**	1.11
2- Family not understanding the term "life-saving measures" and its implications.	3.11	1.13
3- Physicians evasive and avoid family.	2.08	.918
4- Physicians differing in opinion about care of a child.	2.86	1.11
5- Families not accepting poor child prognosis.	3.32	.806
6- Nurse too busy offering life saving measures to provide quality end of life care.	**4.05**	1.35
7- Nurse having to deal with angry family members.	3.81	1.01
8- Nurse having to deal with distraught family while still caring for child.	3.83	1.11
9- Nurse not being able to communicate with the child to learn of his / her wishes regarding treatment due to sedation or depressed neurological status or because of his/her younger age.	**2.26**	1.49
10- Physicians won't allow child to die from the disease process.	2.57	1.64
11- Physicians overly optimistic to family about the child surviving.	**2.22**	1.23
12- Family requesting life- saving measures in spite of poor child prognosis.	3.45	1.34
13- Nurse called away from child and family to perform other duties.	3.14	1.58
14- Child's treatments continue although painful o uncomfortable.	3.40	1.53
15- Family fighting about life support.	2.83	1.43
16- Nurse's opinion about child care not valued.	2.62	1.09
17- Nurse knowing poor prognosis before family.	3.59	1.51
18- Family members not having private place to grieve at child's bedside.	3.27	1.63
19- Family legal action is a threat, thus child intensive care continues despite poor prognosis.	3.07	1.44
20- Child having pain that is difficult to control or alleviate.	**4.14**	5.48

21- Family not present with the child when she / he is dying.	3.87	1.28
22- Nurse not trained regarding family grieving and quality end of life care.	**2.15**	1.38
23- Unavailability of ethics board or committee to review difficult child cases.	2.56	1.72
24- Family not having a support person eg, social worker or religious leader.	2.47	1.58
25- Family visiting hours too liberal and restrictive.	3.18	1.35
26- Continuing to provide advanced treatments to dying children because of financial benefits to hospital.	2.76	1.62

Table 4: Percentage distribution of what the nurses think that is helpful to improve end of life care in their units.

Items	Frequency	Percent
- A written protocol for nursing management of pain, dyspnea, and comfort measurements	20	21.3
- Use of a palliative care team	11	11.7
- Greater emphasis on spiritual care	8	8.5
- Better communication among nurses, physicians, and children' families	9	9.6
- Training and education of physicians, nurses, and family about death, dying, and caring of dying children	39	41.5
- Education in ethical and legal issues.	5	5.3
- Greater family involvement	2	2.1
Total	**94**	**100.0**

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