บทความวิชาการ

การตัดสินใจในระยะสุดท้าย: สถานการณ์ตัวอย่างในการปฏิบัติการพยาบาลในหอผู้ป่วยไอซียู

วราภรณ์ คงสุวรรณ* เยาวรัตน์ มัชฌิม*

บทคัดย่อ

บทความนี้มีวัตถุประสงค์เพื่อ วิเคราะห์และอภิปรายเกี่ยวกับการตัดสินใจในระยะสุดท้ายของชีวิตในคลินิก ตัวอย่างกรณีศึกษาถูกนำมาวิเคราะห์โดยการทบทวนวรรณกรรมที่เกี่ยวข้อง และใช้กรอบแนวคิดของ ธีเลน ซึ่งอธิบายกระบวนการตัดสินใจในระยะสุดท้ายของชีวิตในไอซียู ผลการวิเคราะห์พบว่า วัฒนธรรม การให้คุณค่า ความปรารถนา พยาธิสภาพ และความรุนแรงของโรคของบุคคลใกล้ตาย ระยะเวลา ฐานะเศรษฐกิจ และความผูกพันในครอบครัว ล้วนเป็นปัจจัยสำคัญที่มีผลต่อการตัดสินใจในระยะสุดท้ายของชีวิต ตัวผู้ป่วยเอง บุคคลในครอบครัว แพทย์ พยาบาล และบุคลากรอื่นๆ ในทีมสุขภาพต่างมีส่วนร่วมในการตัดสินใจในระยะสุดท้ายของชีวิต พยาบาลได้รับการยอมรับว่าเป็นผู้ช่วยเหลือ สนับสนุนตลอดกระบวนการเพื่อให้ผู้ป่วยและครอบครัวสามารถเผชิญกับช่วงเวลาที่วิกฤตของการตัดสินใจ และได้ข้อตกลงร่วมกันในการตัดสินใจในระยะสุดท้ายของชีวิต ความรู้ความเข้าใจเกี่ยวกับปรากฏการณ์และปัจจัยที่มีผลต่อการตัดสินใจในระยะสุดท้ายของชีวิต ช่วยให้พยาบาลกระทำบทบาทของตนเองได้มีประสิทธิภาพมากขึ้น กรอบแนวคิดเกี่ยวกับกระบวนการตัดสินใจในระยะสุดท้ายของชีวิตของ ธีเลน อาจประยุกต์ใช้กับกระบวนการตัดสินใจในระยะสุดท้ายของชีวิตในบริบทของสังคมไทยได้

คำสำคัญ: ระยะสุดท้าย; การตัดสินใจ; การปฏิบัติการพยาบาล

* ผู้ช่วยศาสตราจารย์ คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ จังหวัดสงขลา

Introduction

End-of-life decision making is the process that healthcare providers, patients, and patients' families go through when considering what treatments will or will not be used to treat a life-threatening illness (Thelen, 2005). Intensive care units (ICUs) are the setting of many end-of-life decisions for critically ill patients. Most situations that pertain to forms in end of life decision making in the ICU deal with advance directives, Do Not Resuscitation (DNR), withholding or withdrawing life-sustaining therapies, and the decision to shift from cure to comfort care. Making decisions in the end-of-life involves many factors (Jezewski & Meeker, 2005), including differences in cultural values (Giger, Davidhizar, & Fordham, 2006). Decisions at the end-of-life become stressors and burden the patients and families (White, 2005) This paper addresses end-of-life decision making in nursing practice in an ICU by using an exemplar story.

A Story

Mrs. A was a 44 years old, Thai woman. Her diagnosis was brain hemorrhage and severe brain swelling. She had underlying chronic renal failure and received hemodialysis as an outpatient once a week. She fell in the bathroom after hemodialysis and was found unconscious. She received a craniectomy operation. After the operation she was admitted into the intensive care unit and depended on the ventilator. Her prognosis was very poor. She was in a deep coma. Both pupils were fixed and dilated. She had signs of increased intracranial pressure and her cardiac rhythm was sinus tachycardia. Since I was an intensive care nurse, I knew well from my experience and Mrs. A's signs and symptoms and her diagnosis that she was dying and going to leave her loved ones. The doctor talked to her husband about her prognosis about 10 minutes. After Mrs. A's husband talked with the doctor, he walked to me and said to me that the doctor wanted him to make the decision to withhold or withdraw treatment. It was very hard for him to make the decision right at that moment. Mrs. A's husband said that *"If I decided to withdraw treatment, it means that my wife would be dead early. I would feel like I am a murderer. If I decided to withhold, my wife might be like a vegetable and she would be an unconscious person that needed nurturing. I can not make a decision. Why me? She was my wife and I loved her so much. She was a good wife and good mother. Why this event happened with us. We had a plan to travel together"?* He told the story with tears in his eyes. I gave this opportunity for him to release his feelings. I thought he needed time to make decisions and I would tell the doctor about this. I thought he might not be able to make a decision. Mrs. A might make the decision for him because her symptoms were worse. I saw the rising of intracranial pressure from the monitor and her heart rate was very fast. I told the doctor and he asked him to decide again about the

resuscitation if his wife had a cardiac arrest. His face was very pale and he could not stand. I helped him to sit on the chair. He asked me if his wife would be in pain or not if she received resuscitation. I answered yes, she would. He asked me many questions about the effects of resuscitation. After he had enough information, he grabbed his wife's hand and cried. I did not know what to say. I just remained silent and stood beside him. I knew it was very hard to accept death which was coming soon. Finally, he decided to do not resuscitate. I told the doctor that he wanted Mrs. A to pass away peacefully.

Why did Mrs.A's husband have to make a decision about his wife's life?

Many Thai patients lack the capacity to have their decisions guided by verbal and written statements they made before becoming incapacitated (Sittisombut, Maxwell, Love, & Sitthi-Amorn, 2009), unlike patients in the United States or other Western countries. In Thai culture, the strong idea about individual rights or individual autonomy is not a central core. Advance directive or living will by laws is recently enacted in Thailand (National Health Act, 2007). Interdependence between family members is highly valued, not individualism. Family-determination replaces value of the self-determination of patient. Family members have the vital decision making roles in serious health situation and dying situations. Patients unable to speak for themselves may have surrogates who are ethically and legally recognized to make decisions on their behalf. Surrogates can be family members, friends, or other trusted individuals (Winzelberg, Hanson, & Tulsky, 2005). However, most patients have not identified a surrogate prior to ICU admission, some countries including Thailand, have legislated that the closet relative in order of spouse, parents, adult children and siblings can provide substituted judgment (Carlet et al., 2004).

For Mrs. A situation, she was comatose and incompetent to make her own decision like most end-of-life patients in ICU. Therefore, Mrs. A's husband was ethically and legally recognized to make decisions on Mrs. A behalf.

Who participates in end-of-life decision making?

Generally, the stakeholders in making decisions in the hospital consist of patient, family members, physicians, and nurse or may include ethical committee and hospital administrators. In the unexpected event of Mrs. A her husband took the substitute role in making decisions and seemed to be the only one person to deal with this decision. The other family members, his sons were still teenagers. Mrs. A's parent came to visit Mrs. A in the last hour before she died only eight hours after admission to the hospital. Therefore, healthcare providers are the important persons to help Mrs. A's husband to deal with the decision making process in the last moments of Mrs. A's life.

The culture of ICU care is organ

oriented. Physicians who respond for one patient are multiple physicians who are expert in treatment of one specific organ. Numerous physicians are involved in end-of-life decision making. Physicians consult each other and need the consensus before giving the information to the surrogate. However, physicians often deliver end-of-life decision making information dependent on their own needs and may not acknowledge the patient's wish or the need of surrogate (Badger, 2005).

What is the role of the intensive care nurse in end-of-life decision making? Many studies (Halcomb, Daly, Jackson, & Davidson, 2004; Hilden & Honkasalo, 2006; Murray, Miller, Fiset, O' Connor, & Jacobsen, 2004) described that nurses participate in end-of-life discussions with patients, families, and physicians at some point in time and take a limited role in decisions or indirect influence. However, nurses play a key role as a supporter throughout the situation. Assisting patients and families toward consensus can be a valuable nursing role.

In Mrs. A situation, the physician was the initiator in end-of-life decision making. The physician told the bad news or poor prognosis to the family and needed the family to make decisions to withhold or withdraw treatment or resuscitate and rushed time for the decision. Nurses participated in the decision making and stayed with Mrs. A and her family the entire time. Mrs. A's husband always asked the nurse to explain more about what the doctor said to him, the effects of treatments, and patient's progress. The nurse provided information for the family to make their own decision by using language that was more understandable than the physicians. The nurse made the time to listen, to talk, and to explain to the family. The nurse was a middle person between family and physicians. The nurse had the advocate role for the family and was a translator of information for family and physicians. The nurse was the key person to provide support and compassionate care for the family throughout Mrs. A's situation and assisted with decision making that assisted Mrs. A's husband to get though this difficult time.

Wiegand (2006) describes the interactions between patients' family members, healthcare providers, and the healthcare system during withdrawal of life-sustaining therapy after a sudden, unexpected illness or injury. Nineteen families who participated in the process of withdrawal of life-sustaining therapy for a family member were interviewed and observed. The results found that the families' experiences involved a variety of dimensions, including issues with healthcare providers (bonds and consistency with nurses and physicians, physicians' presence, information, coordination of care, family meetings, sensitivity to time, and preparation for the dying process) and issues with the healthcare system (parking, struggles with finding privacy, and transfers of patients). Patients' families need information, guidance, and support as the families participate in the process of withdrawal of life-sustaining therapy. Therefore, Mrs. A's

situation can affirm this study as well.

What factors influence end-of-life decision making?

Culture is important in end-of-life decision making. Cultural understanding and sensitivity are important to healthcare professionals in order to assist patients and families at the end-of-life decision. Misperceptions caused by lack of cultural effective care can lead to unwanted or inappropriate clinical outcome and poor interaction with patients and their families. In some cultures, it is considered inappropriate for the health care professional to tell the patient the truth about the seriousness of their health status. Telling the patient about their health status is considered harmful to the patient. Rather, the serious health information should be provided to designated family members who will determine what to do with this information (Giger, Davidhizar, & Fordham, 2006). This withholding of information is what often occurs in the Thai culture. In general, full disclosure and truth telling are more likely to be found in European American cultures than in non-European American cultures (Giger, Davidhizar, & Fordham, 2006).

Value and preference Family members often lack the knowledge of patients' values and preferences that are needed to function as efficient surrogate decision makers. Advance directives provide an opportunity for patients to express their preferences in writing before the critical illness occurs. However, some people are never heard or do not understand about advance directives (Jezewski & Meeker, 2005). In the event that a patient has never discussed terminal care specifically, Lang and Quill (2004) suggested that a reconstructed values history often is the way to approximate the patient's likely preferences. Families are able to identify comments, behaviors, and attitudes to construct a reasonable values history that can help establish an appropriate plan of care.

In Mrs. A's situation, the intensive care nurse tried to assess Mrs. A's values, beliefs, and wishes from her husband. Mrs. A was Buddhist and believed in the result of action and a peaceful mind. She did good things for others and gave food to the monk every day. From this story, the nurse can reconstruct that Mrs. A. valued peace and did not want to suffer. The nurses ability to assess and communicate these findings, assisted Mrs. A's husband to know the values and wishes of his wife. After, Mrs. A's husband knew and understood that treatment or life saving procedures could make Mrs. A suffer, he was able to critically make his decision. Therefore, he decided to let Mrs. A die peacefully and with dignity, with no resuscitation.

Patients' prognosis and severity of illness Besides knowing the patient's values and preferences, knowing the patients' prognosis and severity of illness are the factors influencing decision making (Murray, Miller, Fiset, O'Connor, & Jacobsen, 2004; White, 2005). Knowing the patients' prognosis and progress in a clinical situation may

assist the family to make appropriate decisions. Knott and Kee (2005) explored the beliefs and experiences of 10 registered nurses about family presence during cardiopulmonary resuscitation and illustrated the outcome of family presence that can be used as a powerful tool in making families decide to continue or stop resuscitative efforts.

In Thailand, family presence during CPR is still a new idea although some hospitals have implemented this policy. A study reported 81% of Thai nurses working in emergency department perceived that family members had a right to be with the patient during CPR (Thipsuwannakool, 2003). Being with patient at this time allows the family to understand the patient's prognosis and progress from the physician. Nurses usually inform the family about the patient's signs and symptoms. However, surrogate presence during unstable signs and symptoms might be a viable way for the surrogates to perceive the reality of the situation. Surrogates may explain to other family member better than nurses so that the family can have a consensus in decision making. In Mrs. A's situation, her husband stayed beside her bed all the time. Therefore, he could understand the reality of the severity of her illness and prognosis.

In addition, there are other factors that could have influenced the decision making of Mrs. A's husband to withhold or withdraw treatment and DNR. These included the duration of time in making decisions, love and connection, unexpected or sudden illness, morals, quality of life of Mrs. A in the future, cost of treatment both in the present and in the future, providers at home if Mrs. A is in the vegetable, and communication of physician.

What are the decision making processes in the story?

Thelen (2005) provided a synthesis of the processes of healthcare providers and patients' family members in making end-of-life decisions about withholding or withdrawal life-sustaining treatment. There are 3 major processes:

1) Laying the ground work
2) Shifting the picture
3) Accepting a new picture.

Laying the ground work focuses on establishing trust relationship between healthcare providers and family members and giving information of patient's illness. Shifting the picture includes continue giving information, allowing family members to be at patient's bedside, providing emotional support to the family members and assisting them to know the patient's wishes and values. Accepting a new picture centers redirect family members' hope from cure to comfort.

The processes of making decision of Mrs. A's situation are examined through the processes of Thelen (in Figure I)

In Mrs. A's situation, the steps in laying the groundwork for this process is different than the stepped of Thelen (2005). Because the acute and severe critical illness of Mrs. A's happened suddenly after admission in ICU, the physician did not have time to develop a trusting relationship

with the family member. The physician had to "plant seeds" or tell the truth about the prognosis of Mrs. A first and needed the family to make decision at that time. The nurse was brought in at this point. Therefore, the nurse built trust a relationship with the patient's family member and provided information as the family needed. During this shifting picture of process, Mrs. A's situation did not have the steps of holding a meeting with family but the nurse let the family to stay with Mrs. A Therefore, family can perceive the changing of signs and symptoms and severity of illness by themselves. The other different steps in shifting the picture are that the nurse provided emotional support to Mrs. A's husband and other family members and this helped them to know the patient's wishes and values. Because this exemplar case was an unexpected admission to the hospital and she was dying, it was very hard for Mrs. A's husband or family to accept even though Mrs. A had a chronic illness before. Therefore, providing emotional support for family members is essential at this time. The nurse helped the family to know the patient's wishes and values because Mrs. A did not have advance directive. In the process of accepting a new picture, the steps in Mrs. A's situation are the same with the steps of Thelen (2005).

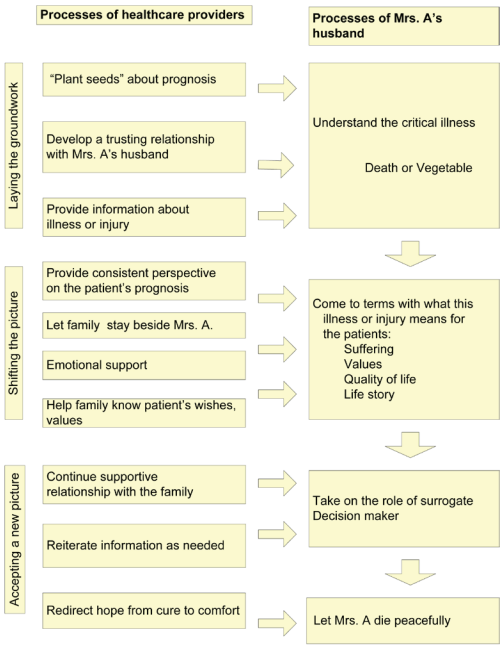

Figure I Processes of healthcare providers and Mrs. A's husband in making end-of-life decisions

Conclusion

Decision making in a limited life-sustaining timeline is very difficult for the suddenly severe critically ill patient. Understanding the factors that influence decision making can assist nurses and other stakeholders to help the decision maker to get through the process of making decisions. This case exemplar of Mrs. A illustrates the picture of end-of-life decision making in ICU. The processes of end-of-life decision making in ICU developed by

Thelen (2005) in the United States can be applied as a guideline for Thai healthcare providers to assist the family member in making end-of-life decisions. However, in order for this knowledge to be applied appropriately, these processes need to be explored and compared with other end-of-life decision making situations.

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End-of-Life Decision Making: An Exemplar Story in Nursing Practice in an ICU

Waraporn Kongsuwan* Yawarat Matchim*

Abstract

Purpose: To analyze and discuss end-of-life decision making in nursing practice.

Method: An exemplar story was examined and discussed using relevant literature and Thelen (2005)'s process of making end-of-life decision.

Findings: Culture, value and preference, prognosis and severity of an end-of-life person, time, economic status, and family connection are important factors in end-of-life decision making. Patient, family members, physicians, nurses, and other healthcare providers involve in making decision at end of life. Nurses' role was acknowledged as a supporter throughout the process in assisting patients and families dealing this critical time and reaching the consensus.

Conclusions: Understanding situations and related factors in making decision at end of life help nurses to perform their role more effectively. The Thelen's process may be fit with making end-of-life decision in Thai context. However, more situations of end-of-life decision making are needed to be explored.

Keywords: end-of-life; decision making; nursing practice

* Assistant Professor, Faculty of Nursing, Prince of Songkla University, Songkhla Province.