NATIONAL SURVEY OF CRITICAL CARE NURSES' PERCEPTIONS OF END-OF-LIFE CARE AND EFFECT OF INCENTIVES ON SURVEY RESPONSE RATES

by

Reneā Lindstrom Beckstrand

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SUPERVISORY COMMITTEE APPROVAL

of a dissertation submitted by

Reneā Lindstrom Beckstrand

This dissertation has been read by each member of the following supervisory committee and by majority vote has been found to be satisfactory.

[redacted] [redacted]
Chair: Karin T. Kirchhoff

[redacted] [redacted]
William T. Alward

[redacted] [redacted]
Maribeth C. Clarke

[redacted] [redacted]
[redacted]

[redacted] [redacted]
B. Lee Walker

THE UNIVERSITY OF UTAH GRADUATE SCHOOL

FINAL READING APPROVAL

To the Graduate Council of the University of Utah:

I have read the dissertation of Reneā Lindstrom Beckstrand in its final form and have found that (1) its format, citations, and bibliographic style are consistent and acceptable; (2) its illustrative materials including figures, tables, and charts are in place; and (3) the final manuscript is satisfactory to the supervisory committee and is ready for submission to The Graduate School.

[redacted]
Date

Karin T. Kirchhoff
Chair, Supervisory Committee

Approved for the Major Department

Chair/Dean

Approved for the Graduate Council

David S. Chapman
Dean of The Graduate School

ABSTRACT

Critical-care nurses care for dying patients daily. The process of dying in an intensive care unit (ICU) is complicated. Research with regard to obstacles and helpful behaviors that impede or support critical-care nurse delivery of end-of-life care is limited. This study advances work completed in the pilot study.

The primary aim was to measure critical-care nurses' perceptions of obstacle severity and frequency and the intensity and frequency of helpful behaviors in providing end-of-life care. A secondary aim was to compare the effect of three different incentives on critical-care nurses' survey response rates using a theory on immediacy.

An experimental, posttest-only, control group design was used. A random sample of the American Association of Critical-Care Nurses (AACN) yielded 861 usable responses from 1,409 eligible respondents (61%).

The three most severe obstacles were frequent calls to the nurse, families not understanding the term "lifesaving measures," and physicians disagreeing about the direction of patient care. The three most intense helps were when nurses allowed the family adequate time alone (after death), provided a peaceful and dignified bedside scene, and taught the family how to act around the dying patient.

Other results included nurses preferring that a patient experience a "good death," more time be provided to care for patients, communication to patients be more open and honest, and education in end-of-life care be provided to physicians and nurses. Nurses reporting more ICU work experience were older and also had cared for more dying patients (75%) than did nurses reporting less experience (62%). Certified critical-care registered nurses (CCRNs) perceive as larger obstacles physicians being overly optimistic about the patient surviving, families not accepting that the patient will die, visiting hours that are too restrictive, and patients who have pain that is difficult to alleviate or control.

For the secondary aim, the $2 incentive was the only one found to be associated with significantly improving response rates. Although overall response rates were less than planned, the theory of immediacy did help explain the outcome of the response rates.

Dedicated to the memory of Edna B. Lindstrom, my mother.

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CHAPTER I

INTRODUCTION AND REVIEW OF THE LITERATURE

Background and Significance for Primary Research Aim

Introduction

> To cure sometimes, to relieve often, to comfort always [15th Century adage]. (Oliverio & Fraulo, 1998, p. 6)

Death is a fact of life. Providing appropriate care for people who are dying is a chief concern in the United States today (Kirchhoff et al., 2000). With more than 2.3 million deaths annually in the United States, most deaths (80%) occur in the hospital setting involving patients who are 65 years or older (Anderson, Kochanek, & Murphy, 1997; McCullough, 1996). Often, critical-care nurses are responsible for caring for these dying patients since about one fifth of intensive care unit (ICU) patients die while hospitalized (Dracup & Bryan-Brown, 1995).

Death, as it occurs in the ICU environment, is neither simple nor natural (Chapple, 1999). Caring for dying patients and their families is believed to be most stressful and painful to the nurses who must constantly attend the patient (Anderson, 1996; Baggs & Schmitt, 1995; Perkin, Young, Freier, Allen, & Orr, 1997), whereas other healthcare providers can visit, then walk away (Chapple, 1999; Maeve, 1998). Gaining an understanding of the perceptions of critical-care nurses with regard to obstacles or helpful behaviors (helps) in providing end-of-life care is necessary so that interventions to support nurses can be developed and implemented, ultimately improving patient care at the end of life.

Despite adequate documentation of the difficulties and inadequacies of providing end-of-life care to dying patients (Alspach, 1997; Baggs & Schmitt, 1995; Ferrell, Virani, Grant, Coyne, & Uman, 2000; Fins et al., 1998; Oliverio & Fraulo, 1998; Stanley, 1998; The SUPPORT Principal Investigators, 1995), investigators who specifically study the obstacles and helpful behaviors that constrain or promote good care of the dying, from the perspective of the critical-care nurse, is limited (Ferrell et al., 2000; Kirchhoff & Beckstrand, 2000; Kirchhoff et al., 2000). Although some studies list reported obstacles, there are no reports documenting both the size and frequency of specific obstacles or helpful behaviors. The present study was designed to measure critical-care nurses' perceptions of both the severity and frequency of listed obstacle items and the intensity and frequency of listed helpful behaviors in providing end-of-life care to dying patients and their families. The research questions included the following:

1. Which obstacles to providing end-of-life care to dying patients do critical-care nurses perceive as being the largest, most frequent, and most severe?

2. Which helpful behaviors (or helps) to providing end-of-life care to dying patients do critical-care nurses perceive as being the largest, most frequent, and most intense?

3. Which aspect of end-of-life care would critical-care nurses most like to see changed?

4. In what ways do critical-care nurses' perceptions of obstacles and helpful behaviors differ based upon length of ICU work experience?

5. Do CCRN-certified critical-care nurses' perceptions of obstacles and helpful behaviors significantly differ from the perceptions of critical-care nurses who have never certified as a CCRN?

The research was designed to lay the foundation for developing interventions that help decrease both the severity and frequency of obstacles to proving end-of-life care and promote or support the intensity and frequency of helpful behaviors. A secondary aim (see Chapter II) was to determine the impact of three different incentives on mailed survey response rates using an experimental design.

End-of-Life Movement

The population in America is growing older as advancements in the diagnosis and treatment of acute and chronic diseases continue to progress. With these advancements in care, lives are spared from imminent death in exchange for later and more likely, prolonged death. Of the 2.3 million Americans who die annually, more than 70% are age 65 or older (Donaldson & Field, 1998; Field & Cassell, 1997; Stanley, 1998), and approximately 80% of deaths occur while patients are hospitalized (McCullough, 1996). In the next 30 years, estimates indicate that the percentage of the total population older than 65 years will increase from 13% (reported in 1994) to 20%, comprising more than 70 million people (Donaldson & Field, 1998).

As treatments and technologies continue to extend life and as the population continues to age, issues with regard to care at the end of life will continue to increase in importance. In order to understand the intricacies of end-of-life care, it is important to reflect on the beginnings and current state of this movement.

Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)

In the 1960s, Kubler-Ross's work brought to light the difficulty the medical field had in dealing with dying patients in the acute hospital setting (Cassel & Vladeck, 1996). Hospice care was introduced in the United States but was only made use of by a small percentage of dying patients (17%) (Cassel & Vladeck, 1996). The limited use of hospice care meant that there was a need for improved care of the dying in hospitals.

The Patient Self-Determination Act was passed by the U.S. Congress in 1990 (Crego, 1999). In December 1991, the Patient Self-Determination Act was implemented, mandating that patients receive education from healthcare professionals about advance directives at the time of hospital admission. The Patient Self-Determination Act further requires that advance directive documentation be a permanent part of the medical record (Crego, 1999; Stanley, 1998). The Patient Self-Determination Act law applies to any healthcare agency that receives Medicare or Medicaid reimbursement for services (Crego, 1999).

In order to assess the current effectiveness of the Patient Self-Determination Act, the SUPPORT project was begun in 1989, funded by the Robert Woods Johnson Foundation at a cost of $28 million (Moody, 1999). The purpose of SUPPORT was to decrease the frequency of mechanically supported, prolonged, and painful patient deaths by improving decision making at the end of life (The SUPPORT Principal Investigators, 1995). The hypothesis of SUPPORT was that reductions in the length of time spent in an undesirable state prior to death could be achieved if early treatment decisions were based upon clearer communication and better understanding of patient prognoses and preferences (The SUPPORT Principal Investigators, 1995).

During Phase I of SUPPORT, 4,301 severely ill hospitalized patients were enrolled with an expectation that 50% or more would die within 6 months (Stanley, 1998). Diagnoses for entry into SUPPORT included multiple organ system failure with sepsis or malignancy, acute respiratory failure, coma, congestive heart failure, chronic obstructive lung disease, cirrhosis, or cancers (nonsmall cell lung or metastatic colon) (Oliverio & Fraulo, 1998). A large percentage of the study patients (38%) spent at least 10 days in an ICU (The SUPPORT Principal Investigators, 1995). After a period of 2 years, the following conclusions were reached: (a) Only a small percentage of patients (30%) discussed issues with regard to care at the end of life with their physicians; (b) less than half of the patients with advance directives (43%) mentioned them to their physicians, and even fewer patients had advance directives documented in their medical records; (c) patients' preferences with regard to resuscitation were not routinely known by physicians (only 47%); (d) the presence of an advance directive had no effect on patient care or treatment decisions; (e) most patients did not want to make decisions with regard to their own resuscitation but preferred that families and physicians make these critical decisions; (f) patients frequently died in the ICU attached to machines; and (g) patients frequently died experiencing moderate to severe pain (Stanley, 1998; The SUPPORT Principal Investigators, 1995).

Based on SUPPORT Phase I findings, a prognostic model was developed and then tested in Phase II. Trained nurse clinicians talked with patients and families about preferences for pain control, treatment alternatives, and resuscitation measures (Oliverio & Fraulo, 1998; The SUPPORT Principal Investigators, 1995). These SUPPORT nurses provided the medical staff with detailed written instructions with regard to treatment issues, attended medical rounds, and documented discussions about patient wishes in the patient's medical record (Stanley, 1998). Physicians were also given estimates of their patients' 6-month prognosis and preferences for care (Oliverio & Fraulo, 1998; The SUPPORT Principal Investigators, 1995).

Unfortunately, the outcomes for Phase II with 2,652 enrolled patients were no better than for the similarly sized control group (Oliverio & Fraulo, 1998; Stanley, 1998; The SUPPORT Principal Investigators, 1995). Despite all of the efforts to better understand and then communicate patient wishes, the way patients died did not change in general (Stanley, 1998). Patients seemed unwilling to accept that death was inevitable and desired any intervention regardless of the chances for success (Stanley, 1998). Further, advance directives were ineffective in communicating patient wishes or failed to provide the necessary detail with regard to when efforts to prolong life should be suspended (Stanley, 1998).

Although the SUPPORT study was the largest ever to document the deficiencies in end-of-life care (Oliverio & Fraulo, 1998), questions with regard to

SUPPORT remained. First, what exactly were the interventions being tested? Second, consistency in how the interventions were implemented and maintained across settings was not described. Third, SUPPORT data contained no description of when interventions were initiated in relation to time of patient admission or demise. Finally, the number of nurse clinician interactions with patients and family (dosage of treatment) was not reported.

Other responses to SUPPORT results from disciplines such as medicine, law, ethics, and education were generally categorized as noting that the interventions tested in SUPPORT were too modest to show any effect. Another major barrier to improving care at the end of life seemed to support the maintenance of a professional culture, with significant financial incentives, that promoted continuing patient treatments (Stanley, 1998).

The conclusions reached by the nurse clinicians involved in SUPPORT were that interventions to promote communication failed to demonstrate a benefit because patients and families were, at times, indecisive, fearful, and offered differing views with regard to the direction in which patient care should proceed. Although only patients with life-threatening diseases were enrolled (with the expectation that greater than 50% would die within 6 months), 75% of the patients were discharged from the hospital with 54% surviving past 6 months (The SUPPORT Principal Investigators, 1995). This high number of live discharges reflected that many SUPPORT patients entered the hospital hoping for aggressive treatment interventions. The nurse clinicians noted that many SUPPORT patients were willing to try aggressive treatments even when they offered only a small chance of survival (Oliverio & Fraulo, 1998). Since patients were being admitted for curative treatments, discussions with regard to their wishes surrounding death were met with resistance. The nurses also reported that patients were adamant about their wishes to be treated aggressively. Surprisingly, interviews with patients revealed that 42% would choose to remain on a ventilator indefinitely and that 27% would rather be comatose than die (Phillips et al., 1996). These findings seemed to support studies by Danis and associates that showed the quality of the patient's life was more important to the nurses than it was to the patients (Danis, Jarr, Southerland, Nocella, & Patrick, 1987).

Critical-Care Nurses and Reports of Euthanasia

Shortly after the SUPPORT study was released, a report of critical-care nurses' roles in euthanasia and assisted suicide was published by Asch and associates (Asch, 1996; Asch, Shea, Jedrziewski, & Bosk, 1997). These articles made front-page news partly due to similar reports in Michigan concerning Dr. Jack Kevorkian's much publicized work in the assisted suicides of patients with (questionable) terminal illness (Alspach, 1997; Matzo, 1997).

Asch and associates randomly sampled 1,600 adult intensive care nurses who were subscribers to the journal Nursing. After three mailings of the same instrument, usable responses were received from 852 nurses who cared for adults in critical-care settings (Asch, 1996; Asch et al., 1997; Maeve, 1998). (No level of education or license was specified.) In the first article, 16% (n = 129) of the nurses reported having engaged in assisted suicide or euthanasia at least once, whereas 41% (n =

342) did not specify performing euthanasia (Asch, 1996; Erlen, 1996; Maeve, 1998). In addition, a content analysis of open-text comments was completed. Although the structured portion of the study specifically dealt with the nurses' active roles in euthanasia and assisted suicide (reported in the first article), the open-text comments used for the second article were much more general in nature, leading the researchers to categorize the comments more in the realm of hastening death than being specifically related to the practice of euthanasia (Asch et al., 1997; Maeve, 1998). Overall, 19% of the 852 nurses indicated they had engaged in euthanasia (Asch et al., 1997).

Many glaring flaws were noted in the report. One of the most egregious flaws occurred in the manner researchers chose to define nurse participation in euthanasia. Nurses who reported the act of pretending to carry out a physician's orders for life-sustaining treatment in an attempt to hasten a patient's death were counted as participating in euthanasia even though the nurses, themselves, did not see this deception as participating in euthanasia. The nonconforming nurses were counted along with nurses who clearly reported engaging in euthanasia. The individual percentages for those reporting engaging in euthanasia and those pretending to carry out a physician's order were not provided—only the total (19%), making it difficult to determine the actual percentage of nurses who actively engaged in or perceived that they had participated in euthanasia (Asch et al., 1997). Further, Asch and colleagues provided neither reliability nor validity data for the questionnaire nor did he allow the entire questionnaire to be examined (American Journal of Nursing Newsline, 1996).

The findings of Asch and colleagues were widely reported in the lay press, with the results startling both the general nursing community and critical-care nurses specifically (American Journal of Nursing Newsline, 1996). A huge outpouring of criticism followed the report's release (American Journal of Nursing Newsline, 1996; Ferrell et al., 2000; Maeve, 1998). Although critical-care nurses had generally been seen as some of the most caring patient advocates, they were suddenly being portrayed as accomplices to murder. Consequently, families became fearful when a family member was admitted to an ICU. The American Association of Critical-Care Nurses (AACN) became so sensitive to the effects of these reports that it became association policy to review any questionnaire being sent to AACN members through purchase of their mailing list. No questions with regard to practices or involvement with euthanasia were allowed (R. L. Beckstrand, personal communication, June 1998). In addition, some professional nursing organizations published position statements on euthanasia, assisted suicide, and other issues surrounding end-of-life care (American Nurses Association, 1994a, 1994b).

Supreme Court Decision With Regard to the Right to Die

Historically, assisted suicide has been illegal in the United States. The Ninth U.S. Circuit Court of Appeals ruled on March 6, 1996, that a ban on assisted suicide by the state of Washington was unconstitutional under the right to privacy (Matzo, 1997). The next month, the Second U.S. Circuit Court of Appeals also ruled against two New York state laws banning assisted suicide (Matzo, 1997).

In 1997, the controversy surrounding physician-assisted suicide and the right to die reached the U.S. Supreme Court. The Supreme Court ruled that there was no such constitutional right to die (Burt, 1997).

The Movement From Aggressive to Palliative Care

In 1996, the Healthcare Financing Administration approved a new diagnostic code for palliative care. This announcement allowed hospital chart reviewers to indicate that a dying patient received palliative care during a hospital stay (Cassel & Vladeck, 1996). Later in 1997, a report by the Institute of Medicine recommended that the focus of end-of-life care shift from very aggressive traditional care to palliative care where patient comfort and quality of life issues were paramount (Field & Cassell, 1997; Grady, 1999).

Soon after publication of the Institute of Medicine report, the National Institute of Nursing Research, along with several other national cosponsoring organizations, held a workshop to address issues of terminal illness (Grady, 1999). The research workshop focused on major symptoms of distress such as pain, disturbances in cognitive function, dyspnea, and cachexia. Recommendations of the workshop emphasized the importance of healthcare practitioners acting to maximize a patient's quality of life during his or her life's final phase (Grady, 1999). The National Institute of Nursing Research was appointed as lead and designated to coordinate all National Institute of Health research efforts surrounding end-of-life care. In 1999, the National Institute of Nursing Research and seven other National Institute of Health agencies initiated a request for applications to generate scientific knowledge leading to improved end-of-life care. Response to the request for applications resulted in 12 grants being awarded in 1999 (Grady, 1999).

In summary, while concern about end-of-life issues began in the 1960s, renewed interest in issues surrounding improving care for dying patients formally started with the 1991 passing of the Patient Self-Determination Act. The SUPPORT study results concerning multiple deficiencies in care and comfort at the end of life brought national attention to the plight of dying patients. Soon after SUPPORT, critical-care nurses were reportedly involved in activities of euthanasia and physician-assisted suicide. The findings were highly criticized because of weak study design and methods. Consequently, nurses became increasingly sensitive to any activity that might suggest participation in euthanasia. The movement to palliative care from traditional aggressive care was supported by both the announcement of a palliative care code by the Health Care Financing Administration and recommendations of the Institute of Medicine.

Critical-Care Nurses and End-of-Life Care

A summary of the research literature with regard to nurses and end-of-life care encompasses five major categories. These categories include (a) advance directives, (b) decision making, (c) perspectives of patients and families, (d) stress or coping strategies, and (e) the effects, impacts, or perceptions of nurses.

Advance directives. An advance directive is a written statement completed prior to any serious illness or injury that documents a person's medical decision related to desired and undesired treatments (Cartwright, Steinberg, Williams, Najman,

& Williams, 1997; Crego, 1999; Ott, 1999). A living will is a type of advance directive (Crego, 1999). A durable power of attorney differs from an advance directive; that is, it names an autonomous person as a proxy to make medical decisions should the person become incapacitated (Crego, 1999).

In a recent research study, Crego and Lipp (1998) studied nurses' knowledge of advance directives while another investigator (Ott, 1999) examined existing research on the use of advance directives. In a sample of 339 registered nurses, a 44-item questionnaire was administered to test nurses' knowledge about advance directives. The average test score was 78% correct, with 55% of the nurses stating that they did not have a good understanding of advance directives. A large percentage (92%) of the sample participants indicated that further education would increase their knowledge base. A very small percentage (14%) had completed their own individual advance directive (Crego & Lipp, 1998).

Extensive review of the literature completed by Ott (1999) showed that research with regard to advance directives covered a vast amount of topics. These topics included (a) patient demographic data, (b) ability to complete the advance directive and total completion rates, (c) patient preferences, (d) decision stability over time, (e) use of proxy decision makers, (f) treatment options, and (g) costs (Ott, 1999). Ott concluded that although improvements in advance directives had been noted, more research was needed to determine the role of those directives in patient care.

Decision-making in the critical-care setting. As nursing has progressed as a profession, the level of nurses' input into decision making has slowly increased (Bucknall & Thomas, 1997). Although the medical profession continues to be legally responsible for medical diagnoses and ordering most therapeutic measures, nurses have attempted to differentiate their own roles by rejecting medical diagnostic terminology through development of their own nursing diagnoses. As nurses gain autonomy and move to a more professional status, nursing roles are expanded and the responsibilities are increased (Bucknall & Thomas, 1997).

Three studies examined the decision-making process in ICUs comparing three groups of healthcare professionals: (a) nurses, (b) residents (house staff), and (c) attending physicians (intensivists). Two of the studies were quantitative and the third was qualitative (Baggs & Schmitt, 1995; Simmonds, 1996; Walter et al., 1998).

Simmonds (1996) conducted 21 interviews with healthcare professionals with regard to their experiences with dying patients in ICUs. None of the respondents found death an easy process with which to deal. The respondents reported a sense of abandonment; that is, doctors believed the dying patients were abandoning them and nurses felt abandoned by the doctors (Simmonds, 1996). As the patient died, it was reported that nurses believed staff physicians were most removed from the process, yet they had the largest responsibility for decision making (Simmonds, 1996). Another finding was that the lack of early decision making about end-of-life care meant that treatment was continued, which was perceived as a way for caregivers to avoid difficult confrontation and ethical dilemma. Physicians did not want to "play God" or cause the death of a patient. Allowing treatment to continue until there was no alternative left seemed the easiest route to take. Simmonds noted that both healthcare providers and clients need to reach the point where death is seen as inevitable rather than merely an undesirable medical outcome.

In one qualitative study (Walter et al., 1998), 12 clinical scenarios were administered to a large group of healthcare providers (N = 1,361). Respondents were asked to decide the level of care (from comfort only to very aggressive) and then to rate their confidence in their own decisions. Staff physicians chose less aggressive levels of care than did the ICU nurses who chose less aggressive levels of care than did the house staff. Respondents were very confident about their decisions 34% of the time, with staff physicians being the most confident. More confidence was shown when respondents chose extreme levels of care rather than intermediate levels. Respondents made contradicting decisions yet were still very confident about the level of care they chose (Walter et al., 1998).

Another study focused primarily on nurse-physician collaboration and satisfaction with the decision-making process. Consensus was met about the amount of collaboration that occurred; however, nurses were less satisfied with decision making than were physicians (Baggs et al., 1997).

Perspectives of patients and families. Content analysis was used in a qualitative study to determine 126 patients' views on end-of-life issues. From patients' perspectives, five domains were identified that encompassed their concept of a "good death." These domains were (a) receiving adequate pain and symptom management,

(b) avoiding a prolonged death, (c) having control, (d) limiting burden, and (e) strengthening relationships with loved ones (Singer, Martin, & Kelner, 1999).

From the perspectives of the family and other survivors, quality end-of-life care encompassed not only the experience of the dying patient but also what memories remained with the family members about the loved one's death (Berns & Colvin, 1998). A highly recurrent survivor memory was whether or not the survivor was present or absent during the patient's death. Almost all of the survivors who were present at the death wished to be there, and of those who were not present, most expressed regret for being absent (Berns & Colvin, 1998).

Families wanted to be kept informed, have open and honest interactions with physicians and healthcare providers, and wanted to help with patient care (Berns & Colvin, 1998; Pierce, 1999). The females were most appreciative of physicians who would speak to them after the death and tell them that all appropriate treatments had been carried out (Berns & Colvin, 1998). Families expressed frustration when physicians gave conflicting status reports, gave false hope (Chesla & Stannard, 1997), or avoided speaking with the family (Berns & Colvin, 1998).

Families also wanted neat, peaceful, and private environments that were conducive to optimal patient interaction (Pierce, 1999). The females did not want to be distanced from their loved one and preferred open visitation for immediate family members (Chesla & Stannard, 1997).

Stress and coping strategies. Caring for critically ill and dying patients is not only stressful for critical-care nurses but it also can cause moral distress and suffering

(Perkin et al., 1997; Sawatzky, 1996). Moral distress is defined as painful feelings, psychologic disequilibrium, or both caused by a situation in which one knows the ideal ethical action to take yet is unable to proceed due to institutionalized obstacles such as lack of time, power, policy, or legal constraints (Corley, 1995). Should moral distress be unrelieved, nurses may exhibit lower self-worth, psychological changes, and physical manifestations (Corley, 1995).

In three research studies, investigators showed (using a total sample of 224 nurses) that the most frequently perceived stressful events involved nurses who were asked to provide life-saving treatments to prolong an inevitable death, continue life support requested by families even though it was not seen to be in the patient's best interest (Corley, 1995; Sawatzky, 1996), care for hopelessly injured patients because no one would terminate support (Corley, 1995), and carry out unnecessary physicians' orders (Corley, 1995). Other causes of distress involved physicians who were not available (Sawatzky, 1996), patients who were in pain, and problems concerning inadequate staffing (Corley, 1995). The authors concluded that, although mean scores showed relatively low levels of distress, suffering among caregivers occurred and that most stress was related to prolonging a patient's inevitable death rather than the death itself (Corley, 1995; Perkin et al., 1997; Sawatzky, 1996).

In an attempt to help critical-care nurses cope with stress, Pelletier-Hibbert (1998) interviewed 17 nurses who worked with organ donors and their families to identify commonly used coping strategies. The nurses reported the need to experience control over their own emotions so that families would not know how they were feeling. For some nurses, emotional control protected their abilities to continue to help the family deal with the dying patient, whereas others stated that they remained in control so as not to upset the family. Once the patient had been diagnosed as brain dead, nurses tended to distance themselves from the patient, with many stating that they had learned over time to leave work at work (Pelletier-Hibbert, 1998). Nurses were comforted by colleagues who praised good nursing care and offered to help the nurses with patient care or relieve them for breaks. Taking "timeout" was seen as especially important after a nurse transported an organ donor to an operating room (Pelletier-Hibbert, 1998). Other reports of coping skills were noted as nurses focused on the positive impact of their own patient care and acknowledged that they had attempted to provide the patient with a good death (O'Hara, Harper, Chartrand, & Johnston, 1996).

Effects, impacts, or perceptions of nurses. Researchers looking at patient deaths in a long-term hospital found that a large portion of nurses (42%) were negatively affected by the deaths of their patients (O'Hara et al., 1996). This finding was especially true if they had been employed in the profession for a long time, if they had experienced a personal loss within the last year, or both. The most commonly recognized effect expressed was low morale. The researchers also found that the affected nurses were more likely to have a more personal relationship with the patient, had a more difficult time caring for younger patients, and were more likely to take work stress home (O'Hara et al., 1996).

Simpson (1997) interviewed 14 critical-care nurses and found that one of the impacts of a patient dying in ICU was the physical separation from family. In other words, this environment was not physically conducive to supporting close family proximity because of the tubes, wires, machines, and noises surrounding the dying patient (Simpson, 1997). Nurses also questioned whether or not the presence of advanced ICU technologies impacted the families by giving false hope that the patient could recover. Nurses stated that receiving more education concerning how to better manage end-of-life care for the family's benefit was needed (Simpson, 1997).

Rooda, Clements, and Jordan (1999) found that nurses' attitudes toward death were related to attitudes toward caring for dying patients. In a descriptive study of 403 nurses, those who had negative attitudes toward death also had less positive attitudes toward caring for patients who were dying. Rooda and colleagues suggested that educational programs that help nurses learn about how to care for dying patients and families should also include an assessment of nurses' attitudes toward death so that a discussion, followed by appropriate interventions aimed at increasing positive attitudes, could be implemented.

Ferrell and associates (2000) also supported the use of adequate nursing education to improve care of patients and families at the end of life (Ferrell et al., 2000). Using a questionnaire, 2,333 nurses responded to the survey, with most of the nurses ($\underline{n}$ = 1,603) working in oncology. Respondents were asked questions with regard to the barriers to effective end-of-life care, education, knowledge, and items related to euthanasia and assisted suicide (Ferrell et al., 2000). Of 12 barriers, respondents were asked to rate how much each item impeded providing good end-of-life care using a three-point Likert scale (1 = not a barrier, 2 = somewhat of a barrier, or 3 = a severe barrier). The top three most frequently cited severe barriers were (a) the influence of managed care on end-of-life care (25%), (b) lack of the continuity of care across settings (23%), and (c) family members' avoidance of death (19%). The researchers suggested that supporting patients' discussions for peaceful deaths would require both educational and policy reform. They also suggested that further nursing research to understand the perspectives of nurses was essential to positively changing end-of-life care (Ferrell et al., 2000).

It is interesting to note that although these barriers might reflect end-of-life care in general, they did not reflect the barriers noted in ICUs. This finding is probably because only 82 of the 2,333 nurses surveyed were critical-care nurses.

Focus group interviews of 21 critical-care nurses' experiences with end-of-life care were completed by Kirchhoff and associates (2000). The nurses reported that good end-of-life care was a priority and that measures such as providing pain relief, maintaining comfort and dignity, and helping or supporting the families' involvement in care were essential. Nurses reported encouraging family members to actively participate in patient care and worked to ensure that family members were given time alone with the dying patient to say goodbye. Religious rituals and cultural mores were supported by nurses, especially when it was known that the patient desired them as part of his or her death.

Nurses did not agree that preserving life at all costs was helpful to patients. They also reported that physicians tended to present a more optimistic prognosis to families that produced false hope (Kirchhoff et al., 2000).

Difficulties with communication between physicians and families put nurses in awkward positions. Types of communication problems included physician use of technical jargon, differences in information from all physicians involved in patient care, and physicians who made themselves unavailable to families (Kirchhoff et al., 2000).

The ICU environment was also noted to be a barrier to end-of-life care. Nurses stated that patient rooms were small and lacked the necessary privacy and room for family members to rest. Decreased availability of support service providers such as clergy and social workers during night shifts was also noted (Kirchhoff et al., 2000).

In attempts to cope with caring for dying patients, nurses expressed a sense of separation; that is, they did not believe others could understand how they felt when their patients died. Some nurses shared feelings with other coworkers, whereas others left work at work. All nurses expressed a need for more education on managing end-of-life care (Kirchhoff et al., 2000).

As an extension of the work of Kirchhoff and associates (2000), Kirchhoff and Beckstrand (2000) developed a questionnaire to identify critical-care nurses' perceptions of the severity of obstacles and the intensity of helpful behaviors in providing end-of-life care to dying patients. A random sample of 288 nurses was surveyed; 199 usable responses were obtained. Nurses were asked to rate 25 listed obstacles using a five-point Likert scale (0 = not an obstacle to 5 = extremely large obstacle). The nurses were also asked to rate 23 helpful behaviors (0 = not a help to 5 = an extremely large help).

The three obstacles with the highest mean scores were frequent family telephone calls to the nurse (M = 3.76, SD = 1.18), family not understanding what the term lifesaving measures meant (M = 3.66, SD = 1.08), and family not accepting the patient's poor prognosis (M = 3.51, SD = 1.0) (Kirchhoff & Beckstrand, 2000). The top helpful behaviors were physicians agreeing about the direction care should go (M = 4.57, SD = 0.61), providing a peaceful and dignified bedside scene for the family (M = 4.55, SD = 0.73), and designating one family contact person for all patient information (M = 4.54, SD = 0.74).

Mean scores for obstacles were lower than expected, most likely due to the highly experienced nature of this sample of nurses (mean age = 41.6 years and mean time as a registered nurse = 16.4 years) (Kirchhoff & Beckstrand, 2000). A complete copy of the published findings is included in Appendix A.

Although the nurses' perceptions were informative, lack of a scale to document the frequency of occurrence of these obstacles and helpful behaviors limited the usefulness of the study. For example, although the highest-rated obstacle was frequent family telephone calls to the nurse, it was unknown if these phone calls were perceived as a large obstacle and a rare occurrence or if they were both large and frequently occurring. This lack of information with regard to frequency of occurrence of obstacles and helpful behaviors was the reason for the current research.

Organizing Theory

For the primary aim of this study, a middle-range theory called "A Proposed Theory of the Peaceful End of Life" was used (Ruland & Moore, 1998). The theory was developed by Ruland and Moore based upon standards of care. Standards of care were known empirical evidences that looked at the connections between process and outcome. Ruland and Moore focused on the nursing care needs of the individual patient and acted as a guide for practice.

The theory was established based on standards of care developed by a group of nurses from Norway who were clinical experts in the university hospital's surgical gastroenterology unit. The central focus in developing the theory was not on the process of dying but rather on making contributions to peaceful and meaningful living regardless of the length of life remaining (Ruland & Moore, 1998).

The final standard of care consisted of 16 outcome criteria that were critically examined and then reduced into five common themes or outcome indicators. These themes were adapted for this study: (a) being pain free, (b) being treated with respect, (c) being at peace, (d) being close to loved ones, and (e) being comfortable (see Figure 1) (Ruland & Moore, 1998). Being pain free was defined as <u>not being in pain</u>. Being respected and valued as a human being was the definition of being <u>treated with respect</u>. Being <u>at peace</u> involved feelings of harmony, contentment, and calmness. Feeling connected to other human beings who cared was expressed as <u>close to loved ones</u>. The <u>experience of being comfortable</u> was determined to be relief from

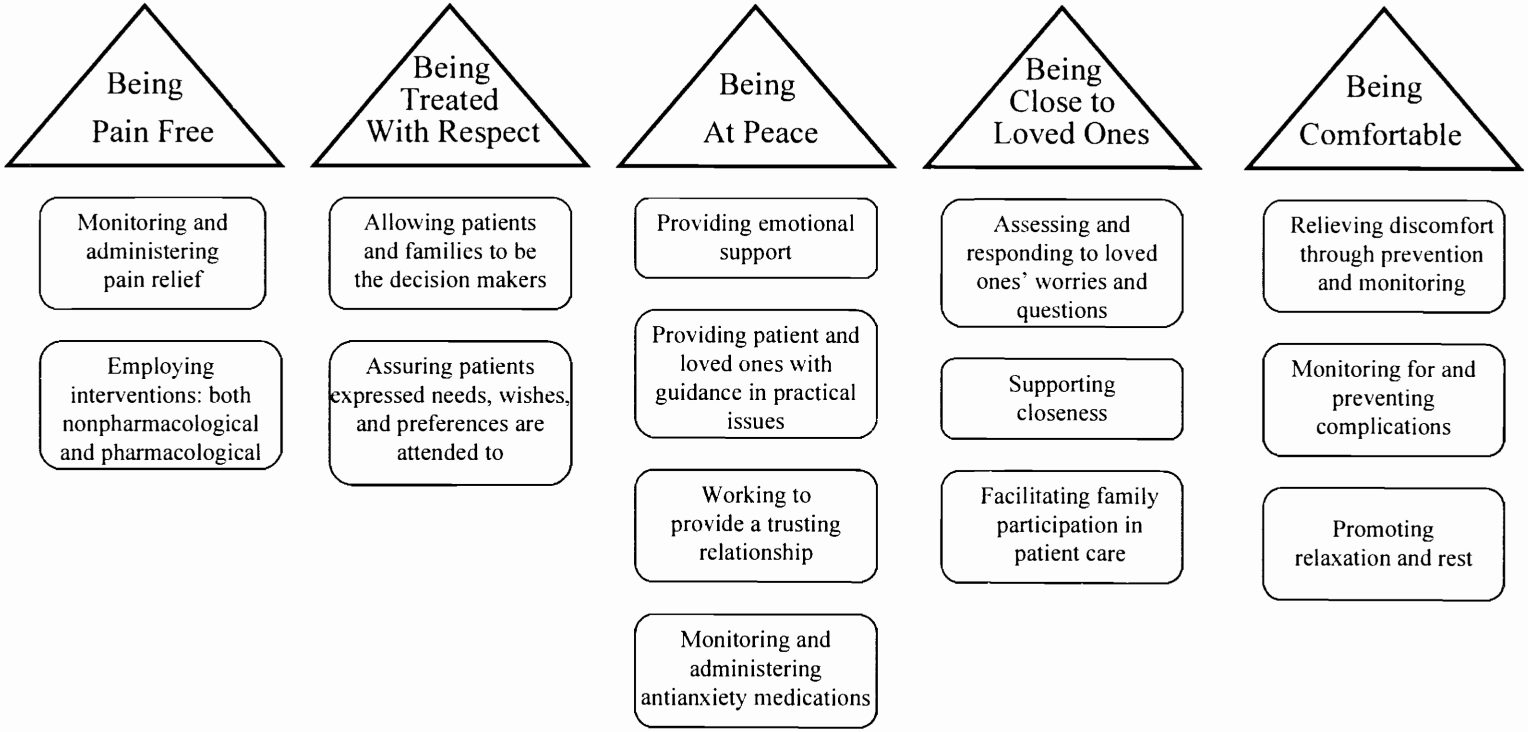

Figure 1. Conceptual relationships for a peaceful end of life. Note. Adapted from "Theory Construction Based on Standards of Care: A Proposed Theory of the Peaceful End of Life" by C. M. Ruland and S. M. Moore, 1998, Nursing Outlook, 46, p. 172.

discomfort, being content, or being in a state of ease (Ruland & Moore, 1998).

Beneath each of the five outcome indicators were specific nursing interventions that contributed to or supported attainment of the desired outcome. Each nursing intervention was described in observable and measurable terms. It was important to note that the large number of relationships that existed in this theory clearly reflected the complex and multidimensional nature of providing good end-of-life care. The proposed questionnaire for the study, entitled "National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care" (see Appendix B), reflected aspects of all five of the adapted outcome indicators and all 14 of the nursing interventions.

The use of Ruland and Moore's (1998) theory was also supported based upon the results of a study identifying and describing the elements of quality end-of-life care as identified by patients. Singer, Martin, and Kelner (1999) completed a qualitative study using in-depth, open-ended, face-to-face interviews of 126 respondents from three groups: (a) long-term care residents ($\underline{n}$ = 38), (b) human immunodeficiency virus (HIV)-infected patients ($\underline{n}$ = 40), and (c) dialysis patients ($\underline{n}$ = 48). Five domains reflecting quality end-of-life care were identified by the respondents: (a) receiving adequate pain and symptom management, (b) avoiding inappropriate prolongation of dying, (c) achieving a sense of control, (d) relieving (family) burden, and (e) strengthening relationships with significant others (Singer, Martin, & Kelner, 1999).

These five domains closely correlated to Ruland and Moore's (1998) outcome indicators; that is, both identify as important the need for relief from pain and good symptom management (being comfortable), expectations that the patient would have ultimate control (treated with respect), and expectations that loved ones would also be cared for and supported (close to loved ones).

The use of a theory for end-of-life care that so closely resembles the quality end-of-life care perspectives of patients means that the theory was authentic, straightforward, patient specific, and less likely to contain vague and expert-derived concepts (Singer, Martin, & Kelner, 1999). By using a theory that echoed the perspectives of patients, there was less chance of overlooking issues of primary concern to patients and their families (Singer, Martin, & Kelner, 1999).

The Problem

Critical-care nurses care for dying patients and their grieving families every day. Providing end-of-life care for critically ill and dying patients and families can be stressful for nurses because they may be insufficiently trained to manage the process of dying (Chapple, 1999; Perkin et al., 1997). Job stress associated with working in ICUs may lead to burnout or a state of emotional and physical exhaustion (Sawatzky, 1996; Wagner & Jason, 1997). This burnout may lead to lower work productivity, emotional withdrawal, absenteeism, and decreased morale (Kennedy & Barloon, 1997; Perkin et al., 1997; Sawatzky, 1996). As working conditions decline, job performance may deteriorate, the quality of care may diminish, and employee turnover may increase (Sawatzky, 1996). Increased employee turnover could lead to ICUs being staffed by less experienced nurses and the quality of patient care might suffer (Sawatzky, 1996).

The process of dying during hospitalization in an ICU can be messy, noisy, and complicated (Chapple, 1999). Those who have chosen to work in a usually ordered ICU environment find the chaos surrounding death occurring in this setting (designed to save lives) distasteful (Chapple, 1999). The quandary for critical-care nurses could be that their ability to provide the patient with a good death may be difficult given the available technologies; however, nurses often provide sufficient medication that may allow for much-needed pain relief yet also hasten death (known as double effect) (Chapple, 1999; Erlen, 1996).

The research of critical-care nurses about the obstacles that impede their delivery of end-of-life care and the helpful behaviors that support end-of-life care has been limited. Which obstacles and helpful behaviors are largest and most frequently occurring, as perceived by critical-care nurses, remain unknown. By gaining a better understanding of the largest and most frequently occurring obstacles inhibiting the nurse from providing quality end-of-life care, interventions could be developed and tested to attempt to lower both the size and frequency of these obstacles, thus lessening the stress on critical-care nurses. By gaining an understanding of the largest and most frequently occurring helpful behaviors that promote or support optimal end-of-life care, interventions could be developed to maintain the most helpful behaviors and increase the lower-rated behaviors to decrease the stress of nurses caring for dying patients.

Significance for Nursing

Critical-care nurses are highly educated, skilled professionals who provide around-the-clock care for dying patients and their families. Providing end-of-life care in ICUs can be stressful and can lead to burnout and high turnover rates. Understanding and then working to decrease the behaviors critical-care nurses perceive as being the largest, most frequently occurring, and most severe obstacles may have the potential to diminish work stress and burnout. Understanding and then acting to support the helpful behaviors critical-care nurses perceive as being the largest, most frequently occurring, and most intense could also increase job satisfaction. Ultimately, patients will have received better care at the end of life while in ICUs.

CHAPTER II

SECONDARY AIM: EFFECT OF INCENTIVES ON SURVEY RESPONSE RATES

Background and Significance

Introduction

A survey is a method for gathering information that describes, compares, or explains attitudes, knowledge, and behavior (Fink, 1995). The three standard methods of collecting survey data are personal interviews, telephone interviews, and self-administered questionnaires (LoBiondo-Wood & Haber, 1998; Polit & Hungler, 1999). Of these three methods, a mailed self-administered questionnaire is the most common avenue for data collection in educational research and in nursing (Fink, 1995; Groves, Price, Olsson, & King, 1997; Kirchhoff, 1999; LoBiondo-Wood & Haber, 1998; Polit & Hungler, 1999). However, studies about improving mailed survey response rates from nurses are almost nonexistent (Summers & Price, 1997). Although the goal for the primary aim was to measure critical-care nurses' perceptions of the severity and frequency of obstacles and the intensity and frequency of helpful behaviors in providing end-of-life care, the goal for this secondary aim was to test the immediacy portion of Christensen's (1996) theory to improve response rates in a national survey using mailed questionnaires.

Theoretical Foundation

Theories, conceptual models, and frameworks are not uncovered by researchers but are invented and created by researchers as a way to describe and explain phenomena (Polit & Hungler, 1999). By observing facts, gathering them together, and then ordering the facts into logical creations, researchers construct theories and conceptual models (Polit & Hungler, 1999).

These theories and conceptual models can never be proved; thus, no theory or framework can ever be considered totally verifiable (Powers & Knapp, 1995). There will always be the possibility that a tested theory will be found wanting and will then be discarded or altered (Polit & Hungler, 1999). Nevertheless, theories, conceptual frameworks, and models allow science to progress by helping make research findings meaningful and generalizable to the population at large, providing researchers with both a direction and a stimulus to extend the bounds of knowledge (Polit & Hungler, 1999). With that background in mind, the best theoretical approach in which to extend the bounds of knowledge for the present study was chaos theory.

Chaos Theory

Chaos theory stemmed from ancient Greek mythology depicting two Gods: (a) Chaos and (b) Gaia. Chaos was an endless, yawning chasm devoid of any form, whereas Gaia was the mother of the earth who brought forth stability and form (Wheatley, 1993). Together, these two Gods became partners creating everything in the known universe. Because of the union, worlds were created and darkness was dispelled, yet new life carried with it a state of total unpredictability (Wheatley, 1993).

Chaos means order without predictability or “orderly disorder” (Phillips, 1991; Wheatley, 1993). Chaos theory may move nurse researchers past linear thinking (Phillips, 1991). For example, a logical, predictable, or linear view of the world would dictate that a large change in some aspect of mailed survey research should cause a large effect. In chaos theory, with its characteristic nonlinearity, a small change may give rise to a large effect (Phillips, 1991). Even the smallest variation in conditions could send a chaotic system off in a different direction (Hayles, 1990).

Arriving at the theoretical framework. Another characteristic of chaotic systems may be that they are very complex and contain large amounts of information. In fact, the more chaotic a system seems to be, the more information it is believed to contain (Phillips, 1991). This characteristic lends credence to the 4-year pilgrimage Christensen (1996) traveled to arrive at a theory on immediacy and salience as significant variables in response rates.

Immediacy is the quality or state of being immediate: (a) occurring or done at once without delay and (b) acting or accomplished without loss or interval of time (Merriam-Webster, 1988). Immediacy is action oriented and is motivated by the management of available resources such as liberation from the external constraints upon energy and time (Christensen, 1996). When a respondent perceives a sense of immediacy, it is immediacy that dictates the urgency and speed of response to the mailed questionnaire. The questionnaire moves to the forefront of the respondents’ concerns. One example of enhancing immediacy is prenotifying the respondents that they are soon to receive an important questionnaire requiring their immediate attention.

Salience is the quality of being important, prominent, or noticeable (Christensen, 1996). When salience is acted upon, respondents are choosing to do or act upon the objects or belongings they value or that are perceived as important to them. In the mailed questionnaire process, salience can be psychologically, politically, sociologically, and geographically motivated (Christensen, 1996). Researchers need to assure that they are surveying the appropriate sample of respondents; otherwise salience will be diminished.

Christensen (1996) initially examined mailed questionnaire constructs piece by piece and then examined the relationships between the pieces. Pieces were merged together into small segments of the process, and then large segments were integrated into a whole framework. Once the whole framework was completed, it was then broken down into parts or pieces again to determine the potential impact of small changes that had occurred within the entire framework.

Following an extensive analysis of the literature, Christensen (1996) formulated a hypothesis that suggested there were specific significant motivating variables involved in the mailed questionnaire response process. Eventually, the "Interdisciplinary Theoretical Framework for the Mailed Questionnaire Process" was proposed, imposing order on chaos.

Coming from that framework, Christensen's (1996) "Theory for Immediacy and Salience as Significant Determinants of Response Rates in the Mailed Questionnaire Process" was broad because it accounted for the impact of immediacy and salience in relationship to both the construction and administration of a questionnaire, as well as the completion of a questionnaire (Christensen, 1996).

A theoretical model on the interaction of immediacy and salience in the response process. Figure 2 presents Christensen's (1996) proposed theoretical model on the interaction of immediacy and salience in the mailed questionnaire response process. This model is presented to illustrate the previously proposed theory. The arrows on the model indicate that there is a continuum within and between each of the four quadrants. Because of the chaotic unpredictability of the universe, quadrants are not truly linear and may overlap at times (Christensen, 1996; Wheatley, 1993).

In the model, a four-quadrant format juxtaposes salience and immediacy against each other. Based upon the presented theory, each of the four quadrants predicts the expected level of response generated from the interaction of the two variables. Immediacy is placed on the horizontal axis of the quadrants, and salience is placed on the vertical axis of the quadrants.

On the proposed model in Quadrant I, responding to the questionnaire is both salient and immediate to the respondent, and the respondent is motivated to return the questionnaire. In principle, the questionnaire acts on the respondent (Polit & Hungler, 1999). With both immediacy and salience at high levels, Quadrant I predicts high response rates (Christensen, 1996). Christensen postulated that hypothetical response

	HIGH IMMEDIACY →	← NO IMMEDIACY
HIGH SALIENCE ↓	I EXTREMELY HIGH RESPONSE Responding to the Questionnaire Is Immediately Important	II MODERATELY HIGH RESPONSE Questionnaire Will Be Complete Between Other Pressing Demands, if Possible
↑ NO SALIENCE	III MODERATE RESPONSE Questionnaire Will Be Completed if Convenient	IV LOW RESPONSE Responding to the Questionnaire Is not Immediately Important

Figure 2. A proposed model for the interaction of immediacy and salience in the mailed questionnaire response-rate process. Note. From An Interdisciplinary Theoretical Framework for the Mailed Questionnaire Process and the Development of a Theory on Immediacy and Salience as Significant Variables of Response Rates (p. 111) by M. Christensen, 1996, Logan, UT: Utah State University. Copyright 1996 by M. Christensen. Reprinted by permission.

rates for Quadrant I could be between 80% and 100%.

An example of a questionnaire that includes both immediacy and salience would be surveying a group of nurses about their current cost-of-living expenses and informing them that responses need to be returned within 1 week (immediacy) because the results of the survey would impact their wage increases for the next budgeted year (salience). It would not be unreasonable to expect a response rate of greater than 80% for this type of survey.

In Quadrant II, responding to the questionnaire is salient but not immediate. The respondent is not motivated by the questionnaire itself but is motivated to complete the questionnaire by the salience of the topic, sponsor, or researcher. In essence, the respondent acts on the questionnaire (Christensen, 1996). The respondent decides to complete the questionnaire because it is deemed important (salient). Because of the salience of the topic, the sponsor, or researcher, the returned questionnaire is likely to be completed thoroughly and correctly, decreasing response bias (Christensen, 1996). Response bias is when the respondent omits answers, is careless, or does not follow instructions correctly (Nunnally & Bernstein, 1994). Nevertheless, without immediacy, the overall response rate in Quadrant II is still predicted to be only moderately high (in the 60% to 80% range) (Christensen, 1996).

The dynamic of having salience without immediacy exposes an important point when examining Quadrant II. Salience alone does not serve as the only significant response rate determinant; that is, a questionnaire may have high salience to the respondent. However, other immediate concerns and responsibilities will override the questionnaire's high salience, and the respondent may delay completing and returning the questionnaire. Some of these phenomena may account for the fact that questionnaires that are mailed to work (or school) addresses have higher return rates than those mailed to the respondents' homes (Christensen, 1996).

In Quadrant III, completion of the questionnaire is immediate but not truly salient to the respondent (Christensen, 1996). The sense of immediacy stems from the illusion of salience that likely exists for someone in addition to the respondent such as the researcher or sponsor. The respondent completes and returns the questionnaire more out of a sense of courtesy than as a requirement (Christensen, 1996). A researcher whose questionnaire is imbedded in Quadrant III can expect only moderate levels of response (between 40% and 60%) (Christensen, 1996).

Again, it is important to point out that salience is in the eye of the respondent. Researchers should not mistake Quadrant I with Quadrant III as they plan, develop, and then pretest their questionnaires (Christensen, 1996). Although researchers may believe that the questionnaire has high salience with the intended sample, only the respondent determines if the questionnaire has salience. It is, therefore, imperative that the questionnaire and the cover letter be pretested to confirm that the intended population to be sampled agrees with the researcher about the salience of the topic. The same problem of the researcher and the respondent disagreeing could be encountered between Quadrant I and II if the researcher misjudges what immediacy means to a group of respondents (Christensen, 1996).

Quadrant IV has the lowest predicted response rate (less than 40%), which comes as a result of questionnaires that have no immediacy or salience to the respondent. Return of the questionnaire by the respondent depends on his or her willingness to take the time to complete the questionnaire rather than throw it away. Respondents may see a questionnaire from this quadrant as a way to depart from other concerns, escape from responsibilities, or just waste time (Covey, Merrill, & Merrill, 1994). An example of a questionnaire that would fit in this quadrant would be asking nurse managers to respond, when convenient, to the question of whether or not they believe current admission criteria to nursing schools are too restrictive. Unless a nurse manager has had a son or daughter who was recently denied admission into his or her choice of nursing school, the salience of the survey is highly questionable for this sample. Further, the notation "respond when convenient" conveys absolutely no immediacy.

Questionnaire to be Mailed

Logically, if a researcher tests a theory on mailed survey response rates, there must have been a questionnaire to mail. Logic also demands that the questionnaire, itself, cannot be about survey response rates or the respondents would be sensitized to the issue (a form of testing threat to internal validity) (Polit & Hungler, 1999), impacting their decision to return the questionnaire and nullifying any chance of testing the theory. Therefore, in order to test this theory, it was necessary to have a questionnaire that had been developed, pretested, administered, and analyzed within a short time frame from the proposed follow-up study. It was also helpful to have records detailing the methodology used, copies of the original cover letters mailed with the questionnaire, and notes documenting the response rates for each mailing.

In 1998, Kirchhoff and Beckstrand developed, pretested, and administered a questionnaire entitled National Survey of Critical-Care Nurses Regarding End-Of-Life Care (see Appendix C) (Kirchhoff & Beckstrand, 2000). The questionnaire was mailed to 300 randomly selected members of the AACN. The objective of the survey was to report the relative importance of various obstacles and helps in providing end-of-life care as perceived by critical-care nurses who have cared for dying patients.

Description

The questionnaire was a three-page (front and back), 64-item instrument. Of the items, 48 required the nurse to respond to a Likert-type scale dealing specifically with the topic of perceived obstacles or helps in end-of-life care. Two items were open-ended and 13 items dealt with demographic data. The questionnaire was developed from focus-group data (Kirchhoff et al., 2000) and an extensive literature review, and it was pretested on 45 critical-care nurses. Recommended changes were made, and a revised questionnaire was mailed to the geographically dispersed random sample using address labels purchased from the AACN.

Response Rates

The response rates after each of the three mailings were 127/300 (42.3%) (cumulative total = 42.3%), 46/173 (26.6%) (cumulative total = 57.7%), and 33/127 (26%) (cumulative total = 68.5%), respectively. Seven of the 206 returned questionnaires were unusable, leaving a total return number of 199 questionnaires. The high response rate, along with the vast amount of interest in end-of-life care, demonstrates that this questionnaire was salient to critical-care nurses. Therefore, only the immediacy portion of Christensen's (1996) theory was tested.

The quantitative data were analyzed and published (Kirchhoff & Beckstrand, 2000). One conclusion noted that nurses seemed to have some difficulties with families and physicians with regard to end-of-life issues. Nurses did not acknowledge having problems providing care to dying patients apart from conflicts that arise because of families and physicians (Kirchhoff & Beckstrand, 2000).

Next Stage

Although the pilot study data provided important descriptions of the perceptions of possible obstacles and helps in providing end-of-life care to dying patients as viewed by this sample of critical-care nurses, I believed that an important piece was missing in the data collection. The questionnaire requested nurses to rate the perceived obstacle (or help) by size or magnitude (0 = not an obstacle, 1 = extremely small obstacle, 2 = small obstacle, 3 = medium obstacle, 4 = large obstacle, and 5 = extremely large obstacle). For helps, the scale was as follows: 0 = not a help, 1 = extremely small help, 2 = small help, 3 = medium help, 4 = large help, and 5 = extremely large help. However, no mechanism was provided for the respondents to identify with what frequency the obstacles or helps occurred. Although the items that were rated from smallest to largest were known, this missing piece meant that no idea with regard to their frequency of occurrence had been reported. It was also possible that the respondents did not differentiate frequency from size because only size was rated. Respondents may have reported a rating for an obstacle or help that combined frequency and size into a single concept.

The questionnaire was redesigned to include both the size and frequency of perceived obstacles and helps in providing end-of-life care to dying patients. The questionnaire was pretested, appropriate changes were made, and it was administered to the new sample. Once the questionnaires were returned and entered into SPSS® (SPSS®, Inc., 1999) for analysis, a perceived severity score, reflective of each obstacle item's severity, was calculated by multiplying each obstacle item's mean size by mean frequency (Kanner, Coyne, Schaefer, & Lazarus, 1981; Sawatzky, 1996). A perceived intensity score was also calculated for each help item by multiplying the help item's mean size by mean frequency.

Since the data for the actual questionnaire were the primary aim of this research study, they were analyzed and compared to the original sample (as close as was possible). It was hoped that the results of the questionnaire would provide a much clearer picture of both the size, frequency, and severity of perceived obstacles and the size, frequency, and intensity of perceived helps in providing end-of-life care to dying patients.

Hypotheses

H_0: There will be no difference in mean response rates of mailed questionnaires for the treatment groups (i.e., $1 charity donation, $2, or $100 lottery) compared to the control group (no incentive); that is, the groups' means are equal.

H_o: $\mu_1 = \mu_2 = \mu_3 = \mu_4$ (Hinkle, Wiersma, & Jurs, 1994).

H_a: There will be significant positive differences in mean response rates of mailed questionnaires for the treatment groups (i.e., $1 charity donation, $2, or $100 lottery) compared to the control group (no incentive); that is, at least one group mean differs from the other group means. H_a: $\mu_1 = \mu_2 = \mu_3 = \mu_4$ (Polit & Hungler, 1999).

Specific Aims

1. Which three logical and reasonable inducements (incentive or written information included in the cover letter) would critical-care nurses report as producing the most perceived immediacy for returning a mailed questionnaire? (Results are reported in Chapter III.)

2. Does implementation of Christensen's (1996) Theory for Immediacy and Salience as Significant Determinants of Response Rates in the Mailed Questionnaire Process significantly improve the mean response rates of mailed questionnaires from a randomly selected, geographically dispersed sample of critical-care nurses compared to the mean response rates of the control group?

CHAPTER III

PILOT WORK

Preliminary work conducted in preparation for this study included (a) development and testing of the National Survey of Critical-Care Nurses Regarding End-of-Life Care questionnaire, (b) completion of the National Survey of Critical-Care Nurses Regarding End-of-Life Care study (Kirchhoff & Beckstrand, 2000), (c) development and pretest of the Nurses' Preferences for Survey Inducements Form, (d) questionnaire redesign and completion of the Nurses' Preferences of Survey Incentives study, and (e) design of the National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care questionnaire. The University of Utah Institutional Review Board and Brigham Young University Institutional Review Board approvals and informed consents were obtained for all preliminary work.

Development and Testing of the National Survey of Critical-Care Nurses Regarding End-of-Life Care Questionnaire

The original questionnaire was developed using focus group information (Kirchhoff et al., 2000), reviews of the literature, and input of content experts (Kirchhoff & Beckstrand, 2000). The questionnaire was pretested on 45 ICU nurses. Input received from nurses resulted in the deletion of some items, whereas other items were reworded for clarification. Cronbach's alpha was .86 for the 25 obstacle items and .82 for the 23 helpful behaviors (Kirchhoff & Beckstrand, 2000).

Completion of the National Survey of Critical-Care Nurses Regarding End-of-Life Care Study

Explanation of the study has been previously reported. The final report was published in the March 2000 issue of the American Journal of Critical Care.

Development and Pretest of the Nurses' Preferences for Survey Inducements Form

Christensen (1996) determined that response-inducement techniques that produce feelings of immediacy or offer financial reward more likely influence the respondent to complete and return the mailed questionnaire. Determining which inducements would be most likely to influence critical-care nurses to feel a sense of immediacy to complete the questionnaire needed to be determined. The criteria for choosing which incentives to ask nurses about included the following: (a) The incentive had to be reasonable to manage (requiring no second mailing to a large group of nurses); (b) the incentive had to be lightweight (minimizing additional mailing costs); and (c) the incentive had to be reasonable in cost since nursing research monies are usually limited. After a review of the literature reporting the use of incentives to influence response rates, a one-page form was developed (Church, 1993; Easton, Price, Telljohann, & Beohm, 1997; Groves et al., 1997; Hare, Price, Flynn, & King, 1998; James & Bolstein, 1992; Kedziera & Harris, 1998; Singer, Groves, & Corning, 1999; Singer, Van Hoewyk, & Maher, 1998; Summers & Price, 1997; Tambor et al., 1993; Warriner, Goyder, Gjertsen, Hohner, & McSpurren, 1996; Willimack, Schuman, Pennell, & Lepkowski, 1995) (see Appendix D). Six inducements were listed with instructions asking the nurse respondents to mark on a scale of 1 = no influence to 5 = large influence how they believed each incentive would influence them to return a 30-minute questionnaire. At the time of development, it was unknown exactly how long the revised questionnaire would take to complete; the original questionnaire was pretested to be 17 minutes. As a result, the estimate of 30 minutes was used as an outer limit.

The form was pretested on 30 registered nurses at one hospital. Immediate feedback at the time of completion yielded two common complaints. First, the nurses believed that a 30-minute questionnaire sounded too long. Second, they wanted the form to include, as one of the items, that they would respond to an important (salient) questionnaire regardless of the incentive.

Although this form was only for pretest, the nurses' responses were entered into SPSS® (SPSS®, Inc., 1999) and analyzed. The incentive with the highest mean (most likely to influence return) was having $1 donated to a national charity for every questionnaire received by the specified date (M = 3.1, SD = 1.2), followed by having their names entered in a drawing for $100 ($M$ = 2.93, SD = 1.3). The third place incentive was a tie between being prenotified that the questionnaire was coming (M = 2.7667, SD = 1.2) and receiving $2 with the questionnaire (M = 2.7667, SD = 1.4).

Questionnaire Modification and Completion of the Nurses' Preferences of Survey Incentives Study

The form was modified (see Appendix E). Input from pretest data and input received from an established nurse researcher were used to modify the form. The item

"I would complete and return it [the questionnaire] even if no incentive was included" was added, bringing the total choices to seven items plus one open-ended question that allowed for additional incentive suggestions. The modified form was administered to 75 nurses. One nurse responded only to the open-ended question, leaving 74 usable responses.

The results were entered into SPSS® (SPSS®, Inc., 1999) and can be found in Table 1. The top three incentives receiving the highest mean scores were (a) being entered in a drawing for $100 cash ($\underline{M}$ = 2.37, $\underline{SD}$ = 1.2), (b) having $2 included with the questionnaire ($\underline{M}$ = 2.08, $\underline{SD}$ = 1.5), and (c) having $1 donated to a national scholarship or charity for every returned questionnaire ($\underline{M}$ = 1.85, $\underline{SD}$ = 1.3). It is unknown why the means for these incentives were so much lower than the pretest. One possibility could be that the text was changed from a 30-minute questionnaire to read an 8-page questionnaire in response to the nurses' original complaints. The lower means could also be related to the differences in sample size ($\underline{n}$ = 30 versus $\underline{n}$ = 74).

Regardless, based on the results, the three treatment groups for the experimental design (secondary aim) were determined to be as follows: (a) Tx_1 = notification of being entered into a drawing to win $100 cash if the questionnaire was returned by a specified date, (b) Tx_2 = inclusion of $2, and (c) Tx_3 = donation of $1 to charity for every returned questionnaire received by the specified date.

Table 1

Nurses' Preferences of Survey Incentives Questionnaire Results

Incentive	M	SD	n[a]
1. Return of the completed survey will enter me into a drawing for $100 cash.	2.37	1.17	73
2. $2 is included with the survey.	2.08	1.45	74
3. $1 is being donated to a national scholarship fund or charity for every returned survey.	1.85	1.32	73
4. I would complete and return it even if no incentive were included.	1.78	1.11	73
5. A $1 gift certificate to Blockbuster™, McDonalds™, or Burger King™ is included in the survey.	1.49	1.42	73
6. A $1 bill is included with the survey.	1.40	1.38	73
7. Prenotification (by letter) that the survey is coming soon.	.73	.87	73

Note. Response choices: 0 = makes no difference, 1 = less likely, 2 = somewhat likely, 3 = very likely, and 4 = extremely likely.

[a] Reflects number of respondents rating this item.

Design of the National Survey of Critical-Care Nurses' Perceptions of End-of-Life Care Questionnaire

Using feedback obtained from the open-ended questions in the pilot study questionnaire along with reviews of recent published end-of-life literature, a new questionnaire was designed. Changes included the addition of frequency-of-occurrence response choices (0 = never occurs, 1 = almost never occurs, 2 = sometimes occurs, 3 = fairly often occurs, 4 = very often occurs, and 5 = always occurs) for both listed obstacles and helps and a slight change in the general layout (lines separated items). In addition, five new obstacle items, one help item, and three open-text response items were added based upon the results of a completed factor analysis of the pilot study results. The questionnaire eventually contained 72 items (see Appendix B).

Factor Analysis

The dimensionality of the 25 items from the obstacles section of the National Survey of Critical-Care Nurses Regarding End-of-Life Care questionnaire was analyzed using principal component analysis. Three criteria were used to determine the number of factors to rotate: (a) the a priori hypothesis that the measure was unidimensional, (b) the scree test, and (c) retention of all factors having eigenvalues greater than one (Green, Salkind, & Akey, 2000). The scree plot indicated that the measure of end-of-life care was multidimensional. Initial eigenvalues reported on total variance explained confirmed that seven factors had eigenvalues greater than one. Consequently, seven factors were rotated using the Promax rotation procedure with Kaiser Normalization.

The dimensionality of the 23 help items was also averaged using principal component analysis. Again, initial eigenvalues reported on total variance explained showed seven factors with values greater than one.

Although not the purpose of the study, the seven factors for the obstacles were categorized as follows: (a) Factor 1, the necessity to dealing with or, in some way, handle obstacles such as nurses dealing with angry family members; (b) Factor 2, obstacles caused by some need such as the lack of adequate staffing, end-of-life education, or a hospital ethics board; (c) Factor 3, care being continued because of an obstacle such as the threat of a law suit; (d) Factor 4, extraneous factors that were outside the control of nurses (patient having uncontrolled pain); (e) Factor 5, obstacles denoting extreme positions such as hospital visiting hours that are too liberal or too restrictive; (f) Factor 6, nurses sensing or knowing the poor condition and prognosis of the patient yet still working to attempt to save the patient's life; and (g) Factor 7, family dysfunction in which the family does not accept what the physician tells them about the patient's poor prognosis or in which family members fight with each other about whether to continue or stop life support.

For helpful behaviors, the seven factors were categorized as follows: (a) Factor 1, some kind of supportive behavior for nurses such as staff members telling the nurse that he or she did all he or she could for the patient; (b) Factor 2, helps that support providing a good death as perceived by families (private place to grieve or peaceful, dignified bedside scene); (c) Factor 3, helps that support providing a good death as perceived by nurses (family accepts that patient is going to die, physicians all agree about direction of care, or physicians putting hope in real, tangible terms); (d) Factor 4, ways nurses support families such as allowing family members unlimited access to dying patients; (e) Factor 5, extraneous factors that support nurses such as having unit staff compile necessary paperwork after patients' deaths; (f) Factor 6, helps that allow nurses to be physically removed from the family (letting the social worker or religious leader take primary care of the grieving family); and (g) Factor 7, physicians' support of the family (seeing the family after the patient's death to validate that all possible care was done). Completion of the factor analysis helped to show that end-of-life care is multidimensional, and it also showed that some factors were essentially weaker than others because they had fewer items loading than did other factors.

Obstacle items that were added to the redesigned questionnaire included the following: (a) 18, physicians who will not allow the patient to die from the disease process; (b) 26, physicians who are evasive and avoid having conversations with family members; (c) 27, multiple physicians involved with the patient who differ in opinion about the direction care should go; (d) 28, continuing to provide treatments to dying patients because of financial benefits to the hospital; and (e) 29, when nurses' opinions about the direction patient care should go is not requested, not valued, or not considered.

Only one obstacle from the original questionnaire was deleted (caring for a patient who has been declared brain dead and is destined to be an organ donor). This obstacle was deleted for lack of space and because it was the lowest perceived obstacle from the pilot sample.

One additional help item was added with regard to having unlicensed personnel available to help care for dying patients. No help items were deleted. The two open-ended items were left unchanged. However, an additional open-ended item was added requesting that nurses respond to the question: "If you had the ability to change just one aspect of end-of-life care to dying ICU patients, what would it be?" The demographic section remained the same except for the inclusion of two open-ended questions asking if the nurse held any other nursing certifications and, if so, to list them. Nurses were also asked to make comments about the study if they wished to do so.

The revised questionnaire was pretested on 21 ICU nurses. Several minor grammatical changes were made in items 7 and 35. The paragraph explaining the directions (on the first page) was also edited for clarity.

Grant Funding Received

Survey research can be expensive to complete, especially when correct research methods have been used and three mailings have been completed. Because of the experimental design for the secondary aim, a large sample of 1,500 nurses was calculated to be necessary to detect a .20 (effect size) increase in response rates from any of the three treatment groups compared to the control group (power = .80; α = .05). Funding was determined to be necessary in order to complete the project. Two grants from the Brigham Young University College of Nursing were obtained. The first grant was for $2,900 and the second grant was for $1,900.

CHAPTER IV

RESEARCH DESIGN AND METHODS

Purpose

The main purpose of this research was to measure critical-care nurses' perceptions of the severity and frequency of listed obstacle items and the intensity and frequency of listed helpful behaviors in providing end-of-life care to dying patients and their families. The research questions were:

1. Which obstacles to providing end-of-life care to dying patients do critical-care nurses perceive as being the largest, most frequent, and most severe?

2. Which helpful behaviors (or helps) to providing end-of-life care to dying patients do critical-care nurses perceive as being the largest, most frequent, and most intense?

3. Which aspect of end-of-life care would critical-care nurses most like to see changed?

4. In what ways do critical-care nurses' perceptions of obstacles and helpful behaviors differ based upon length of ICU work experience?

5. Do CCRN-certified critical-care nurses' perceptions of obstacles and helpful behaviors significantly differ from the perceptions of critical-care nurses who have never certified as a CCRN?

Secondary Aim

A secondary aim of this research was to compare the effect of three different incentives on critical-care nurses' survey response rates compared to a control group. The hypothesis for this secondary aim was: H_0: There will be no difference in mean response rates of mailed questionnaires for the treatment groups (i.e., \$1 charity donation, \$2, or \$100 lottery) compared to the control group (no incentive); that is, the group's means are equal (H_0: $\mu_1 = \mu_2 = \mu_3 = \mu_4$).

Study Design

A design is a way of arranging the environment where a survey takes place. The total survey environment consists of the individual respondents, places, or activities that are to be surveyed (Abramson, 1990). Experimental designs are used to provide the greatest amount of control possible in order to examine causality more closely (Burns & Grove, 1997). The primary purpose of using an experimental design is to test a theory (Brink & Wood, 1998). Part of Christensen's (1996) Theory for Immediacy and Salience as Significant Determinants of Response Rates in the Mailed Questionnaire Process was tested in the secondary aim of this study. An experimental, posttest-only, control group design was used (see Figure 3) (Burns & Grove, 1997).

Settings

The questionnaire was sent to the list of nurses provided by the AACN. For most respondents, the address was their primary residence. The addresses were obtained by purchasing a mailing list from the AACN. The AACN provided (for a fee

Group	Response Rate	
R	X_1	O
	X_2	O
	X_3	O
	C	O

Figure 3. Experimental only, control group, posttest design. Note. Each group (X_{1-3} and control) will have n = 375. R = randomly assigned sample. X = treatment groups X_1-X_3 (independent variable manipulated): X_1 = drawing for $100 cash, X_2 = $2 included with the questionnaire, and X_3 = $1 donated to charity. C = control group. O = mailed survey response rate (dependent variable measured).

of $380) a randomly selected, geographically dispersed sample based upon researcher-chosen criteria.

Sample

After consultation with statisticians from both Brigham Young University and the University of Utah, it was calculated that the geographically dispersed, random sample would consist of four groups of 375 critical-care nurses for a total of 1,500 nurses. Three of the four groups received the previously specified incentives, all of which incorporated or enhanced the sense of immediacy through monetary reward. The fourth group served as the control group receiving the questionnaire and a standard cover letter, which was very similar to the pilot study's cover letter.

Potential respondents were randomly selected from the membership of the AACN whose current membership was 68,000 (American Association of Critical-Care

Nurses, 2000). The subjects were currently employed staff nurses who had worked at least part time in a critical-care setting, were living in the United States, were able to read English, and had cared for at least one patient who was at the end of life. It was recognized that, although it was a relatively small possibility, some nurses from the first pilot study could also have been randomly selected for the current study. The AACN list rental services was contacted. I was informed that the database for the pilot work had been discarded. Consequently, there was no way to know if a respondent for the study was also included in the first pilot study.

Data Management

Primary Aim

Research Questions 1 and 2

1. Which obstacles to providing end-of-life care to dying patients do critical-care nurses perceive as being the largest, most frequent, and most severe?

2. Which helpful behaviors (or helps) to providing end-of-life care to dying patients do critical-care nurses perceive as being the largest, most frequent, and most intense?

Responses were entered into an SPSS® (SPSS®, Inc., 1999) database. The accuracy of the entered data was checked by two people. While one research assistant read the marked responses from the returned questionnaire, the second research assistant verified that the entered data on the printout were correct. When a discrepancy occurred between the marked and printed responses, I made the final decision about which number to enter. All 952 questionnaires were data checked in this manner. Frequencies, measures of central tendency and dispersion, and reliability statistics were calculated for all obstacle and help items. Items were then ranked on the basis of their mean scores to determine which items were perceived to be the largest obstacles or helps and which items were perceived to occur most frequently. Each obstacle item's size mean was then multiplied by the item's frequency mean to obtain a perceived severity score (Sawatzky, 1996). Each help item's size mean was also multiplied by the item's frequency mean to obtain a perceived intensity score. Perceived severity scores for obstacle items and perceived intensity scores for help items were then ranked from highest to lowest.

Research Question 3

3. Which aspect of end-of-life care would critical-care nurses most like to see changed?

Open-text responses for Research Question 3 were typed into a word processing database (WordPerfect™) (Corel Corporation, 1998-2000). The responses were analyzed, common themes were identified, and like responses were sorted into categories. The number of categories and the frequency of responses in each category were then determined and ranked from the highest number of responses to lowest number of responses.

Research Question 4

4. In what ways do critical-care nurses' perceptions of obstacles and helpful behaviors differ based upon length of ICU work experience?

Demographic data were analyzed to determine how best to divide the respondents into two groups based upon the amount of ICU work experience reported. An average length of ICU work experience was used. Nurses who had the same amount or less than an average length of ICU work experience (in years) were placed into one group, whereas nurses with more than average ICU work experience were placed into a second group. Frequencies and measures of central tendency and dispersion were calculated for all obstacle and help sizes and frequency data in both groups. Independent-samples t tests were completed to test for significant differences among the items rated by the two groups.

Research Question 5

5. Do CCRN-certified critical-care nurses' perceptions of obstacles and helpful behaviors significantly differ from critical-care nurses who have never certified as a CCRN?

Demographic data were analyzed with regard to CCRN-certification status. After dividing the respondents into two groups (never CCRN certified or CCRN certified), nurses who had never been certified as CCRNs had their mean responses on obstacle and help items compared to the mean responses of nurses who had certified as CCRNs using independent-samples t tests.

Secondary Aim

A two-way contingency table analysis using crosstabs was utilized to generate a Pearson chi-square value for the secondary aim because the data were nominal (incentive group, four levels; questionnaire returned or not returned). The two-way contingency table analysis compared the actual number returned (or frequency) in each incentive or control group with the expected number. Because the contingency tables were larger than 2 x 2, a Cramér's V statistic was calculated to assess strength of relationships between row and column variables (Green et al., 2000).

Study Procedures

Human subjects. The proposal for this study, the revised questionnaire, and the consent forms were reviewed by the University of Utah Institutional Review Board and Brigham Young University Institutional Review Board. Participation in the study was voluntary and consent was considered to be given if the questionnaire was returned. Respondents were notified that they could leave any question unanswered. In pretests, the questionnaire took 30 minutes to complete. Since the sample was randomly selected, it was assumed that proportions of males and minorities responding would be similar to national demographic data for AACN members. Gender data were collected; however, participants were not asked to report their ethnic origin.

The methods used in the study assured participant confidentiality. Subject names were purchased from the AACN list rental services. Subjects were assigned and identified only by code number. The master code list was kept in a locked office. All information was reported in summary form so that individual subjects could not be identified.

Instruments. In addition to the redesigned questionnaire, which all participants received, a different cover letter was included in each treatment group (see Appendix F) with a standard cover letter sent to the control group.

Only the first mailing of the questionnaire related to the experimental design. After the first mailing, the second and third mailings were sent to all nonresponders, with a standard cover letter requesting their participation.

The questionnaire was pretested using volunteer critical-care nurses from area ICUs to determine accuracy, clarity, and time to complete. After final corrections were completed, the questionnaire was sent for printing. The nurses were randomly assigned to one of four groups using EXCEL™ (Microsoft Corporation, 2000): (a) Group K, (b) Group R, (c) Group A, or (d) Group H. Each group was randomly assigned to be one of three treatment groups or the control group. Again using EXCEL™ (Microsoft Corporation, 2000) to randomly order the four groups, nurses in Group K became treatment Group 1 (lottery drawing for $100), Group R nurses became treatment Group 3 ($1 charity donation of $1 to the AACN scholarship fund), Group A nurses were randomly assigned to be the control group, and Group H nurses were assigned to receive $2 with the questionnaire.

Nurses in treatment Group K, coded K101 through K475, were notified that return of the survey by October 31, 2000 (whether or not completed) would allow that individual to be entered into a drawing to win a check for $100. Nurses in treatment Group H, coded H101 through H475, had $2 attached to the top of their cover letter with a note stating that the money was an honorarium to thank them for completing and returning the questionnaire by October 31, 2000. Nurses in treatment Group R, coded R101 through R475, were notified that for every return of a questionnaire by October 31, 2000, $1 would be donated to the AACN scholarship fund. Finally, the control group, coded A101 through A375, had a standard cover letter requesting that they complete and return the questionnaire by October 31, 2000.

Once coded, the appropriate questionnaire (by group) was collated with the correct cover letter and an addressed business reply envelope and inserted into a stamped envelope addressed to the recipient. For Group H, $2 was also inserted with the questionnaire and cover letter. I was responsible for the final inspection of all envelopes to ensure that the assigned participant was sent the correct cover letter and corresponding incentive based upon his or her random assignment to a group. All 1,500 questionnaires (for the first mailing) were mailed at the same time from the same postoffice.

The postoffice box was checked at 11:00 a.m. daily to retrieve returned questionnaires. Questionnaires were opened one at a time, and the date of return was written on each questionnaire in the upper left-hand corner of the front page. Return of the questionnaire was formally documented by recording the date of return on a specially prepared master list that contained the respondent's code numbers and three columns to note whether the questionnaire had been returned after the first, second, or third mailings.

The first mailing of all 1,500 questionnaires was sent October 14, 2000. Once the first mailing was completed and questionnaires were returned, frequencies were recorded by individual treatment group or the control group, and the secondary aim of the study was concluded. Based upon the total number of questionnaires that were returned from nurses in treatment Group R ($1 charity donation) by October 31, 2000 a check for the amount of $106 was sent to the AACN general scholarship fund (see Appendix G). The AACN acknowledged that the donation had been received via a letter dated January 19, 2001 (see Appendix H). All Group K nurses (who returned a questionnaire by October 31, 2000) had the questionnaire code number copied to a door prize ticket. My research assistant blindly drew one ticket from a bag containing all the coded tickets. The ticket's code number was compared to the master list to identify the name and address of a nurse living in Virginia who was then sent a check for $100 (see Appendix I).

The second mailing of 936 questionnaires to nonresponders occurred on November 18, 2000. The final mailing of 686 questionnaires occurred on January 13, 2001. Second and third mailings of the questionnaires to nonresponders were completed in order to obtain as much data as possible for analysis for the primary aim. Unfortunately, 20 respondents had mistakenly skipped pages when completing the questionnaire. Those respondents were mailed out copies of the missing pages with a request to complete and return missed pages in an enclosed envelope. Of the 20 respondents, 11 returned completed pages. Their responses were entered into the database with their original data.

CHAPTER V

RESULTS

Demographic Data

Of the 1,500 potential respondents, 91 were eliminated from the study sample because the questionnaire could not be delivered (n = 1) or because the recipients self-reported that they were ineligible (n = 90). Usable responses were received from 861 of the 1,409 eligible respondents for a response rate of 61% (Kviz, 1977) or about 1.3% of the total AACN membership as of June 2000 (American Association of Critical-Care Nurses, 2000).

Of the respondents who reported their gender (n = 853), 57 (6.7%) were men and 796 (93.3%) were women, identical to national AACN membership demographics (American Association of Critical-Care Nurses, 2001). Respondents were 27 to 73 years old (M = 45.1 years, SD = 8.1) and were employed as bedside staff nurses (52.4%), charge nurses (37.6%), clinical nurse specialists (4.6%), or other (5.4%). Table 2 lists the other categories of employment listed by the respondents.

Practice settings included ICUs and critical-care units (60.5%), cardiovascular/shock-trauma/neurological ICUs (20%), medical/surgical ICUs (11.3%), or other (8.2%). The majority of respondents practiced in nonprofit, community hospitals (59.5%), with the remainder practicing in university medical centers (15.5%), for-profit community hospitals (14.7%), military or federal hospitals

Table 2

"Other" Categories of Critical-Care Nurse Employment

Category	N
Assistant nurse manager	13
Staff educator	9
Nursing supervisor	5
Nurse practitioner	4
Nursing faculty	3
Infection control	1
Cath laboratory	1
Vascular nurse clinician	1
Ventricular assist coordinator	1
Agency nurse	1
Case manager	1
Total	40

(4.8%), county/state hospitals (3.3%), or other (2.2%).

The number of intensive care beds in the nurses' units ranged from a low of 1 to a high of 88 (M = 15). Eighty-five percent of the respondents were employed more than part time (25 hours or more per week). Respondents had been registered nurses for a mean of 19 years (SD = 8.2) and had worked in critical care for 15.4 years (SD = 7.04). CCRN certification had be achieved at some time in their career by 628 (73.5%) of those reporting. Of those who had ever been certified, 589 (87.6%) were currently certified. The mean number of years as a CCRN was 9.1

(SD = 4.8). More than 23% of the respondents (n = 227) reported other certifications, some listing more than one. The other certifications included (a) advanced lifesaving (n = 87), (b) trauma nursing (n = 33), (c) basic lifesaving (n = 20), (d) pediatric lifesaving (n = 19), (e) certified nurse practitioner (n = 13), (f) clinical nurse specialist (n = 10), (g) certified registered nurse (n = 10), (h) medical-surgical certification (n = 10), and (i) others (n = 84). Nurses in the other category reported having obtained certification in 46 additional nursing specialties such as emergency or neurological and in 7 nonnursing categories such as one nurse who reported being certified to teach grades K-12.

The highest completed level of education for this cohort of nurses was as follows: diploma = 14.1%, associate's degree = 19.5%, bachelor's degree = 51.8%, master's degree = 13.9%, and doctoral degree = 0.8%. More than three fourths of the nurses had cared for 30 or more dying patients (the highest option listed on the instrument).

The number of returns based upon geographic location (time zone) of the respondents is shown in Table 3.

Obstacles Perceived as Being the Largest, Most Frequent, and Most Severe: Research Question 1

Obstacle Size

An internal consistency estimate of reliability was computed for the obstacle size data. Cronbach's alpha was .89 for the 29 obstacle items. On a scale of 0 (not an obstacle) to 5 (extremely large obstacle), mean size scores for items in the obstacle

Table 3

Number and Percentage of Questionnaires Returned by U.S. Time Zone

United States	Returned (N)	Percentage of total returned
Eastern	512	54
Central	229	24
Mountain	47	5
Pacific	154	16
Alaska	5	< 1
Hawaii/Aleutians	4	< 1
APO (military address)	1	< 1
Total	952	100

Note. More returns were received from the Eastern and Central time zones due to the higher percentage of AACN members who live in these areas.

section of the questionnaire ranged from 1.61 to 4.02. The obstacle items receiving the highest mean scores for size (perceived largest obstacle) were (a) when multiple physicians caring for one patient differed in opinion about the direction care should go, (b) when family and friends continually called the nurse for an update on the patient's condition rather than calling the designated contact person, and (c) when physicians were evasive and avoided conversations with family members (see Table 4). These top three items were seen as large obstacles to providing dying patients with end-of-life care and received almost identical mean scores ($M = 4.02$, $SD = 1.1$; $M = 4.015$, $SD = 1.0$; and $M = 3.998$, $SD = 1.1$, respectively).

Table 4

Averages for Obstacle Size Reported by Critical-Care Nurses With Regard to End-of-Life Care

Obstacle	M	SD	n[a]
1. Multiple physicians involved with one patient who differ in opinion about the direction care should go	4.02	1.10	849
2. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information	4.015	.98	848
3. Physicians who are evasive and avoid having conversations with family members	3.998	1.10	846
4. Family members not understanding what lifesaving measures really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube will not allow the patient to talk, or that ribs may be broken during chest compressions	3.92	1.00	849
5. The nurse having to deal with angry family members	3.85	1.02	849
6. Employing life-sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment	3.82	1.18	852
7. Physicians who will not allow the patient to die from the disease process	3.72	1.19	844
8. Families not accepting what the physician is telling them about the patient's poor prognosis	3.64	1.01	856
0.00 The nurse not knowing the patient's wishes with regard to continuing with treatments and tests because of the inability to communicate due to a depressed neurologic status or due to pharmacologic sedation	3.63	1.06	842

Table 4 (Continued)

Obstacle	M	SD	n[a]
10. Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort	3.59	1.23	843
11. Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life	3.578	1.10	850
12. Intrafamily fighting about whether to continue or stop life support	3.57	1.10	854
13. Physicians who are overly optimistic to the family about the patient surviving	3.50	1.10	856
14. When the nurses' opinions about the direction patient care should go are not requested, not valued, or not considered	3.45	1.30	843
15. Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his or her patients	3.27	1.15	848
16. Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family	3.25	1.33	837
17. The nurse having to deal with distraught family members while still providing care for the patient	3.24	1.13	854
18. The patient having pain that is difficult to control or alleviate	2.97	1.34	852
19. Poor design of units that do not allow for the privacy of dying patients or grieving family members	2.84	1.58	853
20. The family, for whatever reason, is not with the patient when he or she is dying	2.71	1.18	843

Table 4 (Continued)

Obstacle	M	SD	n[a]
21. Lack of nursing education and training with regard to family grieving and quality end-of-life care	2.64	1.36	847
22. Dealing with the cultural differences that families employ in grieving for their dying family member	2.47	1.19	849
23. Pressure to limit family grieving after the patient's death to accommodate a new admit to that room	2.46	1.59	843
24. The nurse knowing about the patient's prognosis before the family is told the prognosis	2.28	1.56	856
25. The unavailability of an ethics board or committee to review difficult patient cases	2.278	1.69	840
26. No available support person for the family such as a social worker or religious leader	2.18	1.48	856
27. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital	2.10	1.86	829
28. Unit visiting hours that are too liberal	2.05	1.72	841
29. Unit visiting hours that are too restrictive	1.61	1.69	850

[a] Reflects the number of respondents rating this item.

Four other top 10 obstacle items involved issues with patients' families such as the family not understanding what the term "lifesaving measures" really meant (M = 3.92, SD = 1.0), nurses dealing with angry family members (M = 3.85, SD = 1.02), the family not accepting the patient's prognosis (M = 3.64, SD = 1.0), or the family wanting life-sustaining measures to be continued even though the patient's advance directive requested no such treatment (M = 3.82, SD = 1.18).

The lowest scoring obstacle items related to unit visiting hours. Unit visiting hours being too restrictive (M = 1.61, SD = 1.7) was the lowest rated item, with visiting hours being too liberal rated second lowest (M = 2.05, SD = 1.7).

Obstacle Frequency

An internal consistency estimate of reliability was computed for the obstacle frequency data. Cronbach's alpha was .89 for the 29 obstacle items. On a scale of 0 (never occurs) to 5 (always occurs), mean frequency scores for the items in the obstacle section of the questionnaire ranged from 0.98 to 3.68. The top three obstacle items receiving the highest frequency means were (a) when friends and family continually called the nurse for an update of the patient's condition (M = 3.68, SD = 0.95), (b) when the nurse knew the patient's poor prognosis before the family knew the prognosis (M = 3.40, SD = 1.1), and (c) the family not understanding what the term lifesaving measures really meant (M = 3.31, SD = 1.0) (see Table 5).

Three other top 10 frequency items related to different aspects of physician behaviors such as many physicians (caring for one patient) who did not agree about the direction of patient care (M = 2.92), physicians who avoided talking to the

Table 5

Averages for Obstacle Frequency Reported by Critical-Care Nurses With Regard to End-of-Life Care

Obstacle	M	SD	n[a]
1. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information	3.68	.95	843
2. The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	3.40	1.11	843
3. Family members not understanding what lifesaving measures really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube will not allow the patient to talk, or that ribs may be broken during chest compressions	3.31	1.01	840
4. The nurse having to deal with distraught family members while still providing care for the patient	3.21	1.04	846
5. Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life	3.07	1.04	845
6. Families not accepting what the physician is telling them about the patient's poor prognosis	2.94	.87	848
7. Multiple physicians involved with one patient who differ in opinion about the direction care should go	2.92	1.12	838
8. Physicians who are evasive and avoid having conversations with family members	2.90	1.10	841

Table 5 (Continued)

Obstacle	M	SD	n[a]
9. The nurse not knowing the patient's wishes with regard to continuing with treatments and tests because of the inability to communicate due to a depressed neurologic status or due to pharmacologic sedation	2.83	1.03	837
10. Physicians who are overly optimistic to the family about the patient surviving	2.814	.92	848
11. Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his or her patients	2.807	1.16	840
12. Physicians who will not allow the patient to die from the disease process	2.74	1.08	839
13. The nurse having to deal with angry family members	2.70	.96	842
14. Employing life-sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment	2.62	1.05	845
15. Poor design of units that do not allow for privacy of dying patients or grieving family members	2.60	1.49	840
16. Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort	2.54	1.10	838
17. Intrafamily fighting about whether to continue or stop life support	2.47	.89	849
18. When the nurses' opinions about the direction patient care should go is not requested, not valued, or not considered	2.43	1.18	840
19. Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family	2.21	1.17	843

Table 5 (Continued)

Obstacle	M	SD	n[a]
20. The family, for whatever reason, is not with the patient when he or she is dying	2.13	.81	840
21. Lack of nursing education and training with regard to family grieving and quality end-of-life care	2.11	1.20	840
22. Dealing with the cultural differences that families employ in grieving for their dying family member	2.04	.93	839
23. The patient having pain that is difficult to control or alleviate	2.00	.93	846
24. Unit visiting hours that are too liberal	1.971	.56	831
25. No available support person for the family such as a social worker or religious leader	1.63	1.13	847
26. The unavailability of an ethics board or committee to review difficult patient cases	1.60	1.41	829
27. Pressure to limit family grieving after the patient's death to accommodate a new admit to that room	1.49	1.10	844
28. Unit visiting hours that are too restrictive	1.47	1.39	838
29. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital	.98	1.13	828

[a] Reflects the number of respondents rating this item.

patient's family (M = 2.90), and physicians who were perceived by the nurse as being too optimistic to the family about the patient's chances for survival (M = 2.83).

Nurses also perceived two additional items as being frequent obstacles. These items occurred when there was not enough time to provide end-of-life care due to the nurse being occupied in activities that were trying to save the patient's life (M = 3.07) and when nurses were unable to determine the patient's wishes due to the inability to communicate with the patient for some reason (M = 2.83).

Obstacle Perceived Severity Score

In order to determine which obstacle items were perceived as being both the largest and most frequent, a perceived severity score was calculated (mean obstacle size multiplied by mean obstacle frequency) (Kanner et al., 1981; Sawatzky, 1996). The obstacle item perceived severity scores ranged from 14.78 to 2.06. The highest possible perceived severity score from the data (if the highest rated obstacle was also rated as most frequent) would have been 14.82. The item receiving the highest perceived severity score, in actuality, occurred when family and friends continually called the nurse for patient condition updates rather than calling the designated family member (M = 14.78) (see Table 6). Not only did this item receive the highest perceived severity score, it also ranked 1.81 points higher on the scale than the next closest item (perceived severity score = 12.97). None of the other 28 items had as large a difference between perceived severity scores as were the differences between the highest rated item and the second highest rated item.

Table 6

Perceived Severity Scores for Obstacle Size and Frequency in End-of-Life Care by Critical-Care Nurses

Obstacle	M (size)	M (frequency)	PSS
1. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information	4.02	3.68	14.78
2. Family members not understanding what lifesaving measures really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube will not allow the patient to talk, or that ribs may be broken during chest compressions	3.92	3.31	12.97
3. Multiple physicians involved with one patient who differ in opinion about the direction care should go	4.02	2.92	11.75
4. Physicians who are evasive and avoid having conversations with family members	4.00	2.90	11.61
5. Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life	3.58	3.07	10.98
6. Families not accepting what the physician is telling them about the patient's poor prognosis	3.64	2.94	10.69
7. The nurse having to deal with angry family members	3.85	2.70	10.40
8. The nurse having to deal with distraught family members while still providing care for the patient	3.24	3.21	10.38

Table 6 (Continued)

Obstacle	M (size)	M (frequency)	PSS
9. The nurse not knowing the patient's wishes with regard to continuing with treatments and tests because of the inability to communicate due to a depressed neurologic status or due to pharmacologic sedation	3.63	2.83	10.28
10. Physicians who will not allow the patient to die from the disease process	3.72	2.74	10.22
11. Employing life-sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment	3.82	2.62	10.01
12. Physicians who are overly optimistic to the family about the patient surviving	3.50	2.81	9.85
13. Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his or her patients	3.27	2.81	9.18
14. Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort	3.59	2.54	9.10
15. Intrafamily fighting about whether to continue or stop life support	3.57	2.47	8.82
16. When the nurse's opinion about the direction patient care should go is not requested, not valued, or not considered	3.45	2.43	8.39
17. The nurse knowing about the patient's poor prognosis before the family is told the prognosis	2.28	3.40	7.76
18. Poor design of units that do not allow for privacy of dying patients or grieving family members	2.84	2.60	7.40

Table 6 (Continued)

Obstacle	M (size)	M (frequency)	PSS
19. Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family	3.25	2.21	7.17
20. The patient having pain that is difficult to control or alleviate	2.97	2.00	5.95
21. The family, for whatever reason, is not with the patient when he or she is dying	2.71	2.13	5.78
22. Lack of nursing education and training with regard to family grieving and quality end-of-life care	2.64	2.11	5.57
23. Dealing with the cultural differences that families employ in grieving for their dying family member	2.47	2.04	5.04
24. Unit visiting hours that are too liberal	2.05	1.97	4.04
25. Pressure to limit family grieving after the patient's death to accommodate a new admit to that room	2.46	1.49	3.67
26. The unavailability of an ethics board or committee to review difficult patient cases	2.28	1.60	3.64
27. No available support person for the family such as a social worker or religious leader	2.18	1.63	3.55
28. Unit visiting hours that are too restrictive	1.61	1.47	2.37
29. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital	2.10	.98	2.06

Note. n = 856. PSS = perceived severity score (obstacle size M multiplied by obstacle frequency M).

Of the remaining top 10 most severe obstacles, 4 incorporated family issues such as families not understanding what the term lifesaving measures really meant (perceived severity score = 12.97), family members who did not accept that the patient was dying (perceived severity score = 10.69), and the nurse having to deal with angry (perceived severity score = 10.40) or distraught (perceived severity score = 10.38) family members.

Issues with the physician's behavior included two items that received high perceived severity scores. The two issues were when multiple physicians disagreed about the direction of patient care (perceived severity score = 11.75) and when physicians purposefully avoided talking to the patient's family (perceived severity score = 11.61). Other highly rated nursing concerns occurred when not enough time was available to provide end-of-life care to dying patients (perceived severity score = 10.98) and when the nurse was not able to ask the patient about his or her wishes with regard to continuing treatments (perceived severity score = 10.28).

Items that received the lowest perceived severity scores included the concepts that advanced treatments were being provided to dying patients so that the hospital would benefit financially (perceived severity score = 0.98), that visiting hours were too restrictive (perceived severity score = 1.47), and that no support persons such as social workers or religious leaders were available to the family (perceived severity score = 1.63).

Helpful Behaviors Perceived as Being the Largest, Most Frequent, and Most Intense: Research Question 2

Help Size

An internal consistency estimate of reliability was computed for the help size data. Cronbach's alpha was .86 for the 24 help items. On a scale of 0 (not a help) to 5 (extremely large help), mean size scores for the items in the help section of the questionnaire ranged from 2.62 to 4.58. The help items receiving the highest mean scores for size were when physicians (caring for one patient) agreed about the direction care should go (M = 4.59, SD = 0.6), when the family accepted that the patient was dying (M = 4.57, SD = 0.6), and when one family member became the designated contact person for all the other family members with regard to patient information (M = 4.49, SD = 0.7) (see Table 7).

Of the remaining top 10 items, 4 dealt with helpful behaviors that occurred after the patient's death and were, in some way, supportive of the family. These behaviors included providing a peaceful, dignified bedside scene (M = 4.45, SD = 0.7), allowing family members adequate time to be alone with the patient's body (M = 4.44, SD = 0.7), having a unit designed for private family grieving (M = 4.31, SD = 0.8), and physicians meeting with the family (to offer support) after the patient's death (M = 4.13, SD = 0.9).

The remaining top two most helpful behaviors took place when nurses had enough time to prepare the family for the expected death (M = 4.27, SD = 0.7) and when nurses were able to teach families how to act around the dying patient (M =

Table 7

Averages for Help Size Reported by Critical-Care Nurses With Regard to End-of-Life Care

Help	M	SD	n[a]
1. Having the physicians involved with the patient's care agree about the direction care should go	4.59	.64	850
2. Having family members accept that the patient is dying	4.57	.61	851
3. Having one family member be the designated contact person for all other family members with regard to patient information	4.49	.72	847
4. Providing a peaceful, dignified bedside scene for members once the patient has died	4.45	.69	852
5. Allowing family members adequate time to be alone with the patient after he or she has died	4.44	.70	850
6. Having a unit designed so that the family has a place to go to grieve in private	4.31	.85	846
7. Having family members thank you or in some other way show appreciation for your care of the patient who has died	4.278	.83	849
8. Having enough time to prepare the family for the expected death of the patient	4.274	.75	844
9. Teaching families how to act around the dying patient such as saying to them: "She can still hear. . . . It is okay to talk to her."	4.19	.75	848
10. Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done	4.13	.91	849

Table 7 (Continued)

Help	M	SD	n[a]
11. Having a unit schedule that allows for continuity of care for the dying patient by the same nurses	4.13	.85	848
12. After the patient's death, having support staff compile all the necessary paperwork for you that must be signed by the family before they leave the unit	3.99	1.11	832
13. Talking with the patient about his or her feelings and thoughts about dying	3.92	.91	842
14. Having a fellow nurse tell you that "you did all you could for the patient" or some other words of support	3.90	1.16	849
15. Having the nurse draw on his or her own previous experience with the critical illness or death of a family member	3.84	.98	845
16. Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient	3.71	1.23	847
17. Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times	3.70	1.24	848
18. Having physicians who put hope in real tangible saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover	3.65	1.26	841
19. Having a fellow nurse give some type of brief, physical support such as a hug after your patient dies	3.64	1.26	850
20. Letting the social worker or religious leader take primary care of the grieving family	3.59	1.10	845

Table 7 (Continued)

Help	M	SD	n[a]
21. Having a support person outside of the work setting who will listen to you after the death of your patient	3.57	1.37	846
22. Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later	3.42	1.39	830
23. Having the family physically help care for the dying patient	3.20	1.15	846
24. Having unlicensed personnel available to care for dying patients	2.62	1.50	830

[a] Reflects the number of respondents rating this item.

4.19, SD = 0.7).

Behaviors seen as the least helpful included the availability of unlicensed personnel to help provide care (M = 2.62, SD = 1.5) or when family members physically helped care for the dying patient (M = 3.20, SD = 1.1).

Help Frequency

An internal consistency estimate of reliability was computed for the help frequency data. Cronbach's alpha was .81 for the 24 help items. On a scale of 0 (never occurs) to 5 (always occurs), mean scores for frequency items in the help section of the questionnaire ranged from 0.77 to 3.96. Providing the family with unlimited time alone with the patient and creating a peaceful, dignified bedside scene after the patient's death were noted as the two most frequently occurring help items reported (M = 3.96, SD = 1 and M = 3.9, SD = 1, respectively) (see Table 8). Respondents also reported that helpful behaviors such as teaching families how to act around the dying patient (M = 3.66, SD = 0.9) and the nurse allowing families unlimited access to the patient (M = 3.3, SD = 1.1) occurred frequently.

Also seen as some of the top 10 most frequently occurring helpful behaviors were (a) having families who thanked or showed appreciation to the nurse for caring for the patient (M = 3.04, SD = 1.0), (b) having the nurse draw from his or her own experiences with a critical illness or death of a family member (M = 2.98, SD = 1.08), (c) having fellow staff nurses who offered words of support after the patient died (M = 2.81, SD = 1.18), and (d) having unit schedules that allowed for the same nurses to care for dying patients and family members (M = 2.57, SD =

Table 8

Averages for Help Frequency Reported by Critical-Care Nurses With Regard to End-of-Life Care

Help	M	SD	n[a]
1. Allowing family members adequate time alone with the patient after he or she has died	3.96	.96	844
2. Providing a peaceful, dignified bedside scene for family members once the patient has died	3.90	.96	845
3. Teaching families how to act around the dying patient such as saying to them: "She can still hear. . . . It is okay to talk to her."	3.66	.89	841
4. Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times	3.28	1.10	845
5. Having family members thank you or in some other way show appreciation for your care of the patient who has died	3.04	1.00	844
6. Having the nurse draw on his or her own previous experience with the critical illness or death of a family member	2.98	1.09	837
7. Having a fellow nurse tell you that "you did all you could for that patient" or some other words of support	2.81	1.18	841
8. Having the physicians involved in the patient's care agree about the direction care should go	2.73	.95	837
9. Having family members accept that the patient is dying	2.67	.76	841
10. Having a unit schedule that allows for continuity of care for the dying patient by the same nurses	2.57	1.07	843

Table 8 (Continued)

Help	M	SD	n^a
11. Having one family member be the designated contact person for all other family members with regard to patient information	2.53	1.02	844
12. Having enough time to prepare the family for the expected death of the patient	2.48	.83	838
13. Having a unit designed so that the family has a place to go to grieve in private	2.46	1.46	820
14. After the patient's death, having support staff compile all the necessary paperwork for you that must be signed by the family before they leave the unit	2.40	1.41	828
15. Having a fellow nurse put his or her arm around you, hug you, pat you on the back, or give some other type of brief physical support after the death of your patient	2.33	1.29	844
16. Having a support person outside of the work setting who will listen to you after the death of your patient	2.16	1.60	842
17. Letting the social worker or religious leader take primary care of the grieving family	2.07	1.17	842
18. Having physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover	2.06	.96	833
19. Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient	1.94	1.35	847

Table 8 (Continued)

Help	M	SD	n[a]
20. Having the family physically help care for the dying patient	1.92	.94	841
21. Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done	1.90	1.21	844
22. Talking with the patient about his or her feelings and thoughts about dying	1.85	.92	841
23. Having unlicensed personnel available to help care for dying patients	1.34	1.21	833
24. Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later	.77	1.14	841

[a] Reflects the number of respondents rating this item.

1.07). Helpful behaviors rated as least frequently occurring were when a member of the hospital's ethics committee routinely attended unit rounds (M = 0.77, SD = 1.14) and having unlicensed personnel available to help care for dying patients (M = 1.3, SD = 1.2).

Help Perceived Intensity Score

In order to determine which items were perceived as both the most helpful and most frequent, a perceived intensity score was calculated (mean help size multiplied by mean help frequency). The range for all help item perceived intensity scores was from 0.77 to 3.96. The highest possible perceived intensity score for the help items, if the largest help item was also the item rated as most frequently occurring, would have been 18.17 (see Table 9). In actuality, the items seen as being most helpful and frequently occurring were allowing family members adequate time alone with the patient after death (perceived intensity score = 17.57) followed by providing a peaceful, dignified bedside scene (perceived intensity score = 17.35).

Three other highly scoring items related to nurse-family interactions such as teaching the family how to act around the dying patient (perceived intensity score = 15.32), having family members thank the nurse in some way for caring for the patient (perceived intensity score = 13.02), or having used his or her own experiences with a critical illness or death of a loved one to help the family (perceived intensity score = 11.45).

Families who accepted that the patient was dying (perceived intensity score = 12.20), who were allowed unlimited access to the patient–even at the expense of

Table 9

Perceived Intensity Scores for Help Size and Frequency in End-of-Life Care by Critical-Care Nurses

Help	M (size)	M (frequency)	PIS
1. Allowing family members adequate time to be alone with the patient after he or she has died	4.44	3.96	17.57
2. Providing a peaceful, dignified bedside scene for family members once the patient has died	4.45	3.90	17.35
3. Teaching families how to act around the dying patient such as saying to them: "She can still hear. . . . It is okay to talk to her."	4.19	3.66	15.32
4. Having family members thank you or in some other way show appreciation for your care of the patient who has died	4.28	3.04	13.02
5. Having the physicians involved in the patient's care agree about the direction care should go	4.59	2.73	12.52
6. Having family members accept that the patient is dying	4.57	2.67	12.20
7. Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times	3.70	3.28	12.13
8. Having the nurse draw on his or her own previous experience with the critical illness or death of a family member	3.84	2.98	11.45
9. Having one family member be the designated contact person for all other family members with regard to patient information	4.49	2.53	11.35

Table 9 (Continued)

Help	M (size)	M (frequency)	PIS
10. Having a fellow nurse tell you that "you did all you could for the patient" or some other words of support	3.90	2.81	10.97
11. Having enough time to prepare the family for the expected death of the patient	4.27	2.48	10.61
12. Having a unit schedule that allows for continuity of care for the dying patient by the same nurses	4.13	2.57	10.60
13. Having a unit designed so that the family has a place to go to grieve in private	4.31	2.46	10.58
14. After the patient's death, having support staff compile all the necessary paperwork for you that must be signed by the family before they leave the unit	3.99	2.40	9.59
15. Having a fellow nurse put his or her arm around you, hug you, pat you on the back, or give some other type of brief physical support after the death of your patient	3.64	2.33	8.47
16. Having the physicians meet in person with the family after the patient's death to offer support and validate that all possible care was done	4.13	1.90	7.84
17. Having a support person outside of the work setting who will listen to you after the death	3.57	2.16	7.71
18. Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover	3.65	2.06	7.52

Table 9 (Continued)

Help	M (size)	M (frequency)	PIS
19. Letting the social worker or religious leader take primary care of the grieving family	3.59	2.07	7.43
20. Talking with the patient about his or her feelings and thoughts about dying	3.92	1.84	7.24
21. Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient	3.71	1.94	7.21
22. Having the family physically help care for the dying patient	3.20	1.92	6.16
23. Having unlicensed personnel available to help care for dying patients	2.62	1.34	3.51
24. Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later	3.42	.77	2.62

Note. n = 850. PIS = perceived intensity score (help size M multiplied by help frequency M).

patient care (perceived intensity score = 12.13), and families who designated one contact person for all other family members with regard to patient information (perceived intensity score = 11.35) were seen as the other top 10 most helpful and frequent behaviors.

Lowest items using the intensity scale for help data included having an ethics committee that routinely attended unit rounds (perceived intensity score = 2.62), using unlicensed personnel to help care for dying patients (perceived intensity score = 3.51), and having family members physically help care for the dying patient (perceived intensity score = 6.16).

Which Aspect of End-of-Life Care Would Critical-Care Nurses Most Like to See Changed:
Research Question 3

Of the 861 nurses who returned completed questionnaires, 482 responded with a suggestion (sometimes more than one) related to how they would change end-of-life care in ICUs. Responses were entered into WordPerfect™ (Corel Corporation, 1998-2000) and sorted into common themes. Ten themes emerged. These themes were (a) recommended actions, activities, or behaviors that provide the patient (and their family) with a "good death" ($\underline{n}$ = 143); (b) the need for more time to care for dying patients and families ($\underline{n}$ = 72); (c) physicians (and others) being more open, honest, up-front, and realistic (earlier in the course of treatment) with regard to the patient's condition and prognosis ($\underline{n}$ = 48); (d) requests for education or teaching to physicians, nurses, families, or the community at-large with regard to end-of-life care and dying ($\underline{n}$ = 46); (e) better pain control/management for dying patients ($\underline{n}$ = 41);

(f) knowing, then following the patients' wishes about end-of-life care (n = 40); (g) better communication so that all (who are involved with the patient) are working toward the same goal/plan (n = 37); (h) treatments being stopped earlier (or never started) (n = 35); (i) recognition of futile care (n = 23); (j) physician demeanor (n = 18); and (k) miscellaneous comments (n = 52). Five responses were unintelligible.

Providing a Good Death

The most common response given by this sample of critical-care nurses to the question with regard to what they would change to improve care at the end of life encompassed actions, activities, or behaviors that would provide the patient and his or her family with a good death (Chapple, 1999). Responses for this theme were double in number compared to the next closest category (143 versus 72, respectively). Common suggestions included open, flexible visiting hours to allow families unlimited access to the patient and moving the patient to a private room. One nurse stated, "The ICU is no place to die. It would be nice to have a comfortable, quiet, spacious room for those who are dying. Let everyone in and let the rest of the ICU function as it should."

Two other frequent suggestions with regard to patients having a good death included the concept of dying with dignity and the patient not being alone while dying. Nurses were concerned that patients were not being allowed to die with dignity. Of the 143 responses, 24 nurses commented that there needed to be more dignity with death. Many used the words "allow the patient to die with dignity."

Others believed that no patient should be alone to die. For example: “No one should ever die alone! Every patient needs to have someone present with them at the moment of death—to touch them, speak to them, to let them know it’s okay to go.”

More Time to Care

The second most frequent theme was nurses who wanted patient care assignments changed to include more time to care for dying patients and their families. One nurse stated: “Having more time to spend with the patient and family members. Now that ICU patients are sicker, one is never afforded the ability to care for just this patient. Assignments do not allow for this much needed time.” Another said, “Being able to give my needed time to the patient and family members without being taken away [to care for other patients].”

Some nurses blamed the lack of time for nursing care of the dying on the shortage of nurses saying, “Often, if we are short-staffed, we have little time to spend with the patient and family. With the critical-care [nurse] shortage, it is only going to get worse.” Another stated, “It is rare that dying patients are 1:1 ratio. We don’t have the staff or are told we have to float staff instead of making [the dying patient] 1:1s.”

Open, Honest, Early, and Realistic Communication

Many nurses want physicians to be truthful, realistic, and up-front about the patient’s prognosis when communicating with the patient and family. For example, a nurse wrote, “Physicians being honest with families and with patients. Tell them the truth and be realistic about time and treatment, then let families and patients make decisions." Another said, "Require physicians to be realistic about the patient's condition. Would they [the physician] care for their mother or father this way?"

Nurses also commented that these physician/patient/family discussions need to occur earlier in the treatment plan. One nurse stated, "If physicians were honest about prognosis with families [earlier], it would give them [the family] time to prepare and have quality time with the dying patient. It would also help us help families prepare [for the death]."

Need for Education

Forty-six nurses suggested the need for education and teaching with regard to issues around end-of-life care and dying. Nurses reported that families and patients are most needful of education (n = 20) followed by physicians/medical students (n = 13), the community at-large (n = 11), and nurses (n = 9).

Nurses wanted families to have a better understanding of what being in ICU means for the patient. One nurse stated:

> Talk to the patients and families before they get to ICU. Explain that intubating a patient takes away that individual's last chance to communicate with the important people in their lives [sic]. It is so sad that machines become the focus instead of that person—so sad.

Several nurses believed physicians (and medical students) need to be taught how to discuss end-of-life issues with families, how to provide for painless deaths, more about palliative care, and withdrawal of treatments (once started). One nurse said, "Teach physicians when it is okay to allow the patient to die with dignity so the family isn't unnecessarily stressed and their feelings of guilt are less." Another wrote, "Educate the physicians in medical school [about] holistic palliative care."

General public education about topics and issues at the end of life were also noted to be ways to change end-of-life care. Nurses wanted better community education with regard to organ donation, advance directives, durable power of attorney, and clarification about what the medical profession can realistically do for dying patients. For example: "I would improve the public education to reflect the reality that 'modern medicine' cannot always fix what is broken. Sometimes death is the most natural thing that can happen in an ICU. We are trapped between technology and reality." "Have a nationwide education of what life support is, similar to the 'Stop Smoking' campaign. Education of family members [is needed] as to the [realities] of what medicine can and cannot do." Nurses also wanted education for themselves with regard to ways to discuss the subject of death with patients, more education about death and dying in nursing school courses, how to provide the patient with a painless death, and a better understanding of care at the end of life.

Pain Control/Management

Many nurses were concerned about the suffering they witnessed when patients were at the end of life and dying. These nurses recommended that more pain medication (or sedation) be provided to dying patients for complete pain relief. In the words of one nurse, "Control patients' pain!" Another went further stating, "Alleviate pain even if it hastens death."

Follow the Patient's Wishes

Nurses were very desirous that patients' wishes with regard to what happened to them prior to dying were known and then followed. Nurses wanted better compliance by physicians and family members in following advance directives or living wills. The statement, "We [should] abide by the patient's wishes and not have family override that. Healthcare professionals frequently go against the patient's wishes if any family member disagrees due to fear of legal actions," was written by one nurse. Another wrote, "I would like to have the healthcare system more consistently respect, honor, and adhere to advance directives." A third nurse wrote, "The patient's living will and advance directive are the legal document by which end-of-life decisions [should be] based and [should not be] overridden by family members."

Same Goal/Plan

Having a common goal or plan that helps guide care for patients at the end of life was seen as a desirable change from current end-of-life care practices. Several nurses believed that having a formal team meeting would facilitate communication between healthcare workers and families, thus improving patient care. One nurse stated, "I would like a multidisciplinary team [to include all the physicians] to meet with the family once a week so that everyone is working off the same page and everyone knows the issues. Communication is the key!" Another wrote, "Having all doctors caring for a particular patient concur on treatment, care, and explanations to families to prevent false hope, misunderstanding, and conflict."

Others noted that communication among physicians caring for the same patient and among physicians and nurses could also be improved. One said:

> Improved communication between attending physicians and residents/interns regarding patient outcome [is desired]. [Physicians need to have the] ability to verbalize a plan of treatment with the nursing staff so all understand where treatment is going.

Stop Treatments

Nurses reported that patients suffer when aggressive treatments are continued beyond the point of helping to improve the patient's condition. An experienced critical-care nurse wrote that she "would like physicians to stop prolonging the dying process [by using] a little dopamine drip and a little cardiazem drip and a little more aggressive ventilator settings." Another nurse gave a more emotional appeal saying, "Take them [the patient] off the damn ventilator–sometimes I think that machine prolongs suffering more than anything else." Two other nurses wrote to "stop painful treatments when there is no hope of recovery" and "stop treatments when it is obvious they are not going to prolong the patient's life or return them to any meaningful quality of life."

Futile Care

The 23 comments with regard to futile or hopeless care of dying patients were best summarized by a nurse who said:

> Futile care [should] not be offered as an option to patients and family members but rather an emphasis on supportive and comfort care for the patient and family. We waste precious resources and time doing procedures and treatments we know hold little or no benefit for the patient and family just to say we've done everything.

Physician Demeanor

A few nurses wanted to change specific physician demeanor such as having the physicians be more accepting of the fact that patients die. Nurses wrote that some physicians tend to see a patient's death as a personal failure. For example, one nurse wrote that "physicians need to realize that death is a part of life and not view it as a failure." Another nurse echoed this same sentiment: "Doctors . . . [should] understand that everyone dies and that death is okay. [They should understand] that death is a part of life."

Miscellaneous Suggestions for Improving End-of-Life Care

Miscellaneous suggestions ranged from providing better pastoral staff to having the nurse help families and patients reconcile animosities, grudges, or other conflicts. A few nurses believed that more care should be taken when using valuable resources such as blood products and that these resources should not be wasted on patients who were dying. One nurse stated, "[I would change] intentionally wasting blood products on someone who is not viable when someone could have [the] benefits."

Do Critical-Care Nurses' Perceptions of Obstacles and Helpful Behaviors Differ Based Upon Length of Intensive Care Unit Work Experience:

Research Question 4

The average years of ICU experience reported by respondents was 15.4. Only 30 (3.5%) of the 849 nurses who responded to this question had less than 5 years of ICU work experience. Reported ICU work experience ranged from 2 to 40 years.

Nurses with 15 years or less of ICU work experience averaged 40.5 years old, whereas nurses with 16 years or more of ICU work experience averaged 48.5 years old.

Obstacle Size

Based on the mean, the group was divided into nurses with 15 years or less of ICU work experience (*n* = 466) and nurses with 16 or more years of ICU work experience (*n* = 382). Independent-samples *t* tests were conducted to evaluate whether nurses with 15 years of ICU work experience or less differed from nurses with more ICU work experience in their perceptions of obstacles and helpful behaviors. For the obstacle sizes, the test was significant for two items. Nurses in the 15 years or less group rated questionnaire Item 3 (the nurse having to deal with distraught family members) lower (*M* = 3.14, *SD* = 1.13) than did the more experienced nurses (*M* = 3.35, *SD* = 1.14), *t*(844) = -2.72, *p* = .007. For questionnaire Item 7, the nurses in the less experienced group also gave a lower rating (*M* = 2.73, *SD* = 1.58) to the obstacle with regard to poor unit design (which did not allow for the privacy of dying patients and grieving families) than did the more experienced group of nurses (*M* = 2.96, *SD* = 1.56), *t*(843) = -2.09, *p* = .037.

Obstacle Frequency

Comparing the groups based on years of ICU experience using the obstacle frequency data, two items were found to be significant using independent-samples *t* tests. The nurses in the more experienced group rated the lack of an ethics committee to review difficult patient cases as a more frequently occurring obstacle (M = 1.71, SD = 1.46) than did the less experienced nurses (M = 1.5, SD = 1.35), t(820) = -2.10, p = .036. Interestingly, the less experienced nurses believed unit visiting hours that were too liberal (obstacle Item 21) was a larger obstacle than the more experienced nurses (M = 2.08, SD = 1.60; M = 1.84, SD = 1.50, respectively), t(822) = 2.25, p = .025.

Help Size

Table 10 shows the three help questionnaire items that were significantly different between nursing groups (based upon years of experience) using independent-samples t tests for size data. These items were (a) the nurse drawing on his or her own experiences with the critical illness or death of a family member, (b) having the family physically help care for the dying patient, and (c) having unlicensed personnel available to help care for dying patients.

Help Frequency

For help frequencies, only questionnaire Item 41 and Item 54 showed a significant difference between the nursing groups based upon years of ICU experience. The nurses with less years of ICU work experience found allowing the family unlimited access to the dying patient, even when visits conflicted with nursing care, to be less frequently occurring (M = 3.2, SD = 1.13) than did the nurses with more ICU work experience (M = 3.38, SD = 1.04), t(840) = -2.183, p = .029.

Table 10

Independent t Tests of Selected Significant Help Size Items by Intensive Care Unit Nursing Experience

		t tests			
Item	n	M	SD	t	p
Having nurses draw upon their own experiences with the critical illness or death of a family member				-2.404	.016
Less experienced nurses	462	3.76	.96		
More experienced nurses	381	3.92	.96		
Having the family physically help care for the dying patient				2.054	.040
Less experienced nurses	464	3.27	1.00		
More experienced nurses	380	3.11	1.19		
Having unlicensed personnel available to help care for dying patients				2.22	.027
Less experienced nurses	455	2.72	1.50		
More experienced nurses	372	2.48	1.50		

The less experienced nurses also reported that having unlicensed personnel available to help care for dying patients occurred more often (M = 1.47, SD = 1.26) than did the nurses with more ICU work experience (M = 1.18, SD = 1.13), t(828) = 3.43, p = .001. A summary of the differences in critical-care nurses' perceptions of obstacles and helpful behavior items, based upon ICU work experience, is presented in Table 11.

Do Critical-Care Nurses' Perceptions of Obstacles and Helpful Behaviors Differ Based Upon Critical-Care Registered Nurse Certification Status: Research Question 5

Of 855 nurses who answered the question of whether or not they had ever been CCRN-certified, 227 (26.5%) responded no and 628 (73.5%) responded yes. In

Table 11

Summary of Results for Critical-Care Nurses' Perceptions of Obstacles and Helpful Behaviors Based Upon Length of Intensive Care Unit Work Experience: Research Question 4

More experienced critical-care nurses:	Less experienced critical-care nurses:
1. Dealt with more distraught family members	1. Perceived unit visiting hours as being too liberal
2. Perceived poor unit design as a larger obstacle	2. Perceived physical help with patient care from family members as a larger help
3. Perceived lack of an ethics committee as more frequently occurring	3. Perceived unlicensed personnel as a larger help
4. Drew upon their own experiences with sick or dying family members more often	4. Perceived unlicensed personnel as being available to help with patient care more frequently
5. More frequently allowed unlimited family access to dying patients	

addition, 589 nurses (69.2% of the total sample) stated they were currently certified as CCRNs. Of those reporting how many years they had held the CCRN certification (n = 617), the mean was 9.1 (SD = 4.8, range 1 to 24).

Obstacle Size

When independent-samples t tests were conducted to evaluate whether or not nurses who had never certified as CCRNs rated obstacle sizes differently than nurses who had at one time been CCRN-certified, nine items were shown to have been significantly different between the two groups. Table 12 lists the nine items and the t-test results. In general, the nurses who had earned CCRN certification perceived all nine items to be larger obstacles than did the never CCRN-certified nurses.

Obstacle Frequency

Nurses who had earned CCRN certification rated three questionnaire items differently on frequency than did the never CCRN-certified nurses. First, CCRN-certified nurses rated the item of continuing treatments for dying patients (even though the treatments caused the patient pain or discomfort) as occurring more frequently than did the never CCRN-certified nurses (M = 2.59, SD = 1.09; M = 2.37, SD = 1.11, respectively), t(835) = -2.60, p = .009.

Second, never CCRN-certified nurses rated two items as occurring less frequently than did the CCRN group. The first item was the lack of nursing education and training with regard to family grieving and quality end-of-life care. Never CCRN-certified nurses (n = 223) rated this item at a mean of 1.94 (SD = 1.17) and CCRNs

Table 12

Independent t Tests of Selected Significant Obstacle Size Items by Critical-Care Registered Nurses' Certification Status

Item	n	t tests			p
		M	SD	t	
Physicians who are overly optimistic to the family about the patient surviving member				-2.402	.017
Never CCRNs	227	3.35	1.20		
CCRNs nurses	627	3.56	1.06		
Families not accepting what the physician is telling them about the patient's poor prognosis				-2.432	.015
Never CCRNs	227	3.50	1.05		
CCRNs nurses	627	3.69	.99		
Visiting hours that are too restrictive				-2.116	.035
Never CCRNs	223	1.41	1.62		
CCRNs nurses	625	1.68	1.71		
The patient having pain that is difficult to control or alleviate				-2.232	.026
Never CCRNs	225	2.80	1.34		
CCRNs	625	3.03	1.33		
Employing life-sustaining measures at the families' request even though the patient had signed advance directives requesting no such treatment				-2.077	.039
Never CCRNs	224	3.66	1.31		
CCRNs	627	3.86	1.13		

Table 12 (Continued)

Item	n	t tests			p
		M	SD	t	
Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family				-2.195	.028
Never CCRNs	221	3.07	1.42		
CCRNs	625	3.30	1.30		
Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort				-3.627	.001
Never CCRNs	222	3.31	1.34		
CCRNs	620	3.67	1.18		
Lack of nursing education and training with regard to family grieving and quality end-of-life care				-2.254	.024
Never CCRNs	222	2.46	1.37		
CCRNs	624	2.69	1.35		
Physicians who will not allow the patient to die from the disease process				-2.96	.003
Never CCRNs	221	3.51	1.24		
CCRNs	622	3.79	1.16		

Note. CCRNs = critical-care registered nurses.

(n = 616) rated it as a more frequently occurring obstacle (M = 2.17, SD = 1.20), t(837) = -2.482, p = .013. The second item occurred when the nurse did not know the patient's wishes with regard to continuation of treatments and tests because of the inability to communicate due to a patient's depressed neurological status or due to pharmacologic sedation. Never CCRN-certified nurses (n = 219) rated this item at a mean of 2.69 (SD = 1.03) and CCRNs (n = 617) rated it as a more frequently occurring obstacle (M = 2.89, SD = 1.03), t(834) = -2.440, p = .015.

Help Size

Table 13 shows the results of the independent-sample t tests that were rated significantly different between certified and never CCRN-certified nurses. For all five items, the never CCRN-certified nurses perceived the items to be smaller obstacles to providing end-of-life care than did the certified CCRN nurses.

Help Frequency

Only one help item was significantly different between CCRNs and never CCRN-certified nurses for frequency. Family members physically helping give care for dying patients was rated as more frequently occurring by CCRNs (M = 1.98, SD = .96) than by never CCRN-certified nurses (M = 1.78, SD = .88), t(838) = -2.734, p = .006.

A summary of CCRN-certified critical-care nurses' perceptions of obstacles, based upon size and frequency, is presented in Table 14. A summary of CCRN-certified critical-care nurses' perceptions of helps, based upon size and frequency, is

Table 13

Independent t Tests of Selected Significant Help Size Items by Critical-Care Registered Nurses' Certification Status

Item	n	t tests			p
		M	SD	t	
Having a unit designed so that the family has a place to grieve in private				-2.612	.009
Never CCRNs	222	4.18	.94		
CCRNs nurses	623	4.35	.81		
Having the physicians involved in the patient's care agree about the direction care should go				-1.98	.049
Never CCRNs	224	4.50	.75		
CCRNs nurses	625	4.61	.60		
Having family members accept that the patient is dying				-2.42	.016
Never CCRNs	226	4.48	.67		
CCRNs nurses	624	4.60	.58		
Having physicians who put hope in real tangible terms				-2.09	.037
Never CCRNs	221	3.50	1.34		
CCRNs	619	3.71	1.22		
Having the physician meet with the family after the patient's death to offer support and validate that all possible care was done				-2.09	.016
Never CCRNs	224	4.02	1.02		
CCRNs	624	4.18	.87		

Note. CCRNs = critical-care registered nurses.

Table 14

Summary of Results for Critical-Care Nurses-Certified Critical-Care Nurses' Perceptions of Obstacles Size and Frequency Based Upon Certification Status: Research Question 5

Certified critical-care nurses perceived as larger obstacles:	Certified critical-care nurses perceived as more frequently occurring:
1. Physicians as being overly optimistic about the patient surviving	1. Treatments to dying patients that caused pain or discomfort
2. Families not accepting what the physician told them about the patient's poor prognosis	2. Lack of nurse education and training with regard to family grieving and quality end-of-life care
3. Visiting hours that were too restrictive	3. The nurse not knowing the patient's wishes with regard to continuing treatments due to the inability to communicate with the patient for some reason
4. Patients who had pain that was difficult to control or alleviate	
5. Employing life-sustaining measures at the families' request (even though the patient had signed an advance directive requesting no such treatment)	
6. Continuing intensive care treatments for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family	
7. Continuing treatments that cause the dying patient pain or discomfort	
8. Lack of nurse education and training in family grieving and end-of-life care	
9. Physicians who would not allow the patient to die from the disease process	

presented in Table 15.

Secondary Aim Results for Incentive Data

Two Weeks After First Mailing

A two-way contingency table analysis was conducted to evaluate if any one of three incentives included with the mailed questionnaire significantly improved that group's response rate compared to the control group for the time period 2 weeks after the first mailing. This 2-week time frame corresponded with the deadline (October 31, 2000) suggested in all the groups' cover letters. For Group K, nurses who returned

Table 15

Summary of Results for Critical-Care Nurses-Certified Critical Care Nurses' Perceptions of Help Size and Frequency Based Upon Certification Status: Research Question 5

Certified critical-care nurses perceive as larger helps:	Certified critical-care nurses perceive as more frequently occurring:
1. Units that were designed so that families had a place to grieve	1. Family members who physically helped provide care to dying patients
2. When physicians involved with caring for the patient all agreed about the direction patient care should proceed	
3. Having family members accept that the patient was dying	
4. Physicians who put hope in real, tangible terms	
5. Having the physician meet with the family, after the patient's death, to offer support and validation that all possible care was done	

their questionnaire by October 31, 2000 (whether or not completed) were included in the drawing for a $100 check. For Group R, the number of nurses who returned their questionnaires by the listed date (whether or not completed) were totaled and, based on that number, a check for $106 was donated to the AACN general scholarship fund.

The two variables included in the contingency table analysis were type of incentive with four levels ($100 lottery, $1 charity donation, $2, or control) and whether the questionnaire was returned (yes or no). The $2 incentive and questionnaire returned (yes) were found to be significantly associated, Pearson χ^2 (3, $\underline{N}$ = 1,500) = 30.17, $\underline{p}$ = < .0001 (see Table 16). A Cramér's V statistic, completed at the same time as the Pearson chi square, showed that the strength of the relationship among group membership and return rate was low (ϕ = .14).

In order to ensure that the $2 group was the cause of the significant χ^2, a two-way contingency table analysis was conducted on the three other groups only ($100

Table 16

Chi-Square Test Analysis of Incentive Group and Return Rate at Two Weeks

Group	Questionnaire				χ^2	$\underline{p}$
	Returned		Not returned			
	$\underline{N}$	%	$\underline{N}$	%		
Group K ($100 lottery)	117	23.0	258	26.0	30.17	< .0001
Group R (charity donation)	106	20.9	269	27.1		
Group H ($2)	170	33.5	205	20.7		
Group A (control)	115	22.6	260	26.2		
Total	508	100.0	992	100.0		

lottery, $1 charity donation, and control). The two variables were type of incentive with three levels ($100 lottery, $1 charity donation, and control) and whether the questionnaire was returned (yes or no). No significant relationship was found between the other groups and return of the questionnaire, Pearson χ^2 (2, N = 1,125) = 0.871, p = 0.647 (see Table 17). These results demonstrated that there was no difference in group means for return rates among the remaining three groups and that the only significantly different group mean was for Group H ($2 bill).

Four Weeks After First Mailing

A two-way contingency table analysis was conducted to evaluate if any one of three incentives included with the mailed questionnaire significantly improved that group's response rate compared to the control group for the time immediately preceding the second mailing (4 weeks after the first mailing). The two variables were

Table 17

Chi-Square Test Analysis of Incentive Group and Return Rate at Two Weeks Minus Two Dollars: Group H

Group	Questionnaire				χ^2	p
	Returned		Not returned			
	N	%	N	%		
Group K ($100 lottery)	117	34.6	258	32.8	0.871	0.647
Group R (charity donation)	106	31.4	269	34.2		
Group A (control)	115	34.0	260	33.0		
Total	338	100.0	787	100.0		

type of incentive with four levels ($100 lottery, $2, $1 charity donation, or control) and whether the questionnaire was returned (yes or no). The $2 group and questionnaire returned (yes) variables were found to be significantly associated, Pearson χ^2 (3, $\underline{N}$ = 1,500) = 31.45, $\underline{p}$ = < .0001 (see Table 18). A Cramér's V statistic, completed with the Pearson chi-square, showed that the strength of the relationship between group membership and return rate (ϕ = .15) was low.

In order to ensure that the $2 group was the cause of the significant χ^2, a two-way contingency table analysis was conducted exclusively on the three other groups ($100 lottery, $1 charity donation, and control). The two variables were grouped with three levels ($100 lottery, $1 charity donation, or control) and whether the questionnaire was returned (yes or no). No significant association was noted among group and questionnaire return, Pearson χ^2 (2, $\underline{N}$ = 1,125) = 1.08, $\underline{p}$ = 0.584 (see Table 19). These results show that there was no difference in proportion among the

Table 18

Chi-Square Test Analysis of Incentive Group and Return Rate at Four Weeks

Group	Questionnaire				χ^2	$\underline{p}$
	Returned		Not returned			
	$\underline{N}$	%	$\underline{N}$	%		
Group K ($100 lottery)	139	23.4	236	26.1	31.45	< .0001
Group R (charity donation)	126	21.1	249	27.5		
Group H ($2)	194	32.6	181	20.0		
Group A (control)	136	22.9	239	26.4		
Total	595	100.0	905	100.0		

Table 19

Chi-Square Test Analysis of Incentive Group and Return Rate at Four Weeks Minus Two Dollars: Group H

Group	Questionnaire				χ^2	p
	Returned		Not returned			
	N	%	N	%		
Group K ($100 lottery)	139	34.7	236	32.6	1.08	0.584
Group R (charity donation)	126	31.4	249	34.4		
Group A (control)	136	33.9	239	33.0		
Total	401	100.0	724	100.0		

remaining three groups and that the only significantly different group mean was for Group H ($2 bill).

CHAPTER VI

DISCUSSION AND RECOMMENDATIONS

Results from this research validate the information obtained in the pilot study in several ways. First, the top two pilot study obstacles remained as the largest and most intense obstacles for this sample of nurses. Second, pilot study nurses' suggestions of three additional obstacles were rated as the 3rd, 4th, and 10th most intense (severe) obstacles in this study. Finally, obstacle items rated as extremely small on the pilot study were also seen as the least intense for this study.

Frequency-of-occurrence information helped to clarify the perceived severity of obstacles; that is, 6 of the pilot study obstacles continued to be part of the top 10 most intense items, thus validating their importance. Four items dropped below 10th position and seemed to be smaller obstacles than the pilot study had originally suggested. Three of the added obstacle items were perceived to be both large and frequently occurring, thus scoring above 10th position on severity.

Help items by size changed very little in rank order between the pilot and current studies. Helpful behaviors that were most frequently occurring were noted to be items that nurses control. Other more frequently occurring items related to supportive behavior for the nurse provided by the patient's family or by other staff members. Items seen as both helpful and frequently occurring (high perceived intensity score) were, again, usually in the control of the nurse. Behaviors controlled by physicians received lower perceived intensity scores mainly because they occur less frequently than nurse-controlled behaviors.

Nurses recommended changes to improve care at the end of life. Ten themes emerged. The most frequently recommended theme involved actions, activities, or behaviors that would provide the patient with a good death. Other top recommendations included changing nursing assignments to allow for more time to care for dying patients; more open, honest, and realistic communication between physicians and families; more education about end-of-life issues; and better patient pain control/management.

For the secondary aim, use of a monetary incentive ($2) delivered with the questionnaire significantly increased response rates for the first mailing by enhancing a sense of immediacy; that is, the questionnaire should be completed and returned quickly. No other incentive ($100 lottery or $1 charity donation) significantly improved response rates compared to the control group.

The following discussion presents the sample characteristics and outcomes, conclusions and recommendations for the research questions, and recommendations for future research.

Sample Characteristics and Outcomes

Similarities and differences were found in reported demographics between this sample and the national population of AACN members. The sample population was similar to national AACN membership demographics in breakdown by gender (nationally: males = 7%, females = 93%), average age (nationally: 43% between 40 and 49 years old), and hours worked per week (nationally: 83% work full time). The present sample was different for the following reasons: Nurses reported being registered nurses longer and having more years of ICU work experience than AACN members nationally. AACNs' demographics are that 47% of its membership have been registered nurses for 16 or more years compared to 64.5% for the present study and that 26% of its membership have worked in an ICU for 16 or more years compared to 45% for the present study (American Association of Critical-Care Nurses, 2001).

Only bedside or charge nurses working in adult ICUs were included in the random sample generated by the AACN list rental services. Consequently, it was not possible to compare the current study sample to the national population for demographic data such as type of unit worked or primary position held.

Some of the discrepancies between the total AACN population and the current study sample are likely due to differences in how the demographic questions were asked and how responses were collapsed or categorized for the national demographic data. Although a few differences exist because the sample was randomly selected, geographically dispersed, and of adequate size, the results are generalizable to the population of bedside nurses who are members of the AACN.

Conclusions and Recommendations

Research Question 1

Obstacle Size

Which obstacles to providing end-of-life care to dying patients do critical-care nurses perceive as being the largest, most frequent, and most severe? For obstacle size data, a Cronbach's alpha score of .89 suggests that scale scores are reasonably reliable for respondents like those in this study. This alpha score was slightly higher than the pilot study (.86) due to the addition of five pertinent obstacle items suggested by the pilot study nurses.

The mean score ranges for items in the obstacle size section were higher than were observed in the pilot study, suggesting that serious deficiencies in end-of-life care continue to exist in ICUs across the nation and may be worsening or because more recent attention is being focused on end-of-life care nationally may be a result of nurses being more cognizant of deficiencies in care. It is also possible that this sample of highly experienced, older nurses perceived these obstacles as being larger than the pilot study nurses because they care for the most ill ICU patients and have seen more patients at the end of life. More than 77% of this sample reported having cared for 30 or more dying patients compared to approximately 50% of the pilot study nurses.

Although ranges were higher for obstacle items in the present sample, the highest ranked item (largest perceived obstacle) was still perceived only to be large compared to the highest possibility (extremely large). For the pilot study nurses, this more experienced group may have found ways to work around common obstacles or may have not wished to be seen as being controlled by external factors (Kirchhoff & Beckstrand, 2000). Another possibility, as described in the pilot study, suggested that nurses rated obstacles lower because they were so common in occurrence—a routine part of most patient deaths. This study provided support for this premise; that is, 6 of the top 10 greatest obstacles were also rated in this study to be part of the top 10 most frequently occurring. The other four top 10 pilot study obstacles dropped in frequency rating to positions 13, 14, 16, and 17 most frequently occurring obstacles in this study out of a possible 29.

Of the five obstacle items added to the current study questionnaire because of open-text responses returned with the pilot study, three were rated as part of the top 10 greatest obstacles (items one, three, and seven, respectively). All three items related to different aspects of physician behavior such as multiple physicians (caring for one patient) who disagreed about the direction of patient care, physicians who were evasive and avoided having conversations with family members, and physicians who would not allow the patient to die from the disease process. The high ratings of these obstacles confirm that the pilot study nurses were correct in listing these items as additional obstacles to providing end-of-life care to dying patients (Kirchhoff & Beckstrand, 2000).

Visiting hours that were too liberal or too restrictive were seen as a small or extremely small obstacle—a result similar to the pilot study. These obstacles were the lowest rated obstacles primarily because ICUs are much more open to visitation from family members than units have been in the past, and nurses have experience working around visiting family members.

Obstacle Frequency

Obstacle frequency data cannot be compared to the pilot study results since they were added as part of the current study only. Cronbach's alpha for the 29 obstacle items suggested that frequency scale scores were reliable for respondents in this study.

Mean ranges of frequency data were low: almost never occurs to fairly often occurs. These low ratings suggest some element of uniqueness with regard to the experience of end-of-life care; that is, different combinations of obstacles may occur with each scenario as physicians', family members', and patients' personalities change. Thus, the ratings show that some consistency in frequency of occurrence is most common with the top five listed obstacles (all with means > 3.0, fairly often occurring), whereas most of the obstacles ($n = 18$) were perceived as occurring sometimes. The lowest six items were perceived as almost never occurring.

The top five most frequently occurring obstacles reflect the unique characteristics of the ICU environment. Because patients are so critically ill and often cannot talk on the phone, their family members must call the nurse for updates about the patients' conditions. In addition, visitation in ICUs are restricted to immediate family members, necessitating that communication between extended family and friends be done by phone. Further, the ICU environment was established as a place to save lives using the latest technology. This highly technical environment can be confusing to family members who do not understand what it means to use lifesaving measures or what discomfort these measures may cause to their family member. This lack of understanding, combined with the stress of having a loved one become critically ill, can lead to nurses having to deal with distraught family members. Similarly, because of the availability of extraordinary equipment, drugs, and other treatment protocols, nurses find themselves too busy working to save the patient's life rather than able to prepare the family for a patient's likely death. Finally, these experienced nurses understand that some injuries or diseases are more likely to lead to death than others, consequently knowing, based upon their vast ICU experience, the patient's poor prognosis before the family becomes aware of the prognosis.

Obstacle Severity

The most severe obstacle, as determined by the perceived severity score, is when families frequently call the nurse for patient-condition updates rather than calling the designated family member. This was the primary obstacle in the pilot study and remains on top for the present study primarily because phone calls directly stop the nurse from providing patient care. For example, care activities can still continue when families are in the room asking questions about the patient's condition; however, when the nurse is holding a phone, whether in the room or at the main desk, patient care stops. Adding to the problem is the fact that critically ill patients cannot communicate on their own to family members, thus requiring another person (the nurse or significant other) to become the gatekeeper of information about the their conditions. For families, however, the same technology that monitors the patient's current condition and allows for rapid interventions is also the most sensitive to electrical interference; therefore, no cell phones can be used in ICUs, making family members difficult to contact from outside the hospital. This protective ICU environment acts to isolate families; that is, their competing needs to remain close to their ill loved one while also trying to communicate with others outside the hospital are not facilitated in this setting. Family members can make calls from the waiting room phone (when the phone is not being used), but incoming calls to family members must almost always be routed through the unit to the patient's nurse.

The problem of numerous incoming phone calls is not new. Medland and Ferrans (1998) recognized that providing information about the patient's status is an essential part of patient care; however, they also realized that frequent family interruptions create an additional burden for the patient's nurse. They used a two-group, pretest/posttest, quasi-experimental design of 30 family members of patients in an ICU to test a structured communications program (Medland & Ferrans, 1998). Their program consisted of a three-step process in which half of the families were formally introduced (within 24 hours of patient admittance) to unit procedures with regard to accessing patient status information, given an informational pamphlet, and called daily (by the patient's nurse) informing them of the patient's current condition. The other 15 families served as the control group. The researchers reported that incoming calls from the experimental group were significantly lower than in the control group. Further, satisfaction with care within the experimental group increased significantly (compared to the pretest data) as did the family members' perceptions of how well their information needs were met (Medland & Ferrans, 1998).

The second most severe obstacle ensued when family members did not understand what employing lifesaving measures might really mean to the patient. One possible explanation for this highly rated obstacle can be found in a study conducted by Pierce (1999). Pierce interviewed 29 family members of 75 decedents (39% participation rate) and reported that families wanted to have everything possible done for their dying family member; however, this did not necessarily mean medical interventions (Pierce, 1999). In these participants' minds, "doing everything" meant being physically close to the patient, touching, talking, and keeping the patient clean and comfortable. A majority (62%) of the participants also wished that caregivers would have given them more information about the patient's status and desired the information to be addressed in a more blunt and direct manner than was usually given (Pierce, 1999).

The third most severe obstacle regarded nurses' perceptions that physicians (involved in caring for one patient) often disagreed about the goals of patient care. Physician disagreement about treatment and care goals caused much staff confusion, increasing the nurses' workload by trying to act as arbitrators.

Recommendations for decreasing the severity and frequency of the most highly rated obstacles include (a) exploring new ways of disseminating patient information to family members on a regular basis in order to diminish the number of incoming calls handled by nurses; (b) educating physicians and nurses about families' wishes for direct, clear, and honest patient information; (c) clarifying with patients and family members their understanding of terms such as lifesaving measures in order to assure that all who are involved clearly understand how treatment options might really impact the patient; and (d) educating and encouraging physicians to communicate directly in a more open manner with each other and with patients and families.

For example, when disagreements occur about the direction patient care should go among the different medical specialties (third most severe obstacle), physicians should meet, in a more formal setting, to clarify goals and seek some level of compromise that may help improve patient care. Further, ICU medical directors should help formalize patient/family/physician communication by asking that physicians document (e.g., in the progress notes) an assessment of the families' understanding of the patient's situation and what family needs have been addressed. Further, patient rounds should also include the standard that families be contacted at least daily.

The last recommendation from this section of the study is that better community education with regard to all aspects of the pertinent issues surrounding end-of-life care are necessary in this age of technology. Patients and families need clearer explanations of specific lifesaving treatments, and there needs to be greater public exposure to the benefits and limitations of advance directives, do-not-resuscitate orders, and living wills. People need knowledge to be empowered to make decisions about how they wish to die well before they are at the end of life.

Research Question 2

Which helpful behaviors (or helps) to providing end-of-life care to dying patients do critical-care nurses perceive as being the largest, most frequent, and most intense? For the help-size data, a Cronbach's alpha score of .86 for the 24 items suggests that the scale scores were reasonably reliable for respondents such as those in this study. This alpha score was slightly higher than for the pilot study (.82) due to the addition of a help item recommended by the pilot study nurses.

Help Size

Mean ranges for help-item size were much higher than for obstacles because the top listed helps were more often behaviors the nurse could control and, thus, were perceived by these critical-care nurses as being very helpful. In addition, many of the help items dealt with supporting the family after the patient's death, whereas only one obstacle item concerned a care behavior implemented after a patient's death. This specific period of time (after the death) lends itself to more helpful, nurturing behaviors, whereas the time preceding death is more likely to have obstacles constraining ideal patient care.

When compared to the pilot study data, respondents rated the identical top 10 most helpful behaviors with only minor changes in rank order. Only the top and the 5th rated items remained in the same position for both studies. No other item changed in rank, moving up or down, more than two places. For the remainder of the help items (11 to 24), minor rank changes were noted with the relative mean size of each help item being fairly consistent with the pilot study.

The top three highest rated helps for size were (a) having physicians involved in a patient's care agree about the direction care should proceed, (b) having family members accept that the patient is going to die, and (c) having one designated family member be the contact person for all other family members with regard to patient information.

Critical analysis of these top three items reveals a similar theme. All three items are helpful to nurses because, when they occur, the nurse is removed from being in the middle. For example, when physicians agree about the direction of patient care, the nurse is removed from being in the middle trying to referee different (sometimes opposing) physician orders for treatment. When families accept that a patient is going to die, the nurse is removed from the position of knowing that death is certain yet acting in good faith to try and support family members' needs for hope of recovery. Finally, when a designated contact person is identified, the nurse is removed from the middle position of continually communicating the patient's status.

Help Frequency

Help-frequency items had a larger range of mean scores than did obstacle-frequency items. The highest frequency item was rated as very often occurring, whereas the lowest help item was between not a help (0) and an extremely small help (1). Since five of the help items were in the control of the nurse, a higher frequency-of-occurrence score was expected. It could be argued that, for this same reason, these items should have occurred even more often, more closely approaching the frequency of almost always occurring. However, it is possible that while these items are in the control of nurses, no nurse can force a family to accept help when it is offered, possibly lowering the items' overall frequency ratings.

Reported as frequently occurring were two helpful items that directly support the nurse after a patient's death by the family offering thanks or by other nurses offering words of support. These items show that (a) families are grateful for nurses who care for dying family members and (b) other nurses understand what it is like to lose a patient to death (even a patient who was expected to die) and frequently do provide support for their colleagues.

More consistency between scores on similarly worded obstacle and help items was noted in the current study than in the pilot study. Physicians agreeing about the direction of care was perceived as the largest help, whereas physicians differing on the direction of care was the largest obstacle. Similarly, family members who continually call the nurse for patient information was the second biggest obstacle, whereas having one family member be the designated source for all patient information ranked as the third highest helpful behavior. Having similar items (on both the obstacle and help sections) score in the same direction further supports that the questionnaire was consistent (much as a reverse scoring item would do) (Burns & Grove, 1997).

A difference in ratings did occur for one item common to both the obstacle and help categories. Family acceptance that the patient is dying was seen as the second largest helpful behavior, whereas families not accepting the patient's poor prognosis was rated as only the eighth largest obstacle. This discrepancy in ratings between the help and obstacle categories reflects the distinctive nature of this item; that is, while nurses note the event of families accepting that the patient is dying is a helpful event when it occurs, it does not occur frequently. This rationale can be supported by noting that this item's helpful behavior rating for frequency of occurrence was in the ninth position. Because these experienced nurses understand that families have difficulty accepting that their patient is dying, the nurses did not rate it as a large obstacle.

Help Intensity

Although help-size ratings were very similar for both the current and pilot studies, the computed help perceived intensity scores showed greater changes in the order of the help items seen as most intense (largest and most frequently occurring). Because of a lower frequency-of-occurrence score, the item with regard to physicians agreeing about the direction of patient care moved downward from the 1st position to the 5th position. Other items that moved down in position several places from the pilot study rankings compared to the help perceived intensity score rankings because of their low frequency-of-occurrence scores were (a) having one family member as the designated contact person for all patient information (moved from 3rd to 9th position), (b) having enough time to prepare the family for the patient's death (moved from 6th to 11th position), (c) a unit designed with a place for families to grieve (moved from 7th to 13th position), and (d) physicians who meet with the family after the patient's death (moved from 9th to 16th position). All these items lost their more highly rated helpful position because they were rated as occurring less often than other helpful behaviors. None of these four items received overall frequency-of-occurrence ratings higher than 11th position (out of 24 positions).

In contrast, three items moved up on the help perceived intensity scale from their previous position in the pilot study help rankings. Allowing the family adequate time alone with the patient after death, the nurse teaching families what to say to the dying patient, and families thanking the nurse for caring for the dying patient were all items that scored high on the perceived intensity scale (ranked first, third, and fourth, respectively). The higher perceived intensity score rankings were related directly to their higher frequency-of-occurrence scores (all three in the top five most frequently occurring helps). It is not surprising that the first two items were perceived to be frequently occurring because, again, they were directly controlled by nurses. That families are grateful to nurses who care for sick patients is also not surprising.

In summary, help items by size changed very little in rank order between the pilot and current studies. Helpful behaviors that were most frequently occurring were noted to be items that nurses control. Other more frequently occurring items related to supportive behavior for the nurse provided by the patient's family or by other staff members. Items seen as both helpful and frequently occurring (high perceived intensity score) were, again, usually in the control of the nurse. Behaviors controlled by physicians received lower perceived intensity scores mainly because they occur less frequently than nurse-controlled behaviors.

Recommendations for increasing the frequency of items perceived as being most helpful include the implementation of programs that educate physicians with regard to intraphysician and family communication skills and conflict resolution and formal education in end-of-life care for nurses and physicians.

Research Question 3

Which aspect of end-of-life care would critical-care nurses most like to see changed? The high volume of responses to this question suggests that these experienced nurses have noted deficiencies in current end-of-life care practices and have formulated clear opinions with regard to possible changes. Overwhelmingly, nurses want to assure that dying patients experience a good death (Chapple, 1999; Ruland & Moore, 1998; Singer, Martin, & Kelner, 1999). Unfortunately, these experienced nurses did not believe that such a death was routinely possible while the patient was in ICU.

Of interest in the open comment responses was the importance nurses placed upon the concepts of dying with dignity and not dying while alone. Rankin and associates (1998) defined the nursing outcome of “dignified dying” as maintaining personal comfort and control as the end of life approaches (Rankin et al., 1998). They described dignified dying as a process rather than an event. Further, Berns and Colvin (1998) reported, from their study of interviews with family members of patients who had recently died (within 1 month), that being present (or absent) at the time of death of the loved one was a significant memory for survivors. Nearly all of the family members who were present at death wanted to be with the dying patient. Of those who were not present at death, most indicated that they had planned to be at the bedside. A few family members reported having feelings of guilt for being absent during the death (Berns & Colvin, 1998).

It is possible that nurses from the current study emphasized these two concepts (dying with dignity and not dying alone) as a reflection of their own attitudes, fears, experiences, or regrets. However, further research is necessary to clarify what meaning these concepts specifically have to critical-care nurses.

It is also important to note that responses for this question did not correlate to the obstacle data. For example, although nurses rated phone calls from family and friends as both the most frequently occurring obstacle and the obstacle with the highest perceived severity score, only 2 of the 482 nurses mentioned phone calls as the most important end-of-life care behavior to change. There are two possible explanations for this discrepancy. First, it is possible that frequent phone calls from family members is the most frequent and severe obstacle to providing care to any ICU patient at any given time—not just at the end of life. The questionnaire did not differentiate whether obstacles (or helpful behaviors) were exclusive to care at the end of life or some were also general obstacles and helps for intensive care patients who do not die while in ICU. This rationale could explain why this obstacle item was rated so much higher on the perceived severity score than the other obstacles. Second, nurses rated phone calls as the highest perceived obstacle to providing care; however, when asked for their opinion about how to make end-of-life care better for patients, critical-care nurses put their patients first. Providing patients with dignified, peaceful, and painless deaths was of much more importance to nurses than any annoyance experienced by them, no matter how frequently it occurred.

In summary, open-text responses to Research Question 3 show that critical-care nurses put their patients first and want each patient to experience a good death. Unfortunately, the deaths nurses witness on a daily basis in ICUs are less than exemplary due to problems with the intensive care environment (created to save lives), not enough time for nurses to care for dying patients and families, problems with communication between physicians and family members, a lack of appropriate education for physicians and nurses, and problems with keeping patients comfortable and following their wishes. Nurses report that end-of-life care would be further improved if communication procedures allowed all team members to be working toward the same patient goal, if treatments given to dying patients were stopped earlier in the dying process (or never started—especially when noted to be futile), and if some physicians could be made to understand that death is a natural process and not a direct reflection of physician skill or care.

Research Question 4

In what ways do critical-care nurses' perceptions of obstacles and helpful behaviors differ based upon length of ICU work experience? This sample of critical-care nurses had many years of ICU work experience. Only 30 nurses reported less than 5 years of ICU work experience. This low number of nurses with limited critical-care experience reflects national trends with regard to the advancing age of all nurses (Alspach, 2000), and it also reflects that younger, college-aged women currently have more career options and with more lucrative earning potential than did women in the 1950s, 1960s, and 1970s.

Differences Between Intensive Care Unit Work Experience Groups for Obstacle Size

Two items were different between groups for obstacle size. Nurses in the less experienced ICU group rated dealing with distraught family members lower than did the more experienced nurses for two reasons. First, the more experienced nurses reported caring for more patients at the end of life than did the less experienced group. More than 75% of the experienced group had cared for more than 30 dying patients compared to only 62% of the less experienced nurses. That is, the more experienced nurses had cared for more patients at the end of life and, thus, were more likely to have seen family members more distraught than were the less experienced nurses. Second, the less experienced nurses were, on average, 8 years younger than the more experienced nurses ($\underline{M}$ = 40.5, $\underline{SD}$ = 7.7; $\underline{M}$ = 48.5, $\underline{SD}$ = 6.3) and may not be as affected by family members' behaviors as the more experienced nurses.

The second item that was different between these groups was poor unit design that did not allow for the privacy of dying patients or grieving families. The more experienced nurses reported poor unit design to be a larger obstacle because they have dealt with more dying patients (and grieving families) than the less experienced group. Consequently, they have experienced the problems associated with trying to facilitate a good death in a poorly designed unit (no private rooms for patients, only curtains separating bed spaces).

Differences Between Intensive Care Unit Work Experience Groups for Obstacle Frequency

Two items were different between groups for obstacle frequency. Again, the older age and considerable experience working with dying patients in the more experienced nurses' group accounts for the significant difference in scores on the item related to the availability of an ethics board or committee to review difficult patient cases. The less experienced nurses had cared for fewer patients at the end of life and, consequently, did not see the lack of an ethics committee as a more frequent obstacle.

For the item with regard to unit visiting hours being too liberal, less experienced nurses rated this as a more frequent obstacle to providing end-of-life care because they may not have found ways to work around families as had the more experienced and older group of nurses. It is also possible that the more experienced group of nurses were more sensitive to families' needs, more tolerant of family behavior, relate to the families' stressful experience more deeply, and may have found ways (through previous experiences) to successfully work around visiting family members.

Differences Between Intensive Care Unit Work Experience Groups for Help Size

Three items were different between groups for help size. Nurses with more ICU work experience were older (48.5 years compared to 40.5 years) and, thus, were more likely to have had family members experience a critical illness or death than were the less experienced group of nurses.

For the remaining two items, similarities were noted for the family physically helping care for the patient and having unlicensed personnel available to help care for dying patients. First, both items relate to a person rather than the assigned nurse, physically helping with patient care. In both instances, nurses with less ICU work experience saw these items to be more helpful than did the more experienced nurses. Possible explanations include the older nurses wanting to have more control over patient care and, perhaps, not trusting others to care for "their" patients. It is also possible that less experienced nurses see nothing wrong with obtaining help for patient care, regardless of the source, because their bigger priority is that patient care be completed over the way it is completed. It is also possible that the less experienced, younger nurses received more education and training with regard to correct body mechanics in relation to patient care and, thus, have learned to ask for help rather than trying to do it by themselves.

Differences Between Intensive Care Unit Work Experience Groups for Help Frequency

Two items were different between groups for help frequency. More experienced nurses see allowing unlimited family access as a more frequent help than less experienced nurses. It is unknown if the experienced nurses allow more access to the patient in an attempt to help the patient or support the family. It is also possible that the more experienced group of nurses are more sensitive to families' needs, more tolerant of family behavior, relate to the families' stressful experience more deeply, and have found ways (through previous experiences) to successfully work around visiting family members.

From frequency data for helpful behaviors, it was also shown that the less experienced ICU nurses gave higher frequency-of-occurrence scores to the item of use of unlicensed personnel than did the more experienced nurses. Less experienced nurses may be able to access unlicensed help because their patients are not as critically ill as the more experienced nurses.

In summary, the results showed that nurses in the more experienced group reported dealing with more distraught family members, more frequently used their own experiences with death and dying to care for families, perceived poor unit design as a larger obstacle, and allowed families unlimited access more frequently than nurses in the less experienced group. More experienced nurses also reported caring for a slightly higher number of patients at the end of life ($\underline{M} = 4.93$) than did the less experienced nurses ($\underline{M} = 4.49$).

Less experienced nurses were more likely to perceive unit visiting hours as too liberal and recognized as more helpful both physical help (with patient care) from family members and from unlicensed personnel.

Research Question 5

Do certified critical-care registered nurses' perceptions of obstacles and helpful behaviors significantly differ from noncertified critical-care nurses' perceptions? Of this study's nurses who reported certification, 73.4% had been CCRN-certified and 62% were currently certified. These percentages are very similar to the pilot study data (71% and 65.3%, respectively) (Kirchhoff & Beckstrand, 2000).

Differences between groups cannot be explained by differences in years as a registered nurse or by differences in age. The CCRN-certified group was only about 3 months older, on average, than the never-CCRN-certified group and had less than 1 year more experience as registered nurses.

Differences between groups on demographic data were noted for ICU work experience and number of dying patients the nurse had cared for. The CCRN-certified group had almost 2 years more ICU work experience than did the never-CCRN-certified nurses. The certified nurses also reported caring for a higher percentage of dying patients (30 or more, 71.2%) than did the never-CCRN-certified nurses (60.9%).

Differences Between Certification Groups for Obstacle Size

Nine items were different between certification groups for obstacle size. All nine items were rated as larger obstacles for the CCRN-certified group than for the never-CCRN-certified group. Differences between groups for all nine items can be explained by the fact that the CCRN-certified nurses took care of sicker patients and, thus, experienced more obstacles to providing end-of-life care, as evidenced by the higher percentage of dying patient experience reported by this group of nurses.

Differences Between Certification Groups for Obstacle Frequency

Three items were different between certification groups for obstacle frequency. CCRN-certified nurses rated the item of continuing treatments for dying patients (although the treatments caused the patient pain or discomfort) as occurring more frequently than did the never-CCRN-certified nurses. This difference in reported frequency can also be explained by more experience working in ICU and by having cared for more dying patients.

Because never-CCRN-certified nurses saw fewer patients at the end of life, they also rated the lack of nursing education in end-of-life care as a less frequent obstacle than did the CCRN-certified nurses. They also reported less frequent experience with the item with regard to the nurse not knowing the patient's wishes about end-of-life care than did the CCRN-certified nurses.

Differences Between Certification Groups for Help Size

Five items were different between certification groups for help size. Again, because of less exposure to dying patients, never-CCRN-certified nurses scored all five help size items as being smaller obstacles than did the CCRN-certified group of nurses.

Differences Between Certification Groups for Help Frequency

One item was different between groups for help frequency. For the item with regard to families physically helping care for the dying patient, CCRN-certified nurses rated this as a more frequently occurring behavior than did the never-CCRN-certified group. It is unknown if the certified nurses allowed more access to the patient in an attempt to help the patient or to support the family and, therefore, had more opportunities for the family members to help with care than did the other group of nurses. It is also possible that the CCRN-certified group of nurses was more sensitive to families' needs.

In summary, CCRNs perceive as larger obstacles physicians being overly optimistic about the patient surviving, families not accepting that the patient will die, visiting hours that are too restrictive, and patients who have pain that is difficult to alleviate or control. They also see as large obstacles the use of lifesaving measures (even though the patient's advance directive requested no such treatment) and care provided to dying patients only because of a threat of future legal action by the family. They see that physicians often will not let the patient die of the disease process and that treatments cause pain and discomfort to the patient. CCRNs care for more patients at the end of life and, thus, more frequently do not know the patient's wishes for care. CCRNs also acknowledge a lack of nurse education with regard to quality end-of-life care.

Incentive Hypothesis

The results of the secondary aim are consistent with reports of similar studies with regard to the effects of specified monetary incentives yet differ significantly from what pretest nurses said would influence them to return the questionnaire. Warriner and associates (1996) used an experimental design to test the effects of response rates to mail surveys using prepayment cash incentives ($2, $5, and $10), charitable donations (ranging from $2 to $10), and the chance to win a lottery prize ($200). Using 3,088 households in Ontario, Canada, these researchers received a 70.7%

overall response rate (with three follow-ups). They found a significantly higher return rate for those households receiving the prepaid cash incentive but not for those for the charitable donations or the lottery. They also found that households that received the prepaid incentives were more likely to return the questionnaire earlier than were those in the other groups. James and Bolstein (1992) mailed questionnaires to 1,200 companies using various money incentives (seven groups ranging from $1 to $40 prepaid cash or check and a promise of a $50 check if the questionnaire was returned) to increase response rates. They achieved an overall response rate of 67% after three mailings. They also found that $1 cash significantly increased response rates over the no incentive control group and that as the incentive amount increased from $1 to $5 and from $5 to $20 the response rate also increased significantly. Further, no significant difference in response rates was noted for the group who received the promise of $50 over the control group. Both of these studies confirmed that prepaid incentives significantly increase mail survey response rates over other types of monetary incentives.

The 74 nurses who completed the Nurses' Preferences of Survey Incentives (see Appendix E) rated the seven listed options differently than published reports of actual incentive effects. The incentive scored by these nurses as the most likely to influence them to quickly complete and return a questionnaire was the lottery for $100 followed by $2 prepaid cash and $1 charity donation to a national scholarship fund. In actuality, only the $2 prepaid incentive significantly improved return rates. Interestingly, the $1 charity donation actually had lower response rates (both at 2 weeks and at 4 weeks after the first mailing) than the control group at either time. The $100 lottery group was almost identical to the control group in response rates at both times.

There are at least four possible explanations for the difference in actual results versus the preliminary work results on survey incentives. The nurses who took part in the preliminary work had been fellow staff nurses and perhaps, although the incentive results questionnaires were anonymous, were attempting to look better, smarter, or of more worth with their answers. It is also possible that the 74 critical-care nurses acted differently than the nurses in the actual national study because the preliminary study nurses knew they were being studied, whereas the national sample of nurses did not know that other study nurses were receiving different incentives. This phenomenon, study subjects reacting differently in an experiment than they would in real life because they know they are being studied, is known as reactivity (or the Hawthorne effect) (Neuman, 1997). Another possibility is that the preliminary study nurses were able to evaluate all of the listed incentives at the same time, whereas the national sample were able to react only to the one incentive (or control) group into which they were randomly selected. A fourth possibility is that people do not necessarily do what they say they will do. Although the preliminary nurses chose the largest amount of incentive reward ($100) available (a hoped for reward), in reality, having $2 in hand (instant reward) was more influential.

Beyond the use of incentives, other techniques were implemented to enhance (or at least maintain) the salient qualities of the current study over the pilot work:

(a) appealing to the nurses in the cover letter that "end-of-life care of the exploding aging population is an experiment that is already in process" (set a tone of importance that increased the questionnaire's salience) and (b) adding both Dr. William Alward's signature (male and physician) and Dr. Karin T. Kirchhoff's signature (nationally known critical-care nurse researcher and PhD) to the bottom of the cover letters. Surveys with cover letters that have signatures from persons of stature or rank have higher levels of return responses than do those signed by a graduate student (pilot study) (Christensen, 1996). Also employed to increase the salience of the questionnaire were techniques such as having all 1,500 envelopes laser printed rather than using labels attached to the outside envelope, having the cover letters laser printed with the nurse's first name inserted twice into the actual letter (for example, "Dear Marie" rather than using one copied letter addressed to "Dear Nurse"), using stamps rather than metered postage, and using letterhead stationary and envelopes.

Attempts to enhance immediacy included the use of three different types of monetary incentive: (a) $2 cash, (b) drawing for $100, and (c) $1 donation to the AACN general scholarship fund. A date for requested return of the questionnaires was also included in the cover letter information.

Although both studies' return rates were greater than 60% and, thus, judged acceptable for a national survey (Warriner et al., 1996), the rates for this study were lower (61%) than for the pilot study (69%). Several reasons account for the differences in return rates. First, the questionnaire for the current study was more than double the size of the pilot study questionnaire due to the addition of an extra column, allowing nurses to rate the frequency of occurrence along with perceived size for both obstacle and help items (a total of 53 extra-requested responses over the pilot questionnaire). Further, five additional obstacles items, one additional help item, and three open-text response items were added based upon pilot study recommendations. The most common complaint about the questionnaire was that is was too long. More than doubling the questionnaires' length clearly worked against any attempts to foster immediacy; that is, the total time to complete the questionnaires more than doubled; consequently, more nurses (than the pilot study by percentage) did not complete and return the questionnaire.

A second reason for the difference in response rates was the time of year the questionnaires were mailed. In general, it is not best practice to conduct survey research by mail in the months of November and December. In this case, however, grant money had been obtained with the requirement that a major portion ($2,900) be used by December 31, 2000. Since approval to begin the study was not received until the middle of October 2000, the second mailing of the questionnaire was sent out in the middle of November 2000. The third and final mailing did not occur until the second week of January 2001. Further complicating the timing was the never before occurrence of a national presidential election that was not decided for more than 4 weeks after election day (most of November and early December 2000). It is unknown how much of an effect this national saga had on overall response rates. There is some comfort knowing, however, that all four groups experienced this same history effect.

Again, mailing questionnaires during the annual holiday season, when people are the most busy, and then adding the phenomenon of an entire nation waiting and watching as events unfold (for weeks) while the presidential election was decided clearly could have impacted the amount of discretionary time that the sample nurses would have had available for completing the questionnaire. Unfortunately, both the timing of the mailing and the presidential saga were unavoidable.

Third, compared to summer 1998 when the pilot study was completed, a national nursing shortage was occurring (Alspach, 2000) that made returning the questionnaire a less immediate need for the nurses. It is more likely that nurses would be overworked (mandatory overtime in some cases) during a national nursing shortage, with less free time available, than when there was no nursing shortage.

Fourth, all the cover letters for the pilot study informed the nurse recipients that they were 1 of 300 nurses being asked to complete the enclosed questionnaire. For the current study, the nurses were informed that they were 1 of 1,500 possible respondents. Informing the nurses of the large sample size could have been a deterrent to completion; that is, they might not have seen their individual response to be important given the population size. Consequently, they may have believed that their individual response was of less value and, thus, the questionnaire became less salient to them.

Fifth, the pilot study outer envelope was marked in the lower left-hand corner (by laser printer) with the words "national survey enclosed." These words were not included on the current study because the envelopes were so transparent that specific items on the questionnaire were visible through the envelope paper from the back. It is unknown how much of an effect words informing the nurses that a survey was being conducted would have had on return rates; however, several nurses noted on subsequently returned questionnaires that they had discarded the first (unopened) questionnaire believing it to be an advertisement for continued nursing education since the letterhead stated it was from the University of Utah College of Nursing.

It is possible that some sample nurses looked only at the return address and assumed that an offer for continuing education was enclosed. Because the idea of more nursing education or perhaps the thought of moving to Utah was not appealing to the nurses (not salient), some might have discarded the surveys without opening the envelopes, thus decreasing response rates.

Finally, although remote, it is possible that nurses from the pilot study were also randomly selected to be included in the current study. Since the titles of the pilot and current study questionnaires were similar and since both outer envelopes had University of Utah return addresses, it is possible that some nurses did not return the questionnaire, believing that they had already participated. Clearly, if nurses believed they had already responded, both salience and immediacy would be lower for the "repeat" questionnaire.

Regardless of all these reasons for a lower response rate, the $2 group returned their questionnaires more often than any other group for either time studied (2 weeks after the first mailing and 4 weeks after the first mailing). If the entire sample had received this same incentive based upon return rates for this group, the total return rate would have been 71%. Although the use of incentives did not enhance overall response rates as had been planned, Christensen's (1996) theory of factors that enhance salience and immediacy did help to explain the outcome of the response rates between the four groups.

In summary, nurse researchers who want quicker results or those who do not plan to conduct follow-ups may find that using a modest $2 prepaid cash incentive will increase mail survey return rates significantly over using no incentive.

Future Research

The present study highlights the obstacles and helpful behaviors critical-care nurses perceived as being the most intense or severe. Suggestions for changing current end-of-life care behaviors were offered by critical-care nurses. A multidisciplinary team of clinicians and researchers need to investigate ways to incorporate these results into interventions that decrease or eliminate obstacles to providing end-of-life care and enhance or support helpful behaviors at the end of life.

Specifically, further research is needed to pursue better avenues of communicating information to patients, families, and other healthcare team members. For example, given the current availability of Internet technologies, a program could be instituted and tested where frequent patient updates for all ICU patients would be posted on the Internet where family members (provided with special code numbers to protect confidentiality) could retrieve patient information at any time.

Other suggestions for research would be to include families in future studies to obtain their perceptions with regard to end-of-life care as it currently exists in ICUs.

Educational programs need to be developed to educate nurses and physicians in quality end-of-life care. These programs then need to be studied to determine if improved education of the healthcare provider actually improves care of the patient at the end of life. Ultimately, through additional research studies, dissemination of research information, and through caregiver and community education classes, the care of dying patients in ICUs can be improved.

As far as the use of incentives to increase mail survey response rates, there will always be a need for further research as the economics of inflation revise the optimal amount of payment for the best benefit (Warriner et al., 1996). Research discovering the best incentive for high return rates from nurses needs to be completed, specifically to determine if different amounts of a prepaid reward ($3 or $5) significantly improve response rates over the $2 amount.

APPENDIX A

CRITICAL-CARE NURSES' PERCEPTIONS OF OBSTACLES AND HELPFUL BEHAVIORS IN PROVIDING END-OF-LIFE CARE TO DYING PATIENTS

(ARTICLE)

CRITICAL CARE NURSES' PERCEPTIONS OF OBSTACLES AND HELPFUL BEHAVIORS IN PROVIDING END-OF-LIFE CARE TO DYING PATIENTS

By Karin T. Kirchhoff, RN, PhD, and Renea L. Beckstrand, RN, MS, CCRN. From the University of Utah College of Nursing, Salt Lake City, Utah.

- ***BACKGROUND*** ***Little is known about nurses' perceptions of obstacles or helpful behaviors ("helps") in providing end-of-life care in the intensive care setting.***
- ***OBJECTIVE*** ***To determine the importance of various obstacles and helps in providing end-of-life care as perceived by critical care nurses.***
- ***METHODS*** ***A questionnaire was mailed to 300 members of the American Association of Critical-Care Nurses. Nurses were asked to rate obstacles and helps in giving end-of-life care, add additional obstacles and/or helps, and answer demographic questions.***
- ***RESULTS*** ***Six of the top 10 obstacles were related to issues with patients' families that make care at the end of life more difficult, such as the family's not fully understanding the meaning of life support, not accepting the patient's poor prognosis, requesting more technical treatment than the patient wished, and being angry. Added obstacles related mostly to problems with physicians' behavior. Most helps were ways to make dying easier for patients and patients' families, such as agreement among physicians about care, dying with dignity, and families' acceptance of the prognosis. Added helps included allowing music, pets, and so forth into the patient's room.***
- ***CONCLUSIONS*** ***Nurses have difficulties with patients' families and physicians concerning end-of-life issues, especially when the behaviors remove the nurses from caring for a patient or cause the patient pain or prolong suffering. Nurses do not acknowledge having difficulty providing care to dying patients aside from conflicts that arise because of patients' families and physicians. (American Journal of Critical Care. 2000;9:96-105)***

Death, the ultimate outcome of life, is at once a fact and a profound mystery.[1,2] Of the 2.3 million persons who die annually in the United States, three fourths are elderly.[2] Many die in hospitals; a smaller number die in institutions such as nursing homes.[2] Every day, critical care nurses deal with issues of death and dying[3]; however, little is known about what behaviors critical care nurses perceive as obstacles or as helpful behaviors ("helps") in providing end-of-life care for dying patients and the patients' families. The SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) group[4] found shortcomings in the care of seriously ill, hospitalized adults in communication, frequency of aggressive measures, and the characteristics of the death. However, patients were not categorized by site of care in the hospital.

The purpose of our study was to determine the obstacles and helps in providing quality end-of-life care to dying patients as perceived by critical care nurses.

Reprint requests: InnoVision Communications, 101 Columbia, Aliso Viejo, CA 92656. Phone, (800) 899-1712 or (949) 362-2050 (ext 515); fax, (949) 362-2049; e-mail, ivcReprint@aol.com.

Review of the Literature

Who Cares for the Dying?

Some physicians find decision making and caring for dying patients burdensome.[5] The physicians are removed from the process of dying because of their other professional responsibilities and sometimes by their own choice.[6] Although physicians write the orders to withdraw treatment, critical care nurses most often attend to the end-of-life care of a dying patient in the intensive care unit (ICU). Of interest, little is published about exactly what critical care nurses perceive as obstacles or helps in giving end-of-life care.

Most of the research on critical care nurses and dying patients focused on 1 of 3 aspects of the nurses' response to patients' deaths: nurses' personal experiences with dying patients,[3,5-9] coping strategies after a patient's death,[10,11] and perceived behaviors of nurse experts.[12] Although they do not specifically describe obstacles or helps, these articles do give some insight into what nurses' perceptions of obstacles or helps are in giving end-of-life care.

Nurses' Experiences With Dying Patients

Simmonds[6] reported that nurses want to make a difference in their patients' lives and want to feel good about their work. Simmonds[5] also found that nurses saw their responsibility as providing a pain-free, calm and peaceful, or otherwise "good" death. In Australian surveys,[3,8] however, some critical care nurses reported that they felt powerless to change events that affect patients because the nurses perceived someone else as making the decisions.

In one qualitative study,[12] nurses expressed frustration with aggressive and frequent overtreatment of patients ordered by physicians. Other researchers found that most of this overtreatment was due to either the fear of litigation[3,6] or the attempt to "control" death by not giving up.[6] They acknowledged that most families want "everything done" for patients, but that the families do not understand what "everything" really means.[6]

Another obstacle to providing end-of-life care was the inability to control patients' pain because orders for pain medication were inadequate.[3] Further, poor communication between doctors and nurses and/or between doctors and patients or patients' families about patients' prognosis or care was often perceived as an obstacle.[3,13] Some authors discussed the need for more end-of-life education for health professionals[3] and the need for nurses to have a better understanding of advance directives.[14]

Coping Strategies After a Patient's Death

Two studies[10,11] reported on the coping strategies of nurses who deal with dying patients. O'Hara et al[10] examined the effects of patients' deaths on nurses in a long-term care hospital in Canada, and Pelletier-Hibbert[11] did a qualitative study of nurses who cared for organ and tissue donors in neurological ICUs at 2 hospitals. Although no clear obstacles were discussed in either article, helpful strategies were given. Focusing on the positive care given to a patient during death was the most frequently reported strategy for coping.[10] By focusing on positive care, nurses took comfort in their attempts at helping patients have a peaceful and/or comfortable death. Other strategies were "leaving work at work" (thus separating the nurses' professional and private lives) and having nursing colleagues who gave physical support (allowed the nurse to take a "time out") and/or emotional support (provided a safe environment in which feelings and thoughts could be shared).[10,11]

Perceived Behaviors of Expert Nurses

In another study,[12] 10 nurses designated as experts in caring for dying patients were interviewed. These experts said that providing patients' families with a peaceful, dignified bedside scene was the most important task. Once death had occurred, the most important task was to allow the family adequate time alone with the body.

These nurse experts also indicated that responding to the needs of the patients' families for information about treatment and about patients' responses to that treatment was a high priority, as was helping patients' families during the dying process to lessen the potential for future regret. The nurses helped during the dying process by encouraging family members to talk to the patient regardless of cognitive function, by being flexible with visiting hours, and by encouraging family members to participate in the patient's care. An additional way to provide comfort care was talking to patients about their concerns and listening to them in a nonjudgmental way.

Some expert nurses were also able to show empathy and respect for families who were expressing anger. Although the nurses understood that the anger was not really directed at them, they still admitted that withdrawing from angry family members was, at times, the only option.[12]

Research Questions

Two research questions were addressed in this study:

1. How important are selected obstacles in restricting end-of-life care?
2. How important are selected helps in promoting end-of-life care?

Method

Sample

After the study was approved by the institutional review board, the names of 300 potential subjects were randomly selected from the membership roster of the American Association of Critical-Care Nurses (AACN). (Survey of AACN members does not imply AACN review or endorsement of the study.) Subjects were selected for the study if they were staff nurses who provided direct care, who had been employed full time or part time for at least 2 years in critical care units, and who had taken care of dying patients.

Instrument

We developed the National Survey of Critical Care Nurses Regarding End-of-Life Care by using information from 4 focus groups of ICU nurses (N = 21) who discussed end-of-life issues.[15] To minimize potential investigator bias, we reviewed transcripts of the focus groups to determine potential obstacles or helps mentioned and to determine the participants' responses to open-ended questions on obstacles and helps. To strengthen content validity, we used information from the literature to further develop the initial lists of obstacles and helps. These lists were then reviewed and developed into a 64-item questionnaire, with Likert-type response options and 2 places for free text. The responses were developed to avoid reverse scoring.

The questionnaire was pretested on 45 ICU nurses in a single ICU. Some items were added, and items were reworded and clarified. Mean time for completion of the questionnaire was 17 minutes. The Cronbach α was .86. for the 25 obstacle items and .82 for the 23 helps items. The final items are listed in Tables 1 and 2.

Procedure

Mailing labels were obtained from the National Office of AACN and were sent to a third-party mailer. Names of AACN members who might be providing bedside care in ICUs were randomly chosen from the membership list. Questionnaires were mailed with a cover letter explaining the purpose, and a self-addressed, stamped envelope was included. Two follow-up mailings with letters, copies of the questionnaire, and self-addressed, stamped envelopes were sent to nonrespondents 3 and 7 weeks, respectively, after the initial mailing.

Responses were entered into SPSS+ Data Editor (SPSS, Inc, Chicago, Ill). Research assistants verified accuracy of data entry. Frequencies, measures of central tendency and dispersion, and reliability statistics were calculated. Items were ranked on the basis of their mean scores to determine which items were the most important. The 2 open-ended response questions were analyzed by using content analysis; like items were placed in the same category, and frequency counts were made.

Results

Of the 300 potential respondents, 12 were eliminated from the study sample either because the questionnaire could not be delivered or because the recipient was not currently working in an ICU. Usable responses were received from 199 of the 288 eligible respondents, for a response rate of 69%, or less than 1% of the total AACN membership as of August 1998.

Of those respondents who reported their sex (n = 197), 13 were men and 184 were women. Respondents were 27 to 63 years old (mean, 41.6 years). Respondents were employed as staff nurses (46.7%), charge nurses (42.6%), clinical nurse specialists (6.1%), and nurse educators or practitioners (4.6%). Practice settings included intensive and critical care units (54%), cardiovascular/cardiothoracic ICUs (21.7%), surgical ICUs (16.1%), and other (7.6%). The majority of respondents practiced in not-for-profit community hospitals (61.9%); the remainder practiced in university medical centers (15.7%), for-profit community hospitals (10.7%), county facilities (5.1%), and military or federal hospitals or other (5.6%).

The number of intensive care beds in the nurses' units ranged from a low of 3 to a high of 60, with a mean of 15 beds. The respondents were primarily employed full time, had been registered nurses for a mean of 16.4 years, and had worked in a critical care area for 12.7 years. CCRN certification had been achieved at some time by 141 (71%) of the respondents, and 130 (65.3%) of the sample were currently certified. The mean number of years as a CCRN was 6.9.

The highest completed level of education was as follows: diploma, 12.6%; associate degree, 17.7%; bachelor's degree, 48.5 %; and master's degree, 20.2 %. More than half of the nurses had cared for more than 30 dying patients (the highest option in our instrument).

On a scale of 0 (not an obstacle) to 5 (extremely large obstacle), mean scores for the items in the obstacle section of the questionnaire ranged from 1.35 to 3.76. Six of the top 10 items were associated with issues related to patients' families (Table 1). Most of the top 10 items included obstacles that stand in the way of optimizing care for a patient and inappropriate

Table 1 Perceptions of possible obstacles to providing end-of-life care to dying patients and their families (n = 199)

Obstacles	Mean	SD
1. Family and friends who continually call the nurse rather than calling the designated family member.	3.76	1.18
2. Family members not understanding what the phrase "life-saving measures" really means.	3.66	1.08
3. Family not accepting the patient's poor prognosis.	3.51	1.00
4. Providing life-saving measures at families' request even though patient had signed an advance directive requesting no such care.	3.51	1.41
5. Physicians who are overly optimistic about patient surviving.	3.50	1.16
6. Having to deal with angry family members.	3.36	1.25
7. Family members fighting about use of life support.	3.33	1.14
8. Giving painful treatments to a dying patient.	3.26	1.29
9. Nurse not knowing patient's wishes regarding continuing with tests and treatments.	3.26	1.35
10. Not enough time to provide end-of-life care because nurse is consumed with life-saving activities.	3.25	1.13
11. Continuing care because of threat of legal action.	3.12	1.48
12. Dealing with distraught family members.	2.79	1.23
13. Poor unit design, which limits privacy .	2.62	1.53
14. Nurse being called away from patient to help others.	2.51	1.35
15. The patient having pain that is difficult to control.	2.40	1.34
16. Family unable to be with patient when he or she dies.	2.38	1.35
17. Lack of nursing education in end-of-life care.	2.27	1.38
18. Dealing with cultural differences that families use when grieving for dying patient.	2.08	1.19
19. Unavailability of ethics board to review hard cases.	1.94	1.66
20. No support person available for family such as clergy.	1.78	1.45
21. Pressure to limit grieving after death to accommodate admitting a new patient to that room.	1.75	1.64
22. Nurse knowing poor prognosis before family knows.	1.66	1.56
23. Visiting hours too liberal.	1.53	1.58
24. Visiting hours too restrictive.	1.49	1.62
25. Caring for a "brain dead" patient who is to become an organ donor.	1.35	1.41

Response choices were 0, not an obstacle; 1, extremely small obstacle; 2, small obstacle; 3, medium obstacle; 4, large obstacle; and 5, extremely large obstacle.

use of aggressive care. Items 1, 2, 6, and 9 are concerned with problems of communication.

Fifty-three respondents (26.6%) added comments about possible obstacles not included in the questionnaire; examples are provided in Table 3. The most common additions had to do with physicians' behavior.

Table 2 Perceptions of possible helps to providing end-of-life care to dying patients and their families (n = 199)

Helps	Mean	SD
1. All physicians agreeing about direction of care.	4.57	0.61
2. Providing peaceful, dignified bedside scene for family after patient's death.	4.55	0.73
3. Having 1 family member as designated contact for all patient information.	4.54	0.74
4. Family accepting that patient is dying.	4.53	0.64
5. Allowing family adequate time alone with patient.	4.51	0.78
6. Having enough time to prepare family for patient's death.	4.33	0.84
7. Unit designed with private family grieving place.	4.32	0.87
8. Teaching families how to act/what to say to patient.	4.14	0.86
9. Physician(s) who meet with family after death of patient to offer support and validate care.	4.09	1.14
10. Family thanks the nurse or in some other way shows appreciation for care of patient.	4.05	0.93
11. Having support staff compile necessary paperwork which must be signed by the family after patient's death.	3.91	1.12
12. Unit schedule which allows for continuity of care by same nurse.	3.87	0.96
13. Nurse talking to patient about his/her feelings of death.	3.83	0.90
14. Nurse able to draw on his/her own personal experience with illness or death of a family member.	3.63	1.20
15. Having a fellow nurse give words of support after the patient's death.	3.56	1.47
16. Physicians who put hope in real terms, for example, "Only 1 out of 100 patients in this condition will recover."	3.52	1.55
17. Family has unlimited access to the dying patient even if it conflicts with nursing care.	3.51	1.58
18. Other nurse(s) briefly caring for your other patient(s) after the patient dies.	3.49	1.43
19. Letting social worker/religious leader take primary care of the grieving family.	3.37	1.24
20. Having fellow nurse give some kind of brief, physical support such as a hug after the patient's death.	3.29	1.54
21. Having ethics board member routinely attend unit rounds in case an ethical situation should later arise.	3.03	1.48
22. Having family physically help with care of patient.	3.00	1.29
23. Nurse having support person outside the unit who will listen after death of patient.	2.70	1.43

Response choices were 0, not a help; 1, extremely small help; 2, small help; 3, medium help; 4, large help; and 5, extremely large help.

Interestingly, only 1 of the 25 obstacle items in the questionnaire was about physicians, and it was ranked fifth highest of potential obstacles.

Almost all of the top 10 items in the helps section were related to how to make a patient's death easier for the patient's family (Table 2). The mean scores, ranging from 2.70 to 4.57, for the items in the helps section were higher than those for items in the obstacle section. The help item ranked highest was having all physicians agree about the direction of care.

Table 3 Themes and examples of comments on added possible obstacles to providing end-of-life care to dying patients and their families

Theme	Example
1. Physician disregard for advance directives (n = 13)	They (the physician) often override patients' living wills, families' requests, even consulting doctor's opinions.
2. False hope/family avoidance (n = 8)	Not only are the physicians overly optimistic about patient survival, but they avoid the family altogether. If the family pursues the physician, the physicians are evasive, avoid DNR conversation, and talk in technical terms to the families, so they (the family) are confused and don't know how to answer and pursue more conversation about the matter.
3. Physician won't let patient die (n = 7)	One of the largest problems we have is doctors refusing to give orders to allow patient to die without exhausting every single medication, treatment, etc.
4. Conflicting opinions between families and physicians (n = 7)	Having numerous physicians on the case with different ones giving their perspective to the family, which may differ from that of the others, resulting in the patient's family not knowing who to believe.
5. Short staffed (n = 5)	Being so short staffed that it is almost "looked down upon" to give extra care to a person who is "almost dead" anyway.
6. Lack of adequate pain relief (n = 4)	Physician refusal to order adequate sedation/pain medication for comfort.
7. Nonsupportive coworkers (n = 3)	Coworkers not understanding the family's needs and complaining of them overextending their visit or too many people visiting.
8. Ethics (n = 3)	Ethics committee available only as a retrospective review.
9. Miscellaneous (n = 14)	Difficulty communicating with a family who is non-English speaking even when there is an interpreter. Nurses who stop all but basic care for DNRs.

Numbers represent multiple responses of 53 nurses who added comments.
DNR indicates do not resuscitate.

Items that would be of personal assistance or support to nurses tended to be rated lower. Staff support inside the unit after a death and the availability of a significant other outside the unit were rated as a medium help and as a small help, respectively.

Staffing and time to give care were perceived as both obstacles and helps. In the obstacles section, items related to staffing ranked 10th and 14th, and 5 nurses added comments about staffing aspects as obstacles. In the helps section, items related to staffing and other resources were ranked 11th and 12th, and 5 nurses added comments about staffing and resources.

Thirty-six respondents (18.1%) added comments about helps that they perceived were not addressed. These additional comments are summarized in Table 4. The most frequent comments were related to changes in the ICU routine, such as music or visits by family pets. The need for improvement in communication, facilitating communication with patients' families and families' presence with patients, and needs of nurses for more education and more support were also noted.

Discussion

Because the sample was randomly selected, geographically dispersed, and of an adequate size, we think the results are generalizable to the general population of AACN members who serve as staff nurses. The participants in our survey were an experienced group of nurses, and many were CCRNs. The national rate for CCRN certification for AACN members is 71.4%, almost identical to the rate of our sample. The proportions of the respondents who worked in various types of hospitals and units are similar to national proportions[16]; most of the respondents were employed by not-for-profit community hospitals.

Table 4 Themes and examples of comments on added possible helps to providing end-of-life care to dying patients and their families

Theme	Example
1. Changing environment/routine (n = 10)	Allowing families to adjust the environment in the room to please the dying patient—music, etc.
2. Improving communication (n = 10)	Group meetings between all team members (consults) so everyone is in agreement.
3. Family care (n = 5)	Having clinical nurse specialist offer grief work and education to dying patient and family, from beginning to end of patient's stay in the intensive care unit.
4. Staffing (n = 5)	More staff so other patients get quality care while RN is caring for dying patient and the related issues. Dying patients and family require a lot of care (charting, physical care, meds, etc). RNs also have another critical patient.
5. Nurse education/support (n = 5)	Knowing what to say to a family after a death as they leave the hospital.
6. Other (n = 9) Pain management (n = 3) Spiritual care (n = 2) Miscellaneous (n = 4)	Terminal weaning policy at the institution that has been reviewed by ethics committee and hospital lawyers.

Numbers represent multiple responses of 36 nurses who added comments.

The mean scores for items in the obstacles section are lower than might be expected inasmuch as deficiencies in end-of-life care are well documented.[2,4] The highest ranked item (the largest perceived obstacle) was rated as a medium to large obstacle. Because the nurses in our sample were more experienced and older than the average population of nurses, the respondents may have found ways around common obstacles. They also may have wished to give the impression that they are not controlled by external factors. A less experienced, younger sample might have rated the obstacles higher. Also, these obstacles may be so common or occur so routinely with every death that some futility is associated with them: they do not change much even as a nurse's experience with them increases.

Of the 23 items in the helps section, 22 were rated as medium to extremely large helps or facilitators. The high mean scores could reflect the nurses' appreciation for any assistance because these helps may not be commonly experienced. The help item ranked highest was having all physicians agree about the direction of care. This high ranking could imply concern about the appropriateness of care that seems too aggressive or could reflect that nurses are tired of being "in the middle" as physicians choose not to communicate directly with other physicians. Another possibility is that nurses may feel confused about what nursing care to provide for a patient when one physician wants to end aggressive care and another wants to pursue every available treatment option.

Only 1 of the top 10 help items (item 10; being given an expression of gratitude by the family) could be thought of as being supportive to nurses and may reflect that having family members acknowledge that a nurse did all he or she could supports the desire of nurses to provide a "good death."

Some of the helps are mirror images of the obstacles. For example, the mean score for the obstacle "family not accepting patient's poor prognosis" was 3.51, and the mean score for the similar help item "family accepting that patient is dying" was 4.53. This difference in the mean scores of these similar items may reflect the reality that critical care nurses commonly must deal with families who have a conflict about accepting a poor prognosis yet who still try to be hopeful of the patient's full recovery. The higher mean score for the family accepting that the patient is dying may reflect the rare, but welcomed, occurrence of this acceptance in the ICU setting. The high mean score could also mean that this item is instrumental in nurses' being able to fully begin end-of-life care.[17]

The obstacle with the highest mean score was dealing with telephone calls from patients' families and friends. The continual seeking of information by patients' family members is recognized as an additional burden for nursing staff.[18] Families make these telephone calls because their 3 major needs are assurance, proximity to the patient, and information.[19]

The high ranking of this obstacle has at least 3 possible explanations. First, the high mean score could be a function of how the item was written; the respondents could have reacted to the word "continually," which suggested unlimited numbers of telephone calls from patients' families and friends. Second, any activity that takes a nurse away from caring for a patient, especially for an entire shift, will be perceived negatively. Telephone calls are particularly annoying because they move the nurse away from the bedside to either another part of the patient's room or to the nurses' station. In either case, nurses are prevented from providing any care to the patient during telephone calls. In contrast, when the same family members are visiting in the room and asking questions, nurses can continue caring for the patient. Third, the respondents may have had intense feelings about this obstacle, but it occurs relatively infrequently, or they have intense feelings about it, and it occurs frequently; however, frequency was not measured.

The high ranking of this obstacle should not be interpreted as reflecting that the dying patient's family is considered an obstacle but as reflecting that caring for the patient is the nurse's priority. This interpretation is supported by the finding that these same nurses rated 5 of the top 8 helps in providing end-of-life care as measures that would specifically assist or provide support for patients' families. If these nurses thought that a patient's family was an obstacle, most likely they would not have shown so much concern for the well-being and comfort of patients and patients' families.

The overall high rankings in both the obstacle and the helps sections of items related to the families of dying patients suggest that nurses need assistance with families at this stressful time.[20-22] That assistance could take the form of additional training in crisis management, grieving, and bereavement and additional resources such as availability of pastoral and spiritual care,[23] social workers, or psychiatric liaisons. Assistance for staff in dealing with issues related to patients' families should be considered in any efforts to improve end-of-life care.

The top-ranked obstacles all seem to be items related to situations in which a patient's family or physician has more control than the nurse does; changing these obstacles requires collaboration between nurses and other persons. The nurses rated the lack of nursing education in end-of-life care as a small obstacle, yet they may not know the benefits of an in-depth course in end-of-life care.

O'Hara et al[10] found that the primary coping strategy for nurses after the loss of a patient was concentrating on the positive impact of good nursing care given during the dying process. Our respondents gave a high rating to the help having the family thank the nurse or in some other way show appreciation for the care of the patient. This high ranking could support the concept that appreciation from a patient's family validates that the nurse did indeed provide good nursing care during the dying process.

Nurses feel responsible for providing a "good death,"[6] one that is dignified and peaceful.[12] Our study indicates that providing a peaceful, dignified bedside scene and allowing a patient's family adequate time alone with the patient are important helps. These findings are supported by the results of McClement and Degner's study[12] of expert nursing behaviors in care of dying adults. However, McClement and Degner also reported that their sample of nurses (n = 10) thought that encouraging members of a patient's family to physically help with the care of the patient was important. This activity reportedly helped reduce family members' potential for future regret. Our respondents for this item (n = 193) placed having a patient's family assist with the care of the patient as the second to lowest help. This disparity could be a function of the differences in sample size between studies. It could also be a matter of perspective. In the study by McClement and Degner, nurses were thinking of physical help as a way to help families cope with the dying process; in our study, nurses were asked if that physical help was supportive to nurses.

Pelletier-Hibbert[11] reported that nurses caring for brain-dead patients sought social support from colleagues in the form of taking time away from the unit after the death of a patient. In contrast, our respondents ranked having other nurses briefly care for their other patients, so as to allow the nurse to be alone for a few minutes, in the bottom 5 of perceived helps. Initially, the difference between results could be attributed to the possibility that nurses in the study by Pelletier-Hibbert were in more need of time away from the unit after a death because they cared solely for organ donors, whereas our respondents were caring for dying patients in a wide variety of death scenarios. This notion cannot be supported, however, because the lowest ranked obstacle in our survey was caring for a brain-dead patient who is to become an organ donor. Therefore, our respondents did not judge that caring for a patient who is brain dead or an organ donor was a significant obstacle. Our results might also reflect the realities of staffing; one nurse added, "It never happens."

Stillwell et al[24] assessed the nursing workload associated with caring for 60 patients with do-not-resuscitate orders and found that this group of critically ill patients required high levels of nursing care. The do-not-resuscitate order did not alter the number of hours of care required.[24] Our nurses' rating of issues involving lack of staff and resources is recognition of the need of patients at the end-of-life for high levels of nursing care.

Another possibility is that those nurses who are seriously affected by the death of a patient are also more likely to seek out social support and tend to think that colleagues are "less supportive" than do nurses who are not as affected by a patient's death. Because the nurses in our sample were 5.8 years older and more experienced (1.8 years) than those in the study of Pelletier-Hibbert, our respondents may be in the "less affected" category and thus did not see seeking social support or getting away from the unit as a help in dealing with dying patients.[10]

Limitations

The term obstacle implies a size dimension and also something to be overcome. The intensity and seriousness of the obstacles were inferred on the basis of the ratings. The size dimension of an obstacle is only one view. Not measured are aspects of frequency of occurrence or how successful nurses are in negotiating around the obstacle. In fact, obstacles may be rated lower if a nurse has had experience in overcoming similar difficulties; whereas obstacles that are perceived to be smaller may be rated higher if previous attempts at negotiation were not successful. Highly rated obstacles should not be interpreted as ones that also occur frequently.

Although our respondents accounted for a small percentage of AACN members, the overall response rate and sample size were acceptable. Also the experience of these nurses was substantial, arguing for the seriousness of our findings.

Conclusions

Obstacles

Although many obstacles exist in giving end-of-life care to dying patients, no single obstacle was perceived by our sample of experienced nurses as either large or extremely large. Nurses put caring for patients and following patients' wishes as high priorities. The highest ranked obstacle was behavior of patients' families that removed nurses from caring for patients. The fourth highest obstacle was having a patient's family request more technical care than the patient wanted. Other highly ranked obstacles included family members' not understanding the care that was being suggested, family members' not accepting the patient's poor prognosis, and family members' being angry and fighting within their group about treatment options. All of these obstacles make it difficult for nurses to begin providing end-of-life care.

Five of the 9 themes of the obstacles added by the respondents involved nurses' difficulty with physicians' behaviors. These behaviors included disregarding a patient's wishes for care, giving false hope, avoiding members of the patient's family, not allowing the patient to die of the patient's disease, disagreeing with other physicians about the course of treatment, and not providing nurses with adequate orders for pain relief.

Helps

Mean scores for helps were much higher than those for obstacles. All but one item was rated as either a medium or a large help. The highest rated help was agreement among physicians about the direction of care. The next 7 helps were related to supporting or communicating with patients' families. Our respondents found it helpful when members of a patient's family showed appreciation or somehow thanked nurses after the patient's death, but the respondents did not perceive having a support person outside the unit as particularly helpful. They also did not consider having a patient's family physically help with the care of the patient as relatively helpful.

The most commonly added helps reflected the need for nurses to allow flexibility in patients' environment, in visitation policies, and in improving communication with patients' families. Having staffing concerns addressed and providing nurses education were also considered important helps.

In conclusion, as Simmonds[5(p172)] said so well, "Often we talk about making a decision to let someone die when, in truth, there is no decision to make. Both caregivers and the public need to accept that death is an inevitable life event rather than an undesirable medical outcome."

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Note. From "Critical Care Nurses' Perceptions of Obstacles and Helpful Behaviors in Providing End-of-Life Care to Dying Patients" by K. T. Kirchhoff and R. L. Beckstrand, 2000, American Journal of Critical Care, 9(2), pp. 96-105. Copyright 2000 by K. T. Kirchhoff and R. L. Beckstrand. Reprinted by permission.

APPENDIX B

NATIONAL SURVEY OF CRITICAL-CARE NURSES' PERCEPTIONS OF END-OF-LIFE CARE QUESTIONNAIRE

Code #__________

NATIONAL SURVEY OF CRITICAL CARE NURSES' PERCEPTIONS OF END-OF-LIFE CARE

The end of life is currently being recognized as an important life phase. Critical care nurses are frequently responsible for care of patients who are at the end of life and dying. Care dilemmas arise for nurses as dying patients are placed in an environment created to support and sustain life.

The following items pertain to your perceptions of possible **obstacles** to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large an obstacle** you have found each item to be then mark the box for how **frequently** you have experienced the obstacle as you have cared for dying patients.

		0 - Not an Obstacle 1 - Extremely Small 2 - Small Obstacle 3 - Medium Obstacle 4 - Large Obstacle 5 - Extremely Large	0 - Never Occurs 1 - Almost Never Occurs 2 - Sometimes Occurs 3 - Fairly Often Occurs 4 - Very Often Occurs 5 - Always Occurs
1.	Physicians who are overly optimistic to the family about the patient surviving.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
2.	Families not accepting what the physician is telling them about the patient's poor prognosis.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
3.	The nurse having to deal with distraught family members while still providing care for the patient.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
4.	Intra-family fighting about whether to continue or stop life support.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
5.	The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
6.	Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
7.	Poor design of units which do not allow for privacy of dying patients or grieving family members.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
8.	Unit visiting hours that are too restrictive.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
9.	The patient having pain that is difficult to control or alleviate.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
10.	Dealing with the cultural differences that families employ in grieving for their dying family member.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
11.	No available support person for the family such as a social worker or religious leader.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
12.	Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐

The following items pertain to your perceptions of possible **obstacles** to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large an obstacle** you have found each item to be then mark the box for how **frequently** you have experienced the obstacle as you have cared for dying patients.

		0 = Not an Obstacle	1 = Extremely Small	2 = Small Obstacle	3 = Medium Obstacle	4 = Large Obstacle	5 = Extremely Large	0 = Never Occurs	1 = Almost Never Occurs	2 = Sometimes Occurs	3 = Fairly Often Occurs	4 = Very Often Occurs	5 = Always Occurs
13.	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
14.	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
15.	Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
16.	Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
17.	Lack of nursing education and training regarding family grieving and quality end-of-life care.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
18.	Physicians who won't allow the patient to die from the disease process.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
19.	The unavailability of an ethics board or committee to review difficult patient cases.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
20.	Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
21.	Unit visiting hours that are too liberal.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
22.	Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
23.	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
24.	The nurse having to deal with angry family members.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

The following items pertain to your perceptions of possible **obstacles** to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large an obstacle** you have found each item to be then mark the box for how **frequently** you have experienced the obstacle as you have cared for dying patients.

		0 - Not an Obstacle	1 - Extremely Small	2 - Small Obstacle	3 - Medium Obstacle	4 - Large Obstacle	5 - Extremely Large	0 - Never Occurs	1 - Almost Never Occurs	2 - Sometimes Occurs	3 - Fairly Often Occurs	4 - Very Often Occurs	5 - Always Occurs
25.	The family, for whatever reason, is not with the patient when he or she is dying.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
26.	Physicians who are evasive and avoid having conversations with family members.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
27.	Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
28.	Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
29.	When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

30. Please describe any missing obstacles in detail. Indicate how large each obstacle is and how frequently it occurs.

a. ______________________________

b. ______________________________

c. ______________________________

The following items pertain to your perceptions of possible helps to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large a help** you have found each item to be then mark the box for how **frequently** you have experienced the helpful behavior as you have cared for dying patients.

		0 - Not a Help	1 - Extremely Small	2 - Small Help	3 - Medium Help	4 - Large Help	5 - Extremely Large	0 - Never Occurs	1 - Almost Never Occurs	2 - Sometimes Occurs	3 - Fairly Often Occurs	4 - Very Often Occurs	5 - Always Occurs
31.	Having one family member be the designated contact person for all other family members regarding patient information.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
32.	Having enough time to prepare the family for the expected death of the patient.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
33.	A unit designed so that the family has a place to go to grieve in private.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
34.	Having the physicians involved in the patient's care agree about the direction care should go.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
35.	Having a unit schedule that allows for continuity of care for the dying patient by the same nurses.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

The following items pertain to your perceptions of possible helps to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large a help** you have found each item to be then mark the box for how **frequently** you have experienced the helpful behavior as you have cared for dying patients.

		0 - Not a Help	1 - Extremely Small	2 - Small Help	3 - Medium Help	4 - Large Help	5 - Extremely Large	0 - Never Occurs	1 - Almost Never Occurs	2 - Sometimes Occurs	3 - Fairly Often Occurs	4 - Very Often Occurs	5 - Always Occurs
36.	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
37.	Having the family physically help care for the dying patient.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
38.	Talking with the patient about his or her feelings and thoughts about dying.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
39.	Letting the social worker or religious leader take primary care of the grieving family.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
40.	Teaching families how to act around the dying patient such as saying to them, "She can still hear...it is OK to talk to her."	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
41.	Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
42.	Providing a peaceful, dignified bedside scene for family members once the patient has died.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
43.	Allowing family members adequate time to be alone with the patient after he or she has died.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
44.	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
45.	Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give some other kind of brief physical support after the death of your patient.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
46.	Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
47.	Having a support person outside of the work setting who will listen to you after the death of your patient.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
48.	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
49.	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	0 ○	1 ○	2 ○	3 ○	4 ○	5 ○	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

The following items pertain to your perceptions of possible helpful behaviors to providing end-of-life care to dying patients and their families. As you read each item, please mark the circle that most closely characterizes how **large a help** you have found each item to be then mark the box for how **frequently** you have experienced the helpful behavior as you have cared for dying patients.

		0 - Not a Help 1 - Extremely Small 2 - Small Help 3 - Medium Help 4 - Large Help 5 - Extremely Large	0 - Never Occurs 1 - Almost Never Occurs 2 - Sometimes Occurs 3 - Fairly Often Occurs 4 - Very Often Occurs 5 - Always Occurs
50.	Having family members accept that the patient is dying.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
51.	After the patient's death, having support staff compile all the necessary paper work for you which must be signed by the family before they leave the unit.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
52.	Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
53.	Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐
54.	Having un-licensed personnel available to help care for dying patients.	0 1 2 3 4 5 ○ ○ ○ ○ ○ ○	0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐

55. Please describe any missing helpful behaviors in detail. Indicate how large the help is and how frequently it occurs.

a. ____

b. ____

56. If you had the ability to change just one aspect of the end-of-life care given to dying ICU patients, what would it be?

____

____

____

____

Now please tell a little about yourself by filling in the appropriate boxes below.

57. How many years experience to you have as an **RN**? ☐☐

58. How many years of **ICU** experience do you have? ☐☐

59. What is your gender? ☐ Male ☐ Female

60. What year were your born? 19☐☐

61. What is your **highest completed** level of education?

☐ Diploma in Nursing
☐ Associate degree, Nursing
☐ Associate degree, Other
☐ Bachelors degree, Nursing
☐ Bachelors degree, Other
☐ Masters degree, Nursing
☐ Masters degree (other)
☐ Doctoral degree
☐ Other __________

62. Over your nursing career, how many ICU patients have you, yourself given immediate end-of-life care to?

☐ Less than 5
☐ Between 5 and 10
☐ Between 11 and 20
☐ Between 21 and 30
☐ More than 30
☐ Other __________

63. In which **type of ICU** are you primarily employed?

☐ Intensive Care Unit
☐ Coronary Care Unit
☐ Combined ICU/CCU
☐ Other (Please specify) ____________________
☐ Medical ICU
☐ Surgical ICU
☐ Respiratory ICU
☐ Neuro/Neurosurgical ICU
☐ Shock/Trauma Unit
☐ Cardiovascular/Surgical ICU

64. In which **type of facility** are you primarily employed?

☐ Community Hospital, Non-profit
☐ Community Hospital, Profit
☐ University Medical Center
☐ Federal Hospital
☐ State Hospital
☐ County Hospital
☐ Military Hospital
☐ Other ____________

65. The **position** you hold at the facility is?

☐ Direct care/Bedside/Staff Nurse
☐ Charge Nurse/Staff Nurse
☐ Clinical Nurse Specialist
☐ Other (Please specify) ____________________

66. What is the number of beds in your unit? ☐☐

67. How many **hours per week** do you usually work as an **RN**? ☐☐

68. Have you ever been certified as a Critical Care Registered Nurse (CCRN)?
☐ No (Please go to question #71).
☐ Yes (Please go to question #69).

69. Are you currently a CCRN? ☐ No ☐ Yes

70. How many years have you held (or did you hold) the CCRN certification? ☐☐ years.

71. Do you currently have any other nursing certifications? If so, please list them now. ____________

72. Do you have any comments about this study? ____________

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY.

PLEASE RETURN THE QUESTIONNAIRE TODAY
IN THE ENCLOSED, STAMPED ENVELOPE
OR MAIL TO:
Renea L Beckstrand, Ph.D(c), RN, CCRN
P.O. Box 25432, SWKT, Provo, UT 84602

APPENDIX C

NATIONAL SURVEY OF CRITICAL-CARE NURSES REGARDING END-OF-LIFE CARE QUESTIONNAIRE

Code #____________________

NATIONAL SURVEY OF CRITICAL CARE NURSES REGARDING END-OF-LIFE CARE

The end of life is currently being recognized as an important life phase. Critical care nurses are frequently responsible for care of patients who are dying and are at the end of life. Care dilemmas arise for nurses as dying patients are cared for in an environment created to support and sustain life.

The following questions pertain to your perceptions of possible **obstacles** to providing quality end-of-life care to a dying patient and his or her family. As you read each question, please mark the box that most closely characterizes how big an **obstacle** you have found each item to be.

Response Choices:
0= Not an Obstacle 1= Extremely Small Obstacle 2= Small Obstacle
3= Medium Obstacle 4= Large Obstacle 5= Extremely Large Obstacle

1.	Some physicians who are overly optimistic to the family about the patient surviving.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
2.	Families not accepting what the physician is telling them about the poor prognosis of the patient.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
3.	The nurse having to deal with distraught family members while still providing care for the patient.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
4.	Intra-family fighting about whether to continue or stop life support.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
5.	The nurse knowing about the poor prognosis of the patient before the family.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
6.	Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
7.	Poor design of units which do not allow for privacy for dying patients or grieving family members.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
8.	Unit visiting hours that are too restrictive.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
9.	The patient having pain that is difficult to control or alleviate.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐

Please continue on page 2 →

Continued from page 1:

Response Choices:

0= Not an Obstacle 1= Extremely Small Obstacle 2= Small Obstacle
3= Medium Obstacle 4= Large Obstacle 5= Extremely Large Obstacle

		0	1	2	3	4	5
10.	Dealing with the cultural differences that families employ in grieving for their dying family member.	☐	☐	☐	☐	☐	☐
11.	No available support person for the family such as a social worker or religious leader.	☐	☐	☐	☐	☐	☐
12.	Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care.	☐	☐	☐	☐	☐	☐
13.	Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	☐	☐	☐	☐	☐	☐
14.	Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	☐	☐	☐	☐	☐	☐
15.	Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	☐	☐	☐	☐	☐	☐
16.	Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	☐	☐	☐	☐	☐	☐
17.	Lack of nursing education and training regarding family grieving and quality end-of-life care.	☐	☐	☐	☐	☐	☐
18.	Caring for a patient who has been declared brain dead and is soon to become an organ donor.	☐	☐	☐	☐	☐	☐
19.	The unavailability of an ethics board or committee to review difficult patient cases.	☐	☐	☐	☐	☐	☐
20.	Being called away from the patient and family because of the need to help with a new admit or to help another nurse care for his/her patients.	☐	☐	☐	☐	☐	☐
21.	Unit or hospital visiting hours that are too liberal.	☐	☐	☐	☐	☐	☐

Please continue on page 3 ➔

Continued from page 2:

Response Choices:

0= Not an Obstacle 1= Extremely Small Obstacle 2= Small Obstacle
3= Medium Obstacle 4= Large Obstacle 5= Extremely Large Obstacle

		0	1	2	3	4	5
22.	Family members not understanding what "life-saving measures" really mean, i.e., that multiple needle sticks can cause pain and bruising, that placement of an ET tube won't allow the patient to talk, or that ribs may be broken during chest compressions and so forth.	☐	☐	☐	☐	☐	☐
23.	The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to the patient's depressed neurological status or due to pharmacologic sedation.	☐	☐	☐	☐	☐	☐
24.	The nurse having to deal with angry family members.	☐	☐	☐	☐	☐	☐
25.	The family, for whatever reason, is not with the patient when he or she is dying.	☐	☐	☐	☐	☐	☐

26. Have we missed any **obstacles** to giving end-of-life care to dying patients? Please describe any other obstacles below in detail. Attach an extra sheet if necessary.

a. ______________________________

b. ______________________________

We would now like to ask you about your perceptions of possible **helps** or facilitators to providing quality end-of-life care for the dying patient and his or her grieving family. As you read each question, please mark the box that most closely characterizes how big of a **help** you have found each item to be.

Response Choices:

0= Not a Help 1= Extremely Small Help 2= Small Help
3= Medium Help 4= Large Help 5= Extremely Large Help

		0	1	2	3	4	5
27.	Having one family member be the designated contact person for all other family members regarding information about the patient.	☐	☐	☐	☐	☐	☐
28.	Having enough time to prepare the family for the expected death of the patient.	☐	☐	☐	☐	☐	☐
29.	A unit designed so that the family has a place to go to grieve in private.	☐	☐	☐	☐	☐	☐

Please continue on page 4 →

Continued from page 3:

Response Choices:
0= Not a Help 1= Extremely Small Help 2= Small Help
3= Medium Help 4= Large Help 5= Extremely Large Help

30.	Having the physicians involved in the care of the patient agree about the direction care should go.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
31.	Having a unit schedule that allows for continuity of care of the dying patient by the same nurse(s).	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
32.	The nurse drawing on his/her own previous experience with the critical illness or death of a family member.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
33.	Having the family physically help with care of the dying patient.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
34.	Talking with the patient about his or her feelings and thoughts about dying.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
35.	Letting the social worker or religious leader take primary care of the grieving family.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
36.	Teaching families how to act around the dying patient such as saying to them, "She can still hear you...it is OK to talk to her."	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
37.	Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
38.	Providing a peaceful, dignified bedside scene for family members once the patient has died.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
39.	Allowing family members adequate time to be alone with the patient after he or she has died.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
40.	Having a fellow nurse tell you that, "You did all you could for that patient," or some other words of support.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
41.	Having a fellow nurse put his or her arm around you, hug you, pat you on the back or give you some other kind of brief physical support after the death of your patient.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐

Please continue on page 5 →

Continued from page 4:

Response Choices:
0= Not a Help 1= Extremely Small Help 2= Small Help
3= Medium Help 4= Large Help 5= Extremely Large Help

42.	Having fellow nurses take care of your other patient(s) while you get away from the unit for a few moments after the death of your patient.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
43.	Having a support person outside of the unit setting who will listen to you after the death of your patient.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
44.	Having family members thank you or in some other way show appreciation for your care of the patient who has died.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
45.	Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
46.	Having family members accept that the patient is dying.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
47.	After the death of the patient, having support staff compile for you the necessary paper work which must be signed by the family before they leave the unit.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
48.	Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient's condition will completely recover.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐
49.	Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done.	**0** ☐	**1** ☐	**2** ☐	**3** ☐	**4** ☐	**5** ☐

50. What other things do you perceive as **helps** in giving end-of-life care to dying patients and their grieving families? Please describe them below in detail. Attach an extra sheet if necessary.

a. ____

b. ____

Now please tell us a little about yourself by filling in the appropriate boxes below.

51. How many years of experience do you have as an **RN**? ☐☐

52. How many years of **ICU** experience do you have? ☐☐

53. What year were you born? 19☐☐

Please continue on page 6 →

Continued from page 5:

54. What is your gender? ☐ Male ☐ Female

55. What is your **highest completed** level of education?
☐ Diploma in Nursing
☐ Associate degree, Nursing
☐ Associate degree (other)
☐ Bachelors degree, Nursing
☐ Bachelors degree (other)
☐ Masters degree, Nursing
☐ Masters degree (other)
☐ Doctoral degree
☐ Other ____________

56. Over your nursing career, how many ICU patients have you been assigned to whom you, yourself have given immediate end-of-life care?
☐ Less than 5
☐ Between 5 and 10
☐ Between 11 and 20
☐ Between 21 and 30
☐ More than 30
☐ Other ____________

57. In which type of intensive care unit are you **primarily** employed?
☐ Intensive Care Unit
☐ Coronary Care Unit
☐ Combined ICU/CCU
☐ Medical ICU
☐ Surgical ICU
☐ Respiratory ICU
☐ Neuro/Neurosurgical ICU
☐ Trauma Unit
☐ Cardiovascular/Surgical ICU
☐ Other (Please specify) ____

58. In which type of facility are you **primarily** employed?
☐ Community Hospital-Non Profit
☐ Community Hospital-Profit
☐ University Medical Center
☐ Federal Hospital
☐ State Hospital
☐ County Hospital
☐ Military Hospital
☐ Other ________________

59. The position you hold at the facility is?
☐ Direct care/Bedside/Staff nurse
☐ Charge nurse/Staff nurse
☐ Clinical Nurse Specialist
☐ Other (Please specify) ____________________

60. What is the number of beds in your **unit**? ☐☐

61. How many hours per week do you usually work as an **RN**? ☐☐

62. Have you ever been certified as a Critical Care Registered Nurse (**CCRN**)?
☐ No (Thank you for your time, you are done with the survey!)
☐ Yes (Please go to question # 59)

63. Are you currently certified as a **CCRN**?
☐ No
☐ Yes

64. How many years have you held (or did you hold) the **CCRN** certification? ☐☐

THANK YOU VERY MUCH FOR YOUR PARTICIPATION IN THIS SURVEY.

PLEASE RETURN IT TODAY
IN THE ENCLOSED, STAMPED ENVELOPE.

APPENDIX D

NURSES' PREFERENCES OF SURVEY INDUCEMENTS FORM

Nurses' Preferences for Survey Inducements

Gathering information by survey is a time-consuming, complex, and expensive process. Success of survey research is determined by the number of respondents who complete and return questionnaires. These respondents, through a complex interaction of internal and external motivating factors, choose to either contribute their personal knowledge to a study or ignore it. The purpose of this questionnaire is to explore what amount of influence the listed inducements would have as perceived by nurses.

Please take a few minutes to answer how the following listed inducements would influence you to quickly return a 30-minute survey about an *important nursing topic that directly impacts patient care or nurses*. There are no right or wrong answers so be as accurate as possible.

Response choices:

Receiving __X__(one of the inducements below), included with a 30-minute questionnaire would influence my rapid completion and return of the survey in which of the following ways?

1 = No Influence **2** = Very Small Influence **3** = Small Influence
4 = Moderately Large Influence **5** = Large Influence

A $1 bill included with the survey.	1 2 3 4 5
Information stating that by returning the survey within two weeks, I would be entered into a drawing for $100 cash.	1 2 3 4 5
Pre-notification (by letter) informing me that I had been chosen to be part of a nationwide sample of nurses for an important research project, that I would receive a survey within 7 days, and would I please quickly complete and return it.	1 2 3 4 5
Information stating that for every survey returned within two weeks $1 would be donated to a specialty charity organization such as the March of Dimes, United Way, or American Cancer Society.	1 2 3 4 5
A small token of appreciation being included with the survey such as three U.S. postage stamps or a $1 gift certificate to McDonalds, Burger King, Blockbuster, or other national chain.	1 2 3 4 5
A $2 bill included with the survey.	1 2 3 4 5

Are there any other inducements we may have missed that would positively influence your quick completion and return of a 30-minute survey? ________________________________

Now please tell us a little about yourself my marking the boxes below.

7. What year were you born? 19☐☐
8. What is your gender? ☐ Male ☐ Female

9. In which type of <u>intensive care unit</u> are you **primarily** employed?
   ☐ Intensive Care Unit ☐ Combined ICU/CCU ☐ Trauma Unit
   ☐ Coronary Care Unit ☐ Surgical ICU ☐ Other ________________

Thank you for your participation.

APPENDIX E

NURSES' PREFERENCES OF SURVEY INCENTIVES

(MODIFICATION)

Nurses' Preferences of Survey Incentives

Gathering information by survey is a time-consuming, and expensive process. Success is determined by the number of respondents who complete and return the survey. These respondents choose to either contribute their personal knowledge to a study or ignore it. The purpose of this questionnaire is to explore what amount of influence a listed incentive would have on you, the nurse.

Please take a few minutes to answer how the following listed incentives would influence you to quickly return an 8-page survey about end-of-life care in the ICU. There are no right or wrong answers so be as accurate as possible.

Response choices:

If I were to receive and 8-page questionnaire about end-of-life care in the ICU, which of the following inducements would most likely motivate me to complete and return the questionnaire within two weeks?

0 = Makes No Difference 1 = Less Likely 2 = Somewhat Likely
3 = Very Likely 4 = Extremely Likely

1. A $1 bill included with the survey.	0	1	2	3	4
2. Return of the completed survey would enter me into a drawing for $100 cash.	0	1	2	3	4
3. Pre-notification (by letter) that the survey would be coming soon.	0	1	2	3	4
4. I would complete and return it even if no incentive were included.	0	1	2	3	4
5. $1 being donated to a national scholarship fund or charity for every returned survey.	0	1	2	3	4
6. A $1 gift certificate to Blockbuster, McDonalds, or Burger King included with the survey.	0	1	2	3	4
7. A $2 bill included with the survey.	0	1	2	3	4

8. Are there any other incentives that would positively influence your quick completion and return of an 8-page survey? ______________________________

9. Choose which one of the following you would prefer received a $1 contribution:
Circle one: A. AACN's General Scholarship Fund B. National Breast Cancer Research Fund

Now, please tell us a little about yourself by marking the boxes below.

10. In what year were you born? 19☐☐
11. What is your gender? ☐Male ☐Female
12. In which type of ICU are you primarily employed?
☐ Intensive Care ☐ Surgical ICU ☐ Trauma/Shock
☐ Coronary Care ☐ Combined ICU/CCU/SICU ☐ Other ____________

Thank you for your participation.

APPENDIX F

COVER LETTERS FOR TREATMENT AND CONTROL GROUPS

October 16, 2000

Dear FIELD(First):

It has been estimated that 80% of patients die in hospitals. Of these deaths, approximately 50% occur in Intensive Care Units (ICUs). Yet, no one seems to know how to care for dying patients who are still receiving intensive care. You are invited to be one of 1,500 critical-care RNs who are being asked to participate in a nation-wide study. The purpose of this study is to gain a better understand of both the intensity and frequency of listed obstacles that may inhibit a nurse's ability to provide quality end-of-life care and the helpful behaviors that support the nurse in providing quality end-of-life care.

Enclosed is a questionnaire that takes about 25 minutes to complete. Returning the questionnaire will imply your consent to participate. You are free to omit answering any question you do not wish to answer. All information will be kept strictly confidential. The questionnaire has been assigned a code number so that we can follow-up if necessary. The list that links names with code numbers is being kept in a locked office. Although the results of this study will be published and presented at research conferences, no information that can identify individual respondents will be presented.

If you do not feel eligible to respond for some reason, please write on the questionnaire "not eligible" and return it in the enclosed, stamped envelope. We will then remove your name from the mailing list and send you no further questionnaires.

Your peers have suggested that, as an expression of appreciation for your quick response, we offer you a chance to win **$100.00**. Just return your questionnaire by October 31, 2000 and the survey code number will be written on an entry form and placed in a drawing to be held on November 13, 2000. One code number will be randomly selected and that nurse will be sent a check for **$100.00.** This is our way of saying thank you for your time and participation.

Should you have any questions about this study, please feel free to contact Renea L. Beckstrand. If you have questions regarding your rights as a research subject or if problems arise which you do not feel you can discuss with the investigator, please contact the University of Utah Institutional Review Board Office at (801) 581-3655.

FIELD(First), end-of-life care of the exploding aging population is an experiment that is already in process. Your input on this topic is vital. Please complete the questionnaire and return it in the enclosed stamped envelope by **October 31, 2000.** Thank you for your participation.

Sincerely,

Reneã L. Beckstrand William T. Alward Karin T. Kirchhoff

Reneā L. Beckstrand, RN, CCRN
Associate Professor, BYU
(801) 378-3873

William Alward, MD, FCCP
Director of Respiratory Care
UVRMC, Provo, UT

Karin T. Kirchhoff, Ph.D, RN
Rodefer Professor
University of Wisconsin

October 16, 2000

Dear FIELD(First):

It has been estimated that 80% of patients die in hospitals. Of these deaths, approximately 50% occur in Intensive Care Units (ICUs). Yet, no one seems to know how to care for dying patients who are still receiving intensive care. We need your help to better understand how to improve the care of dying patients in ICUs. You are invited to be one of 1,500 critical-care RNs who are being asked to participate in a nation-wide study. The purpose of this study is to gain a better understand of both the intensity and frequency of listed obstacles that may inhibit a nurse's ability to provide quality end-of-life care and the helpful behaviors that support the nurse in providing quality end-of-life care.

Enclosed is a questionnaire that takes about 25 minutes to complete. Returning the questionnaire will imply your consent to participate. You are free to omit answering any question you do not wish to answer. All information will be kept strictly confidential. The questionnaire has been assigned a code number so that we can follow-up if necessary. The list that links names with code numbers is being kept in a locked office. Although the results of this study will be published and presented at research conferences, no information that can identify individual respondents will be presented.

If you do not feel eligible to respond for some reason, please write on the questionnaire "not eligible" and return it in the enclosed, stamped envelope. We will then remove your name from the mailing list and send you no further questionnaires.

Your peers have suggested, that as an expression of our appreciation for your quick response, we include a **$2.00** bill with the questionnaire. All we ask is that you return your questionnaire by October 31, 2000. This is our way of saying thank you for your time and participation.

Should you have any questions about this study, please feel free to contact Renea L. Beckstrand. If you have questions regarding your rights as a research subject or if problems arise which you do not feel you can discuss with the investigator, please contact the University of Utah Institutional Review Board Office at (801) 581-3655.

FIELD(First), end-of-life care of the exploding aging population is an experiment that is already in process. Your input on this topic is vital. Please complete the questionnaire and return it in the enclosed stamped envelope by **October 31, 2000.** Thank you for your participation.

Sincerely,

Reneã L. Beckstrand	William T. Alward	Karin T. Kirchhoff
Reneã L. Beckstrand, RN, CCRN	William Alward, MD, FCCP	Karin T. Kirchhoff, Ph.D, RN
Associate Professor, BYU	Director of Respiratory Care	Rodefer Professor
(801) 378-3873	UVRMC, Provo, UT	University of Wisconsin

October 16, 2000

Dear FIELD(First):

It has been estimated that 80% of patients die in hospitals. Of these deaths, approximately 50% occur in Intensive Care Units (ICUs). Yet, no one seems to know how to care for dying patients who are still receiving intensive care. We need your help to better understand how to improve the care of dying patients in ICUs.

You are invited to be one of 1,500 critical-care RNs who are being asked to participate in a nation-wide study. The purpose of this study is to gain a better understand of both the intensity and frequency of listed obstacles that may inhibit a nurse's ability to provide quality end-of-life care and the helpful behaviors that support the nurse in providing quality end-of-life care.

Enclosed is a questionnaire that takes about 25 minutes to complete. Returning the questionnaire will imply your consent to participate. You are free to omit answering any question you do not wish to answer. All information will be kept strictly confidential. The questionnaire has been assigned a code number so that we can follow-up if necessary. The list that links names with code numbers is being kept in a locked office. Although the results of this study will be published and presented at research conferences, no information that can identify individual respondents will be presented.

If you do not feel eligible to respond for some reason, please write on the questionnaire "not eligible" and return it in the enclosed, stamped envelope. We will then remove your name from the mailing list and send you no further questionnaires.

Your peers have suggested, that as an expression of appreciation for your quick response, we offer to donate **$1.00** to AACN's General Scholarship Fund for every questionnaire returned by October 31, 2000. This is our way of saying thank you for your time and participation.

Should you have any questions about this study, please feel free to contact Renea L. Beckstrand. If you have questions regarding your rights as a research subject or if problems arise which you do not feel you can discuss with the investigator, please contact the University of Utah Institutional Review Board Office at (801) 581-3655.

FIELD(First), end-of-life care of the exploding aging population is an experiment that is already in process. Your input on this topic is vital. Please complete the questionnaire and return it in the enclosed stamped envelope by **October 31, 2000.** Thank you for your participation.

Sincerely,

Reneã L. Beckstrand

Reneã L. Beckstrand, RN, CCRN
Associate Professor, BYU
(801) 378-3873

William T. Alward

William Alward, MD, FCCP
Director of Respiratory Care
UVRMC, Provo, UT

Karin T. Kirchhoff

Karin T. Kirchhoff, Ph.D, RN
Rodefer Professor
University of Wisconsin

October 16, 2000

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University of Wisconsin

APPENDIX G

LETTER OF DONATION TO THE AMERICAN ASSOCIATION OF CRITICAL-CARE NURSES' GENERAL SCHOLARSHIP FUND

December 18, 2000

AACN
101 Columbia
Aliso Viejo, CA 92656

Dear AACN:

Please accept the enclosed check for the amount of $106.00 as a donation to the AACN general scholarship fund.

As part of a current national study regarding critical care nurses' perceptions of end-of-life care, I offered to donate $1.00 to AACN for every response received by a specified date. Of the 375 nurses in that incentive group, 106 responded as requested. Therefore, I am pleased to send this check as a donation to the general scholarship fund.

Sincerely,

Renea L. Beckstrand

Renea L. Beckstrand, RN, MS, CCRN
Associate Professor, Brigham Young University
College of Nursing
P.O. Box 25432, 572 SWKT
Provo, UT 84602

APPENDIX H

AMERICAN ASSOCIATION OF CRITICAL-CARE NURSES' LETTER ACKNOWLEDGING DONATION

January 12, 2001

Renea L. Beckstrand, RN, MS, CCRN
Associate Professor, Brigham Young University
College of Nursing
Box 25432, 572 SWKT
Provo, UT 84602

Dear Renea:

Thank you so much for your recent gift in the amount of $106 to our Scholarship Fund. **Friends like you help ensure that the programs and services that have made AACN one of the premier nursing associations can be not only maintained, but also strengthened.**

Critical care nurses play a pivotal role in today's healthcare delivery system. We are here to ensure that their training prepares them for this vital role that can result in more than saved lives. It can also save on the daunting medical expenses facing those families dealing with the enormous challenge of serious illness. That is why your support is so valued.

From all of us at AACN, thank you for your belief in and support of our mission. It means a great deal to each of us.

Best wishes for a wonderful new year,

Shirley

Shirley Lorenz
Resource Development Director

P.S. Please use this letter as official documentation required by the Internal Revenue Service that this gift has been made without consideration of any goods or services because of that gift.

APPENDIX I

LETTER TO $100 LOTTERY WINNER

December 7, 2000

Tanya A. Huff, RN, MSN, CCRN
8103 Braxton Court
Mechanicsville, VA 23116-3972

Dear Tanya:

This letter is to inform you that because of your recent participation in the *National Survey of Critical Care Nurses' Perceptions of End-of-Life Care* study, you are the lucky winner of a check for $100.00. Your code number was drawn out from a bag containing all eligible code numbers that were returned to my office by October 31, 2000.

Unless you give me permission to disclose more, I will maintain your anonymity and report to any inquiries only "that a nurse from Virginia won the money."

Congratulations on being the winner and thank you for your participation in this study. If you need to communicate with me for any reason, please contact me at my office number below.

Sincerely,

Renea L. Beckstrand, RN, MS, CCRN
Associate Professor, Brigham Young University
College of Nursing
P.O. Box 25432, 572 SWKT
Provo, UT 84602
(801) 378-3873

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