Nursing Roles in End-of-Life Decision Making in Critical Care Settings

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This study used a grounded theory approach to formulate a conceptual framework of the nursing role in end-of-life decision making in a critical care setting. Fourteen nurses from an intensive care unit and cardio-respiratory care unit were interviewed. The core concept, Supporting the Journey, became evident in four major themes: Being There, A Voice to Speak Up, Enable Coming to Terms, and Helping to Let Go. Nurses described being present with patients and families to validate feelings and give emotional support. Nursing work, while bridging the journey between life and death, imparted strength and resilience and helped overcome barriers to ensure that patients received holistic care. The conceptual framework challenges nurses to be present with patients and families at the end of life, clarify and interpret information, and help families come to terms with end-of-life decisions and release their loved ones.

Keywords: *end of life; decision making; grounded theory; nursing; ICU; critical care*

The contemporary approach to death "diminishes our society's understanding of death as a life event" (Haisfield-Wolfe, 1996, p. 932). Today, it is rare that death or dying is encountered in the media, other than violent death, or spoken about freely during ordinary conversation. Moreover, our present technological abilities present us with many dilemmas, including the ability to postpone death, facilitating the process of "letting go" and the accompanying challenge of wondering if more could have been done

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(Kyba, 2002; Pattison, 2004; Prendergast & Puntillo, 2002). This article describes the nursing role in decision making at the end of life in the critical care setting.

Many patients spend their final days in critical care settings. For patients who die in institutions, such as hospitals, half spend at least the last 3 days of their lives in special care units such as the intensive care unit (ICU) and cardio-respiratory care unit (CRCU), and approximately one third spend at least 10 days in an ICU before their death (Curtis et al., 2001). A cross-sectional study of Canadian death records to determine number of deaths in special care units such as ICU and CRCU found that in teaching hospitals more than one fourth, or 27%, of deaths occurred in critical care, whereas in nonteaching hospitals 15% died in critical care (Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000).

End of life in the ICU is a challenge. Nature and spirituality have been supplanted by all that medical science has to offer by way of technology and life support, prolonging the dying process and dictating the time of death (Miller, Forbes, & Boyle, 2001). Cook, Giacomini, Johnson, and Willms's (1999) qualitative study observed ICU rounds and family meetings during which staff discussed whether to withdraw or withhold life support. Interviews were carried out with clinicians, ethicists, and those involved in pastoral services. Their study described a different rhythm to the dying process, a slowing down and controlling of the process of death to give the team, family, and clinicians time to come together and collaborate on their differing understandings and plans for the dying person. However, decision making and planning were complicated by the specifics of withdrawal sequences and which technological support would be withdrawn first. Their findings revealed that advanced planning could be overshadowed by situations that were unexpected, leaving key decisions or issues unspoken or implied, issues that could negatively affect dying.

Dawson's (2008) case study in the ICU found a focus on cure rather than improving the end-of-life experience. In her analysis, Dawson viewed critical care nurses as crucial in decision making to improve the quality of the end-of-life experience; nurses had accountabilities at the end of life including supporting family members and being aware of and acting on the goals of patients who were dying. However, as members of the ICU team, nurses could not deliver care that was responsive to patients' needs and prevent a cascade of treatment. This was in part because of a lack of education and a lack of understanding of palliative care principles as well as the team's inability to holistically identify the issues affecting patient quality of life.

Thelan (2005) examined research on end-of-life decision making in the ICU. She defined end-of-life decision making as a process into which families and patients entered, and participants included physicians and nurses. Thelan found that there was an identified decision-making role for nurses as the link between families and physicians in decisions at the end of life while interpreting and explaining information. However nurses' participation was limited as discussions and decisions were led mainly by physicians.

Baggs et al. (2007) conducted an ethnographic study in four ICUs to examine end-of-life decision making, using both observational and interview data. Their findings revealed that the nursing voice was limited in end-of-life decisions. Nurses adjusted their manner of approaching physicians when seeking decisions to obtain the care outcomes that they required for their patients. Nurses also reported waiting for particular physician rotations before making requests on behalf of their patients. These studies alone highlight the difficulties and conflicting forces that shape the dying experience.

End-of-Life Decision Making and the Nursing Role

When looking specifically at the nursing role in end-of-life decision making, there is a growing body of literature describing the methods used by registered nurses (RNs) to facilitate decision making at the end of life (Bottorff et al., 2000; Hancock et al., 2007; Norton & Talerico, 2000; Scherer, Jezewski, Graves, Wu, & Bu, 2006). However, the process of facilitation has not been described, and actually the concept is only superficially understood (Bottorff et al., 2000). Researchers' findings support the nursing role in facilitating patient and family participation in end-of-life decision making and describe this role as identifying needs and assisting patients and their families through the process of dying, supporting choices made by patients, and developing relationships of trust with patients and families while maintaining consistent communication (Bottorff et al., 2000; Norton & Talerico, 2000; Scherer et al., 2006). However, the specific ways in which RN roles are played out in end-of-life care remain poorly defined and described.

A number of qualitative studies have looked at end-of-life decision making in the ICU, specifically the nursing role (Jezewski & Finnell, 1998; Norton & Talerico, 2000). These studies help to shed light on the impact of the nursing role in the ICU and also nursing interaction with other members of the ICU team. Jezewski and Finnell (1998) used a grounded theory approach and interviewed 21 oncology nurses working in an acute care setting in an attempt to clarify the nursing role in the decision-making process, in this

case specifically related to advanced directives. The authors found that communication was a key role for nurses, with the nurse acting as mediator to reduce conflict and support cohesion and understanding.

Norton and Talerico (2000) described specific strategies that nurses and physicians used to facilitate end-of-life decision making in a variety of settings including the ICU. This grounded theory study found that certain issues such as a willingness to initiate and enter into the discussion were central to the process of decision making for nurses.

Little is known about the role of nurses in end of life in the critical care setting, and therefore a grounded theory study in this area is needed to further understand this important role. Previous studies have focused more narrowly on advanced directives (Jezewski & Finnell, 1998) and on communication in a variety of practice settings (Norton & Talerico, 2000). Some of the strengths of a grounded theory approach to this topic include (a) a focus on the complexity of phenomena and human actions, (b) the recognition that people take active roles in responding to problematic situations, (c) the acknowledgement that people act on the basis of meaning that is defined through interaction, and (d) the development of a relevant framework or theory, grounded in the data, that serves as a basis for action (Strauss & Corbin, 1998).

Purpose

The purpose of this study is to bring to light the role of critical care nurses in decision making at the end of life. A grounded theory approach as described by Strauss and Corbin (1998) was used. The research question was, what role do nurses have in end-of-life decision making in the critical care setting?

Method

Sample and Setting

Participants were recruited from an ICU and a CRCU in a large teaching hospital in southwestern Ontario, Canada. These settings were chosen because, as previously indicated, approximately 42% of patients spend their last days in complex care settings (Heyland et al., 2000) and yet the role of nurses in end-of-life decision making in such settings has not been extensively studied.

Together, these two units have 17 beds and admit patients with a mean age of 60 years. Patients admitted to this particular ICU and CRCU experience complex medical, surgical, and cardiac issues and often require mechanical ventilation, dialysis, and fluid resuscitation related to drug overdose; the mortality rate is approximately 22% per year.

Participant recruitment involved the use of a variety of methods, including posters, informal meetings, and direct requests for participation. All clinical managers were given a poster, which briefly outlined the purpose of the research study and gave the researcher's name and contact information, to place in their units. A more personal approach was also used, where the researcher was present in the unit on several occasions to identify and gather groups of three to four nurses to speak with informally. It was hoped that this more personal approach, rather than a poster, would encourage some of the nurses to participate, would express the value of hearing their voices, and would emphasize the importance of understanding their nursing role at the end of life. Over the next several weeks, with little response to the above methods, nurses were effectively recruited through the researcher spending time on the units and identifying nurses who would be available for a spontaneous interview. The charge nurses also supported recruitment by posting a schedule and asking nurses to choose their interview times.

Potential participants were identified by purposive sample techniques. Participants had to be working in their unit for at least 2 years and therefore had to have reached a level of competence and had to have an awareness of the overall goals of their working environment (Benner, 1984). Consistent with Strauss and Corbin (1998), theoretical sampling was used to deliberately choose individuals who could contribute to the evolving conceptual framework. The participants would be able to provide rich descriptions of the phenomenon being explored and through their experience could further our understanding of the emergent themes. Sampling continued until saturation of categories and their properties was reached.

Data Collection

Data were collected and analyzed concurrently throughout the research process (Strauss & Corbin, 1998). Data collection occurred through a process of guided, semistructured interviews lasting from 18 to 40 minutes. Interviews were conducted at the work setting in a quiet meeting room, which ensured privacy, and were digitally recorded and transcribed verbatim.

An interview guide was used to provide a starting point for data collection. Interview questions were derived from the first author's (V.B.) own

work experiences and a review of the literature. Interview questions addressed demographic data and the nurses' views of their own experiences with end-of-life care. Questions explored their involvement in end-of-life decisions and their thoughts on this role. Examples of questions asked include the following: "Describe some of the situations that you have been involved in with patients who are dying" and "Describe any decisions or situations that you would like to have been involved in but were unable to." Participants were encouraged to share their stories and experiences and given the opportunity at the end of the interview to add further information that was not specifically asked through the interview process. As new concepts and gaps in understanding were identified, the interview guide was revised (see Table 1 for the final version of the interview guide). The computer program N-VIVO was used to help organize the data.

Data Analysis

A three-phase process of open, axial, and selective coding was used to examine and interpret the data by isolating words and phrases to discover meaning and create connections (Strauss & Corbin, 1998). Open coding identified main concepts or phenomena in the data through a line-by-line review to examine parts of the data for variation and associations (Priest, Roberts, & Woods, 2002) and disclose concepts and categories. The most useful method of coding was one that used the actual words and phrases of the participants.

Analysis continued through axial coding, which began the "process of reassembling data that were fractured during open coding" (Strauss & Corbin, 1998, p. 124). At this point in the analysis, categories were grouped together and relationships related to the nurses' role in end-of-life decision making were constructed as a new and deeper understanding of the data emerged (Priest et al., 2002).

Through selective coding, categories were examined to discover broader relationships and identify main themes while allowing a framework to emerge and recreate data into a conceptual framework. Four main themes were identified, and an ongoing data analysis identified the central theme (Supporting the Journey) that was referred to by all but one of the participants and was integral to each of the main themes. From the data analysis, the substantive grounded conceptual framework of the nursing role in end-of-life decision making in critical care settings was generated. Data analysis was conducted by the first author (V.B.), with ongoing review by the other authors. Although V.B. determined the themes and defined and expanded meanings, all of the

Table 1
Interview Guide—Final

Phase 1—Establishment
   Intent: Open communication and dialogue; make the participant at ease. Establish context through brief description of nursing role, continuing education.
     1. How long have you been a nurse? How long in this unit?
     2. Have you attended workshops or participated in further education having to do with palliative care?
Phase 2—Decision exploration
     3. Describe a situation that you have been involved in with an older patient who was dying.
     4. Can you tell me what end-of-life decisions are?
     5. Who has been involved in these decisions?
     6. Describe your actions or involvement related to these decisions.
Phase 3—Registered nursing role
   Intent: Explore the registered nursing role in health-related decisions as well as the types of decisions registered nurses are being asked to facilitate.
     7. Do you think there is a specific role for registered nurses related to decision making at end of life?
     8. If no, why not? If yes, what is that role?
     9. Was there a decision or situation that you would like to have been involved in but were unable to?
     10. Is there anything that you would do differently?
Phase 4—Conclusion
     11. Is there anything else you would like to add?
   If you have nothing else to add, I will now turn the tape recorder off. Thank you again for agreeing to participate in this research.

authors reviewed the coding, read transcripts to understand the reality of the interpretation, and give appropriate feedback, and all authors reached consensus on the final themes.

A number of strategies were used to address the criteria for evaluation of grounded theory studies described by Strauss and Corbin (1998). First, to promote credibility of study findings, negative case analysis was used to test for rival hypotheses. Selected interview transcripts were reviewed by two investigators during the development of categories. The main themes were reviewed by all research team members, and consensus was reached on the final themes. The research process was also clearly described, including sample selection, theoretical sampling, analysis procedures, and identification of the overall theme and major categories.

The first author's (V.B.) own experiences also informed the study. V.B. worked with a palliative care team in a large teaching hospital at the same

time that V.B.'s 89-year-old father was admitted to a hospital and died 3 weeks later. The conjunction of these two experiences led to the development of this research topic, specifically the role of nurses in decision making at the end of life.

Ethics

Prior to the interview, all nurses received a detailed information letter outlining the purpose and methods of the study as well as a consent form informing them that they could withdraw from the study at any time. The study was approved by the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board.

Results

Participants

The sample consisted of 14 RNs, including 12 women and 2 men. In all, 10 worked in the ICU and 4 in the CRCU. Their nursing experience ranged from 5 to 32 years, with an average of 13 years. Their experience in their respective units ranged from 2 to 20 years, with an average of 9 years spent in critical care. Ten participants had not received any palliative care education.

Supporting the Journey

The overall theme or basic social process related to the nursing role in end-of-life decision making, as identified from the perceptions of the nurses, was Supporting the Journey. In examining the collected data, 13 out of the 14 nurses interviewed talked about support. Support was described as an ongoing process that accommodated itself to the needs of each situation. Support was a bridge between life and death, which the nurses talked about as "all measures taken to support . . . life" or acknowledging that the time had come to "decide to support the death." Through giving of themselves in a range of capacities, the nurses endeavored to journey with patients and families where it was difficult for others to go and to support the patients to reach end of life peacefully and in comfort.

Further reflection on and analysis of the data resulted in the identification of four main themes that composed the process of nurses being present to support both patients and their families in the journey toward end of life:

(a) Being There, (b) A Voice to Speak Up, (c) Enable Coming to Terms, and (d) Helping to Let Go. Although these themes are overlapping, they are considered separately. Pseudonyms are used to indicate participants.

Being There

The nurses articulated an important part of the nursing role in end-of-life decision making when they described their understanding of the nursing role as being there as a presence to listen and to be a witness to the discussions. As part of this theme, some of the nurses described the listening that occurred between the nurse and the family to provide acknowledgement for the families as well as a confirmation that they were being heard. Lorraine spoke about listening to and receiving family members' emotions at the end of life, saying, "A lot of anger, and . . . fear, a lot of fear and sometimes just good listening, just really good listening 'cause sometimes that's all they can do, just to be heard by somebody." Being present with the patient at the bedside was paramount to "make the end of life a very pleasant, comfortable kind of experience" by working to "minimize the amount of pain and suffering and . . . make it more so a holistic kind of experience." Being present to listen was also coupled with providing comfort, often a combination of hand holding and medication to minimize pain. The nurses spoke about those patients who were alone at the end of life and described it as part of their "job" to be there with the patients, to be "up close and personal." The participants reflected on the meaning of providing comfort and its effect on end of life and spoke passionately about their need to minimize suffering. As Sarah reflected, "I want them to be comfortable. . . . I want them to just slip away. I don't want anybody suffering on their way out. . . . What's the point?" She continued, "Let them be comfortable, let them go easy."

A Voice to Speak Up

The second major theme was that of speaking up, as explained by Alice, who said that sometimes nurses were the only "safeguard [patients and families] have as a voice to speak up for them." This theme of speaking up required the nurses to take initiative to start end-of-life discussions or to clarify and interpret information that had been given to families and patients.

Nurses discussed examples of speaking up, such as giving their opinions at family meetings to convey patients' requests or express family concerns or further explain medical plans in language that would be understood by

all. Participation at family meetings or at the bedside drew on nursing knowledge and went hand in hand with the ability to absorb, synthesize, and clarify information. Rose talked about her role at family meetings and coupled listening with clarifying when she commented, "I feel that being a nurse, you're there to listen and sort of clarify amongst the people." Lorraine described initiating family conferences and said, "I'm comfortable with initiating a family conversation where the family's involved in the decision-making process." Laura described her role as helping families to think about what type of care the patient, their family member, would have wanted. She described taking initiative, saying, "I usually try to introduce to the family, what would they have wanted, have you ever discussed it?" She noted that when she saw families in distress, she would take the opportunity to start discussions. Laura maintained that it was part of her nursing role to speak up in family meetings, and when the prognosis became unclear it was her role to bring up any issues that would add clarity to the discussion. Adding her voice to the discussions was not always easy, and she said, "I just think it takes some years of being in the ICU to feel comfortable to speak up, to know enough . . . to have enough knowledge of what's going on." These nurses emphasized the importance of families having understandable information as part of the decision-making process that occurred between families and the care team. The nurses viewed information giving as a method of clarifying the care plan, enabling families to participate in the decision-making process.

One aspect of speaking up was truth telling, which frequently became a contentious issue. The nurses expressed differing approaches with regard to truth telling, including responsibility for information and decisions on how information was to be handled. Some of the nurses supported being straightforward with families, saying that "nurses spend far more time with a family" and "it's the nurse they end up speaking to." As one participant commented, the nurse was "better off telling them . . . being honest." However, some nurses tempered this direct approach by expressing the need for compassion and not taking away hope. Alice said that although she did believe in honesty, and "although telling [families and patients] this is the worst scenario . . . there's always hope that people can do better."

Nurses also described speaking up by initiating discussions with physicians related to patient and family end-of-life wishes. Elly said, "I will go to the doctor and tell him . . . that he needs to have a discussion with the family and that . . . this is their wishes and we should be going with their wishes." Nurses frequently took opportunities to let physicians know what questions families needed answered, and some saw it as their responsibility

to bring the physician in or question physicians on their course of action. The nurses talked about their responsibility to "care for the whole patient," and it was through knowing the patients and their health situations that nurses could effectively speak up on their behalf.

Enable Coming to Terms

The third major theme was helping patients and families come to terms with end-of-life decisions. This theme included the concepts of knowing the patients and giving families details that would help with their decision making. Providing emotional support and coordinating resources were also significant aspects of this theme. Ben spoke about this as "a supportive role, somebody here to . . . help the family after a family meeting to come to terms with it, answer any questions." For these nurses, coming to terms meant ensuring that all family members understood the health situation and prognoses and that they were all in agreement with the plan of care. This involved the nurses in a variety of roles. Jane described her role as expanding on the implications of a diagnosis and asking questions for the families. She affirmed the importance of detailed information for families to be able to make informed decisions because often once families understood all the information, "they may not have agreed . . . if they'd known all that." However, some of the participants commented that nurses with less experience had difficulty gaining a wider perspective and said, "The newer nurses, they're still overwhelmed with just looking after the patient that they don't always see the whole picture."

Helping to Let Go

The final theme identified by participants was Helping to Let Go. This theme involved nurses helping the patient and family to acknowledge and accept the conclusion of the patient's journey toward death. Nurses helped families emotionally release their loved ones and helped them to understand what the future might look like. Nurses then advocated for patients and families, although this was a complex and delicate task. The nurses advocated for the patient with the family and the medical team and also advocated for the family with the medical team. Laura discussed physicians who had difficulty "letting go" when she said, "Often doctors have a hard time, the nurses seem to be more accepting of these things 'cause they see the suffering that goes on."

Nurses also described the challenges they faced in helping families let go of their loved ones, in particular those challenges created by machines: the IVs, monitors, and life support. As Rose said, "A lot of families . . . don't want to stop treatment, even though . . . there's probably not much that can be done and they just want to hang on. . . . They want everything done." Laura spoke about families not understanding life support or the implications of having a family member on life support. She thought that families often felt guilty that there was "so much [technology] available and they can be saved so we should do it, at all cost."

Discussion

This research makes a number of important contributions to the literature of end-of-life decision making in critical care settings and the role of nursing. First, study findings revealed the critically important role of nurses in supporting the journey to end of life in critical care settings. Nurses played a number of key roles in being present to help patients to die in comfort and in helping patients and families come to terms with the expected death and to let go. Maxwell (2006) discussed comfort as an ICU nursing focus to ensure that comfort and dignity are maintained. Previous studies have acknowledged that there is limited evidence of how nurses are actually performing end-of-life roles (Scherer et al., 2006) or of their actual participation in end-of-life decision making (Thelan, 2005).

Second, this study revealed that one of the most fundamental roles nurses play is being present at the bedside, providing comfort, a caring touch, and a listening ear. Other literature has also talked about the importance of a nursing presence. Ciccarello (2003) described the use of presence by nursing as "one of the most powerful albeit simple interventions at end-of-life" (p. 219). The main elements of presence are being attentive, being open and sensitive to experience, being accountable, and consistently remaining in the moment. Shaw (2008) described the need for recognition of the nursing practice of being with patients that is separate from tasks and technology. Rather, it is a human interaction that supports being intimate and connected. In this study, nurses were present with their patients and families, not only actively attending family meetings but also simply being with and letting patients and families express their emotions while actively listening and supporting. The results of this study are supported by the theoretical framework of Rushton (2005), which blends the concepts of being and doing. Although it is from a pediatric perspective, Rushton's framework can be applied to

adults and families in palliative care as she stated that nursing presence requires action, which includes helping patients to cope and endure and supporting families in their need to understand the dying experience.

Third, this study confirmed the vital end-of-life role nurses have in explaining and interpreting. In a study of communication at the end of life, Hancock et al. (2007) stated that patients did not recall up to half of the information they received because of stress, misunderstanding related to terminology, or blocking of information as a method of coping. The nursing role of giving or clarifying information is well supported in the literature. Wilkin and Slevin's (2004) study supported this role as part of caring actions, which included information giving as well as explaining. Scherer et al. (2006) expanded this role to giving information to patients to help them define their illness experience so that when they were no longer able to speak for themselves the nurses could communicate with families to assist in decision making.

Also seen in this study is the issue of truth telling, which involved differences in nursing approach. In being truthful, the nurses endeavored to balance honesty with hope. Telling the truth can be interpreted as giving information to help patients and/or families make informed care decisions. Therefore, language must be understandable. From an ethical perspective, not telling the truth denies trust and denies the patient or family an ethical and legal right (Hebert, Hoffmaster, Glass, & Singer, 1997). In their article on hope and truth telling, Begley and Blackwood (2000) identified hope as having a positive effect on health and stated that promoting hope in patients is significant for nursing. However, the two concepts, hope and truth telling, need a careful and deliberate balance, with full collaboration and agreement within the care team to ensure that patients and families receive the care they need and deserve (Vivian, 2006).

Fourth, study findings affirm tensions experienced by nurses between caring for the patient and family and taking care of technology in a critical care setting. Baggs et al. (2007) described an "overuse of technology" as problematic and not compatible with patient preferences. Pattison (2004) described delaying death through sustaining life with technology, however at a cost to the patient, through care that is highly medicalized and not holistic.

Finally, this study emphasizes the lack of preparation critical care nurses receive to provide skilled, sensitive end-of-life care in a critical care setting. Only 4 of the 14 nurses interviewed had received any palliative care education. In their qualitative studies, both Ciccarello (2003) and Dawson (2008) stated nurses in critical care settings are poorly prepared to deliver holistic, supportive care.

There are several important implications for nursing practice based on the findings of this research. This model of Supporting the Journey fosters and creates value for nursing care at the end of life in critical care settings. Nurses are involved in decision making at the end of life, but it is time to stop "leading quietly" and become part of an active, knowledgeable, and caring force. Nurses can accomplish this through (a) being fully present with the patient and family during end of life; (b) advocating for the patient's end-of-life wishes; (c) advancing their practice with patients, families, and other members of the health care team by actively participating in family meetings and strengthening working relationships with health care staff; (d) mentoring novice nurses and encouraging them to value their own "voice" and develop their holistic practice; and (e) participating in ongoing learning related to leading practices in end-of-life care.

Nursing education can evolve to support the development of nursing practice in end-of-life decision making. Education in both palliative care and end-of-life care, including grief and bereavement, should be included in the nursing curriculum. In addition, education on the role of the critical care nurse in the ICU and CRCU is needed to understand the implications of combining humanistic care with technology.

Interprofessional education is needed with regard to palliative care, end-of-life care, and clarification of interprofessional roles. This can be combined with education on how to work within a multidisciplinary team to ensure that everyone is able to communicate and contribute to the common goal—patient care and comfort at the end of life. Interprofessional learning creates an opportunity for members of the health care team, in this context specifically physicians and nurses, to "learn with, from and about one another to facilitate collaboration in practice" (Ker, Mole, & Bradley, 2003, p. 248). Interprofessional education offers the potential of a "holistic approach to health care," where health professionals "broaden their perspectives beyond their own specialist area and . . . draw on the expertise and approaches of other professional groups" (Mandy, Milton, & Mandy, 2004, pp. 154-155).

Education is also needed for families and patients. The ICU and CRCU remain unknown territory, often frightening and overwhelming for the lay public who enter this demanding environment at some of the saddest and most tension-filled times of their lives. An educational program, offered in the hospital and specifically directed toward families, could help to diminish their fears.

Although this research contributes a valuable understanding of the nurse's role in end-of-life care in a critical care setting, there were a number of study

limitations. This study had a moderate sample size of 14. It is recommended that grounded theory studies start with at least 20 participants (Creswell, 1998). The sample size may have limited the depth of information that would have been available through further interviews. Further confirmation and testing of this preliminary conceptual framework is required. We did not engage in member checking to avoid burdening staff who had found the initial interview difficult to schedule. However, transcripts and findings were consistently reviewed by two investigators. Also, through constant comparative analysis, it became obvious after the first nine interviews that consistent themes were found. The next five interviews confirmed what had been found, giving the research internal validity.

The study was carried out in only one ICU and one CRCU in one hospital. Because of the nature of the environment, it was not possible to conduct nonparticipatory observations of RN staff. In addition, interviews with patients and families were not conducted. These data collection strategies of observations and interviews with patients and families may have added an additional dimension to understanding the role of the nurse and perhaps a deeper insight into the barriers that nurses encounter in carrying out this role. Last, although we intended to specifically look at the end-of-life experiences of elderly individuals in critical care settings, many of the responses did not specifically address the older population.

Further research is needed to better understand the role of the nurse in end-of-life care and decision making in critical care units. Specifically, research with larger samples and in multiple critical care units would be valuable. We still know relatively little about the factors that facilitate and hinder effective nursing roles in decision making at the end of life in critical care units. Additional research could focus on the nurse–physician relationship within the end-of-life critical care context, the influence of technology on end-of-life decisions, and the impact of the sense of loss experienced daily by the critical care nurse.

This research study has given voice to the roles played by critical care nurses in supporting the end-of-life journey of patients and caring for their family members. The overall theme of Supporting the Journey and the subthemes that are described illustrate the key roles nurses enact in supporting patient and family decision making at the end of life. Given the complexity of the critical care setting, the integration of the bridging role of nursing decision making at end-of-life care is a worthy goal of the critical care team.

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