The cardiovascular intensive care unit nurse’s experience with end-of-life care: A qualitative descriptive study

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Accepted 3 May 2009

Summary

Purpose: Nurses in the cardiovascular intensive care unit (CVICU) informally expressed moral angst when caring for patients who are approaching the end of life. The purpose of this study was to better understand CVICU nurses’ perceptions about their roles and responsibilities in the decision-making process about change in intensity of care and end-of-life care for patients within the CVICU setting.

Participants and methods: Nineteen nurses from one CVICU consented to being interviewed individually regarding their experiences caring for patients approaching the end of life, and specifically regarding the initiation of a change in code status. Investigators used a qualitative descriptive approach to collect and analyse the data. Transcript data were analysed and as concepts emerged they were compared with those from earlier interviews to establish similarities and differences. Investigators reached consensus about the major themes.

Findings: Analysis revealed four major themes: (a) exhausting patient treatments; (b) promoting family presence; (c) acknowledging physician authority; and (d) walking a fine line.

Conclusions: This research adds to the limited body of knowledge concerning CVICU nurses’ experiences with end-of-life care. Results of this study provide a basis for putting in place support systems for CVICU nurses.
Introduction

Determining when curative care becomes futile has become today more complicated than ever, in light of the advances in the last 30 years in technology and treatment options (Ferrell, 2006). "It has been a time of 'Star Wars' medicine, in which many conditions and illnesses that previously were considered fatal now are deemed manageable and in many instances, curable," leading to the belief "that death can be avoided" (Ferrell, 2006). Nurses often find themselves struggling with this belief, in conflict between their role as autonomous providers and advocates for the patients versus their role as assistants simply carrying out physicians' orders.

Patients and their families are challenged to understand treatments and their risks and implications because of the advanced technology available in the modern critical care unit (Meltzer and Huckabay, 2004; Scherer et al., 2006). The nurse, as educator and advocate to the patient, bears much of the burden of providing the level of education needed by patients and families when curative care no longer appears to equate with quality care (Meltzer and Huckabay, 2004). However, nurses may feel frustrated by their lack of influence in decision-making regarding end-of-life care (Scherer et al., 2006). Nurses, like other clinicians, enter into relationships with patients and other healthcare providers with personal moral values (McClendon and Buckner, 2007). Providing aggressive care to patients not expected to survive was found by Elpern et al. (2005) to cause nurses high levels of distress. Experiences of moral distress are expected to increase as ever more advanced technologies become available (Elpern et al., 2005).

When a patient dies, the nurse grieves. This grief however, is often concealed or suppressed possibly due to the unacknowledged right of the nurse to grieve. Suppression of grief can lead to further stress to the critical care nurse (Brosche, 2003).

Among all members of the healthcare team, it is the nurse, constantly at the bedside, who bears the most stress in caring for the dying patient (Beckstrand and Kirchoff, 2005). Moral distress occurs frequently among registered nurses when they are asked to perform ordered tests and treatments they consider unnecessary, and when life support is continued due to family wishes if nurses feel it is not in the patients' best interest (Zuzelo, 2007). Moral distress from such situations can lead to emotional exhaustion and burnout in the critical care nurse (Meltzer and Huckabay, 2004). Nurses with these dilemmas are often without any formal ethics education (Zuzelo, 2007). In a study examining moral distress of nurses working in a medical intensive care unit, many participants expressed concern that their own distress was "unique and disproportionate to what other nurses experienced" (Elpern et al., 2005).

Communication among all involved members; nurses, patient, family and other members of the healthcare team is vital to effective care (Ferrell, 2006; McClendon and Buckner, 2007). Differing opinions among multiple physicians caring for a patient has been identified by nurses as one of the largest obstacles to providing end-of-life care (Beckstrand and Kirchoff, 2005; Torjuul and Sørlie, 2006).

Part of the responsibility for effective communication among healthcare team members, patients and families resides with the institution itself. There must be strategies in place to deal with conflict among the involved parties. Otherwise nurses who feel they cannot effectively advocate for patients will experience moral distress (Corley et al., 2005). Certain ethical conflicts may necessitate the formation of multidisciplinary teams (Mobley et al., 2007). Oberle and Hughes (2001) stressed the value of communication between physicians and nurses, concluding that any differences are more a product of their designated roles within the hierarchy of the hospital than differences in morality or ethics.

Nurses in one cardiovascular intensive care unit (CVICU) informally expressed moral angst when caring for patients who are approaching the end of life. The purpose of the study was to better understand the CVICU nurses' perceptions about their roles and responsibilities in the decision-making process about change in intensity of care, palliative care, and end-of-life (EOL) care for patients within the CVICU setting. The objectives of the study were to:

(a) Describe the nurse's experience with initiation and the decision-making process related to change in the intensity of care, palliative care, and EOL care for acutely ill patients in the CVICU.
(b) Describe the nurse's perception of the nurse's role in change in intensity of care, palliative care, and EOL decisions.
(c) Describe the factors that influence EOL decision-making in the CVICU setting.

Methods

The investigators used a qualitative descriptive design to generate a complete, organised, descriptive summary of the data (Sandelowski, 2000). Methods for a previous study with neuroscience ICU nurses at the same facility were replicated for this study (Calvin et al., 2007).

Setting and participants

Approximately 120 licensed registered nurses, employed part-time or full-time in a 51-bed CVICU at a tertiary care teaching hospital, were invited to participate in this study. The unit manages 45 post-operative patients with open heart and vascular surgeries (e.g., aorto-coronary bypass, aortic and mitral valve replacement, carotid endarterectomy, femoral-popliteal bypass, thoracic/abdominal aortic aneurysm repair, transplants, ventricular assist device placement) and six pre-operative patients. The length of stay of stable patients is on average 24–48 h. Typical technologies used include intra-aortic balloon pumps, continuous venous to venous haemodialysis, pulmonary artery catheter monitoring, left and right ventricular assist devices, and extracorporeal membrane oxygenation.

After obtaining approval by the hospital and university Institutional Review Boards for the protection of human subjects, a flier about the study was placed in the mailbox of each nursing staff member. The nurses' response to the fliers was poor, so one of the investigators (C.L.) approached nurses while they were on duty to personally invite partici-
Table 1 | Demographic characteristics of study participants.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
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<tbody>
<tr>
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<td>Gender distribution (male:female)</td>
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<tr>
<td>Educational level</td>
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<tr>
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</tr>
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<td>Mean years (range)</td>
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<tr>
<td>Length of time in CVICU</td>
<td></td>
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<tr>
<td>Mean years (range)</td>
<td>6 (0.75–20)</td>
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</tbody>
</table>

Abbreviations: MSN, master of science in nursing; BSN, bachelor of science in nursing; ADN, associate’s degree in nursing; CVICU, cardiovascular intensive care unit.

Table 2 | Interview guide.

1. Tell me what it’s like to work with patients in the cardiovascular ICU who are approaching the end of life.
2. What’s it like to initiate a change in code status? (How do you go about initiating a change in code status?)
3. Describe your role in treatment decisions regarding end-of-life care.
   (a) How do you feel about this role?
   (b) What are the advantages and disadvantages of this role?
4. What factors influence end-of-life decisions in the cardiovascular ICU?
   (a) What helps or does not help?
   (b) Who helps or does not help?

Note. Code status is the designation of resuscitation efforts: Code I = all possible means of support including cardiopulmonary resuscitation (CPR) and mechanical ventilation; Code II = active medical treatment except initiation of CPR and mechanical ventilation; Code III = comfort care only with no attempt to resuscitate.

Data collection

Individual interviews with CVICU nurses were audi-taped and took place in a private office near the CVICU. One researcher (C.L.) conducted all initial and follow-up interviews. Participants were asked moderately structured questions (Sandelowski, 2000) that had been generated for a previous study (Calvin et al., 2007; see Table 2). Consistent with qualitative methodology, end of life was not defined by the investigators; rather, participants spoke freely about what it meant to them. Interviews were approximately one hour in duration. Second interviews with nine participants gave nurses an opportunity to read and react to a one-page summary of the findings. Participants generally endorsed the synopsis or made clarifications and offered further examples to support the existing data. Field notes primarily about the content and tone of the interview were documented after each interview for the purpose of contributing to an audit trail, thereby enhancing trustworthiness of the data (Lincoln and Guba, 1985).

Data analysis

Audiotapes were transcribed word for word by a transcriber, and then confirmed by the investigators. Transcript data were content analysed by scrutinising each line and then codes (i.e., key concepts or phrases) were written in the margin, creating a label for each sentence (Glaser, 1978; Lincoln and Guba, 1985; Sandelowski, 2000). As codes surfaced they were weighed against those from previous interviews to determine parallels and disparities. By the seventeenth interview, no new codes emanated, suggesting that redundancy in the data was reached (Glaser and Strauss, 1967). The last two interviews verified data saturation. The three investigators met on five occasions to discuss the codes until representation of the data was mutually agreed upon. Microsoft Office Word was used to manage the data. Codes were clustered and labelled using broader categories, yet words remained consistent with those used by nurse participants (Sandelowski, 2000). The data were then structured to summarise the nurses’ perceptions about EOL care in the CVICU.

Findings

Nurses in the CVICU discussed their perceptions of EOL care in view of their care-giving position, situated between the patient and family members and the physicians (see Fig. 1). We identified four themes that summarise nurses’ perceptions: exhausting medical treatment, promoting family presence, acknowledging physician authority and walking a fine line. In this section, we use the feminine pronoun because the majority (74%) of study participants was female;
further, the consistent use of a single pronoun (i.e., she or her) does not encumber the text like the use of both pronouns (i.e., he/she or him/her).

Exhausting medical treatment

In the CVICU, the nurse's usual role is to assist patients in their recovery post-cardiovascular surgery using state-of-the-art, life-saving technologies. The focus on recovery and cure shifts for some patients as the nurse begins to see signs of sustained patient deterioration. One nurse (RN05) described the nurse's role in the CVICU:

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\text{I think it's the closest thing to being the hand of God as you can be. Because sometimes you're delivering people from the hands of death and sometimes you're delivering them gently to that place. You know we're always the hands that carry out the order and we're touching the patient.}
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The CVICU nurse takes part in phasing out medical treatments at the point when the patient is beyond recovery. One nurse (RN04) said plainly, "There's nothing more to do." The nurse perceives without a doubt that the patient's chance for recovery is slim (RN01). She sees patient pain, suffering, and poor quality of life. The nurse also witnesses family members' grief: "It's tough to see family members go through this; it's heartbreaking." (RN04). In the nurse's mind, the physician has exhausted possible medical and surgical treatments.

Knowing for certain that treatments have been exhausted is not always the case. Particularly when the patient's prognosis is bleak, the nurse resorts to personal faith and spirituality to extend nursing care. For example, one nurse (RN10) prays for her patients, "Sometimes I pray for my patients, ""I have my little prayer book with me, in my pocket, and I always say a prayer."" The nurse sometimes witnesses the rare miraculous recovery and one nurse (RN10) cited an instance where the patient "beat the odds":

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The cardiologist actually wanted to name her a Code III [comfort measures only], and I said, 'No.' I said, 'There's no way. This girl is too young. She's only twenty years old. Give her a chance; she was on ECMO [extracorporeal membrane oxygenation] for two days. Don't give up so early.' They consulted a neurologist and he said that she's decerebrating and blah, blah, blah. I said, 'No, there's something there.' You know you have that feeling, you have that instinct. I think most nurses at the bedside have that instinct that there is something underneath there. And that particular day, when they had done all that and spoke with the family and everything, the mom came to me and she said to me, 'What do you think?' I said, 'If it was my child and if it was me I would give her a chance. There's always another chance. And the mother said, 'No.' She said she will not make her a Code III as well. She was a very sick girl, very, very sick. Then the following day when we got on shift, she was beginning to wake up, opening her eyes and moving, not moving appropriately. And then she was full blown awake the following day. I think God was with her because the day after, a double lung and a heart, became available for her. We transplanted her. She did wonderful; she's right now out in the community.
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The nurse may also be unsure if the patient will turn around or not. One nurse (RN06) said,

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The family will start asking you, 'Have you seen anyone this sick turn around?' Then you can feel comfortable to say yes or no, but again nothing is for sure, because you cannot tell who will absolutely. So a lot of times, you can kind of help the family to think.
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As difficult as it is to lose a patient, the death of a patient does not appear to create moral strife for the nurse when "God says this is it" (RN02) or "patients make the decision themselves and just die" (RN05). The nurse acknowledges a bit of solace in instances where active decision-making is unnecessary. Other patients, however, cling to life.

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I've seen people hold on with blood pressures of 30 for hours until they hear the voice of whatever family members they're waiting for. And then they go. It's amazing; it just proves that all that we can humanly do to support life isn't always the thing that will get a patient through that situation. It's often the will of the person. That makes the difference. (RN07)
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Some patients "linger beyond the point that is humanly kind... It's something that you struggle with when you see a patient with black fingers and black toes and major skin breakdown issues, barely having a pressure, except for the external support and sometimes that is prolonged beyond reason, in my opinion." (RN07)

Promoting family presence

Patients in the CVICU invariably have compromised decision-making capacity due to the severity of their health condition. Health care professionals turn to patients' family members for their opinion regarding patient treatment options. The nurse is sensitive to the need for patient and family togetherness, but the nurse's ability to maximise patient and family time together is compromised. The nature of the CVICU offers limited privacy and visiting hours restrict family presence.

The nurse appreciates family presence for the sake of the patient. For example, family members personalise a patient who has become obscured by technology. Patient relatives tell the patient's story and relatives form a bond with the nurse.

The nurse values family presence for the purpose of preparing the family and for contributing to the family's acceptance of the patient's demise. The nurse describes family members' difficulty accepting the severity of the patient situation. One nurse (RN11) said:

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You don't want to be the bad guy. Because they're going to remember, 'You told me my loved one was going to die.' And then the doctor gets to be the good guy. But you get to the point where I think they need to know. I don't think they should be left in the dark and it's a surprise. They need to know how sick their family member is.
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When asked if the nurse ever initiated a conversation to tell family members about the severity of the patient’s condition, the nurse (RN11) responded,

Yeah I told them, I just hoped that I wouldn’t get into trouble, but I found, if they’re asking me, I’m like ask one of the doctors, ‘What’s the doctor said to you?’ And then I just explain, you know, we’re on all these medicines to keep a blood pressure, we’re on a ventilator so he can breathe, we’re on an LVAD [left ventricular assist device] that’s his heart, we’re on dialysis that’s his kidney. I said if you took all that away, he couldn’t do anything on his own. I think that sometimes brings them around.

The nurse acknowledges that family members are frequently not ready to let go. When family members are allowed more time with the patient, the process of letting go is facilitated. The nurse believes that the family’s receptivity to reality is fostered by greater family presence. One nurse (RN14) opined:

I think as a bedside nurse we have a lot more interaction with family and I think with families being able to see what all we’re doing, that gives them time to help their family member and hopefully get a sense of trust for the bedside nurse.

Despite family members and physicians being essential contributors to the decision-making process, nurses view the communication between these two parties as fragmented.

Acknowledging physician authority

Nurses have a hard time preparing families for the patient’s death. The end seems to be clearly approaching, but typically, physicians do not perceive that medical treatments have been exhausted and that the patient’s condition is irreversible. The CVICU nurse clearly acknowledges physician authority when it comes to EOL decision-making. The nurse perceives the physician as the rightful initiator of the discussion as well as the final decision maker.

Usually, I don’t talk to the families, unless I’ve already talked to the doctors and know what’s going on. I want the doctors to talk to the families first, because there are a lot of questions they’ll ask and I’ll just tell the family, ‘That is a doctor question. I, as a nurse, can’t answer that for you.’ (RN08)

The nurse is ‘on the sidelines’ (RN02) allowing the physician to explain the patient’s condition, treatment options, and prognosis. Making EOL decisions is ‘not our job’ and being on the sidelines or the ‘middle man’ (RN15) can be uncomfortable.

We have quite a few physicians that don’t have time to speak with these family members or they’re just trying to avoid a situation. Unfortunately, it’s a common occurrence when we’ll have a family member that wants to speak to a physician and they’ll go for days without actually being able to speak to them [physicians] personally. And that’s really hard on us and the family members because we have to, we as nurses have to be kind of the middle man. Sometimes we have to just make up excuses for the doctors and I know that’s not right, but there’s not much we can do about that. We just have to tell the family members, ‘Oh, you know, I’m sure that the doctor is busy and we’re doing everything we can to try to get in touch with him.’ Makes you feel pretty bad because these family members, they don’t know exactly what’s going on. (RN15)

For the most part, the nurse is at ease with the physician’s authority; yet, the nurse is frustrated by physician reluctance to discuss with family members the option to stop medical and surgical treatments. The nurse readily speculates on reasons for physicians’ reluctance. For example, ‘I think physicians are unwilling to let go... doctors fight for life beyond all else. Sometimes I feel like they’re using the patients as experiments’ (RN07). The nurse doubts the extent of her influence or feels perplexed when she questions the physician’s plan of care. One nurse (RN11) said,

I’ve asked physicians, ‘Are we going to change code status?’ ‘Well, why would we want to do that?’ That’s the response I got one day; yet, the day before, he said, ‘Well, I don’t think there’s much else we can do for this person.’ I’m like, ‘I must have missed something.’

Walking a fine line

The CVICU nurse who cares for patients who are approaching the end of life does not hesitate to say that EOL care is difficult. The nurse perceives one of her primary duties to be clarifying patient values and treatment wishes. The nurse ‘walks a fine line’ when she hints about the patient’s demise to the patient’s family members or physician (RN02).

You try to lead them [family members] without being obvious about it. And you don’t flat out just say he’s [the patient] not going to make it and there’s nothing else we can do, because [one physician] will go out there and tell them, ‘Oh yeah, he’s looking better today.’ And you just told them that you’re not sure he’s going to make the day. So you just learn to walk on that line there with those types of patients.

To avoid verbal reprimand by the physician, the nurse takes into consideration individual physician receptivity to the topic of changing the patient’s code status. ‘Sometimes they [physicians] just chop you at the legs if you mention something like that [change of code status]’ (RN03). In fact, some nurses held back during the interview, while others were confidently verbose. A nurse (RN02) spoke about one physician in particular:

He’s jumped down the nurse’s throat. And if the family ever says ‘the nurses said...’ he comes and jumps down the nurse’s throat because you said something he didn’t want the family to know. And he’s done it; he’s come in and chewed out the nurse at the bedside, ‘You told the family and you shouldn’t have told them that.’ So, it’s a very fine line that you’re walking on with what to let them [family members] know.

Being careful with her words or keeping silent puts a strain on the nurse who interacts with the patient’s family members and elicits clarification of the patient’s values and
treatment wishes. When appropriate, the nurse encourages the physician to talk honestly to family. One nurse (RN11) said, "...getting the doctors to talk with the family, I think that's the hardest part; it's getting them [physicians] to truthfully tell the family, we can't do any more. And I think some doctors find it hard."

Despite the emotional difficulty, the nurse learns to mask her emotions or "separate yourself" and "just do your job" (RN15). One nurse (RN16) said:

_We nurses handle our emotions real well. We can't be much involved in this [code status] change for the patient. We have some emotions, then we have to block it to function as a professional. I never have yet yielded to that; it's the right thing to do._

A novice nurse expressed experiencing fear or discomfort with death, dying, and talking to family members in the CVICU. Support from more experienced nurses is helpful.

**Discussion**

This study offers information regarding the CVICU nurses' perceptions about their roles and responsibilities in the decision-making process about change in intensity of care, palliative care, and EOL care for patients. What is unique about this study is that the nurse participants spoke about their experiences in the cardiovascular intensive care unit, as opposed to general medical and surgical intensive care units where the majority of participants were recruited for previously published research.

Participants in this study expressed the importance of family presence at the end of life. Nurses (N=281) in one study reported that extending care to the patient's family is a way to promote dignified dying, as family care offers the opportunity to teach the family about the process of dying and allows privacy (Wilson et al., 2006).

Nurses in this study described being "on the sidelines" or being the "middle man" and considered the physician to hold the authority regarding EOL decisions, just as nurses (N=12) did in a previous study (Calvin et al., 2007). Nurses (N=14) reported feeling loneliness and uncertainty related to their "in-between position" of having to administer treatment dictated by physicians, regardless of the nurses' own beliefs (Hov et al., 2006). The vast majority of critical care nurses (202 of a sample of 210) agreed with the statement that nurses should help inform patients of their condition and treatment options (Scherer et al., 2006). Ideally, providing information to patients is something that nurses know they should do; however, nurses in the current study expressed reluctance to do so fearing reprimand by the physician. Physicians are likely to be unaware or unsure of nurses' role in EOL care. For example, in a paper intended to guide medical students, residents, and physicians regarding medical treatment futility, Kasman (2004) made no mention of nurses in the decision-making process.

Nurses in this study as well as neuroscience ICU nurses in a preceding study (Calvin et al., 2007) expressed the serious challenges and frustrations involved in communicating with family members and physicians about EOL care. Nurses talked about their moral struggle when patients appear to be lingering and medical treatments continue. Nurses are distressed by patients being treated as experiments (Zuzelo, 2007). Investigators showed that critical care nurses' (N=44) highest source of moral distress related to providing futile care (Mobley et al., 2007). Other investigators found that critical care nurses' (N=60) moral distress related to futile or nonbeneficial treatments is significantly related to emotional exhaustion (r = 0.317, P = 0.05; Meltzer and Huckabay, 2004).

Patients in the ICU expect nurses to provide them with information and explanation (Hofhuis et al., 2008). The nurses in the present study related to being torn between their responsibility to do so with respect to families and the authority accorded to them by the institutional hierarchy. If ICU nurses are to contribute optimally to quality patient care, and in a manner that reduces moral distress, the ICU culture and administration must find a way to accommodate patients' and families' desire for information and explanation and the health care team's goal of consistent and mutually agreed upon plan of care.

Nurses in this study and previous studies (Calvin et al., 2007; McClendon and Buckner, 2007; Zuzelo, 2007) spoke of the need for physicians to speak frankly with family members. In a study of 864 nurses, physician evasiveness and avoidance of family members was one of the greatest obstacles to providing quality EOL care (Beckstrand and Kirchoff, 2005).

The investigators employed measures to ensure scientific rigor (e.g., transcript verification, meetings to reach theme consensus). The generalisability of this study's findings is limited due to its qualitative design and that it was conducted in a single unit at a single acute care facility.

An implication of this study is that nurses in the CVICU are challenged to respect the values of patients, family members, and physicians while being true to their own values. To ease this challenge, nurse administrators might introduce mechanisms and resources whereby all parties can effectively communicate about the patient's best plan of care. Findings of this study also imply that a formal senior nurse support structure be in place for novice nurses in the CVICU for instances where ethical issues arise. In addition, both the expert and novice nurse would likely benefit from a spiritual support system. Nurses in the CVICU might explore alternative visiting hours for family members to promote greater togetherness. A direction for future research might be to test the effectiveness of a senior nurse support structure and a spiritual support system for CVICU nurses.

**Conclusion**

This descriptive summary of CVICU nurses' perceptions about caring for patients at the end of life offers evidence that CVICU nurses are challenged in caring for patients at the end of life. Existing research of nurses' experiences at the end of patients' life is limited, especially research involving CVICU nurses. This study contributes to that body of research and offers evidence to base support structures for the CVICU nurse.
Conflict of interest

The authors of this manuscript have no affiliations or financial involvement with others that inappropriately influenced or biased the work presented herein.

Acknowledgments

The authors thank all the dedicated nurses who participated in this study and Sandra Hanneman, PhD, RN, FAAN, Jerold B. Katz Distinguished Professor for Nursing Research for editorial assistance. The authors also gratefully acknowledge financial support for this research from St. Luke’s Episcopal Hospital.

References


