Supporting Families of Dying Patients in the Intensive Care Units

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Family support in the intensive care units is a challenge for nurses who take care of dying patients. This article aimed to determine the Iranian nurses' experience of supporting families in end-of-life care. Using grounded theory methodology, 23 critical care nurses were interviewed. The theme of family support was extracted and divided into 5 categories: death with dignity; facilitate visitation; value orientation; preparing; and distress. With implementation of family support approaches, family-centered care plans will be realized in the standard framework. **KEY WORDS:** *dying*, *end-of-life care*, *family support*, *intensive care unit* *Holist Nurs Pract* 2014;28(5):316–322

Death is a natural part of life.[1] The Quran states that "wherever you are, even in sturdy palaces, death overtakes you."[2] In developing countries, a large percentage of hospital deaths occur in the intensive care unit (ICU).[3] There are differences and similarities for end-of-life care in the ICU.[4] In the final stages of life, patients lose many things: physical function, independence, and communication.[5] Because of these problems, many patients will need to receive care at the end of life.[6] Therefore, the clinicians and nurses are responsible for providing comprehensive care and meeting the needs of families.[1,7] Although there is a spiritual image of death in nursing profession, patients and their families are exposed to the psychological effects of their decisions at the end of life.[8,9] Also, end-of-life care can lead to more stress and intention to leave the job by ICU nurses.[10] End-of-life care brings more suffering and stress for the nurses and families who participate in the long care process of dying patients.[8] However, because of the aggressive nature of care in the ICU, applying the concept of family- and patient-centered care is always difficult.[11]

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Critical care nurses can develop end-of-life care by using proper strategies such as assessing family perception about the situation and communicating with them about the patient's wishes before death.[12] Inconsistent and inadequate communication between health care providers and patients and their families, differences in consensus on goals of care, and unrealistic expectations of patients and their families and care team are the challenges in providing optimal end-of-life care in the ICU.[11] Critical care nurses requires more knowledge, skills, and cultural competency to provide quality care, whereas patients' families need direct, clear, and consistent information about care.[13] The relationship between patients and their families and staff is an integral part of the nursing process in coping with patient death.[14] Lack of education, professional experience, or cultural barriers may lead to negative attitudes on some aspects of caring of dying patients. In an in-depth interview with 10 ICU nurses in Thailand, Kongsuwan et al[15] identified 4 processes of knowing the occasion of a peaceful death: visual, technical, intuitive, and relationship knowledge. Kongsuwan[16] stated that ICU nurses can improve the peaceful death through the knowledge of death, creating a compassionate environment, and providing sympathetic end-of-life care. Although there is a framework for the care of dying patients in their final stages of life, most nurses work on the basis of their experiences. The evaluation of end-of-life care in critical care units fulfilled the perception of nurses' knowledge regarding support of patients and their families in crisis situations.[17] This recognition can reduce barriers and enhance

supportive behaviors in the care of dying patients.[18] Because nurses interact directly with patients and their families, their experiences can lead to better care in the final stages of life.[19]

Considering the importance of concept of family support in the care of dying patients, this study explore a detailed and in-depth explanation of critical care nurses' experiences in supporting families of dying patients.

METHODS

As the philosophical foundation, the symbolic interactionism was used for this study.[20] Semi-structured interviews were used for data collection. The interviews were conducted in a private room at the hospital that provided good relaxation conditions. To achieve the goals of grounded theory, the researcher asked questions to explore the participants' experiences and not their theoretical knowledge. Before the interview, the investigator oriented each participant to the study and obtained a written consent. The participants were informed that they had the freedom to refuse participation at any time during the study and were told that the results would be anonymous and would be used only for academic purposes. The length of each interview ranged from 25 to 75 minutes. Each interview was audio-taped. The transcript of each interview was typed into a MS Word document.[21] Data were collected from August 2009 to November 2010. Data collection was continued until data saturation was achieved. Constant comparative methods were applied throughout data analysis to establish an analytical view of the collected data.[22] Sampling began with purposive sampling and continued with theoretical sampling, along with development of categories.[23] The methodology of Strauss and Corbin[24] was used to explore nurses' experiences of dying patients and their families. Data analyses were conducted with open, axial, and selective coding by repeated line-by-line reading of transcripts and memos. In the process of open coding, the data were broken down and categorized. Axial coding was performed by making connections between categories and subcategories. In selective coding, categories were linked to the central concept. Data accuracy was confirmed by reviewing techniques, approval by the participants, researcher validity, evaluation and constant observation, integration of data collection methods, and also comments made by the colleagues.[25]

RESULTS

According to the characteristics proposed by Strauss and Corbin on the central category, the family support was extracted as the main theme. The Table summarizes main categories and subcategories.

Findings showed that death with dignity, value orientation, facilitating visitation, preparing, and

TABLE. Main Theme, Categories, and Subcategories About Perception of Intensive Care Unit Nurses Caring for the Families of Dying Patients

Main Theme	Categories	Subcategories
Family support	Death with dignity	• Caring for the dead without the presence of the family • Preparation of the private environment for reading the Quran • Cleaning the body • Caring for the dead by colleagues
	Facilitate visitation	• Devoting more time to visitation • Possibility of family presence during resuscitation • Allowing family presence
	Value orientation	• Providing privacy • Condolences • Ask the physician for more explanations • Explain the cause of patient death • Attention to different cultures in mourning
	Preparing	• Gradual preparation of the family • Inform the family • Inform indirectly
	Distress	• Severe emotional reactions by nurses • Whimpering by the family

distress are surrounded by family support theme.[24] In the open coding of data, 3 categories of value orientation, facilitating visitation, and preparing were specified as "strategy" and the category of comfort was considered as "consequence" (Figure).

For explanation of the family support concept, following are some quotes from the participants:

A. Strategies

a. *Value orientation*

Understanding of the cultural and religious values of patient and family arises from nurses' perception and sensitivity. Nurses use a variety of strategies to improve end-of-life care in the ICUs. In this regard, a participant said: "Generally I am an emotional person ... in 90% of cases, I read the *Sura al Fatiha*. I solve the problem myself. I remember colleagues don't laugh, be careful. The effort is to put the deceased towards *Qiblah*."

b. *Facilitating visitation*

Most of the nurses have considered death a natural part of life and a journey to the next world. Therefore, they were facing problem in helping families at the dying patient's bedside. Nurses' experience shows that the more the family presence, easier the acceptance of patient death. Facilitating visitation was conceptualized as one strategy used by nurses. A participant said:

> When the patient reaches this stage, although families have not let to visit patient ... but we allowed them to come and go. Those moments I think patient cannot understand anything. Not that he knows, however, he is oriented to time and place but not as much to his family. In this case, families are injured too. And I think patient confidence in the final moments is the right of every person that we can give.

In this regard, other participant said:

> Generally, when the patient reaches the end stage, from the corridor whoever comes to visit, we allow them and give them the key to open the door and come to see their patient ... but we let them to come and see their patient even for diseases that may not lead to patient death. But the moment that patient is very ill, just we try to calm family mentally.

c. *Preparing*

End-of-life care is very important in the high-technology care units; meanwhile, preparing the family for dealing calmly with the worst physical conditions of the patient is important. Poor communication can cause stress and dissatisfaction among caregivers and family members. One of the participants said:

> We explain to family that your patient is at the critical care unit, a critical care unit is a ward that your patient needs acute care, so your patient will be here for a few days, 3 to 5 days, or at least 7 days. At this time, you're patient condition is known. Drug therapy is going to be done, it is done for your patient. And God know what is the result of that work. Since we are the device and the extent that doctor and nurses can do, but you're going to get ready, if God forbid, if it happen, we have told it you.

d. *Death with dignity*

Dying with dignity is expected when it is tailored to the patient's personal values. Respecting a

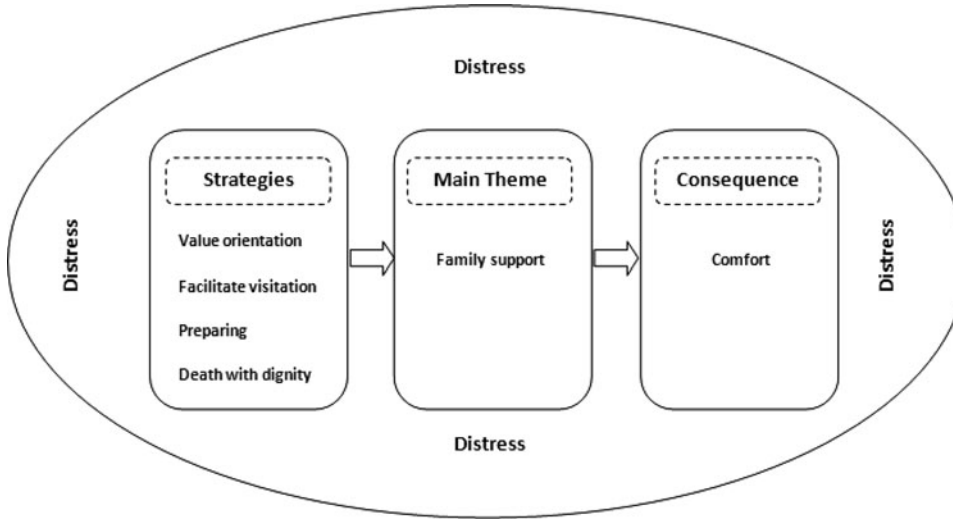

FIGURE. Developing the theory of family support.

patient's care needs after death needs special attention in different cultures. Also, caring for the dead is a unique aspect of nursing activities. It is the respect for the dignity and individuality of all patients. A participant said:

> We had covered the patient, because his face was dirty and bloody, I left the expired patient in the isolation and said to clean his face and body and even we removed the bandage and got a clean bed linen over him.

B. Context: Distress

In addition to causing distress to the families of dying patients, critical care nurses are particularly vulnerable to developing distress due to caring for families in crisis and participation in stressful moral situations. In this regard, one participant noted:

> Sometimes, I fell in love with a dead patient for up to 6 months. I cry at the patient's bedside. My supervisor says if you cry, what can I do with others, it really bothers me. Our house is in mourning for a week, and my husband gets upset with my behavior.

Another participant said: "The effect put on my mind, for a month, a kid picture was on my eyes and I was worried not get PTSD. I had problem to sleep nights."

C. Consequence: Comfort

Death is an inevitable and unexpected phenomenon that is difficult to accept. Critical care nurses can communicate directly with the families of dying patients. Clinical experiences in nursing of dying patients can improve the comfort of families at end-of-life care. Educating families on the dying process may help the family accept the worst condition of the patient with more peace of mind. In this regard, a participant said:

> He arrested at 7 PM, and his situation was unstable. At 19.30 PM, he went by the mercy of God. After Iftar, his sons said they wanted to talk with me. I was very distressed. How would I say this, "It was very difficult for me. I gave them hope in the afternoon that his blood pressure is good and there is a possibility of recovery. However, I was happy, I have said them to come and visit the patient from near. In this shock, and after greetings, they asked about their father's condition. I replied: "Your father was waiting to hear 'Adhan' sound and then leaves this world." However, after a few seconds of silence, they appreciated me. It seemed they have reached a comfort level. May be that sentence helped them. Many times, we invite family to come here. I say them, "If you want, you can stay behind the door of the ICU and pray for him."

DISCUSSION

Value orientation

Religious and cultural beliefs impact on end-of-life care. Understanding patients' beliefs and respect for religious practices enhances humanitarian aspects in relationship to patients and family caregivers. Study results demonstrate nurses' attention to culture and religious values in patients and their families. Also, Høye and Severinsson[26] showed that with human interaction and understanding of cultural traditions, nurses can meet family expectations in dealing with their critically ill loved ones. Joolaee et al[27] indicated respect for religious and cultural beliefs as the main themes. Calvillo et al[28] concluded that to provide a good and effective care, nurses must be sensitive to beliefs in health and illness, the impact of religion, language, values, and culture, and social and economic factors on health and health care decision making.

Facilitate visitation

Participation of a support person in the ICU may increase the family and staff satisfaction and improve interaction between patients and their families. According to cultural beliefs, to some families, it is important to be with their patients during the dying process.[29] Kjerulf et al[30] showed that the presence of family members with dying loved ones causes family satisfaction. For this purpose, facilitating visitations is a good nursing strategy for families. Schumacher[31] pointed to the necessity of family presence in care activities. However, in the Kirchhoff et al[32] study, ICU nurses believed that family visitation can result in family's exhaustion and interfere with care delivery. Liu et al[33] showed that most ICUs have restrictive policies regarding family visitation. Lombardo et al[34] suggest that the families are not equipped to deal with the privacy and relaxation of patients and there are some limitations regarding access to families in patient care. Beckstrand et al[35] describe that "good death" refers to facilitating family presence, making changes in environment, pain and suffering management, and not leaving the patient at the time of death. Fridh et al[36] indicated the necessity of improving the ICU environment and emphasized that family visitation should not interfere with end-of-life care decisions. Nelson et al[37] pointed to the lack of enough space for visitation as a challenge for families. In the Beckstrand and Kirchhoff[38] study, giving enough time to families to stay with their dying

patients, providing a calm and respectful setting at death, teaching families how to act at the end of life were helpful behaviors in nurses' perception.

Preparing

Families may have particular needs in terms of end-of-life care and should be supported through the last days of a patient's life. Staff training on how to communicate bad news should also be implemented as a vital and urgent subject.[39] In this study, gradual preparation of the families and communicating bad news indirectly were important for family support. But Crump et al[13] emphasized that families need direct, clear, and consistent information about end-of-life care.

Death with dignity

The analysis of the narratives allowed us to identify the meaning of dignified death and the interventions performed by critical care nurses to promote dignified death in the context of end-of-life care. Subcategories related to death with dignity were care of the deceased body without family presence, preparation of the private environment for reading Quran, cleaning the dead body, and caring of the body by colleagues. In this study, the nurses reported several interventions to promote a dignified death for both the patient and help the family accept the situation. The narratives describe the strategies that directly result in care of the body (cleaning the body and preparing for transition from the ICU) after death and especially offering a good presentation for grieving families. These activities mainly describe how nurses deal with the dead patient and also some considerations (such as reading the Quran to the dying patient) in Muslim families. However, keeping privacy is considered a mark of respect for the dignity of the family and the deceased. In our study, dignity is more often described for after-death care, with focus on body care. This activity may be related to nurses' attention to provide good presentation for families dealing with the dead body. Some researchers have considered dignity in different activities that may be related not just for after-death preparation. For example, Clark et al[40] reminded dignity as dying in peace for the critical ill patients. Van Gennip et al[39] determined that patients feeling peaceful and ready to die, absence of anxiety and depression, presence of fatigue, and a clear communication by the physician about end-of-life treatment as the predictors for dignified death among families.

Distress

Frequent contact with death and sorrow can cause job stress and effect on the quality of care of dying patients and their families.[41] In the care of dying patients in a critical care environment, not only the family but also the nurses face stress and severe anxiety. Inevitably, witnessing the scene of death and sorrow, with families crying around, intensifies nurses' distress. In the Polat et al[42] study, nurses experience moderate to severe anxiety at the time of a patient death. Also, Pascual and Fernández[43] reported high levels of anxiety in the pediatric ICU nurses. In the Curtis and Vincent[10] study, end-of-life care was an important factor for increasing nurses' distress and leaving their job. In the Hinderer[44] study, personal distress was reported by ICU nurses in caring for dying patients. The Boroujeni et al[45] study, caring for dying patients is distressful and even a threatening experience for nurses Boyle et al[46] indicated that poor communication among therapists and families can lead to stress and dissatisfaction, as well as neglect of patients' needs. According to the study finding, a nurse reported crying and another reported flashbacks of the image of a deceased child. Crying may have a profound therapeutic effect in helping nurses deal with feelings of distress. When a patient whom a nurse takes care of for a long time passes away, the nurse feels attached to the patient and sees the patient as his or her own family. As a result, the nurse would cry but still help the family finish the remaining care and without interrupting care for other patients. Therefore, in the long-term care, crying can be a good strategy to provide emotional support. If, however, there are no tears in the nurse's eyes, it cannot reflect negative comments and thoughts such as being "not professional," "emotional," and even "putting too many feelings toward the patients." In any case, weeping and mourning for a long time are likely due to nonadaptation after bereavement.

Comfort

In this study, comfort was the consequence of family support. Facilitated conversations between nurses and family members of the recently deceased loved ones may improve comfort and knowledge about end-of-life discussions.[47] Gutierrez[48] stated that families need to

be informed about their patients' prognosis, and because hearing bad news is always difficult, communication should be with compassion, respect, and tenderness. Reassuring families about patient's comfort or that the patient will not suffer in dying process is considered as a supporting behavior in the ICU. Also, respect for patient culture or religious beliefs may provide comfort to the family.[49] Nurses with a sense of appreciation in the relationship with the family can help family comfort and satisfaction during the painful dying process.[50] According to the findings, keeping the patient clean and providing privacy were also helpful to the family. Thus, nurses involved in the end-of-life care can provide comfort care with a complex process of nursing activities.

CONCLUSION

Many patients die despite the use of advanced technologies in the ICUs. In such circumstances, the presence of family members in the ICU should be a useful practice to improve care of the dying patient. However, nurses are always faced with difficult situations. End-of-life care may affect families more than the other persons. So, family support remains an important and complex issue. In our proposed theory, the emphasis is on family participation in the end-of-life care process and preparation to accept the patient's death and compliance with the grief process. Family care of dying patients in intensive care environments could be achieved in the context of understanding of themes extracted from this study.

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