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Oncology Nurses' Impact Scores for Obstacles and
Supportive Behaviors at the End-of-Life

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A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of

Master of Science

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ABSTRACT

Oncology Nurses' Impact Scores for Obstacles and Supportive Behaviors at the End-of-Life

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Introduction: Oncology nurses provide end-of-life (EOL) care to their patients daily. Oncology nurses' perceptions regarding how to provide quality care to dying patients could be an important addition to the ongoing research on quality EOL care. The purpose of this study was to determine the impact of specific obstacle and supportive behaviors in EOL care as perceived by hospital-based oncology nurses. This study extended the work of Beckstrand, Moore, Callister, and Bond (2009).

Methods: A 69-item questionnaire adapted from previous studies (Beckstrand & Kirchhoff, 2005; Beckstrand, Smith, Heaston, & Bond, 2008) was sent to 1,000 nurses who were members of the Oncology Nursing Society (ONS) and who had provided EOL care to dying oncology patients. Three mailings of the questionnaire yielded 380 usable responses from 907 eligible respondents, which resulted in a 41.9% return rate. Oncology nurses were asked to rate obstacle and supportive items on both size and frequency of occurrence as they related to oncology patients in a hospital setting.

Results: Obstacle items which received the three highest perceived impact scores were: (1) dealing with anxious family members, (2) families not accepting what the physician is telling them about the patient's poor prognosis, and (3) 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.

Supportive behavior items which received the three highest impact scores were: (1) allowing family members adequate time to be alone with the patient after he or she has died, (2) providing a peaceful, dignified bedside scene for family members once the patient has died, and (3) allowing families unlimited access to the dying patient even if it conflicts with nursing care at times.

Implications: Oncology nurses are dedicated to providing the best EOL care to their patients and patients' families. This study identified obstacle and supportive behavior items with the largest impact on providing quality EOL care.

Recommendations: Results of this research demonstrated the need for more EOL education and guidance in forming teams of nurses, social and palliative care workers, and physicians to support the giving of quality care. Nurses also reported the need for more time to support the dying patient and family.

Keywords: End-of-Life, oncology, oncology nurses, death, cancer

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Oncology Nurses' Impact Scores for Obstacles and Supportive Behaviors at the End-of-Life

The need for effective and compassionate end-of-life care grows more critical as the number of people dying from cancer continues to increase. Cancer is the second leading cause of death in the United States overall and the leading cause of death in people ages 45 - 64 (National Center for Injury Prevention and Control, 2007). In 2010 an estimated 569,000 people died of cancer (Altekruse et al., 2009). In the United States, more than 50% of deaths of those 65 years or older occurred in hospitals (National Center for Injury Prevention and Control, 2007). These statistics on national cancer death and hospital death rates reinforce the reality that hospital-based oncology nurses are at the forefront of health care providers who care for dying patients.

In 2010, the Oncology Nursing Society (ONS) and Association of Oncology Social Work issued a joint position statement outlining the importance of providing quality palliative end-of-life (EOL) care (Oncology Nursing Society & Association of Oncology Social Work, 2010). The American Society for Pain Management Nursing also issued a position statement on EOL care, which stated that comprehensive and compassionate EOL care was the responsibility of nurses (American Society for Pain Management Nursing, 2003).

Nurses regularly care for patients who are in the final stages of life and can thus identify behaviors that improve EOL care for patients and families (Pavlish & Ceronsky, 2009). More than 30% of patients diagnosed with cancer will die from the disease (American Cancer Society, 2010); therefore, identifying supportive behaviors and eliminating obstacles to quality EOL care is critical.

Literature Review

In 1995, investigators found major shortfalls in the care of dying adults hospitalized in America during observation of over 9,000 patients (Support Investigators, 1995). The SUPPORT study showed a significant deficiency in communication of patients' desires for EOL care to their healthcare team. Hoping to improve patient-family-physician communication that could lead to better EOL care, a SUPPORT phase II intervention was developed; however, no improvement was seen in communication of the wants and needs of the hospitalized patient regarding EOL care.

The SUPPORT study illustrated that the American healthcare system has not been successful in providing the type of care where palliative rather than curative services are needed; providing comfort over cure (Rutledge, Donaldson, & Pravikoff, 2001). Since SUPPORT, other studies have attempted to identify obstacles and supportive behaviors and other interventions to increase the quality of EOL care both in the United States and globally (Beckstrand, Callister, & Kirchhoff, 2006; Beckstrand, Smith, Heaston, & Bond, 2008; Coyne et al., 2007; Heyland et al., 2006; Singer & Bowman, 2002; Steinhauser et al., 2000; Yabroff, Mandelblatt, & Ingham, 2004). While these studies add to the body of knowledge regarding EOL care, more data is needed regarding oncology nurse perceptions of obstacle and supportive behaviors in EOL care.

In the literature review conducted for this study, three needs were identified. These needs were: (1) better and more frequent communication between the patient, family and healthcare team and between healthcare team members, (2) more time for nurses to perform EOL care, and (3) quality EOL training for the oncology nurse.

The Need for Communication

Multiple studies in EOL care identified good communication as important to patients, families, and oncology nurses. Albinsson and Strang (2003) asked 121 participants in a national course on palliative cancer care to define the two most important measures to support families of severely ill oncology patients. *Listening* was identified as important by 65% of participants and *giving information* was identified by 52%.

Royak-schaler et al. (2006) explored communication regarding EOL care from the perspective of family members of dying patients with cancer and concluded that EOL care satisfaction was closely associated with how the family perceived the quality of communication from the healthcare team. The study reported that families wanted timely and accurate information in order to make informed decisions about EOL care.

In a study conducted by White, Coyne, and Patel (2001) oncology nurses ranked *how to communicate with dying patients and their families* as the number one EOL competency they would have liked more education while in nursing school. Therefore, families and nurses agree that good communication is crucial to providing quality oncology EOL care.

A qualitative study of 33 hospital oncology nurses by Pavlish and Ceronsky (2009), identified five key nursing roles in providing palliative care at the EOL. The researchers noted that the five identified roles of teaching, caring, coordinating, advocating, and mobilizing all had communication as a common theme. The roles of teaching, caring, and mobilizing required communication specifically between nurse and the patient and family, whereas the roles of coordinating and advocating required communication with all members of the healthcare team.

The Need for Time

Nurses reported that adequate time was necessary to provide quality EOL care. Albinsson and Strang (2003) found issues relating to time were lack of nurse availability and providing support. Availability required *being there* for the patient and creating a sense of security for anxious family members through behaviors such as listening and taking time with them. Providing support involved showing empathy to and providing support for the family at the time of death. Cramer (2010) also reported the importance of having the time to *be there* for the patient and family and referred to it as *the power of presence*.

In a study with 33 oncology nurses at a Midwestern healthcare service organization, Pavlish and Ceronsky (2007) explored the nurses' perceptions about the context of palliative care. The most frequent concern in the acute care setting was the limited time available to give compassionate and comprehensive palliative care. Nurses also reported being torn between time demands of palliative care and the emotions accompanying involvement with the patient and family at the EOL.

The Need for EOL Training

The third identified theme was the need for and/or lack of EOL training for oncology nurses. Braun, Gordon, and Uziely (2010) found that nurses' personal attitudes toward death affected their care of dying patients. They concluded that training should include discussions of attitudes toward death, such as death avoidance and fear of death. Lange, Thom, and Kline (2008) assessed nursing attitudes in a cancer care center in New York and found that oncology nurses had a generally positive attitude toward death, but the most positive attitudes were present in the more experienced nurses. Implementing educational

programs taught by experienced nurses offered less experienced nurses the knowledge they needed to offer better EOL care.

Obstacles and Supportive Behaviors

In 2009, Beckstrand, Moore, Callister, and Bond published results of oncology nurses' perceptions of obstacles and helps or supportive behaviors at the EOL. The three largest obstacles were: (1) having to deal with angry family members, (2) families not accepting what the physician is telling them about the patient's poor prognosis, and (3) 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. The three largest supportive behaviors were: (1) allowing family members adequate time to be alone with the patient after he or she has died, (2) having social work or palliative care as part of the patient care team, and (3) having family members accept that the patient is dying. No frequency of occurrence data was included in this report so it was not known if these highly rated obstacles or supportive behaviors were also frequently occurring.

Information from oncology nurses about both obstacle and supportive behavior item size along with frequency of occurrence data could help reveal current priorities in EOL care. The purpose of this study was to add frequency of occurrence data to both obstacle and supportive behavior item size to determine individual item impact scores. The research questions were: (1) what do oncology nurses perceive to be the largest and most frequently occurring obstacles to providing quality EOL care? And (2) what do oncology nurses perceive to be the largest and most frequently occurring supportive behaviors to providing quality EOL care?

Method

Sample

Following Institutional Review Board approval, a national, random, geographically dispersed sample of 1,000 oncology nurses was obtained from the ONS. Inclusion criteria for subjects included having cared for at least one hospitalized cancer patient at the EOL and the ability to read and understand English. Consent to participate was assumed upon return of the questionnaire.

Tool

The questionnaire used was adapted from two similar studies with critical care nurses (Beckstrand & Kirchhoff, 2005) and emergency room nurses (Beckstrand, Smith, Heaston, & Bond, 2008). After information was gathered from literature and expert opinion, revisions were made to more closely apply the questionnaire to oncology EOL care. The questionnaire was then piloted with 28 experienced oncology nurses from three different hospitals in one western state. The final questionnaire contained 68 items including 50 Likert-type items, 4 open-ended questions, and 14 demographic questions.

Participants were asked to rate both obstacle and supportive behavior items on two criteria, which were size and frequency of occurrence. Items were rated on a size scale from 0 (not an obstacle or supportive behavior) to 5 (an extremely large obstacle or supportive behavior) and a frequency scale of 0 (never occurs) to 5 (always occurs). After questionnaires were returned, results were entered into IBM® SPSS® (IBM, Inc., 2009). Mean scores for obstacle items and for supportive behavior items on both size and frequency of occurrence were then calculated. The size mean score and frequency mean score for each individual item were then multiplied to yield an impact score (size

multiplied by frequency of occurrence) (Swatzky, 1996) for each obstacle and supportive behavior item. Items were then ranked from highest to lowest impact score to determine which obstacle and which supportive behavior items were perceived to have the greatest impact.

Results

After three mailings, 93 out of 1,000 questionnaires were eliminated from the study because they were either undeliverable ($n = 4$), the nurse stated being retired ($n = 4$), or respondents reported they were ineligible ($n = 85$). The return after three mailings yielded 380 usable questionnaires from 907 eligible respondents for a return rate of 41.9%.

Of those in the sample who reported gender ($n = 355$), 93.4% were women. The median age of respondents was 40 years old with a range of ages between 23 – 72 years. Years as an RN ranged from 1.5 – 45 years; years in oncology nursing ranged from 1 - 40 years with a mean of 12.5 years (see Table 1).

Obstacles

Subjects rated 26 obstacle items for size and frequency of occurrence which yielded a perceived obstacle impact scores (POIS) ranging from a high of 11.48 to a low of 0.59 (see Table 2). The highest ranked obstacle by the nurses was dealing with anxious family members (POIS = 11.48). Obstacle items ranked second and fourth were similar in context: family not accepting patient's poor prognosis (POIS = 10.23), and families being overly optimistic despite the patient's poor prognosis (POIS = 9.54). The obstacle item ranked third was 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 (POIS = 10.14).

In addition, 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 was ranked fifth (POIS = 9.31). The nurse having to deal with distraught family members while still providing care for the patient was ranked sixth (POIS = 9.30), and family members not understanding the consequences of continuing aggressive treatments such as nausea, diarrhea, and anemia from chemotherapy treatments was ranked seventh (POIS = 8.51).

Oncology nurses ranked the nurse having to deal with angry family members (POIS = 8.43), the patient's family not wanting the patient to be overly sedated due to too many doses of pain medication (POIS = 8.0), and physicians who are overly optimistic to the patient and/or family about the patient surviving (POIS = 7.76) as eighth, ninth, and tenth, respectively.

The lowest scored items were no social work or clergy support person (POIS = 2.86), pressure to limit grieving time after a patient's death in order to accommodate a new admit (POIS = 2.39), and restrictive visiting hours (POIS = 0.59).

Supportive Behaviors

There were 24 supportive behavior items scored. Perceived supportive behavior impact scores (PSBIS) ranged from a high of 19.6 to a low of 6.5 (see Table 3). The number one supportive behavior by impact score was allowing family members adequate time to be alone with the patient after he or she has died (PSBIS = 19.6), followed by providing a peaceful bedside scene for family after the patient has died (PSBIS = 18.1). Allowing family unlimited access to the dying patient (PSBIS = 16.4) was third and teaching family

members how to act around the dying patient (PSBIS = 15.7) was the fourth highest ranked item.

Other helpful behaviors/supports ranked in the top ten by PSBIS were having social work or palliative care as part of the patient care team (PSBIS = 15.5), having the physicians involved in the patient's care agree about the direction of care (PSBIS = 14.1), and having family members thank the nurse or in some other way show appreciation (PSBIS = 14.01), which were fifth, sixth and seventh respectively. The final three supportive behaviors were having family members accept that the patient is dying (PSBIS = 13.7), having social work and/or palliative care establish rapport with patient and family before patient is actively dying (PSBIS = 13.3), and having a fellow nurse tell you, "you gave great care to that patient," or other words of support after the patient has died (PSBIS = 12.3).

The bottom three supportive behavior items were having educational inservices on how to care for the dying patient (PSBIS = 7.8), having a fellow nurse observe patients while the primary nurse "gets away" (PSBIS = 7.3), and having the physician meet in person with the family after the patient's death to offer support (PSBIS = 6.5). Significant in all three of these supportive behavior items was that size scores for each item were relatively high, which indicated that oncology nurses felt these items were important; however, frequency scores for items were very low, which indicated they rarely occurred.

Discussion

Participants in the EOL survey were members of ONS and had an average of 18 years of nursing experience. Subjects were highly educated in oncology nursing, with 68% having been either an Oncology Certified Nurse (OCN), an Advanced Oncology Certified Nurse (AOCN), or a Certified Pediatric Oncology Nurse (CPON) at some time in their practice. The

sample was randomly selected, geographically dispersed, and of a statistically significant size, so results can be generalized to ONS members who work in a hospital-based setting.

Similarities were found between the current study and the previous study of oncology nurses' perceptions of obstacles and supportive behaviors to EOL care (Beckstrand, Moore, Callister, & Bond, 2009). Eight of the top ten obstacles and eight of the top ten supportive behavior items identified by POIS and PSBIS in this study were also found to be in the top ten items of the previous study. However, significant discrepancies were also found between the two studies.

Four obstacle items and four supportive behavior items ranked significantly different with the addition of frequency of occurrence data. For example, the highest ranked obstacle by size in the 2009 study (the nurse having to deal with angry family members) decreased to the 8th rank by POIS. In addition, the 5th ranked obstacle in the 2009 study (doctor's insisting on aggressive care) dropped to 11th. Two other obstacle items were ranked higher with the addition of frequency of occurrence data moving from 13th to 6th position (nurse having to deal with distraught family while still providing care) and from 23rd to 14th (nurse knowing patient's poor prognosis before family).

Four supportive behavior items increased in ranking significantly after frequency of occurrence data was added to the study. Allowing families unlimited access to the dying patient escalated from 14th to 3rd and teaching family members how to act around the dying patient increased from 9th to 4th. Item number seven (having family members show appreciation for the care of patient) increased from 15th, whereas the nurse drawing on previous EOL experience moved from 23rd to 12th.

Obstacles

Interestingly, four of the top eight obstacles dealing with families also had the component of emotion as in dealing with anxious, overly optimistic, distraught, or angry family members. The other four top ten items surrounding family issues regarded the family not accepting the poor prognosis, family and friends who continually call the nurse, family not understanding consequences of aggressive treatment, and patient's family not wanting patient to be overly sedated. This data surrounding family issues at the end of life is validated by other studies. Popejoy, Brandt, Beck, and Antal (2009) identified that helping the patient through the dying process also involved helping the family and that the family became the patient. Waldrop (2007) found that caregiver grief during EOL care included the components of heightened responsiveness, anxiety, depression, anger and fear. Similarly, the obstacles of family not understanding lifesaving treatment, frequent telephone calls from family, and dealing with distraught and angry family members were found among critical care and emergency room nurses (Beckstrand & Kirchhoff, 2005; Beckstrand, Smith, Heaston, & Bond, 2008).

Inadequate time to provide quality EOL care was identified as the third (being called away to help with another nurse) and fifth (family and friends continually call the nurse) most commonly rated obstacle issues. However, among critical care and emergency nurses, lack of time was the most highly rated obstacle (Beckstrand, Callister, & Kirchhoff, 2006; Beckstrand & Kirchhoff, 2005; Beckstrand, Smith, Heaston, & Bond, 2008). The issue of limited time for offering compassionate and comprehensive EOL care among oncology nurses was also identified by Pavlish and Ceronsky (2007).

Other highly rated obstacle items were the nurse being called away from the patient, ranked 7th, and two issues regarding physicians, doctors being overly optimistic about survival, and doctors insisting on aggressive care, ranked 10th and 11th respectively. Critical care nurses (Beckstrand & Kirchhoff, 2005) also identified the item of physicians being overly optimistic about survival as an important obstacle but ranked differing opinions among physicians and physicians being evasive as even higher obstacles.

Interestingly, although previous research identified lack of communication as a major obstacle (Beckstrand, Callister, & Kirchhoff, 2006; Cherlin et al., 2005; Heyland et al., 2006; Popejoy, Brandt, Beck, & Antal, 2009; Royak-schaler et al., 2006) none of the top ten items in this study involved communication, perhaps because this highly experienced group of oncology nurses has developed the skills to better communicate with patients, families, and healthcare providers. For example, the communication problem of the nurse knowing the prognosis before the patient was second by frequency of occurrence but 23rd by size. Although this obstacle occurs frequently, nurses did not find it to be a difficult obstacle, possibly because families often were not ready for this information and nurses understood the need for hope.

The need for or lack of EOL care training for nurses was also identified in previous studies (Caton & Klemm, 2006; Coyne et al., 2007; Deffner and Bell 2005; Kruse, Melhado, Convertine, & Stecher, 2008; Lange et al., 2008; Mallory, 2003; White, Coyne, & Patel, 2001). However, in this study, three obstacles, which related to EOL education for nurses, were identified but ranked in the bottom half by POIS. Each was similarly ranked by size mean, frequency mean, and POIS. These education-related obstacles were lack of nursing training and education in EOL care and family grieving, dealing with cultural differences, and not

knowing what to say to a grieving patient or family, ranked by POIS as 18th, 21st, and 22nd respectively. The lower rankings for these items might be explained by the fact that the average years worked in oncology by this sample of oncology nurses was 12.5 years whereas less experienced nurses might have found these items to be greater obstacles. In addition, although these obstacles were not ranked higher by POIS many obstacles that did rank higher might also be improved by better EOL training such as obstacles related to distraught, angry, and anxious family members and items related to the family not understanding the plan of care or prognosis.

Supportive Behaviors

Significantly higher impact scores were reported in supportive behavior items than in obstacle items. Supportive behavior items likely received higher scores because nurses are more in control of these behaviors, especially regarding how frequently each occurs.

The top four supportive behavior items by PSBIS indicated the importance nurses placed on caring for the grieving family once a patient has died. The top two items, allowing family members adequate time alone with the patient after death and providing a peaceful bedside scene for family, related to behaviors the nurse could facilitate. The supportive behavior items ranked third (allowing family members unlimited access to dying patient) and fourth (teaching family members how to act around the dying patient) were also items the nurse could control for the family.

The top supportive behaviors identified by critical care (Beckstrand & Kirchhoff, 2005) and emergency room nurses (Beckstrand, Smith, Heaston, & Bond, 2008) were similar to the oncology nurses in this study and included allowing family members adequate time alone with the patients after death; providing a peaceful, dignified bedside

scene; and teaching family members how to act around the dying patient. Albinsson and Strang, 2003 and Mcmillen, 2008 also identified providing support for the family at the time of death and afterwards as an important nursing supportive behavior.

Social work or palliative care team members could help the family accept the anticipated death of the patient. Having social workers as part of the team had a size mean score of two but a frequency of occurrence ranking of five, indicating it did not occur as often as oncology nurses would have liked.

Literature supported the need for greater training and selection of mentors (Caton & Klemm, 2006); improved EOL education (Caton & Klemm, 2006; Coyne et al., 2007; Mallory, 2003); and improved EOL competencies in communication, comfort care, and dealing with families (White, Coyne, & Patel, 2001). However, in this study, the supportive behavior items, having experienced RNs model EOL care for newer RNs and educational inservices on how to care for dying patients, were ranked 11th and 22nd respectively. The low ranking in this study might be explained by the demographics of the survey. Nurses who were selected for the study were all members of ONS and most (68%) had been certified with OCN, AOCN, or POCN at some time, which possibly indicated a higher degree of professionalism, experience, and knowledge.

Recommendations

The purpose of this study was to determine impact scores for obstacle and supportive behavior items in EOL care as perceived by hospital-based oncology nurses. Results indicate that nurses understand the importance of family issues and attitudes in improving EOL care. Recommendations to improve communication, provide effective education, and

promote teamwork can be made as a result of this study and could improve EOL care for the patients and families.

Improve communication between family, nurse, and patient. Traditionally, a patient's preferences regarding EOL have been communicated via advanced directives such as living wills and do-not-resuscitate orders. However, advanced directives have not always been effectively communicated to the healthcare team, especially in cases where the patient has been transferred among facilities.

To address this problem, physician orders for life-sustaining treatment (POLST) have been developed (Mitchell, 2011). POLST seeks to clarify and solidify wishes already expressed in a living will or advanced directive. The goal is to transfer a patient's wishes into medical orders via a brightly colored form that addresses artificial nutrition, pain management, antibiotics, comfort measures, and other medical interventions.

POLST programs are meant to complement, not replace, advanced directives, and are based on EOL conversations with a healthcare provider. Because oncology nurses in this study identified several areas where communication between patients, families, and caregivers was less than optimal, the use of POLST or a similar tool is highly recommended.

Provide effective education. The end-of-life nursing education consortium (ELNEC) program was shown to be effective in improving EOL care education with oncology nurses (Coyne et al., 2007). The ELNEC program provides oncology nurses with the tools and training to effectively provide palliative care to patients and families. Curriculum includes cultural considerations, communication, and preparation for death, all of which were identified in this study as barriers to EOL care. Oncology nurses and their patients and

patients' families would benefit from nurses receiving more education as provided by the ELNEC program.

Promote a team approach. Oncology nurses in this study understood that having social workers, palliative care providers, physicians, and nurses on the same team could improve EOL care. The act of dying is complicated for the patient and family as it involves intense physical and emotional work. Only if participants work together can this transition from life to death be a more positive experience.

Conclusions

This study validates what many oncology nurses have experienced—that dealing with the family is vital to the care of the oncology patient. As high-quality EOL care continues to be a pressing issue for oncology patients and their families, medical professionals must access the expertise and input of hospital-based oncology nurses. By carefully considering their experience, concerns and recommendations, the most compassionate care can be possible. Only then will medical professionals, patients and their families realize the optimal outcomes all desire.

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Table 1
Demographics

Table 1			
Demographics of Nurses. N = 1000, 473 returned, 380 usable, 93 not eligible = 41.9% response rate.			
Characteristics			
Sex	<u>n</u>	<u>%</u>	
Female	355	(93.4)	
Male	18	(4.7)	
Did not report	7	(1.8)	
	<u>M</u>	<u>SD</u>	<u>Range</u>
Age	48.0	10.7	23 - 72
Years as RN	17.9	11.1	1.5 - 45
Years in oncology	12.5	8.3	1 - 40
Hours worked/week	36.2	10.4	0 - 80
Number of beds in oncology unit	28.3	11.6	0 - 100
Dying patients cared for:		<u>%</u>	
>30		68.9	
21 - 30		7.8	
11 - 20		12.8	
5 - 10		7.0	
<5		3.5	
Highest degree:		<u>%</u>	
Diploma		7.8	
Associate		22.4	
Bachelor		49.2	
Master		19.2	
Doctoral		1.1	
Ever certified as OCN or AOCN	<u>n</u>	<u>%</u>	
Yes	245	(67.6)	
No	118	(32.4)	
Currently OCN or AOCN	<u>n</u>	<u>%</u>	
Yes	211	(59.3)	
No	145	(40.7)	
Years as OCN	7.3	5.6	0.5 - 25
Years as AOCN	7.7	3.1	1 - 12
Ever participated in ELNEC program	<u>n</u>	<u>%</u>	

Yes	69 (20.5)		
No	268 (79.5)		
Practice area:		<u>%</u>	
Bedside/Direct Care Nurse		31.2	
Staff/Charge Nurse		39.5	
Clinical Nurse Specialist		6.7	
Other (Manager, Educator, etc.)		22.7	
Hospital type:		<u>%</u>	
Community, non-profit		57.6	
Community, profit		10.7	
University medical center		19.8	
Federal hospital		1.9	
State hospital		1.1	
County hospital		4.6	
Military hospital		0.5	
Other		3.35	

Table 2

Size Mean, Standard Deviation, and Rank; Frequency Mean, Standard Deviation, and Rank; and Perceived Obstacle Impact Score (POIS) for Obstacles in End-of-Life Care

Obstacles	Size <u>M</u>	Inten- sity <u>SD</u>	Inten- sity Rank	Freq ^{**} <u>M</u>	Freq <u>SD</u>	Freq Rank	POIS ^{***}
1. Dealing with anxious family	3.51	1.03	1	3.27	0.91	1	11.48
2. Family not accepting pt's poor prognosis	3.54	0.98	2	2.89	0.93	4	10.23
3. Called away to help with new admit or to help another nurse	3.51	1.09	4	2.89	1.1	5	10.14
4. Families being overly optimistic despite pt's poor prognosis	3.43	1.10	6	2.78	0.94	6	9.535
5. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member	3.36	1.25	7	2.77	1.13	7	9.312
6. Nurse having to deal with distraught family while still providing patient care	3.12	1.13	13	2.98	0.97	3	9.298
7. Family not understanding consequences of aggressive treatment: nausea, vomiting, diarrhea, anemia	3.30	1.16	11	2.58	0.97	8	8.514

Obstacles	Size M ⁺	Inten- sity SD	Inten- sity Rank	Freq M ^{**}	Freq SD	Freq Rank	POIS ***
8. Nurse having to deal with angry family members	3.54	1.08	3	2.38	0.95	12	8.425
9. Patient's family not wanting patient to be overly sedated due to pain meds	3.35	1.21	8	2.38	0.93	13	7.973
10. Drs overly optimistic about survival	3.08	1.22	14	2.52	0.99	10	7.76
11. Doctors insist on aggressive care	3.47	1.40	5	2.23	1.07	16	7.738
12. Intra-family fighting about whether to cont. or stop aggressive treatment	3.31	1.15	9	2.31	0.87	14	7.646
13. Not enough time to provide quality EOL care because nurse trying to save pt's life	3.07	1.23	15	2.47	1.09	11	7.583
14. Nurse knowing pt's poor prognosis before family	2.40	1.40	23	3.04	1.09	2	7.296
15. Patient's pain difficult to control or alleviate	3.30	1.30	10	2.18	0.93	17	7.194
16. Patient having too many visitors	2.61	1.39	19	2.53	1.15	9	6.603
17. Poor unit design: no privacy for patient or family	2.71	1.79	18	2.29	1.56	15	6.206
18. Lack of nursing training and education in EOL care and family grieving	2.83	1.5	17	2.14	1.18	18	6.06

Obstacles	Size <u>M</u>	Inten- sity <u>SD</u>	Inten- sity Rank	Freq <u>M</u> **	Freq <u>SD</u>	Freq Rank	POIS ***
19. Employing life sustaining measures at family request	3.17	1.64	12	1.72	0.97	23	5.452
20. Continuing treatments that cause pain	3.00	1.51	16	1.73	0.99	22	5.19
21. Dealing with cultural differences	2.53	1.21	21	2.05	0.93	19	5.187
22. Not knowing what to say to grieving patient or family	2.56	1.46	20	1.99	1.09	20	5.094
23. Family not with patient when patient is dying	2.46	1.22	22	1.95	0.81	21	4.797
24. No support person (social worker or clergy)	2.03	1.49	25	1.41	1.05	24	2.862
25. Limit grieving time for new admit	2.13	1.75	24	1.12	1.08	25	2.386
26. Restrictive visiting hours	1.02	1.59	26	0.58	0.95	26	0.592

*Size of obstacle response choices were: 0 = Not an Obstacle to 5 = Extremely Large.

**Frequency of obstacle response choices were: 0 = Never Occurs to 5 = Always Occurs.

***POM = Perceived Obstacle Magnitude (obstacle size M multiplied by obstacle frequency M).

Table 3

Size Mean, Standard Deviation, and Rank; Frequency Mean, Standard Deviation, and Rank; and Perceived Supportive Behavior Impact Score (PSBIS) for Supportive/Helpful Behaviors in End-of-Life Care

Supportive Behaviors	Size <u>M</u>	Inten- sity <u>SD</u>	Inten- sity Rank	Freq. <u>M</u>	Freq. <u>SD</u>	Freq. Rank	PSBIS* **
1. Allowing family members adequate time alone with the patient after death	4.59	0.61	1	4.26	0.93	1	19.55
2. Providing peaceful bedside scene for family after patient has died	4.50	0.71	5	4.02	0.95	2	18.09
3. Allowing families unlimited access to dying patient	4.22	1.05	14	3.88	1.07	3	16.37
4. Teaching family members how to act around the dying patient such as saying to them, "she can still hear...it's okay to talk to her."	4.33	0.76	9	3.62	0.98	4	15.67
5. Having social work or palliative care as part of the team	4.55	0.68	2	3.41	1.20	5	15.52
6. Doctors agree about direction of care	4.51	0.69	4	3.13	0.95	7	14.12
7. Having family members show appreciation for care of patient	4.22	0.90	15	3.32	0.99	6	14.01
8. Family accepts patient is dying	4.53	0.65	3	3.03	0.78	9	13.73

Supportive Behaviors	Size M	Inten- sity SD	Inten- sity Rank	Freq. M	Freq. SD	Freq. Rank	PSBIS* **
9. Social work or palliative care established rapport with family before patient is actively dying	4.39	0.75	8	3.03	1.18	10	13.30
10. Having fellow nurse give words of support after death of patient	4.39	0.79	7	2.80	1.19	11	12.29
11. Having experienced RNs model EOL care for new RN	4.40	0.79	6	2.76	1.25	12	12.14
12. Nurse draws on previous EOL experience	3.78	1.04	23	3.10	1.08	8	11.72
13. Having time to educate family about dying process	4.27	0.77	11	2.69	0.97	13	11.49
14. Unit schedule allowing for continuity of care	4.25	0.84	13	2.64	1.19	14	11.22
15. Talking with patient about his/her own feelings about dying	4.19	0.82	16	2.55	1.01	16	10.68
16. Having one family member be the contact person regarding patient information	4.33	0.81	10	2.45	0.97	17	10.61
17. Having fellow nurse give physical support after death of patient	4.02	1.09	18	2.60	1.28	15	10.45
18. Unit designed so family can grieve in private	4.27	0.85	12	2.36	1.51	20	10.08
19. Support staff gathers necessary paperwork after patient death	3.94	1.13	19	2.40	1.52	19	9.46

Supportive Behaviors	Size <u>M</u>	Inten- sity <u>SD</u>	Inten- sity Rank	Freq. <u>M</u>	Freq. <u>SD</u>	Freq. Rank	PSBIS* **
20. Having family physically help with care of dying patient	3.72	1.06	24	2.44	1.04	18	9.08
21. Having a support person outside of work to listen after death of patient	3.83	1.22	21	2.36	1.46	21	9.04
22. Educational inservices on how to care for dying patients	4.09	0.94	17	1.90	1.20	23	7.77
23. Fellow nurse covers to allow you to "get away"	3.78	1.07	22	1.94	1.34	22	7.33
24. Having physician meet in person with family after patient's death to offer support	3.85	1.13	20	1.69	1.20	24	6.51

*Size of helpful behavior response choices were: 0 = Not a help to 5 = Extremely helpful.

**Frequency of helpful behavior response choices were: 0 = Never occurs to 5 = Always Occurs.

***PSBM = Perceived Supportive Behavior Magnitude (behavior size M multiplied by behavior frequency M).