

Oncology End-of-Life Nursing Education Consortium Training Program: Improving Palliative Care in Cancer

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Purpose/Objectives: To describe an evaluation of the oncology version of the End-of-Life Nursing Education Consortium (ELNEC–Oncology) training program, which is designed to provide oncology nurses with the knowledge and materials necessary to disseminate palliative care information to their colleagues in local chapters of the Oncology Nursing Society (ONS).

Data Sources: Participant reports.

Data Synthesis: 124 nurses representing 74 ONS chapters attended the first two courses. Dyads of ONS members from local chapters applied to attend ELNEC and completed surveys regarding their goals and expectations for implementing end-of-life (EOL) education and training after completion of the program. Participants educated more than 26,000 nurses after attending the program, including 7,593 nurses within their ONS chapters and 18,517 colleagues within their workplaces. Barriers to implementation included a lack of funding and time constraints. Participants sought additional palliative care learning opportunities, including attending other workshops, subscribing to palliative care journals, and becoming involved in committees focused on palliative care.

Conclusion: The ELNEC–Oncology program is a national collaboration with ONS that provides oncology nurses with the tools and expertise to effectively disseminate palliative care content to colleagues within their local chapters and work settings.

Implications for Nursing: EOL care information remains critical to the science of oncology nursing, and ELNEC–Oncology provides an effective strategy for disseminating the information.

Key Points . . .

- ▶ End-of-life education is extremely important to oncology nursing.
- ▶ The oncology version of the End-of-Life Nursing Education Consortium (ELNEC–Oncology) program is very helpful in improving palliative care education with Oncology Nursing Society local chapter members and within course participants' work settings.
- ▶ Participants sought other palliative care professional development opportunities after attending ELNEC–Oncology, including subscribing to end-of-life care-oriented publications, attending additional workshops or conferences, and seeking clinical experiences or volunteering to increase their skills.

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Almost 10 million people in the United States currently are living with a diagnosis of cancer. Despite innovative agents and technologies, an estimated 600,000 people will die of cancer in 2007 (Jemal et al., 2007). Unfortunately, studies document that many of those with cancer or other life-threatening illnesses will die in institutionalized settings, with unrelieved symptoms, and without their goals or wishes addressed (Coyle, Adelhardt, Foley, & Portenoy, 1990; Desbiens & Wu, 2000; Drake, Frost, & Collins, 2003; Hall, Schroder, & Weaver, 2002; Lichter & Hunt, 1990; McCarthy, Phillips, Zhong, Drews, & Lynn, 2000; Morita, Ichiki, Tsunoda, Inoue, & Chihara, 1998). A crisis in cancer care exists despite significant attention to the need for professional education about end-of-life (EOL) care. An Institute of Medicine (1997) report

asserted that people with potentially fatal illnesses, including cancer, should be able to receive competent, skillful care. That report and others (Last Acts) detailed the reasons for inadequate EOL care, including inadequate knowledge and education of healthcare professionals in symptom management and other palliative care skills (Ferrell & McCaffery, 1997; Hollen, Hollen, & Stolte, 2000; Levin, Berry, & Leiter, 1998; McCaffery & Ferrell, 1997; McCaffery, Ferrell, & Pasero, 2000; McMillan, Tittle, Hagan, Laughlin, & Tabler, 2000; O'Brien, Dalton, Konsler, & Carlson, 1996; White, Coyne, & Patel, 2001). Those reports emphasized the need for well-trained professionals to overcome the crisis in care of the dying that exists today. Strategies include the expansion of educational materials and curriculum designed to promote palliative care.

As the largest group of oncology healthcare professionals, oncology nurses are a key target for palliative care education. Oncology nurses have the potential to correct the current dismal state of dying with malignancy (Ferrell, Virani, Smith, & Juarez, 2003). In recent years, oncology nurses have received increased continuing education to address pain and symptom management problems common in cancer care. Oncology nurses also serve in diverse settings from inpatient to outpatient and home environments, as well as in a variety of specializations, including surgery, radiotherapy, chemotherapy, biotherapy, and transplantation. Finally, oncology nurses provide care to those with cancer across the lifespan and throughout the disease trajectory.

Unfortunately, little information about care of the dying currently is included in undergraduate and graduate nursing curricula in the United States (Ferrell & Grant, 2001; Ferrell, Grant, & Virani, 1999; Ferrell, Virani, Grant, & Rhome, 2000; Katz & Ferrell, 1999; Sherman, Matzo, Coyne, Ferrell, & Penn, 2004). For the promise of improved EOL care to be realized, oncology nurses must have the knowledge and tools to effectively provide care to individuals with life-threatening illness. The Oncology Nursing Society (ONS), with more than 33,000 oncology nursing members, recognizes the need for advancing palliative care through education of its members. The ONS (2003) position statement on EOL care (developed jointly with the Association of Oncology Social Work) asserted that "all individuals with life-limiting illnesses and their caregivers deserve reliable and expert supportive care that improves quality of life and supports living as actively as possible until death." To that end, the position statement indicated that mandatory curricula in palliative care at all levels of education, including continuing education programs, are necessary to ensure that sufficient numbers of nurses are skilled in the essential elements of care.

To address the needs outlined in the ONS position statement and current curricular limitations, investigators representing the highly successful End-of-Life Nursing Education Consortium (ELNEC) training program collaborated with ONS to develop a course that would meet the needs of oncology nurses caring for patients with cancer in the last stages of life. ELNEC is a national education initiative to improve EOL care in the United States. The project, which began in February 2000, was initially funded by a major grant from the Robert Wood Johnson Foundation. Additional funding has been received from the National Cancer Institute, Aetna Foundation, Archstone Foundation, and California Healthcare Foundation.

The project provides undergraduate and graduate nursing faculty, continuing education providers, staff development educators, pediatric nurses, and other nurses with training in EOL care so that they can teach that essential information to nursing students and practicing nurses. To date, approximately 4,000 nurses representing 50 states have been trained (for more information, visit www.aacn.nche.edu/el nec/about.htm). This article describes the oncology version of the ELNEC (ELNEC–Oncology) experience, including data from one year of follow-up of the 124 participants who attended the first two courses, representing 74 ONS chapters. The following outcomes were included in the program evaluation.

- How effective was the ELNEC–Oncology training conference in providing education and support materials to participants so they might disseminate this information?
- How many nurses did participants educate about palliative care using the curriculum provided during the ELNEC–Oncology program?
- Did participants perceive the status of EOL education provided by their local ONS chapters to be improved one year after participating in ELNEC–Oncology?
- Did participants perceive a change in the quality of EOL care provided to people with cancer as a result of the ELNEC–Oncology program?
- Did participants engage in other palliative care–related professional activities as a result of the ELNEC–Oncology project?
- What were the barriers faced when participants attempted to disseminate ELNEC–Oncology within their local ONS chapters?

The Program

Participants

Prospective participant dyads were identified by their local ONS chapters as individuals willing to attend the training program and implement the training in their ONS chapters. The rationale for recruiting dyads, rather than individuals, was based on the awareness that asking one volunteer to implement a substantial curriculum to chapter members would be overwhelming. A collaborative effort between two colleagues would allow for division of tasks and offer diverse expertise in content and educational program development. In addition, the pair could provide support to one another when the project seemed overwhelming.

The dyads completed a joint course application form that requested demographic information, professional clinical and teaching experience, and personal goals and expectations for attending the training program. Because successful implementation of the ELNEC–Oncology program depended on collaboration and encouragement from chapter leadership, a letter of support from the president and board of each ONS local chapter was required. In addition, applicants jointly completed a survey of their ONS chapters, addressing questions regarding previous EOL content provided at local chapter meetings, the importance of EOL care content to oncology nursing, the efficacy of current EOL teaching efforts, and the perceived receptiveness of chapter members to increasing EOL care education. Participants were selected to attend ELNEC–Oncology based on analysis of the information provided in the application and survey. Geographic distribution and underserved populations were considered when applicants were selected.

Educational Intervention

The ELNEC–Oncology curriculum was based on the original ELNEC program, which was developed by nurse researchers at the City of Hope National Medical Center in Southern California in collaboration with the American Association of Colleges of Nursing. The original program included a core curriculum to expand EOL expertise in faculty teaching in undergraduate nursing programs, in continuing education programs, and through the National Council of State Boards of Nursing (Ferrell et al., 2005; Malloy et al., 2006; Matzo, Sherman, Penn, & Ferrell, 2003; Sherman et al., 2004). The curriculum was based on an American Association of Colleges of Nursing (1997) document and includes nine core areas in EOL care: overview of care at EOL; pain management; symptom management; cultural considerations; ethical or legal issues; communication; loss, grief, and bereavement; preparation for and care at the time of death; and achieving quality care at EOL. Universal themes are woven throughout the ELNEC–Oncology curriculum, including the family as the unit of care; the important role of oncology nurses as advocates; the importance of culture as an influence at EOL; the critical need for attention to special populations such as children, older adults, the poor, and the uninsured; the relevance of EOL issues in all systems of care across all settings; the influence of critical financial issues in EOL care; and the essential need for interdisciplinary care at EOL.

Content experts in oncology and palliative care extensively revised the original curriculum to reflect the specialized needs of oncology nurses to provide excellent care to patients with cancer throughout the disease continuum and during the final hours of life. In addition to didactic presentations, case and group discussions, role play, video clips, and breakout sessions were included to enhance adult learning. A Web site (www.aacn.nche.edu/ELNEC/undergradtrainers.htm) is available to foster networking among those who have completed ELNEC training.

Program Evaluation

The program evaluation plan for ELNEC–Oncology is extensive and parallels that of the core ELNEC project (Ferrell et al., 2005). The evaluation study was approved by the investigational review board at the City of Hope National Medical Center and includes the course application form, a precourse chapter team survey and goal development form, a course evaluation form (daily and final evaluation), and a postcourse activity evaluation at 6 and 12 months.

Evaluation Forms

Course application form and goal development form: The application form included demographic information for each dyad member, including gender, ethnicity, and highest degree earned. Chapter information also was requested, particularly the number of members and the percentage of ethnic group members. In addition, each dyad applicant was asked to submit a curriculum vitae or resume, including information regarding professional education, specialty certification, teaching experience, and involvement in the ONS chapters. The dyads were asked to submit three goals describing how they might implement the curriculum within

their ONS chapter. Goal development was refined with faculty assistance throughout the course. The goals provided a guide as participants returned to their local ONS chapters and began implementing a strategy to present EOL content during chapter meetings or conferences.

Precourse chapter team survey: Once selected to attend the ELNEC–Oncology conference, each dyad was asked to complete a mailed survey asking about the adequacy of EOL content in their chapter. Using the nine modules of ELNEC–Oncology, they were asked whether their ONS chapter had offered an educational program in those areas. They were asked to respond to several questions regarding the importance of EOL content to oncology nurses and whether they would be receptive to the content. Additional questions focused on the frequency of chapter meetings and whether the chapter hosted conferences in addition to monthly or quarterly meetings. The dyads also were asked to list potential barriers to improving EOL care in their communities. The surveys were returned several weeks prior to the course.

Course evaluation form: During each day of the course, participants were asked to rate each module and speaker on the clarity of the presentation, the quality of the content, and the value of the module to clinical practice. Training sessions (e.g., listening exercises, case study roundtables, role play) were rated on the methods and techniques used, as well as their usefulness for teaching. All of the ratings used a Likert scale ranging from 1 (lowest level) to 5 (highest level). Participants responded to open-ended questions regarding the strengths and weaknesses of the content presented each day and offered suggestions for improvement. At the end of the course, they rated their overall opinion of the conference and the extent to which the course met their objectives and expectations from 1 (poor) to 5 (excellent). They were asked again to describe strengths and weaknesses and make suggestions for improvement of the entire course. At the end of each day, course faculty reviewed the documents for the potential need for immediate changes or modifications to the course.

Postcourse activity evaluation: Participants provided written evaluation of their accomplishments 6 and 12 months after the course. The evaluations included progress made toward their goals, the number of nurses taught, obstacles or challenges, and an appraisal of the effectiveness of the ELNEC–Oncology curriculum in helping to disseminate EOL care information. ELNEC investigators and consultants were available to participants as they faced challenges in dissemination.

Data Analysis

All evaluation data were entered into ASCII files or SPSS for Windows® 12.0 (SPSS Inc.) and audited for accuracy. All instruments included a unique identifier (subject identification number) for each participant and were matched with that same identifier to enable repeat testing. Descriptive statistics were used to evaluate many variables. Questions regarding content adequacy and EOL education improvement were analyzed using dependent t tests. Data derived from open-ended questions were transcribed and evaluated by several members of the ELNEC–Oncology faculty. Themes were identified, concordance among reviewers established, and frequency of responses determined.

Table 1. Demographic Characteristics of Participants and Their Oncology Nursing Society Chapters

Participant Characteristic	n	%
Ethnicity		
Caucasian	110	89
Asian	5	4
African American	4	3
Hispanic or Latino	2	2
Other	3	3
Gender		
Male	2	2
Female	122	98
Geographic location		
Northeast	23	19
South	53	43
Midwest	27	22
West	21	17
Chapter Characteristic		
Membership size		
Range = 18–275	–	–
Years of existence		
Range = 2–30	–	–
Frequency of meetings		
Monthly	76	61
Every other month	18	15
Quarterly	10	8
Other	20	16

N = 124

Note. Because of rounding, not all percentages total 100.

Results

Sample Demographics

One hundred thirty-three nurses attended the first two ELNEC–Oncology courses. Course 1 was held in February 2004 (N = 63), and course 2 was in September 2004 (N = 70). Although chapters were invited to send two participants, some could send only one nurse. The nurses represented 74 ONS chapters from throughout the United States (see Table 1). One hundred twenty-four (93%) attendees provided data 12 months after the course.

Project Effectiveness

Conference attendees rated each presentation's clarity, content, and value on an average of 4.9 (course 1) and 4.96 (course 2) out of 5. They highly rated the extent to which the course met their objectives and expectations (course 1 = 4.88, course 2 = 4.94) and found the information to be stimulating and thought-provoking (course 1 = 4.92, course 2 = 4.94).

In open-ended questions about the greatest benefits of ELNEC–Oncology training, participants listed the knowledge gained during the course, the support materials, and the interaction with experts in the field frequently. Although the program was designed to foster teaching of other oncology nurses, many respondents reported that they had incorporated the content delivered during ELNEC–Oncology into their clinical practice.

Number of Oncology Nurses Taught

Participants were asked to document how many nurses were taught the content from each module of the ELNEC–Oncology curriculum one year after the training program (see Table 2). They were asked to report not only how many nurses were taught within their local ONS chapters, but because past ELNEC programs demonstrated that the materials often were disseminated more widely than originally designed, participants also were asked to list how many nurses were educated within work settings. The participants were employed as nurses in addition to their voluntary activities within ONS; therefore, many used the ELNEC–Oncology curriculum to teach other nurses in their work settings, which is not surprising. As a result of the first two ELNEC–Oncology training programs, more than 26,000 nurses were trained in EOL care; almost 7,600 nurses were taught in ONS chapter meetings and more than 18,500 nurses were taught in the workplace.

Perceptions of the Importance and Effectiveness of End-of-Life Education

Participants were consistent in their beliefs that EOL care content is very important to oncology nursing. Using a 0 (not important) to 10 (very important) rating, the mean score was 9.48 ± 1.44 prior to and 9.36 ± 1.85 12 months after the course. Significant differences were found in the perceived effectiveness of oncology nurses in caring for dying patients. Using a similar 0 (not effective) to 10 (very effective) scale, participants rated oncology nurses as moderately effective ($\bar{X} = 6.54 \pm 1.81$) prior to attending ELNEC–Oncology and extremely effective ($\bar{X} = 7.76 \pm 2.14$) after attending the program ($p \leq 0.001$). Regarding the effectiveness of their ONS chapters in teaching EOL content, statistically significant improvements were noted when comparing pre- ($\bar{X} = 3.85 \pm 2.36$) and postcourse ($\bar{X} = 4.89 \pm 2.95$) measures ($p = 0.001$). The data are noteworthy because the changes occurred within only 12 months of the training course.

Table 2. Oncology Nurses Educated in End-of-Life Care One Year After the Course

Module or Content	Chapter Total	Workplace Total	Total
Palliative care in oncology nursing	1,162	2,317	3,479
Pain management	639	3,531	4,170
Symptom management	917	2,191	3,108
Cultural considerations in end-of-life care	635	1,380	2,015
Ethical or legal issues	973	1,613	2,586
Communication	953	2,215	3,168
Grief, loss, and bereavement	774	1,843	2,617
Preparation and care for time of death	733	1,551	2,284
Achieving quality palliative care	767	1,741	2,508
Other	40	135	175
Total	7,593	18,517	26,110

Professional Development in End-of-Life Care

Experience with participants from other ELNEC training programs suggests that attendees are stimulated to engage in other palliative care or EOL professional activities after attending the course. Participants were asked to describe any additional professional activities in which they may have engaged that might have been stimulated by their attendance in ELNEC–Oncology. They included joining professional palliative care groups and subscribing to journals (see Table 3).

Barriers to Using the Curriculum

Participants were asked to address limitations and barriers to use of the ELNEC–Oncology curriculum for improving EOL care through their ONS chapters. Respondents consistently described lack of funding to support meetings and poor attendance as significant obstacles. Respondents reported that ONS chapter members are extremely busy and that geographic limitations compound the difficulty in drawing attendance at meetings. Another barrier identified by the participants was time constraints, including professional and personal commitments impeding their ability to organize a presentation. In addition, several respondents reported that their chapters planned regular meetings one year in advance. Thus, they were not able to present during the year following attendance at ELNEC–Oncology but were assured they were scheduled to present the next year. Despite barriers, many of the chapters were creative and innovative in their approach to implementing ELNEC–Oncology (see Figure 1).

Discussion

Oncology nurses are critical to the care of those dying from cancer. Lack of knowledge consistently is identified as an obstacle to nursing efforts to improve palliative care (Institute of Medicine, 1997). Education regarding symptom management, communication strategies, and other aspects of palliative care specific to the needs of those with cancer is needed urgently. Although efforts to increase EOL care in most undergraduate and graduate nursing curricula are under way (Ferrell et al., 2005; Malloy et al., 2006; Paice et al., 2006), most practicing oncology nurses have not received formal training in palliative care. The ELNEC–Oncology program is a highly successful educational effort that addresses that

Table 3. Professional Development in Palliative or End-of-Life Care Reported by Program Participants

Activity	%
Attended other continuing education conferences or workshops on palliative care	68
Subscribed to or read palliative care publications	66
Became involved in a committee or task force focused on palliative care	47
Sought personal clinical experiences to increase end-of-life skills	34
Sought certification (e.g., OCN®, AOCNP®, AOCNS®, CHPN)	27
Joined a palliative care organization	25
Joined a palliative care-oriented list serve	23

N = 124

Chapter Meetings and Activities

Wrote an article about attending the oncology version of the End-of-Life Nursing Education Consortium (ELNEC–Oncology) training in an ONS chapter newsletter
 Wrote articles for a chapter newsletter about each of the nine ELNEC modules
 Sent a summary of the loss, grief, and bereavement module to chapter members
 Conducted a needs assessment survey of chapter members
 Presented an overview of ELNEC–Oncology at a chapter meeting
 Provided a two-day ELNEC–Oncology course to chapter members
 The ELNEC–Oncology curriculum was an agenda item for all board and membership meetings for the first 18 months after training.
 Collaborated with other ONS chapter presidents to plan training programs
 Presented a poster on end-of-life and palliative care at a state conference
 Established a quarterly dinner series to review various ELNEC modules

Implementation in Clinical Settings and Staff Education

Instrumental in starting a palliative care team
 Use ELNEC–Oncology curriculum in new graduate and employee orientation
 Worked with a pharmacist to teach pain and symptom management modules to the interdisciplinary team
 Collaborated in preparing and opening two “comfort care suites”
 Developed standard orders and pathways that have improved patient care and nurse advocacy for patients
 Provided leadership with critical care nurses in developing and improving end-of-life care
 Presented a class to hospice nurses titled “Palliative Chemotherapy: How Does It Fit With Hospice?”
 Worked with an interdisciplinary team to open a palliative and supportive care clinic for patients receiving radiation and chemotherapy
 Participated in the development of a model of palliative care that addresses the specific needs of those living in remote settings
 Presented various modules at grand rounds
 Implemented an oncology unit primary care nursing model and started a bereavement program on the unit
 Assisted in structuring a bereavement program as part of the oncology service, including holding a memorial service annually

Conferences and Other Efforts

Collaborated with local university and hospice to bring ELNEC–Oncology to students, faculty, and staff
 Worked on the state level to provide ELNEC–Oncology training to hospice and palliative care nurses
 Collaborated with state pain initiative to integrate end-of-life content into long-term care facilities through 50 various educational programs
 Presented “Loss, Grief, and Bereavement” at the Leukemia and Lymphoma Society’s First Connection Program
 Partnered with the American Cancer Society to provide education regarding palliative care awareness
 Provided an educational program for parents of three- and four-year-olds on “How to Talk About Death and Dying to Young Children”
 Developed a symptom management nook from the ELNEC–Oncology curriculum

Figure 1. Examples of the Ways Participants Disseminated Program Content

need by adapting an existing curriculum to concentrate on the requirements of nurses caring for people with cancer. The linkage between the comprehensive oncology-focused EOL curriculum and ONS’s established infrastructure of local chapters and dedicated members supports wide dissemination. The extensive support materials, including CD-ROMs, Web sites, newsletters, and textbooks, reduce the burden on nurses who report significant time and funding constraints.

Ongoing support from investigators, regular newsletters sent by e-mail, and Web sites with numerous resources provide additional support.

The results of ELNEC–Oncology’s first year’s efforts are encouraging. Significant numbers of oncology nurses within local ONS chapters and participants’ work environments received education regarding palliative care. Participants continued to perceive the value of EOL content to oncology nursing and reported significant improvements in the effectiveness of their local chapters in providing EOL education as a result of ELNEC–Oncology. Most important, they voiced improved care of patients dying from cancer after attending the course. Furthermore, participants sought out other palliative care–focused professional development as a result of their attendance at ELNEC–Oncology.

Despite those accomplishments, participants faced many obstacles to the dissemination of EOL content. Not surprisingly, time is a significant limitation because workload expands and the acuity of patients being treated increases. Compounding the increased demand on time at work is the volunteer nature of activity within ONS and other professional organizations. Personal responsibilities and return to school to obtain undergraduate or graduate degrees were cited as additional competitors to volunteer activity. Funding for programs is a serious problem for many of the ONS chapters represented in the study sample. EOL care does not usually entail new or unique pharmacologic agents, so funding to sponsor presentations on palliative care topics is more difficult to obtain.

Limitations

The limitations of the evaluation include the potential for self-selection bias. Attendees were likely to be highly motivated because they volunteered to participate. They also may have felt compelled to attend because they were selected by their local ONS chapter leadership. The potential for response bias also existed because attendees are unlikely to report decreases in the effectiveness of their chapters in providing EOL content.

The reported number of nurses taught may be skewed. Although many respondents had written attendance records of their presentations, particularly those provided at ONS chapter

meetings, some of the numbers were estimates. Determining whether some of the total number of nurses taught might represent some duplication (i.e., a participant attending more than one presentation) is not possible.

Participants perceived that EOL care improved, but that is a reflection of their perception. Strategies to investigate improvement in patient outcomes as a result of educational interventions have been notoriously difficult to accomplish. Additional research in this area is warranted.

Finally, the reporting period of 12 months after attending ELNEC–Oncology may be insufficient. Several participants reported that their chapters had already designated their regular meetings almost one year in advance. As a result, the participants were not yet able to implement EOL content in the 12-month period following the training course.

Conclusion

The ELNEC–Oncology training program was designed to provide palliative care knowledge and resources to ONS chapter members so that they can widely disseminate the information to other ONS members. All four courses have been conducted, incorporating 141 chapters in 49 states and the District of Columbia with ONS representation (at the time of the evaluation, no chapter existed in Wyoming), training a total of 259 oncology nurses. In addition, the ELNEC–Oncology experience was presented at the ONS Congress in 2005, at the Institutes of Learning in 2006, and through other dissemination efforts. The final result of the activities will be education of oncology nurses to deliver palliative care to patients with cancer of all ages being treated in all settings where oncology care is delivered. The ultimate goal is to improve the quality of life for patients with cancer and their families.

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