ABSTRACT
Advanced practice nurses (APRNs) have key roles in the care of patients who are nearing death and those living with a disabling chronic disease. This article describes a mixed-method formative assessment of 36 graduate nursing students’ knowledge about and attitudes toward palliative care preliminary to curricular integration of the End-of-Life Nursing Education Consortium (ELNEC) graduate core modules. Students’ knowledge about palliative care was assessed using the 106-item ELNEC examination. In addition, qualitative data were gathered regarding students’ definitions of palliative care, the role of the APRN in palliative care, and their definitions of a “good” and “bad” death. Results revealed students’ limited knowledge about palliative care. Qualitative findings indicated that most students exclusively linked palliative care with end-of-life care and believed that the treatment they provide should have the goal of prolonging life over maintaining quality of life. Implications for curriculum design, advanced practice role development, and collaboration with community health partners are discussed.

There are multiple studies of nurses’ end-of-life knowledge, attitudes, and skills indicating the need for more education of nursing students, practicing nurses, and nursing faculty (Copp, 1994; Frommelt, 2003; Kwekkeboom, Vahl, & Eland, 2005; Lehna, 2003; Meraviglia, McGuire, & Chesley, 2003; White, Coyne, & Patel, 2001). Advanced practice nurses (APRNs) are in a unique position to substantially contribute to the improvement of care provided to dying patients and patients with end-stage chronic illness. Because nurses spend more time with patients at the end of life than do any other health care professionals, they can readily identify the need for and facilitate the use of hospice and palliative care programs (Gelband, 2001). Current research indicates that these programs are vastly underused (Duggleby & Berry, 2005) and that referrals are typically made late in the course of illness (National Hospice and Palliative Care Organization, 2007). The Institute of Medicine states in its report Approaching Death: Improving Care at the End of Life that all patients with potentially fatal advanced chronic illnesses should receive competent care (Field & Cassel, 1997). APRNs can refer patients to hospice and palliative care programs at much earlier points in the illness-dying trajectory so that patients and their families gain maximum benefit from these end-of-life services.

With its roots in the hospice movement, palliative care seeks to improve the quality of life for patients and their families as they face life-threatening and other chronic and debilitating illnesses. The goals of quality palliative care include providing relief from pain and other symptoms as well as spiritual and psychosocial support (National Consensus Project for Quality Palliative Care, 2004). Evidence reveals that people seldom receive appropriate treatment for symptoms that occur at the end of their lives (Duggleby & Berry, 2005; Ersek & Ferrell, 2005). Symptom management is also inadequate for patients with advanced chronic illness. Studies about nurses’
end-of-life and palliative care knowledge and attitudes suggest that further education of nursing students, practitioners, and faculty is needed (Ersek & Ferrell, 2005; Meraviglia et al., 2003). Given our increasing aging population and the limited education regarding palliative care that most nurses have had in their undergraduate programs, it is imperative that APRNs gain this knowledge and practice skill set.

APRNs are in a position to shape the future of the American health care system by modeling quality palliative care in their practice, specifically by incorporating approaches that seek to cure what can be cured and to palliate the symptoms related to the disease or its treatment. Researchers have found that nurses who have confidence in their knowledge and skills regarding end-of-life care will be less anxious, stressed, and vulnerable to burnout (Caton & Klemm, 2006). In addition, the APRN with experience caring for end-of-life patients and families may begin to view death as a positive culmination, rather than as a treatment failure (American Association of Colleges of Nursing [AACN], 2007). In the interest of developing advanced practice palliative care competencies in nurse practitioner (NP) students, the authors conducted a mixed-method assessment of graduate students’ perceptions, knowledge, and experience with and desire to learn about palliative and end-of-life care as background to the integration of the End-of-Life Nursing Education Consortium (ELNEC) curriculum into a graduate program.

LITERATURE REVIEW

End-of-life care is clearly influenced by the values of the larger society. In general, health care in the United States continues to reinforce the use of high technology, critical care, and a focus on a cure, even at the end of life. Death is considered to be the worst possible outcome of illness by most individuals. This belief leads to a desire for loved ones to receive every drug and treatment possible to prolong life. One study found that, among a cohort of 77 hospitals in the United States with reputations for high quality care in managing chronic illness, there was significant variation in the use of health care resources by patients during the last 6 months of life (Wennberg et al., 2004). In particular, hospice enrollment ranged from 10.8% to 43.8%. The General Accounting Office (2000) reported on the use of hospice by Medicare beneficiaries and stated that the number of patients enrolled in a hospice program doubled from 1992 to 1998. However, the average number of days that hospice was used declined from 74 to 59 days in the same period, with half of the patients receiving care for 19 days or less. It seems that acceptance of the concept of hospice is growing but that the referral to, and actual use of, services begins much too late.

Nurses are considered by some to be the logical practitioners to lead interdisciplinary (rather than multidisciplinary) efforts to provide holistic palliative care to patients (Matzo & Sherman, 2006). Throughout their education, APRNs are prepared to assess the whole patient, providing holistic care and addressing the multiple aspects of their response to illness. Within this framework, a significant part of the APRN’s role is also to help patients have a comfortable and peaceful death (Ferrell, 2006).

There are few schools of nursing that have palliative care graduate programs for APRNs, and there are also a limited number of graduates from these programs. The coordinator of the first palliative care master’s program at New York University has described a need for more nursing programs to develop palliative care master’s programs, post-master’s certificate programs, or dual concentrations with the combination of palliative care and adult, family, or geriatric NP programs (D. Sherman, personal communication, October 21, 2007). Certification for clinical nurse specialists and NPs is offered through the Hospice and Palliative Nursing Association. Currently, the National Board for Certification of Hospice & Palliative Nursing (2008) lists 400 APRN Certificants. In contrast, the American Board of Medical Specialties established Hospice and Palliative Medicine as a recognized subspecialty in 2006; nationally, there are now 2,883 physicians certified in this specialty (American Academy of Hospice and Palliative Medicine, 2008).

Beyond the need for specialty programs, a lack of end-of-life care content in graduate programs and a general need for education of APRNs regarding palliative care have been identified (Paice et al., 2006b). Experts in the area of end-of-life care have said that “advanced practice nurses [are] poorly prepared to meet the needs of those approaching the end of their lives” (Paice et al., 2006a, p. 353). Several studies have also demonstrated the lack of palliative care information in nursing texts, where only 2% of the books include content on end-of-life care (Ferrell, Virani, & Grant, 1999; Ferrell, Virani, Grant, Vallerand, & McCaffery, 2000).

Additional studies have indicated that nurses do not feel competent or confident in implementing end-of-life care (Ferrell, Virani, Grant, Coyne, & Uman, 2000). In 1997, the Institute of Medicine demanded that changes be made in the way undergraduate, graduate, and continuing education programs were educating health care providers regarding end-of-life care. They called on educators in the health care professions to assist in helping all providers gain "relevant attitudes, knowledge, and skills to care well for the dying patient" (Field & Cassel, 1997, pp. 268-269). In response to this, the AACN (2008) and the City of Hope National Medical Center formed the ELNEC with funding from the Robert Wood Johnson Foundation. This initiative featured a national educational program for RNs with a focus on nine modules covering end-of-life care: introduction to palliative care; pain management; symptom management; ethical and legal issues; cultural considerations; communication; loss, grief, and bereavement; achieving quality care; and final hours of death. A program for APRNs and graduate program faculty was also established and consisted of eight modules with cultural considerations integrated throughout. As of 2007, 278 (63%) of all graduate nursing programs in the United
States had collectively sent 300 graduate faculty to the ELNEC Train-the-Trainer Programs (AACN, 2007).

The ELNEC core graduate education program is based on the eight modules, with participants receiving an ELNEC Training Certificate upon completion. A Web site with information on ELNEC graduate courses, a description of the modules, and publications of the multiple outcomes that have been generated by ELNEC graduates is accessible (AACN, 2008). No studies were found that had used the 106-item ELNEC examination to assess knowledge of graduate students and competencies related to palliative care. The current study was part of a larger project aimed at integrating the ELNEC curriculum into a school of nursing graduate program, with the goal of educating advanced practice nursing students so they can become competent in the practice of high quality end-of-life and palliative care. Graduate nursing faculty were interested in finding out what experienced nurses returning for an advanced practice degree already knew about providing palliative care for patients and their families, and they wanted to use that information to inform palliative care curriculum development.

**METHOD**

A descriptive study design was implemented at a small, private Jesuit university in the northeast United States during the first week of classes for the semester. All data were gathered onsite at the school of nursing, and data collection preceded the integration of the graduate ELNEC modules into the curriculum. Because the study was developed as part of a program evaluation, the university’s institutional review board determined that the proposal met the criteria for exempt status. However, in the interest of full disclosure, all participants received and signed an informed consent, indicating the purpose of the study and specifics as to their involvement. All graduate students entering \( n = 15 \) or already matriculated \( n = 31 \) in any of the four specialty tracks at the school of nursing were asked to take part; each student was given the opportunity to not participate without consequences to their course grade or program status. Thirty-six students chose to participate in the study for a response rate of 78%; several of the students who declined to participate cited the time involved in completing the tools as a reason for their refusal.

Once informed consent was obtained, participants were asked to complete a demographic information sheet, a qualitative interview questionnaire, and the 106-item ELNEC multiple-choice examination. The qualitative questionnaire focused on six open-ended questions designed to capture in-depth information about each participants’ definition or description of palliative care, essential characteristics of palliative care, the role of the APRN in delivering palliative care, personal or professional experiences related to palliative care, educational needs related to palliative care, and descriptions of “good” and “bad” death. The qualitative ELNEC examination was derived from the original version, which contained 109 questions, representing nine modules identified from a review of the literature as important domains in end-of-life care (Ferrell et al., 2005). The domains and relevance of the items in each domain were validated by a panel of experts prior to administering the questionnaire to 661 faculty and 1,463 students. Three items with less than a 0.10 item-to-total correlation were dropped, and the final version consisted of 106 multiple-choice questions. Scores were computed based on the percent of correct answers. Significantly higher faculty scores on the examination versus student scores were cited as evidence for discriminate validity \( F(1, 2120) = 85.85, p < 0.001 \). Coefficient alphas for the nine modules ranged from 0.51 to 0.72, with a total alpha of 0.92. Significantly different pretraining and posttraining test scores indicated that the test is sensitive enough to measure changes in knowledge level regarding end-of-life care (Ferrell et al., 2005).

To allow for minimum burden, students who elected to participate in the study were given time at the end of the first class of the semester to complete the forms. Student responses were coded to preserve confidentiality of their responses. The principal investigators were the only individuals who had access to the list of student names connected to the code numbers, and these were kept locked in a separate file from the data sheets. Results from the quantitative measures were summarized and reported as aggregate scores, and no identifying information was included. The SPSS Program version 16 was used to analyze the demographic data. Pearson Correlations were used to look for relationships between demographic characteristics and scores on the ELNEC examination. Content analysis was used to evaluate individual qualitative responses.

**RESULTS**

A total of 36 graduate students completed the ELNEC examination composed of 106 multiple-choice questions. Of these, 30 completed corresponding demographic questionnaires. Participants’ ages ranged from 27 to 54 years, with a mean age of 41.23 years \( SD = 11.01 \). All participants completing the questionnaire were female. The participants represented the four graduate specialty tracks within the school of nursing: 17 family nurse practitioner (FNP) students (56.7%), 6 psychiatric NP students (20%), 4 health care management students (13.3%), and 3 nurse anesthesia students (10%). Only 13 of the participants reported on the number of program credits completed; these ranged from 0 to 38 credits, with the majority of students (61.5%) having completed 6 credits or less. Participants reported a range of 4 to 32 years of nursing experience, with a mean of 18 years \( SD = 9.72 \) years. The majority (66.7%) of participants indicated that they had no prior palliative care experience, whereas a greater percentage (86.7%) reported that they had no previous education in hospice or palliative care. Additional demographic information about the sample is provided in the Table. In this study, the typical participant was a 41-year-old married White woman of Catholic faith, in the early
phases of the FNP program who had little palliative care experience or education.

To assess the graduate students’ baseline knowledge regarding palliative care, the 106-item ELNEC examination was administered prior to the integration of the graduate modules in the curriculum. Scores on the examination ranged from 49% to 90%, with a mean of 68.72 (SD = 9.82). In the university where the study took place, this average translates to “D,” representing an unsatisfactory evaluation of the students’ grasp of palliative care nursing knowledge. Pearson correlations between ELNEC examination scores and interval and ratio level demographic statistics, including age and years of nursing experience, were not significant. However, there was a decline in scores on palliative care knowledge as age and years of nursing experience increased, which possibly reflects the more recent focus on palliative care in nursing education and clinical training to which older and more experienced nurses were not exposed. Although the data are limited, a trend toward positive correlation is also seen between completed program credits and palliative care knowledge.

Participants also provided responses to six open-ended questions. A total of 29 qualitative data sheets were completed, and responses were analyzed for content and theme. Responding to the question “How would you define/describe palliative care?”, 13 participants linked palliative care directly with end-of-life care: “care given to patient and family at the end of life,” “during terminal illness,” and “care and relief from suffering caused by...terminal disease.” Six participants linked palliative care to the related concept of comfort: “taking all active measures to ensure complete comfort as defined or requested by an individual,” “comfort care,” “care that is focused on patient comfort,” and providing “comfort and support for patient and family.” Palliative care as a means of addressing holistic patient needs was raised by five participants: care that “addresses physical and psychosocial issues related to end-of-life care,” “physical, emotional, and spiritual care,” “comprehensive care of a patient diagnosed with a terminal illness,” “care delivered to patient as a whole,” and “providing comfort through [physical] treatment, emotional support, and spiritual support.” In addition, four participants saw palliative care being used when curative measures are exhausted: “care when no cure is possible,” “when technology can no longer be of assistance,” “cure is no longer the goal,” and “designed to ensure comfort rather than cure.”

Four themes were also identified in the responses to the question, “What would you consider to be the essential elements of palliative care?” Eleven participants identified pain control as one of the required characteristics, whereas 8 participants found providing comfort (“emotional and spiritual support” and “compassion for patient and families”) to be an essential element. A theme of offering respect was identified by 6 participants, who felt that “providing the patient with choices,” “respecting the patient’s autonomy,” “respecting the patient’s wishes,” and “understanding [respecting] the patient’s culture” were essential parts of palliative care. The final theme raised was addressing the needs of family: four participants identified efforts to “care for the family” and “listening so family can voice concerns and feelings” as an essential element of palliative care.

Addressing the link between nursing and palliative care, participants were asked, “How would you describe the role of the APRN in delivering palliative care to a client?” The most common theme, raised by 12 participants, focused on the role of the APRN as coordinator, organizing the multidisciplinary team that provides palliative care to a patient. They saw the APRN as the ‘go-to’ person for all matters regarding care of patient and family,” as the “facilitator,” “liaison,” or “collaborator.” Two additional themes were identified by 11 participants each: the role of the APRN as counselor—providing “emotional support” to the patient and being “sensitive and caring”—and the

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<td>13.3%</td>
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role of manager—with primary responsibility to “provide appropriate end-of-life care,” to “manage patient's condition,” “order necessary treatment,” and “[use] skills and knowledge to provide the desired care.” Finally, 7 participants saw a specific role for the APRN in pain control, prescribing medications to adequately control the patient’s pain.

Although only one third of the participants who completed the qualitative questionnaire (n = 10) reported that they had personal or professional experience or education related to palliative care, all were able to identify “examples of how you’ve delivered palliative care to a client or family member.” Themes that emerged were similar to those associated with the participants’ perspectives of the APRN role. Pain control was the most common theme, as 11 participants recounted efforts they had made to provide adequate “pain control and sedation for patient” with the goal of “keeping [the] patient comfortable.” Seven participants described various ways in which they had provided counseling to patients, offering “spiritual and psychological support,” “emotional support,” “comfort,” “reassurance,” and “companionship.” In addition, 7 participants felt they had been able to offer family support, with one individual describing her use of “active listening” in response to family members of a patient in a coma. Specific examples of this theme included allowing family members to remain with a patient after normal visiting hours, allowing parents to “hold, wash, take pictures of their babies,” and arranging for a terminally ill father to be present at the birth of his child.

A further question asked, “What do you need [from this graduate program] in order to practice palliative care?”, which prompted responses that yielded five main themes. The most common request was for basic knowledge and skills; 10 participants identified their desire to have a class (or even a course) “devoted to caring for the terminally ill.” They sought the tools they would need, and opportunities to gain “knowledge and experience with patients who would require palliative care.” In the words of one participant, she wanted “a better understanding of what patients and family members most often need or want during their end of life.” Seven participants wanted information on pharmacology for end-of-life, the “protocol for meds” with patients receiving palliative care, and instruction on “pain management for different diagnoses.” Two themes were each identified by four participants: availability of supervision by a “knowledgeable and experienced individual” and exposure to a variety of palliative care cases, and information about the dying process, specifically “what happens to a person physically when they die” and “what to expect (psychiatric, physical, and spiritual).” Closely related to this was information about talking to patients and their families; three participants were looking to develop the “ability to communicate with family” and to “provide counseling.”

The final two questions asked participants to “Describe what a ‘good death’ means to you” and “Describe what a ‘bad death’ means to you.” Twenty participants (69%) identified the experience of comfort as key to a “good death”: “being free from pain,” “being physically comfortable,” and “not suffering.” Having a peaceful experience was a theme identified by 14 participants who mentioned being “calm,” “peaceful,” “quiet,” and “without fear” as necessary for a “good death.” A final theme of support and connections was raised by 11 participants, who felt that a “good death” required “not being alone when you die,” having family present, being at home or in a “peaceful, loving setting,” or being able to “see outdoors.”

In contrast, the main theme raised in relation to a “bad death” was the experience of pain: 24 participants (83%) felt that a “bad death” would be “one that is very painful...for [the] patient and [their] family,” or one in which the “patient suffers” or “dies in distress and fear.” Opposite to the support experienced by individuals in a “good death” scenario, 11 participants identified isolation (“where you are alone without any support”) as key to a “bad death.” Five participants identified denial of choice, in which the death scenario would be “contrary to patient's wishes,” in which the “patient's wishes are not respected,” and in which the dying process is “not fulfilling the way you wanted to [die].” These deaths would be driven by the Health Care Team rather than by the patient. Five participants also noted that prolonged suffering—“months of agony,” “a slow death,” and “extended suffering”—would contribute to a “bad death.”

DISCUSSION

Data from this initial assessment of graduate nursing students’ knowledge of and attitudes toward palliative care support previous studies that have demonstrated the lack of preparation of nurses in general (Paice et al., 2006b) and their lack of confidence in providing end-of-life care (Ferrell, Virani, Grant, Coyne, & Uman, 2000). Of interest is the fact that individuals who had been out of school for the longest time had lower scores on the ELNEC examination, which possibly reflects an earlier lack of palliative care content in nursing curricula. Professionals who have years of work experience may report having knowledge of “what to do” with patients at end-of-life, but their scores indicate a lack of familiarity with specific palliative care interventions.

The current study was undertaken to determine the baseline knowledge and attitudes of graduate nursing students toward palliative care. Results indicate that many students continue to solely equate palliative care with end-of-life care. In addition to the planned integration of all ELNEC graduate modules throughout the curriculum, faculty have also discussed ways in which they can expose students to a variety of palliative care clinical experiences. It is hoped that these efforts will lead to students’ appropriate use of palliative care among a greater variety of patient populations, improvement in their overall ability to meet patients’ needs, and an increase in the satisfaction they find through interactions with patients. The current project has already had an unanticipated outcome for one FNP student, who became so intrigued with palliative care that a 110-hour ro-

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tation with a certified palliative care FNP has been planned for part of her practicum in the final clinical course.

Several other students have stated that they plan to attend an ELNEC Train-the-Trainer Program, which will certify them to teach palliative care to other health care providers. Some participants in this study were already aware of the multiple dimensions of palliative care, possibly because of their personal or professional experiences and education. The four essential elements of palliative care they identified (pain control, providing comfort, offering respect, and addressing the needs of family) are consistent with the World Health Organization’s (2007) definition of palliative care and the domains of quality care that emerged from the National Consensus Project for Quality Palliative Care (2004).

In their responses to the qualitative questions, participants were able to clearly articulate what they felt they would individually need from the program to competently deliver palliative and end-of-life care. Their statements have direct implications for curriculum planning. For example, students without prior experience or education with palliative care sought information and experiences that would help develop basic knowledge and skills, whereas younger students sought information about the dying process itself. Student responses indicated some confusion about the role of APRNs as “coordinator” versus “deliverer” of palliative care and ways that family members may be involved in the delivery of that care. Students, especially those outside of a psychiatric NP tract, may benefit from additional content and experiences in the area of counseling. Curricula need to be flexible enough to meet the needs of younger versus older students and comprehensive enough to meet the needs of students in various areas of specialization.

Although the results were informative, this study had several limitations. The small sample size limits the confidence placed in the quantitative results. A larger sample may have yielded significant correlations between ELNEC examination scores and demographic variables. The sample was also homogeneous on demographic characteristics, resulting in limited generalizability of the findings. Consideration must also be given to the fact that the sample was drawn from students attending a Jesuit, Catholic university, and that religion might have had a significant influence on the stated views of the participants. Future studies will need to include a greater emphasis on understanding the role of religion in student attitudes toward palliative care.

**CONCLUSION**

Graduate nursing education programs provide students with opportunities to develop the content and skill set needed to practice in an advanced role. In addition to providing the ELNEC graduate core curricula, faculty can incorporate creative opportunities within individual courses to bring the principles of best palliative care practices to light and stimulate interest in graduate nursing students. As the predominant providers for vulnerable populations (i.e., older adults, prisoners, homeless individuals, and the mentally and physically challenged), APRNs can be leaders in initiating palliative care measures. Nurse practitioners can also take the lead in collaborating with other health care providers to expand the focus of care for patients with advanced chronic disease or at the end-of-life to include palliative, as well as curative, efforts. As Ferrell (2006) noted, “We need role models who can show how the dying process can be transformed.” Nurse practitioner graduates can, and should, demand and advocate for palliative care and hospice programs to improve the way people die. Advance practice nurses are prepared in a unique fashion to influence policy makers, consumers, and other providers to develop strategies that can improve palliative care for all Americans.

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