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**Project Title:** Oncology Nursing Education in End of Life Care

**Abstract:** *The primary aim of this proposal is to improve end of life care for cancer patients through the national network of oncology nurses in chapters of the Oncology Nursing Society (ONS). Recent national initiatives and major consensus documents have provided strong evidence of the need for improved professional education to impact end of life care in cancer care. The National Cancer Policy Board and Institute of Medicine's report of improved end-of-life care published in 2001 has documented the considerable need for improved end-of-life care for more than 550,000 individuals who will die of cancer this year in the United States. This primary aim will be achieved through 4 workshops for teams selected nationwide through ONS chapters. Each conference will be attended by 60 oncology nurses for a total of 240 participants representing their 120 ONS chapters and the project will later reach the remaining chapters through dissemination efforts. The project combines the efforts of the City of Hope National Medical Center, the American Association of Colleges of Nursing, and the Oncology Nursing Society. Specific aims include: 1) Adapt the existing End of Life Nursing Education Consortium (ELNEC) curriculum and teaching materials to be cancer specific for use in this Oncology Nursing Education End of Life Care (ONE-EOLC) project. 2) Evaluate the impact of the curriculum on participants' knowledge and attitudes about end-of-life care. 3) Support the network of ONE-EOLC educators through the ONS chapters to share experiences in dissemination of the curriculum. 4) Evaluate the effectiveness of participants' implementation efforts within the ONS chapters. 5) Describe issues related to dissemination of EOL education through CE efforts of ONS chapters. This project focuses on palliative care in the cancer network of ONS chapters to provide nationwide education as an efficient means to build upon the extremely successful project in progress, ELNEC. Supported by the Robert Wood Johnson Foundation, ELNEC has targeted undergraduate nursing programs and continuing education providers. The 9 content areas of the curriculum are nursing care at EOL, pain management, symptom management, ethical issues, culture, communication, grief/loss and bereavement, achieving quality care at EOL, and preparation and care at the time of death. This proposal includes extensive evaluation planned to monitor individual and institutional dissemination.*

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## **A. Specific Aims:**

The primary aim of this proposal is to improve end-of-life (EOL) care for cancer patients through the education of nurses trained through the national network of the ONS chapters. In the year 2001, approximately 553,400 Americans are expected to die of cancer-more than 1,500 people each day <sup>(1)</sup>. This represents one in every four deaths in the United States. Disturbingly, more than 50% of patients at EOL experience under-treatment of symptoms, including pain, dyspnea, nausea, confusion, sadness, and existential distress. One of the primary reasons for this inadequate care is lack of knowledge by healthcare professionals, in large part due to limited education regarding EOL care <sup>(1)</sup>. Oncology nurses are leaders in cancer care, serving in clinical, educational, research, and administrative roles. They are uniquely prepared to address the needs for improved care at end of life, yet little EOL information is currently included within oncology education. The primary aim of this proposal will be achieved through 4 workshops for oncology nurse leaders representing their ONS chapters. Workshop participants will receive approximately 22 hours of didactic and experiential training, supported by extensive written resources with all written and slide materials on CD-ROM to facilitate teaching of EOL content. There will be 60 nurses in attendance at each course composed of teams of 2 nurses from an ONS chapter, thus, a total of 240 participants is planned representing 120 ONS chapters competitively selected from across the nation. Additional reinforcement and dissemination methods and extensive evaluation will provide a basis for the continuing education of these oncology nursing educators beyond the project period. These nursing educators will be expected to teach EOL content through the continuing education efforts of their ONS chapter.

The project builds on the investigators' previous experience with similar national workshops on pain management and palliative care education. Specifically, this project is an extension of the End of Life Nursing Education Consortium (ELNEC) developed by the City of Hope (COH) with the American Association of Colleges of Nursing (AACN) and funded by the Robert Wood Johnson Foundation. Whereas ELNEC focused on and was restricted to undergraduate nursing faculty (both associate degree and baccalaureate) and continuing education (CE) providers, the proposed project will be directed towards the nation's oncology nurses through this very innovative project partnering the ELNEC investigators (COH and AACN) with the Oncology Nursing Society (ONS).

Specific aims to be accomplished are to:

1. Adapt the existing ELNEC curriculum and teaching materials to be cancer specific for use in this Oncology Nursing Education End of Life Care (ONE-EOLC) project.
2. Evaluate the impact of the curriculum on participants' knowledge and attitudes about EOL care.
3. Support the network of ONE-EOLC educators through the ONS chapters to share experiences in dissemination of the curriculum.
4. Evaluate the effectiveness of participants' implementation efforts within the ONS chapters.
5. Describe issues related to dissemination of EOL education through CE efforts of ONS chapters.

## **B. Background and Significance**

### **Need for Improved End of Life (EOL) Care**

The Institute of Medicine (IOM) released the highly influential report *Approaching Death: Improving Care at the End of Life* in 1997<sup>(2)</sup>. This report identified gaps in knowledge about care of those at end of life and the need for attention from biomedical, social sciences, and health service researchers. The report attempted to define what constitutes good care at the end of life and set forth an agenda to improve EOL care. In 1999, the National Cancer Policy Board (NCPB) identified the need for, but lack of, excellent palliative care for those dying from cancer in their report *Ensuring Quality Cancer Care*<sup>(3)</sup>. This report recommended the provision of quality care at the end of life, with particular attention to management of cancer-related pain and appropriate referrals to palliative and hospice care. More recently, the IOM in collaboration with the NCPB and the National Research Council released *Improving Palliative Care for Cancer* (2001)<sup>(4)</sup>. This report builds upon and advances the agenda set out in the IOM's earlier document. Despite advances in the treatment of cancer, more than a half million people in the US will die of cancer each year, a number that will increase as the population ages<sup>(1)</sup>. Currently, cancer patients often must choose between treatment with curative intent or comfort care. The report stresses that there is a need for both, in varying degrees throughout the course of the illness, with the goal being the best possible quality of life (QOL). The report details a disturbing picture of the present condition of those dying from cancer including the finding that approximately 50% of those dying from cancer experience under-treatment of symptoms such as pain, dyspnea, nausea, confusion, and other physical problems. Anxiety, depression, and existential distress are also under-recognized and under-treated.

Numerous studies support the findings of the IOM report, detailing needless suffering from pain and physical symptoms, as well as emotional concerns<sup>(5-17)</sup>. This lack of attention to physical and emotional distress occurs in the face of huge financial expenditures and significant emotional burden for families and caregivers. One quarter of Medicare dollars are spent in the last year of life, with half of that spent in the last month of life. Additionally, the patient, family, and society are confronted with significant costs, with the expenses associated with dying from cancer are approximately 20% higher when compared to other chronic illnesses<sup>(18)</sup>. Few studies explore the long-term effects on family members and caregivers, but the emotional burden for those surviving the death of a loved one appears to be significant<sup>(19)</sup>.

The recent IOM/NCPB report details the reasons for these inadequacies in cancer care, including:

- Separation of palliative and hospice care from potentially life-prolonging treatment.
- Inadequate training of health care professionals in symptom management and other palliative care skills.
- Inadequate standards of care and lack of accountability.
- Disparities in care for African-Americans and other ethnic and socioeconomic segments of the population.
- Insufficient public information related to end-of-life care.
- Lack of data regarding the quality of care provided to those dying from cancer, and a lack of accountability for providing excellent care.

The IOM/NCPB report emphasizes strategies for overcoming these inadequacies, including the need to correct the insufficient training of health care personnel. Several of these strategies include promotion of nursing, medicine, and social work faculty, along with expansion of

educational materials and curriculum development. This proposal focuses on this exact challenge presented by the IOM/NCPB and offers a national network of oncology leaders through the established strength of the Oncology Nursing Society.

### **Cancer Care at End of Life**

In the United States, cancer remains second only to heart disease as a cause of death and currently accounts for approximately 22 percent of all deaths<sup>(1)</sup>. More than one million newly diagnosed cancers occur annually, and approximately 550,000 deaths are attributed to cancer each year. On average, \$32,000 is spent on the last year of life for cancer patients<sup>(18)</sup>. Among women, aged 35-74, cancer remains the leading cause of death. While recent data have begun to demonstrate a decline in the mortality rate attributable to heart disease, the overall mortality rate for the majority of adult onset cancers has remained somewhat steady during the past sixty years<sup>(20)</sup>. While people are living longer after diagnosis secondary to earlier diagnosis, better prevention, and treatments improving survival time, actual disease specific mortality rates have been difficult to affect<sup>(2)</sup>. Despite tremendous advances being made in both basic science laboratories as well as clinical research, the preponderance of epidemiological data would suggest only modest gains in five-year survival rates for most cancers. Patients continue to present with advanced disease, often for which little or no data exists for efficacy of treatment in improving survival rates. Lung cancer is now the most common cancer for both men and women in the United States, and accounts for approximately 20% of all cancer deaths<sup>(1)</sup>. Unlike colorectal or prostate cancer where effective screening is available, little progress has been made in early detection of lung cancer, resulting in the majority of lung cancer patients presenting with later stage disease<sup>(1)</sup>.

Despite the explosion of growth in the pharmaceutical industry and accompanying expansion in chemotherapy options, and continued improvement in surgical techniques and safety, many cancers remain refractory to effective treatment. While continued widespread support in funding to better understand and eventually find a cure for cancer is strongly justified, the reality of the situation suggests that patients will continue to die of cancer in large numbers in the coming years. The goal of providing a comfortable and dignified death for cancer patients and their families therefore appears to be a worthwhile pursuit.

Cancer patients are unique in that the majority is likely to undergo a multitude of treatment options throughout the course of their illness. The care of these patients is often interdisciplinary in nature, potentially involving a team of physicians, nurses, social workers and other healthcare professionals such as psychologists, physical therapists, pharmacists, occupational therapists, and clergy<sup>(5, 18)</sup>. The nature of their disease can often result in a wide variety of treatment modalities, such as surgery, radiation therapy, and chemotherapy<sup>(21)</sup>. Despite the best intentions for cure, these treatment modalities can all too often end with patients who are debilitated, weakened, financially strained and emotionally vulnerable<sup>(22)</sup>. Illnesses can be prolonged and requirements for retreatment can be multiple. Identifying points of futility in further treatment can be extremely difficult for both the health care professionals caring for these patients as well as the patients themselves and their families<sup>(23, 24)</sup>.

The hospice movement has been a tremendous success in demonstrating the ability to provide a comfortable death under circumstances that are more acceptable to cancer patients. This has resulted in a much wider acceptance in the last decade of the importance of EOL care, and the ability of patients and family members to have a dignified, acceptable, and comfortable death. Most recent estimates demonstrated that over half of Medicare patients dying with a cancer diagnosis used at least some form of hospice care in 1998<sup>(18)</sup>. Despite the expansion of the hospice movement, however, the greatest majority of deaths in the United States continue to

occur within healthcare institutions. Over the last century, a gradual industrialization of society, combined with the expansion of health care, and the disappearance of extended families, there was a tremendous shift in the place of death for individuals out of home and into institutions <sup>(2)</sup>. By 1949, national statistics revealed that 49.5 percent of deaths occurred in institutions, with nearly 40 percent within hospitals. By 1958 this figure had risen to 61 percent and mortality statistics for 1980 showed that 74 percent of deaths occurred within institutions, with 60 percent of those in hospitals. With the expansion of the hospice movement and changes in both Medicare and private insurance coverage for hospice, there has been some migration in the setting of deaths back into private homes and hospice care facilities. Nevertheless, late 1990 data would suggest that approximately 40 percent of deaths continue to occur within hospitals, the vast majority being on inpatient wards <sup>(2)</sup>.

Hospice care, however, is certainly not without problems. The six month prognosis required for admission is extremely difficult to pinpoint in individual patient circumstances. Also, physicians and other health care professionals are historically poor at estimating prognosis, often delaying admission to hospice <sup>(25)</sup>. In addition, the requirement to formally consent that no additional attempts at curative medical care be made can result in the loss of this valuable service to younger patients who, along with their families and physicians, are more reluctant to withhold curative options, even when faced with equally bleak prognoses as an older population <sup>(26)</sup>. Furthermore, the aggressive pursuit of Medicare fraud by the federal government may likely limit hospice care further, as healthcare providers seek additional assurance that their dying patients will not exceed the six month allowable time frame. This unfortunate combination of events has resulted in shorter and shorter mean hospice stays, diminishing from a mean of 90 days and a median of 36 days in 1990 down to only a mean of 51 days and a median of 25 days in 1998 <sup>(27)</sup>. Improving the quality of life for cancer patients at a much earlier stage, allowing the opportunity for family closure and family togetherness without unnecessarily financially burdening patients and families is all part of quality EOL care <sup>(28, 29)</sup>. The need to address EOL care in cancer patients ideally needs to occur much earlier within our healthcare systems. To achieve this goal, however, a much broader acceptance of the understanding of EOL issues needs to be achieved among health care providers <sup>(30-32)</sup>.

### **Nursing Education in End of Life Care**

Since the first IOM report on improving care at the end of life was issued in 1997, and with the gradual expansion and acceptance of the field of palliative care, there have been increasing reports about the slow expansion in education efforts in end of life care <sup>(32-43)</sup>. The IOM/NCPB report documents continued and widespread deficiencies in the training of health care professionals in end of life care <sup>(5, 44-48)</sup>. Specifically, care for the dying is absent from most nursing and medical curricula. Among medical and nursing schools offering coursework in end-of-life care, the majority have incorporated it within the context of other courses, or offered it as elective coursework <sup>(49-54)</sup>. Despite the publication of numerous consensus reports, standards and position statements from nursing organizations, attention to EOL care is limited in nursing curriculums <sup>(55-61)</sup>. Regarding nursing education and teaching resources, studies document that commonly used nursing textbooks dedicate very little attention, only 2% of content, to end-of-life care <sup>(62)</sup>. Additional studies by Ferrell and colleagues further demonstrated deficiencies in nursing education regarding EOL care <sup>(62-66)</sup>.

### **ONS Chapter Needs Assessment**

In order to assess the need for this proposed project, the ONS Education department conducted a brief e-mail survey of the chapter presidents in July, 2002. Twenty-nine (29) chapters responded to the survey within 4 weeks time. Twenty eight (28) said they were extremely interested in participating in the 3-day national conference and implementing the ELNEC

oncology curriculum at the local level. One chapter stated that their chapter was small and did not have the resources or interest at this time. All (100%) stated that this program was appealing to oncology nurses. They were asked to rate on a scale of 0-10 the importance to oncology nursing practice of topics such as nursing care at the end of life, symptom management, grief, loss and bereavement and others. The average rating for all the topics was 8, which indicates that these are areas of high importance to oncology nursing. They were also asked how their chapter would implement the ELNEC curriculum at the chapter level and most responded that the information would be disseminated at the monthly chapter educational meetings. Other ideas for dissemination included all day conferences, regional workshops, hospital inservices, and by communication via chapter e-mail and newsletter. Strong interest and support of the project was demonstrated as summarized in Table 1.

**Table 1**

<b>ONS Chapter Survey Needs Assessment n= 29 Chapters Conducted July, 2002</b>	
<b>Question</b>	<b>Response</b>
1. Would your chapter be interested in participating in the ELNEC ONCOLOGY programs by sending two local chapter members to attend a 3-day national conference and commit to implementing ELNEC at the local level?	<u>28</u> Yes <u>1</u> No
2. Does this program sound appealing to you as an oncology nurse?	<u>29</u> Yes <u>0</u> No
3. On a scale of (0=not important to 10=very important), how important are the following topics to the practice oncology nursing?	Mean <u>8.38</u> Nursing Care at the End of Life <u>8.41</u> Pain Management <u>8.38</u> Symptom Management <u>8.55</u> Ethical/Legal Issues <u>8.14</u> Cultural Considerations <u>8.69</u> Communication <u>8.59</u> Grief, Loss, Bereavement <u>8.52</u> Preparation and Care for Time of Death <u>8.72</u> Achieving Quality Care at the End of Life
4. How would your chapter implement ELNEC at the chapter level?	Most common responses: - Monthly meetings - Inservices at local hospitals - Half day program - Annual all day program - Make this a community effort - Host a regional conference - Plan a conference in conjunction with local hospices and nursing schools

Additional studies report lack of knowledge by nurses regarding advance directives, as well as a desire to have had EOL care training during nursing education<sup>(67-68)</sup>. These serious deficiencies in nursing education occur despite reports outlining the need for symptom management and palliative care content within formal and continuing nursing education<sup>(69)</sup>.

One strategy to overcome these deficiencies, and to meet the recommendations advanced by the IOM reports, has been the development of the ELNEC. This 3 ½ year program, which began in February, 2000, was developed by the COH investigators in collaboration with the AACN to coordinate national nursing efforts related to EOL care issues. The overall goal of the program has been to enhance understanding among future nurses in caring for patients in the last stages of life. The ELNEC project, funded by the Robert Wood Johnson Foundation, has developed a core training curriculum to develop EOL expertise in faculty of undergraduate nursing programs and continuing education programs. Graduate educators are now being trained through a Graduate ELNEC project which began in July, 2002 funded by NCI. Based on the AACN "Peaceful Death" document<sup>(11)</sup>, the curriculum focuses on nine core areas in EOL care: overview of care at the EOL; pain management; symptom management; cultural considerations; ethical/legal issues; communication; grief, loss, and bereavement; preparation and care for the time of death; and achieving QOL at the EOL. Outlines of the ELNEC program modules are included in Appendix C.

Seven extremely successful ELNEC training programs have been held to date; 5 being undergraduate and 2 CE providers. The 550 participants from the 5 undergraduate ELNEC courses were experienced faculty with an average of 14 years in their faculty position (range=1-48). Pre-course curriculum surveys revealed both an interest and a need for EOL education improvement, and clear deficits across all content areas. The adequacy of specific curriculum content in the schools was rated from 1=not adequate to 10=very adequate with the following results: cultural considerations of EOL care=4.5; preparation and care for the time of death=4.3; quality of care at the end of life=4.3; nursing care at the end of life=4.5; symptom management=5.0; ethical/legal issues=5.7; grief and bereavement=5.7; pain management=5.8 and communication skills=5.8. Surveys also revealed that the overall importance of EOL care content in the basic nursing education programs was high, at 9.2, with faculty receptiveness to increased EOL content at 8.0, but current teaching effectiveness at 7.1. Effectiveness of their new graduates was rated a low 5.5 and overall curriculum effectiveness in EOL care 5.1.

The 12 month follow-up data analysis for the two CE provider courses is still pending; however, data analysis of 12 month follow-up is complete for the first two undergraduate courses. There was a response from 203 of 214 participants (95%). On a scale of 0 = not effective to 10 = very effective, the faculty reported an improvement in their curriculum in each of the nine EOL content areas with an overall effectiveness of mean = 4.9 (pre-course) to mean = 6.7 (12 months post-course). The perceived importance of EOL was not altered and was still considered important at 12 months. Faculty were asked the amount of time in the curriculum that had been added, modified, or revised to address EOL content from the ELNEC modules. The overall amount of time added or modified in a packed nursing curriculum was 10.4 hours after just 12-months post training. Also reported was that 13,827 nursing students from 203 schools received EOL education during the 12 months along with 2,585 practicing nurses from CE programs conducted through these schools. These results provide clear evidence of the deficits found in the curriculum of nursing schools and the need for support in improving undergraduate education.

## **Need for Oncology Nursing Education**

By design, the ELNEC courses to date have been focused on audiences other than oncology. The core courses supported through the COH/AACN ELNEC Project have been limited to faculty teaching in undergraduate nursing programs for five of the seven courses. The final two courses have focused on continuing education providers, state boards of nursing, accrediting groups, and staff development educators. Additionally, the Robert Wood Johnson Last Acts project included ELNEC training in five regional conferences over September, 2001 – September, 2002. These courses were focused on hospices and palliative care programs and did attract some oncology educators. In reviewing nurses who have attended ELNEC from all of the continuing education courses (Last Acts courses and COH/AACN CE provider courses) a total of 101 of 535 clinical educators (19%) were identified as being from the area of oncology, which equals only two educators per state. The ELNEC investigators held a strategy session in June, 2002 to identify future needs and recognized the significant need for a project focused specifically on oncology nursing, and thus have designed this proposed project.

### **C. Previous Research by the Investigators**

The COH investigators have an extensive record of training and research in areas of pain, quality of life, and end-of-life care. Following is a brief summary of their related experience:

#### **COH Research**

(1) The first project, HOPE: Home care Outreach for Palliative care Education, began with a one-year pilot project from 1996 to 1997 funded by the Project on Death in America which developed and tested a curriculum to improve EOL care in home care.<sup>(65)</sup> This program has been extended for the time period of 1998-2002 through a training grant funded by NCI with Dr. Ferrell as P.I. which is providing further implementation of the HOPE curriculum and a national trainers conference. The content of the HOPE curriculum covers five modules of general palliative care principles, pain management, symptom management, family/communication and care at the actual time of death. Through the NCI funded project, the HOPE curriculum has been extensively revised and implemented in 5 additional agencies with 153 participants completing the training. Comparison of pre- and post- scores on end-of-life knowledge improved ( $p < .01$ ) and overall rating of the course training was mean = 9.3 and for the course materials was mean = 9.4 (on a scale of 0 = poor to 10 = excellent). The HOPE curriculum was further disseminated through a national conference attended by 50 home care agencies held in March, 2001. This project concluded in March, 2002<sup>(70)</sup>.

(2) The second project, the End of Life Nursing Education Consortium (ELNEC) is a comprehensive national effort led by Dr. Ferrell to improve EOL care by nurses and has been described above. This 3 ½ year effort, which began February, 2000, entails the partnership of AACN and COH to coordinate national nursing efforts related to EOL issues. The ELNEC project is also supported by an Advisory Board including multiple nursing and health care organizations. Faculty attending the five undergraduate courses totaled 550 from 543 schools teaching undergraduate nursing students and represented all 50 states plus Washington DC, Virgin Islands and Puerto Rico. Follow up evaluation averaged over these five courses rated the overall course effectiveness as 4.9 on a scale of 0 = low to 5 = high.

(3) The third project, Dissemination of End of Life Education to Cancer Centers (DELEtCC) is a comprehensive, interdisciplinary project aimed at improving EOL care in cancer centers. Led by Dr. Grant, the primary objective of this proposal will be achieved through four annual workshops for two representatives each from 75 cancer treatment centers. Funded by the NCI in June, 2001, the first course was held in June, 2002. A total of 600 participants is planned with one course per year for four years. Content includes topics identified through the ELNEC project expanded to include aspects of change related to institutional commitment, and a framework of

continuous quality improvement. Participants are selected from two tiers of staff at cancer centers: Tier 1 consists of nurses, social workers, administrators, and physicians, and tier 2 consists of clergy, pharmacists, psychologists, rehabilitation professionals, and unlicensed personnel. Dissemination methods and extensive evaluation provides a basis for the continuing education of health care professionals beyond the project period.

(4) Studies by Dr. Grant and colleagues led to the assessment of QOL as an outcome variable for cancer and the development of QOL instruments<sup>(71-72)</sup> in a study published in the journal *Cancer*, Dr. Ferrell applied the QOL concept to pain research through a study including cancer patients with and without pain and non-cancer patients (N = 150) to test QOL as an outcome for pain research<sup>(73)</sup>. This study had particular significance in demonstrating that pain is a significant factor in overall QOL and that cancer patients with pain had significantly decreased QOL when compared to cancer patients without pain. In 1988-1989, the investigators (Grant and Ferrell) extended their research in QOL as an outcome of uncontrolled pain through a study that included interviews with 41 cancer patients with pain. This study was published in *Cancer Nursing*.<sup>(74)</sup>

(5) Dr. Grant's interest in improving pain management practice through education began through her research in QOL and symptom management, and in her commitment to improving cancer practice through education and research. Initial courses related to the management of cancer pain were conducted through continuing education efforts at COH. Requests for these classes were received from hospitals, home care agencies, and skilled nursing facilities. A grant from the United Way provided resources to implement a community outreach education program in which 57 half-day classes were provided to 21 community hospitals reaching 1,200 nurse participants. In skilled nursing facilities, 2,453 participants in 49 facilities attended classes. Pre- and post-course measures revealed significant increases in knowledge and skills. Results have been published in *The Journal of Continuing Education in Nursing*.<sup>(75)</sup>

(6) The demand for courses of increased depth and length was recognized and led to the development of a multi-day course for nurses. The Pain Resource Nurse (PRN) Training Program was implemented in 1992 by Drs. Ferrell and Grant and involved a structured educational program on pain content to prepare one COH staff nurse on every unit and on every shift to function as a resource and role model for nursing assessment and intervention in pain management. To assist the PRNs with role implementation and to maintain the momentum of the program, a variety of approaches were used. Because of the success of the program, it has been extended to include nurses from COH and the community and repeated annually since 1992 with an average attendance of 150 nurses per course. Results of the first year of the PRN program were published in the *Journal of Pain and Symptom Management*.<sup>(76)</sup> The program has been replicated in more than 80 institutions across the country and the 11<sup>th</sup> course was held at COH in September, 2002.

(7) An additional education program involved the development, implementation, and evaluation of a project titled "An Institutional Commitment to Pain Management" which was supported by the Mayday Fund. The program disseminated the tested COH pain education model to 32 physician/nurse teams in settings throughout California. Teams returned to their institutions to serve as role models and catalysts to change the practice of pain management. Pre- and post-course data included the Knowledge and Attitudes K&A Survey Related to Pain, the Pain Management Audit Tool (PMAT), and a summary of activities projected and completed over an eight-month period following the course. Results revealed a wide variety of approaches to changing practice in the participating institutions to improve the management of pain. Results were published in the *Journal of Clinical Oncology*.<sup>(77)</sup>

(8) Interest in evaluating the improvement of institutional resources for improved cancer pain management was the impetus for a study examining re-admissions for uncontrolled pain. Drs. Grant and Ferrell designed a study to compare all admissions in two time periods (1989-1990 and 1993-1994) and to compare characteristics of those patients readmitted for uncontrolled pain. It was hypothesized that institutional resources implemented between the two time periods would decrease the unscheduled re-admissions for uncontrolled pain. Nursing strategies included the Pain Resource Nurse (PRN) Training Program, a hospital-wide pain audit, pain management as a Continuous Quality Improvement indicator, and a Clinical Nurse Specialist for pain management. Readmission data included marital status, gender, ethnicity, number of days since previous discharge, nature of readmission, diagnosis, previous admission characteristics, secondary diagnoses, and procedures. Unscheduled re-admissions for pain management decreased from 2,977 in the 1989-1990 fiscal year to 1,626 in the 1992-1993 fiscal year. The percentage of patients re-admitted for uncontrolled pain decreased from 8.6% (255 patients) of the unscheduled re-admitted population in 1989-1990 to 6.3% (103 patients) in 1993-1994. With 152 fewer re-admissions, a cost savings estimate of \$1,500,400 is realized, using \$1,700/day hospitalization costs for a six-day average readmission period. Results were published in *Nursing Clinics of North America*.<sup>(78)</sup> This study provided experience in assessing institutional outcomes of clinical practice change through education.

(9) In recent years, advances in the treatment of cancer pain have resulted in a number of guidelines, standards, and various other resources to improve pain management. In 1995, Dr. Ferrell received support from the Mayday Foundation to establish the Mayday Pain Resource Center (MPRC) to serve as a dissemination point linking resources derived from research, education, and clinical practice to settings where the quality of pain management could be improved. Within the first three years, the MPRC's distribution of resources totaled 41,525 items provided to 19,612 individuals which included reprints of COH pain publications, standards of pain management, patient teaching materials, research instruments, documentation forms, policies and procedures. Materials were mailed to individuals in 35 countries and all 50 states. In 1999, the resource center name was changed to the City of Hope Pain/Palliative Care Resource Center (PRC) to include palliative care resources. Participants of this proposed project will have access to the PRC and these resources will assist participants to improve EOL care in their institutions. An initial evaluation of the PRC project was completed and published in the *Journal of Pharmaceutical Care in Pain and Symptom Management*.<sup>(79)</sup> The PRC became available on the Web effective January 1, 1998. Website visits have increased from 36,670 in 1999 to 268,630 in 2001. More than 300 materials are listed and more than 200 are available on the website (<http://prc.coh.org>) which is updated monthly.

(10) A recently completed study by Drs. Grant and Ferrell supported by NCI was "Cancer Pain Management Course for Nurse Educators" (R-25CA 57882, 1992-1996). The purpose of this course was to provide pain management knowledge and related teaching approaches to undergraduate nursing school faculty. Programs were held for 86 competitively selected nurse educators from 86 different undergraduate nursing schools representing 42 states. Pre-course requirements included faculty demographics, pain management audits, pain curriculum evaluation, faculty knowledge and attitudes related to pain (K&A), and student K&A. A total of 1,635 undergraduate nursing students participated. Students' scores revealed major deficits in pain knowledge and attitudes. Curriculum surveys revealed a need for increased pain management content in the curricula of participating schools. Comparison of participants' pre- and post-program goals illustrated that participants moved from increasing their own knowledge (pre-course) to implementing curriculum changes in their individual institutions (post-course).

Analysis of four and nine-month follow up of goals revealed similar trends. Participants' pre- and post-K&As revealed improved scores following the program.<sup>(80-83)</sup>

(11) Dr. Grant's study funded by the National Cancer Institute (NCI) titled "Improving Clinical Practice in Cancer Pain Management." provided three-day courses conducted by nationally recognized experts in pain management within a framework of Continuous Quality Improvement. Competitively selected participants were drawn from hospitals, ambulatory care, physicians offices, and home care settings across the country. A total of 144 nurses from 144 institutions representing 40 states attended the courses. Institutional commitment was fostered through required letters from the chief nurse, chief physician, and the CEO. Pre-course requirements included pain K&A surveys from participants and a minimum of 20 staff from their institutions, chart audits from each institution, and a description of the institution's current pain program. Post course requirements included immediate post course K&A by participants, 12 month-post course K&A from both participants and their staff, and 12 month evaluation of participants' goal implementation and changes in the institution's pain program. Improvement in participants' pre- and post K&A surveys revealed significant increases in knowledge. Goal refinement during the course revealed a change in focus from improvement of participants' own knowledge to the need to improve knowledge and skills of those in their institutions. Goals achieved within the first 12 months post-course focused on improving assessment of pain management, education of professional staff, and developing ways to evaluate the success of implementing pain standards. Analysis of outcomes continues as the final 12 month data are being collected. Preliminary results have been published and presented at a number of conferences.<sup>(84-87)</sup>

(12) Dr. Ferrell currently directs a training program funded by NCI for "Patient and Public Education in Cancer Pain Management" (R-25-CA77189, 1999-2002). This course included 3 national conferences to assist institutions with improving patient/public pain education. Originally intended for only 50 participants per course, the first course announcement resulted in 180 applicants from 40 states. A supplemental grant was received which provided 148 individuals opportunity to attend the first course in January, 2000. The second course held in October, 2000 filled to capacity without a mailing or course announcement from those on the waiting list or who have heard about the course from the first participants. Follow-up evaluation from the program rated the overall course effectiveness at mean = 4.84 on a scale of 0 = low to 5 = high. The third and final course was held in October, 2001. A paper based on this project was published in the *Journal of Pain and Symptom Management*<sup>(88)</sup>. This project concludes in October, 2002.

(13) A major EOL care project involved a grant funded by the Robert Wood Johnson Foundation from 1997-2000. This project, "Strengthening Nursing Education in End of Life Care", involved several strategies for improved nursing education. A major activity of this project involved review of more than 45,000 pages in 50 major nursing textbooks for content across nine EOL topics<sup>(62)</sup>. The final analysis revealed that only 2% of textbook content was related to EOL care. A parallel project done by medical investigators in collaboration with the COH found almost identical results in medical texts.<sup>(50)</sup> This project also involved working with the National Council of State Boards of Nursing to improve EOL content in the nurse licensure examination, collaboration with several national nursing organizations and surveys of nurse educators and clinicians regarding EOL care.<sup>(63, 66)</sup> This project led to the development of the ELNEC project. This project has resulted in several publications in journals including the *Journal of Pain and Symptom Management*, *Oncology Nursing Forum*, *Nursing Outlook*, *Journal of Palliative Medicine* and others.

### AACN Research

In response to important professional priorities, AACN has administered large grant-funded specialty education programs in end-of-life care, gerontology nursing, and community-based education. The following grants and contracts are presently in operation:

- Helene Fuld Health Trust – Extension of Community- based Undergraduate Nursing Education Initiatives; Leadership Grant for Development of Deans
- John A. Hartford Foundation Grant – Enhancing Geriatric Nursing Education At Baccalaureate and Advanced Practice Levels; Award for Exceptional Curriculum in Geriatrics
- Robert Wood Johnson Foundation - National Nursing Workforce Initiative; End of Life Nursing Education Consortium (ELNEC).
- U.S. Public Health Service, Health Resources & Services Administration – Secretary’s Award for Disease Prevention and Health Promotion; Development of National Competencies for Primary Care Nurse Practitioner Specialties

### ONS Research

The ONS Steering Council annually reviews and develops the Oncology Nursing Society's Educational Blueprint using data about cancer nursing trends and ONS member needs. Information is compiled from a variety of surveys, needs assessments, member comments, and other sources. The Educational Blueprint is meant to give guidance on the organization's educational priorities for the year. EOL care is one of the key educational priorities for ONS related to clinical care. EOL care/hospice, pain, and quality of life ranked in the top 10 research priorities in the 2000 ONS Research Priorities Survey.

A recent survey conducted by ONS shows the demand for palliative care education is overwhelming. The survey asked 2,300 nurses what they saw as their major concerns in day-to-day practices. The nurses reported the following major concerns related to EOL care: use of advanced directives; preserving patient choice; fear of causing death by giving pain medications; discontinuing life sustaining treatments; withholding nutrition and hydration; legal issues; request for assisted suicide; and, request for euthanasia. Nurses also reported the need for more educational workshops involving EOL care. To help provide this need, several palliative care sessions were held at the ONS 2002 Annual Congress. These sessions covered such topics as Death and Dying (428 attendees), Pain in the Media (714 attendees) and Palliative Care Issues (504 attendees). Additionally, a six-hour institute on EOL care was presented at the 2001 Institute of Learning Conference and was attended by 481 oncology professionals.

ONS participated as one of the 23 specialty nursing organizations that took part in the Nursing Leadership Academy on End-of-Life Care sponsored by Johns Hopkins University and supported by a grant from the Robert Wood Johnson Foundation. The ONS project for this program was entitled "Improving Care at the End-of-Life Care". The project supported ten ONS chapters in their efforts to develop community coalitions with the intended purpose of increasing public awareness regarding end-of-life issues. The ONS Foundation provided a \$20,000 grant to support seed money to ten chapters at \$2,000 each to a) assist in the development of a community EOL coalition or join an existing coalition; b) raise awareness of EOL issues among diverse community members; c) assist in the development of a local EOL resource center; and d) provide educational events for professional and lay community members on EOL issues.

The ONS chapters' efforts encompassed community forums and educational offerings; professional educational programs; train-the-trainer programs; development of community resource centers, websites, and printed documents; attendance at health fairs; investigation into and development of programs that reflect cultural competence; significant publicity from local newspapers, talk radio shows, and local cable programming; and writing grant proposals to support ongoing work. Approximately 440 professionals and 3330 laypersons were reached through this project. Laura Fennimore, RN, MSN served as one of the ONS coordinators for this project.

### Summary of Previous Research

In summary, the above studies illustrate the investigators' wide range of experiences related to this proposal. The investigators have a well-established record of educational research including topics of EOL care, pain management, K&A regarding pain, institutional barriers related to changing practice as well as pain and QOL issues. Drs. Ferrell and Grant have worked together for 13 years and have benefited from these and numerous other experiences in conducting national oncology training programs. They have collaborated with the Oncology Nursing Society and the American Association of Colleges of Nursing in numerous projects over

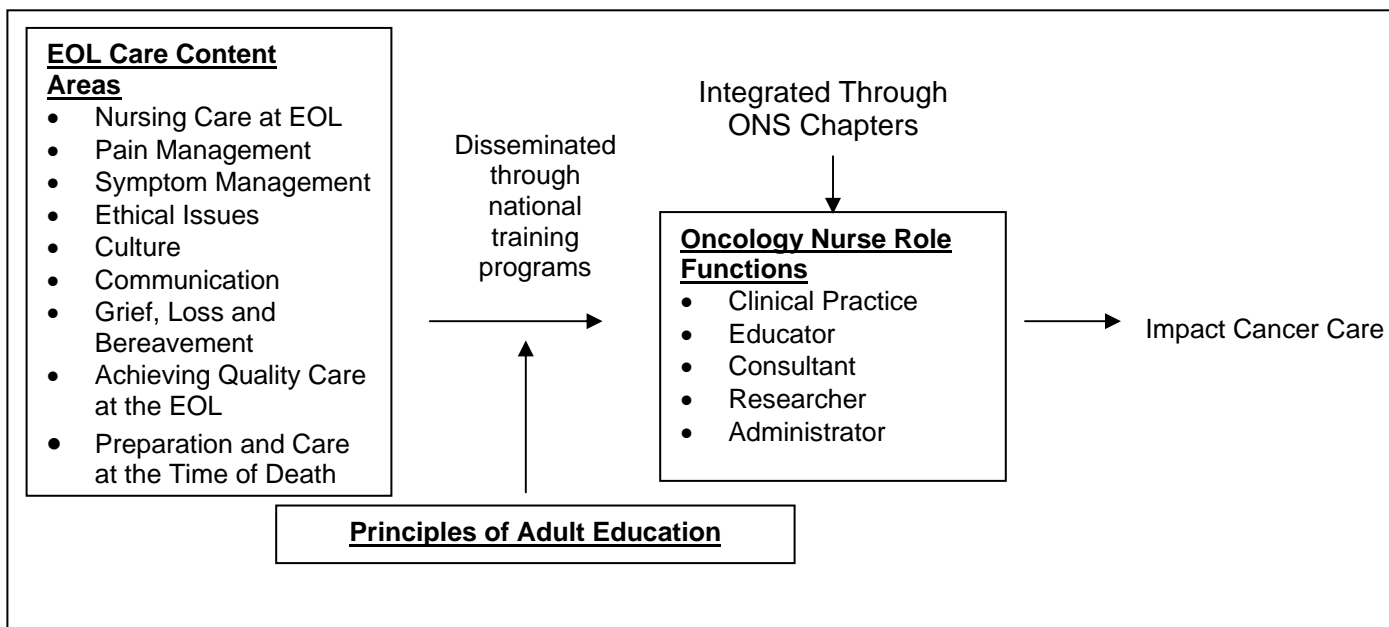
their careers. These previous studies will contribute to the proposed content of the training program and will build on the investigators' experiences in conducting and evaluating educational programs.

## **D. Research Design and Method**

### **1. Framework**

This training program responds to the findings of the NCPB-IOM study (2001) on improving EOL care for cancer patients as has been described above. The framework designed for this educational program has three components: 1) Principles of Adult Education, 2) End-of-Life Care Content Areas and 3) Role Functions of Oncology Nurses. The program design, implementation and evaluation are based on this framework (Figure 1). The end-of-life content will be disseminated through national training programs based on principles of adult education. The content will then be disseminated through ONS Chapters and implemented through the role functions of oncology nurses to impact cancer care.

**Figure 1**  
**Oncology Nursing Education in End of Life Care (ONE-EOLC) Framework**



### **Principles of Adult Education**

Assumptions about adult learning are based largely on the works of Knowles<sup>(89)</sup>. He views adult learners as self-directed, having a resource of life experience, being ready to learn, and concerned with solving problems. The adult learner needs immediate application of knowledge rather than delayed application. These assumptions and principles of adult learning will be emphasized in faculty preparation and used to plan appropriate education methods for the overall courses and for the curriculum dissemination during the final year. Teaching methods planned will vary dependent upon the content and include lectures for new information, discussion sessions for sharing and clarification, case studies and use of the case method, as well as demonstration and role playing. Participants will be provided with multiple learning resources including lecture notes, slides, video clips and other educational tools. Course content will also include teaching participants the principles of adult education so that

participants can apply them as a foundation for implementing EOL content in the curriculum at their specific institutions.

### End of Life Content Areas

The ONE-EOLC program will be a modification of the existing ELNEC curriculum. The nine content areas of ELNEC are 1) Nursing Care at EOL, 2) Pain Management, 3) Symptom Management, 4) Ethical/ Legal Issues, 5) Culture, 6) Communication, 7) Grief, Loss and Bereavement, 8) Achieving Quality Care at the End of Life and 9) Preparation and Care at the Time of Death. They were derived from an extensive review of palliative care literature and based on key documents such as the Precepts of Palliative Care which were identified by the Last Acts Palliative Care Task Force and published in December 1997<sup>(90)</sup>. Five overall precepts are identified: Respecting Patient Goals, Preferences, and Choices; Comprehensive Caring; Utilizing the Strengths of Interdisciplinary Resources; Acknowledging and Addressing Caregiver Concerns; and Building Systems and Mechanisms of Support. The nine specific content areas of ELNEC are based on an extensive literature review, input from project advisors and consultants and from extensive peer review that resulted in the final nine content areas. These nine areas will be retained for this oncology education program as they reflect the needs of cancer patients at the EOL, but content will be extensively revised within these areas to meet the specific needs of oncology care. We anticipate these changes to address the special considerations of EOL care in cancer centers, unique settings such as hematology/BMT units, complex pain syndromes associated with cancer and symptoms common in advanced cancer or associated with treatment. The content will reflect the many unique ethical issues in cancer such as decisions related to discontinuing treatment, communication of information regarding cancer diagnosis and prognosis and improving care at the time of death in cancer settings.

### Oncology Nursing Role Functions

Oncology nursing practice occurs along a continuum of care across care delivery settings. The nature of this nursing care spans the spectrum from prevention and acute care through rehabilitative and supportive care. Each of these aspects of oncology nursing care may be provided in a variety of settings: inpatient, outpatient, hospice, and home care. The scope of oncology nursing encompasses clinical practice, education, consultation, research and administration. Oncology nursing is directed toward the care of individuals, families, groups, and communities with potential or actual diagnosis of cancer. The Education committee of the ONS believes that nurses involved in cancer care have the responsibility to develop knowledge, skills, and attitudes that promote competence in the field<sup>(91, 92)</sup>.

## **2. Content and Scope of Educational Activities**

The objectives for this course are found in Appendix A. The objectives address the nine components of end of life care reflected in the framework and course content. The proposed agenda for the course is included in Appendix B. The three day course timeframe is adapted from the undergraduate ELNEC courses. The proposed agenda will be reviewed by the investigators and modified as needed as the final content revisions are completed. The course materials are organized by the nine modules on EOL care. Each of these modules will be reviewed by Patrick Coyne, RN, MSN, as content consultant, the faculty and the investigators in order to revise the materials from their current format for undergraduate use content appropriate for oncology education. These revisions would include increasing the level of content as it has been written for basic nursing education, as well as making all content specific to oncology. Universal themes, referred to as “common threads” which are integrated throughout the curriculum include:

- The family as the unit of care

- The important role of the nurse as advocate
- The importance of culture as an influence at the end of life
- The critical need for attention to special populations such as children, the elderly, the poor, and the uninsured
- End of life issues impact all systems of care across all settings
- Critical financial issues influence end of life care
- Interdisciplinary care is essential for quality care at the end of life

The syllabus will include the following materials for each module: an overview, key messages, objectives, student outline, detailed faculty outline, case studies, references, Power Point slide content and other teaching resources. The total current undergraduate syllabus is 974 pages in length, and it is anticipated that the ONE-EOLC syllabus will be of similar length. ELNEC participants have consistently commented that these materials are invaluable in overcoming many obstacles to teaching EOL care such as limited time and resources. Outlines of all current modules and an example of one complete undergraduate module (Module 7—Grief, Loss and Bereavement) are included in Appendix C. The materials are also provided on a CD-ROM for easy use by the faculty to integrate ELNEC into existing materials or lectures.

Course content is provided over a three-day period and through a total of four annual courses. (See Appendix B for agenda). Day 1 begins with a welcome from the ONS by Laura Fennimore, RN, MSN, Director of Education. She will provide a background of ONS involvement in EOL Education and discuss opportunities for ONS chapters' dissemination. This session is followed by a "getting started" session, presented by Dr. Marcia Grant. Dr. Grant will present a summary of the pre-course survey completed by the chapters as well as give a background of the ELNEC project. The next session is provided by Patrick Coyne, RN, MSN, which is an overview of the curriculum. As one of the original ELNEC consultants, Patrick will trace the background of the ELNEC project and then focus the conference on the unique issues in cancer care. He will review the curriculum changes that have occurred to make this an oncology specific course. He will also review the syllabus contents and CD materials so the participants are aware of all of the resources available to them.

The day proceeds with the presentation of the first module, Oncology Nursing Care at the End of Life, by Joan Panke, MA, RN, APRN. This is followed by the training session for Module 1 presented by Dr. Betty Ferrell and Laura Fennimore, RN, MSN. This session incorporates brainstorming by the participants of all of the opportunities for implementing ONE-EOLC through the ONS chapters. Module 2 is presented by Denice Economou, RN, MSN, AOCN, on the topic of pain management followed by the training session discussion on teaching pain management to oncology nurses by Denice Economou and Joan Panke. Module 3 on symptom management is presented by Patrick Coyne, RN, MSN. The day concludes with a symptom management non-drug lab which has been a highly successful component of the ELNEC courses. In this non-drug lab, the participants rotate to 6 stations where they actually demonstrate various techniques of non-drug treatments for pain and other symptoms. This highly interactive common demonstration format has been very effective as a teaching modality. A description of the lab stations is attached to the program agenda.

Day 2 is moderated by Patrick Coyne, RN, MSN, and begins with the presentation of Module 4 on ethical/legal issues in oncology/palliative care by Connie Dahlin, RN, CS, ANP. This is followed by an ethical/legal breakout session in which all faculty participate as small group leaders. The small groups discuss common ethical dilemmas in oncology and how to best teach ethics content to oncology nurses. This is a time where oncology nurses can discuss the

common dilemmas they face such as discontinuing hydration or nutrition, family decisions regarding resuscitation, etc.

Day 2 proceeds with the presentation of Module 5 on culture. This is presented by Polly Mazanec, MSN, APRN, AOCN and is followed by a training session with use of video and also discussion of teaching strategies for increasing nurses awareness of cultural diversity in end of life care. Following lunch, Module 6 is presented on the topic of communication by Maureen Lynch, RN, MSN. The training session includes video clips and discussion as well as a role play listening exercise. The day concludes with the presentation of Module 7 on grief, loss, and bereavement by Nessa Coyle, RN, MS, NP, FAAN. The breakout session for Module 7 includes a focus on the oncology nurses own grief in dealing with chronic loss of cancer patients.

Day 3 is moderated by Laura Fennimore, RN, MSN. It begins with instructions regarding final goal refinement by Dr. Marcia Grant who guides the group through their goals for dissemination and also reminds them of the evaluation process. The first formal presentation on Day 3, Module 8, is focused on achieving quality care at the end of life. This module focuses on systems change and the importance of oncology nurses as leaders and change agents. The final module preparation and care at the time of death is presented by Dr. Judy Paice. This module focuses on ways to improve care in the hours surrounding the death and care of the body after death. After the break, the chapter teams will then have two hours of time devoted to work together on their plans for dissemination. This will also be a time of networking where teams can discuss ideas with each other and where the total faculty will be available for consultation. The day concludes with a program summary and an emphasis on follow-up evaluation.

Continuing education units (CEU's) are provided to the participants and the training materials have been formatted to meet standard requirements for CEU's provision to facilitate the chapters also being able to provide CEU's in their dissemination efforts. All of the role play, discussion, case studies, etc. in the curriculum will be refined or revised to focus specifically on oncology care. As the previous ELNEC courses have attempted to be very generic addressing all types of chronic and terminal illnesses and all disease populations, it will be important to conduct this thorough revision to prepare the ONE-EOLC curriculum to ensure that it meets the unique and specific needs of oncology nurses.

The COH/AACN investigators identified the very significant gap in their previous ELNEC activities in reaching oncology nurses, the target of this proposed project. The optimum means of accessing oncology nurses is through the ONS chapters. These local chapters implement the ONS Strategic Plan at the grassroots level and execute the Society's mission – to promote excellence in oncology nursing and quality cancer care. ONS offers members the opportunity to join a chapter, where they will have local access to education, information, peer support and leadership opportunities.

ONS has partnered with the chapters to successfully provide local programming for national initiatives. Most recently, ONS partnered with 30 chapters across the country to provide community-based Lung Cancer Awareness programs as one component of the National Lung Cancer Awareness Campaign. Chapters host six to ten membership meetings annually, depending on size and participation. A traditional chapter meeting is held over dinner followed by a continuing education program. Many chapters also sponsor annual oncology nursing conferences, generally 1-2 days in length, to meet the educational needs of their members.

Approximately 40% of the more than 30,000 ONS members belong to a local chapter. ONS currently has 212 chapters in 49 states in the U.S. The chapters range in size from 10-350 members. The average number of members in an ONS chapter is approximately 65. To facilitate implementation, the investigators have designed the project so that each participating chapter will send a team of 2 participants thus 30 chapter teams will attend the conference. Thus a total of 60 participants will be selected for each course. The total project involves 240 participants representing 120 ONS chapters. This will mean 120 of the 212 chapters (57%) will be trained in end of life nursing care in the courses. Additional chapters will likely be reached as they participate in the dissemination efforts by other chapters. For example, smaller or newer chapters may attend training sponsored by a chapter from their geographic area who attend the national training. All chapters will be targeted through the end dissemination described below.

### **3. Procedures for Recruitment**

Applications will be sent from the national ONS office to all chapter presidents. An article about the programs will appear in the ONS NEWS, which serves as the monthly newsletter that is distributed to all members. Information about the program will also be distributed via the ONS E-NEWS and will be available on ONS ONLINE. More than 18,000 ONS members are active users of the ONS website (see Appendix K for example of the website).

The announcement of the ONE-EOLC courses will be sent electronically to the chapter president with multiple other forms of announcement of the course through the ONS and through the ELNEC website. The announcement will direct the chapter president to the instructions for completing the chapter application. Each chapter can nominate one team of two individuals from the chapter. These individuals should be members who have the ability to implement education over the next two years through the chapter. This may be a chapter officer such as the president, another elected official, a member of the education committee, or other active member of the chapter. The investigators recognize that change may occur over the two years such as one of the trained participants moving away from the chapter. The chapter board will be asked to make a commitment to see that the chapter goals for implementing ONE-EOLC continues should such change occur. The chapters will be directed that the ONE-EOLC education can be implemented through monthly chapter meetings, annual conferences, or any other creative means by the chapters. We anticipate that innovative models will occur across the chapters such as co-sponsorship with area cancer centers, collaboration with other clinical settings or education groups in the community, and perhaps co-sponsorship across chapters in the same geographic area. Chapters will be allowed to charge usual registration fees for any conferences similar to those they would for other educational programs. Chapters will be strongly encouraged to promote the ONE-EOLC training sessions throughout the community to nurses other than those who belong to their ONS chapter.

We anticipate very successful recruitment for the project through ONS working in conjunction with the COH. The ELNEC courses have been filled to capacity and there is tremendous interest from oncology nursing for this project as evidenced by the data in the needs assessment survey described above in the Background section, and letters of support (Appendix I). A one-time mailing sent in the summer of 2000 for the ELNEC undergraduate program yielded 427 completed applicants for only 100 slots. This was particularly impressive for a summer mailing and since only one faculty member per school was allowed. We anticipate the oncology courses to be in even greater demand given the success and reputation of the ELNEC training to date and having the current situation of national awareness by oncology nursing of the need for improved end of life education. This topic is also extremely timely given growing attention to the need for professional end of life education such as cited in the NCPB-IOM report and numerous other publications. Increasingly, states such as Virginia are

mandating palliative care training programs for health care professionals (Virginia House Resolution No. 369).

Announcements will also be published in key ONS publications including the monthly newsletter (ONS News), the official journal, (Oncology Nursing Forum) and the clinical journal (Clinical Journal of Oncology Nursing). The application form is included as Appendix G and is modified from the previous ELNEC courses. It provides information about the chapter team participants and their chapter. The application process also requires a letter of support from the chapter board and asks the applicants to write goals for the implementation of the ONE-EOLC education. This application process has been very successful in each of the R25 funded projects conducted by Drs. Ferrell and Grant as described in the preliminary studies section and in the previous ELNEC courses. The application is designed to provide individual and chapter commitment to implementation of the education.

A copy of the instrument used to evaluate the applications is also included in Appendix G. Priority is given to chapters in ethnically diverse communities. Prior to attending the course, selected participants will be required to submit the pre-course materials as described in the evaluation section below. Any team who fails to complete these pre-assessment tools will be replaced by an applicant from a waiting list. This process was effective in obtaining 100% pre-course data for the previous ELNEC courses.

#### **4. Qualifications of Faculty**

Faculty qualifications are described based on the content they will be presenting in the training courses. Biosketches for the faculty are provided in Appendix E. Most of these faculty have presented this content in the ELNEC undergraduate courses and all have averaged a rating of >4.5 (on a scale of 0 = poor to 5 = excellent) in the evaluations from their previous ELNEC course presentation. All have enthusiastically agreed to participate in this oncology education project. All are experienced oncology nurses, involved in ONS and most have held leadership positions in their ONS chapters.

The welcome session is presented by Laura Fennimore, RN, MSN. She is a co-investigator and the Director of Education for ONS. This session provides an official statement by the professional organization (ONS) of the importance of their participation. Laura also presents in the Module 1 training session and moderates Day 3 of the training program.

Marcia Grant DNSc, FAAN presents the initial session of evaluation data. She is a coinvestigator and her work has been extensively described in the preliminary studies section above. This session provides participants with demographic information about their participant colleagues and insight into the current status of end-of-life content in graduate education. She also provides instructions regarding goal refinement on day 3. Dr. Grant has been involved in ONS for over 20 years.

Judy Paice PhD, FAAN provides the lecture on Module 9 – Care at the Time of Death. Dr. Paice is an ELNEC project consultant and faculty member and an expert in pain management and palliative care. She has extensive involvement in ONS.

Joan Panke MA, RN, APRN provides Module 1 and the Module 2 training session. Joan is a graduate of the New York University Advanced Practice Palliative Care program and has been an ELNEC consultant and faculty member. She has extensive clinical experience in hospice and palliative care and is currently executive director of DC Partnership to improve End-of-Life Care. She is an ONS member.

Maureen Lynch, RN, MSN presents the Module 6 content and training session. Maureen is a nurse practitioner in the Pain and Palliative Care Program at Dana-Farber Cancer Institute. She has been an ONS member since 1985 and a member of the Boston chapter (BONS) where she was director at large, 1993-1994 & 1998-2000 and held other chapter leadership roles.

Denice Economou, RN MSN, AOCN presents Module 2 on pain management. Denice is immediate Past President of the Greater Los Angeles Chapter of ONS, an ELNEC trainer and a leading lecturer in pain management.

Betty Ferrell PhD, FAAN will present in the Module 1 training session; moderate Day 1 and provide the Program Summary. As P.I. of this proposed project, her expertise is described above.

Patrick Coyne RN, MSN presents the overview of the curriculum and Module 3 on Symptom Management. He is a Clinical Nurse Specialist for Palliative Care at the Medical College of Virginia/ Virginia Commonwealth University in Richmond . He was one of the four ELNEC content consultants and a faculty member. In 2001, he was named a Faculty Scholar by the Project on Death in America. He also moderates Day 2 of the training. He is also the content consultant for the project.

Connie Dahlin, RN, CS, ANP presents Module 4 on Ethical/Legal Issues. She has been involved with end-of-life care for over 15 years. She is the advanced practice nurse with the Palliative Care Service at Massachusetts General Hospital. She is an adjunct faculty member of the MGH Institute of Health Professions and a faculty member of the Harvard Medical School Center for Palliative Care in Boston. She is a visiting instructor for the Yale School of Nursing, is trained as an oncology clinical nurse specialist and is certified both in hospice nursing and in adult primary care as a nurse practitioner. She is an ELNEC trainer and has been an ONS member since 1987.

Anne Rhome, RN, MPH presents the welcome session. She is a co-investigator and Deputy Executive Director of the American Association of Colleges of Nursing, Washington, DC. This session provides an official statement by the professional organization (AACN) of the importance of their participation.

Nessa Coyle, RN, MS, NP, FAAN presents in the Module 6 communication training session and Module 7 on grief. She is the Director of the Supportive Care Program, Pain and Palliative Care Service in the Department of Neurology at Memorial Sloan-Kettering Cancer Center and has a faculty appointment at Columbia University School of Nursing in New York. She is the co-editor, with Dr. Betty Ferrell, of the Textbook of Palliative Nursing (Oxford Press).

Polly Mazanec, MSN, APRN, AOCN presents Module 5 on Culture. She is a Palliative Care Clinical Nurse Specialist at the Hospice of the Western Reserve. She has been an excellent lecturer in ELNEC courses and also serves as a role model for this course as an advanced practice nurse. She is an active ONS member.

## **5. Potential Benefits to Cancer Patients**

This project is designed to train the nation's leading oncology nurses in improved end-of-life care through a national educational effort of ONS chapters. The nine topics of the ELNEC curriculum address key patient concerns such as pain, symptom management, grief and care at the time of death. The content also addresses important themes such as staff support, quality

improvement and cultural considerations which also directly impact patient care. Our planned courses will reach 120 of the 212 ONS chapters directly. All of the remaining chapters that do not attend an ONE-EOLC training course will receive a copy of the curriculum in the final dissemination. If each of these 120 chapters reach only 50 nurses through their dissemination, this will result in 6,000 oncology nurses trained in end-of-life care and we anticipate a far greater outreach. We also expect many of those trained in ONS chapter programs will go on to educate staff in their clinical settings. The well established, strong network of ONS chapters provides an ideal means of national dissemination and a strong network of support.

## 6. Methods of Evaluation

To evaluate the implementation of the curriculum in oncology chapters, an extensive evaluation plan has been developed which is based on the current evaluation of the ELNEC undergraduate courses. These tools have been used in 12 ELNEC courses. Data used for evaluation includes information derived from pre-course application materials and continuing through 24 months following each of the first 3 courses and 12 month evaluation of the final course (Appendix G). These tools have now been revised to reflect the goals of oncology education and ONS chapters. Evaluation addresses both process and outcomes of the project. Table 2 identifies the evaluation plan by aim. Table 3 provides the time frame for evaluation.

**Table 2**  
**Evaluation Plan by Aim**

<u>Aims</u>	<u>Evaluation Methods/Instruments</u>
1. Adapt the existing ELNEC curriculum and teaching materials as an oncology specific curriculum for use in the Oncology Nursing Education (ONE-EOLC) Project.	<ul style="list-style-type: none"> <li>• Module Evaluation Instrument used by investigators, faculty and consultant in evaluation of content</li> <li>• Faculty Debriefing Tool completed after each course</li> </ul>
2. Evaluate the impact of the curriculum on participants' knowledge and attitudes about EOL care.	<ul style="list-style-type: none"> <li>• Pre- and Post-course Knowledge Tool scores</li> <li>• Daily Evaluation Form completed by participants</li> </ul>
3. Support the network of ONE-EOLC educators through the ONS chapters to share experiences in dissemination of the curriculum.	<ul style="list-style-type: none"> <li>• Newsletter articles and responses</li> <li>• Monitoring of calls to COH and ONS</li> <li>• Website use monitoring</li> </ul>
4. Evaluate the effectiveness of participants' implementation efforts within the ONS chapters.	<ul style="list-style-type: none"> <li>• Pre-Course Chapter Survey</li> <li>• Post-Course Chapter Survey &amp; Activity Evaluation (12 and 24 months)</li> </ul>
5. Describe issues related to dissemination of EOL education through CE efforts of ONS chapters.	<ul style="list-style-type: none"> <li>• Pre-Course Goals and Follow Up Goal Evaluation at 6, 12, and 24 months</li> <li>• Participant Application provides data for analysis of participant and chapter characteristics</li> </ul>

**Table 3**  
**Evaluation Components by Time Period**

<b>Instrument</b>	<b>Pre-Course</b>	<b>Course Day 1</b>	<b>Course Day 2</b>	<b>Course Day 3</b>	<b>6 months</b>	<b>12 months</b>	<b>24 months</b>
Chapter Application	X						
Chapter Board Letter of Support	X						
Participant Knowledge & Attitude Survey		X		X			
Chapter Survey	X					X	X
Pre-course goals	X						
Faculty debriefing		X	X	X			
Daily course evaluation		X	X	X			
Module Evaluation	X						
Post-course goals				X	X	X	X
Post-course activity evaluation						X	X

The evaluation instruments are described as follows:

Application and Application Evaluation Form (Appendix G-1)

The application provides information about the experience of the course applicants. It includes a request for their curriculum vitae as a source of information regarding their end-of-life education experiences. The application also asks for a letter of support from the chapter board in order to establish commitment and support from the chapter for implementing this content into chapter's educational efforts. Data will be used from this instrument for process and outcome evaluation. Also included in Appendix G is the evaluation form used by the investigators to rate and select applicants as we expect to have far more applicants than spaces available. The checklist provides information regarding geographic distribution, and other data to support the applicant.

Pre-Course Chapter Team Survey (Appendix G-2)

This instrument will be used as a key outcome measure in order to determine the previous end of life education within the chapter. Items assess the EOL topics addressed and their perceptions about EOL education prior to the course.

#### Pre/Post-Course Knowledge and Attitude (K & A) Tool (Appendix G-3)

This survey has been developed based on extensive work by the ELNEC undergraduate project. The tool was developed over a period of approximately 1 year with extensive involvement by the ELNEC investigators, consultants and faculty. Ten items have been developed for each of the nine modules for a total test pool of 90 items. Each item has also been classified according to the course objective, the level within the cognitive domain and the phase in nursing process. These items have also been reviewed by the National Council State Boards of Nursing to achieve consistency with the format used for national nursing license testing. The items are now in the process of being evaluated as outcome measures in the undergraduate curriculum. For the purpose of the pre- and post- participant testing, we will select 3 items for each module or a total of 27 items in order to accommodate the limited time we have at the course for testing. A copy of the current version used is included as Appendix G. For the ONE-EOLC courses, we will select items from the total test pool most specific for oncology education. The test will be used as an evaluation measure for our course participants and is a valuable self-assessment.

#### Daily Course Evaluation Form (Appendix G-4)

This evaluation format has been used extensively by the City of Hope investigators. It provides evaluation from the participants on the actual course for each day. Data are used to revise subsequent courses and refine content. Data are reviewed at the end of each day of the course to respond to any immediate issues. Extensive written comments are generally provided by the participants. These are compiled in a word processing file and reviewed and summarized after the course according to key topics. The course evaluation data is shared with the faculty and used by the investigators in their evaluation.

#### Goal Forms (Pre and Follow-Up) (Appendix G-5)

The investigators have used the strategy of establishment and evaluation of individualized participant goals over the past several training courses and have found this to be extremely valuable. Participants are asked to complete their goals for attending the course and implementing through their chapter as part of the application process. On the first day of the course, they are provided with feedback regarding goals and instructed on refining the goals during the 3 days as they develop new ideas or more realistic strategies. The use of participant goals is consistent with adult learning principles as described in the framework. On the third day of the course, an opening session is devoted to a group discussion of their goals in which participants are given an opportunity to share with each other the goals that they developed, how they have revised these during the course and to discuss successful strategies for their implementation. During the course follow-up at 6, 12 and 24 months, the participants are sent a copy of their goals, which is entered as part of the evaluation database. This ongoing evaluation linked to the participant's own goals has been very effective in sustaining commitment to other education projects and helping to keep efforts focused. The aggregate data is then very useful in determining which goals have been best achieved across programs and to identify both barriers and strengths for future efforts by other schools in implementing end-of-life education. Their achievements will be published in the newsletter and on the ELNEC website.

#### Post Course Activity Evaluation (Appendix G-6)

This instrument is used as a primary outcome measure to record activities of participants following the course. The survey replicates some items from the pre-course survey to document change and also captures quantitative data regarding numbers of nurses taught the various modules. It will be completed at 12 and 24 months. It also documents benefits/barriers to

teaching EOL care. We anticipate that the chapters will conduct the evaluation program within their chapters over the 12-24 months following the course. We also expect that by 24 months, many of the nurses they have trained through the chapter sessions will proceed to conduct training in their own clinical settings. Thus, at 24 months the participating team members are asked to survey their members to document this secondary level of dissemination, and a means to tally this information is included in this form.

#### Faculty Debriefing Form (Appendix G-7)

This form will be completed by all faculty following each session they present. It is used as a self-evaluation as well as input for the investigators.

#### Module Evaluation Form (Appendix G-8)

This form will be used by the investigators, faculty, and consultants and the Advisory Board to document their rating of the revised curriculum.

### **7. Project Timeline (Appendix D)**

The first 6 months of the project will be used to adapt the ELNEC curriculum from the current undergraduate version to focus on oncology education. This will be done through correspondence with the clinical consultant, Patrick Coyne, RN, MSN, as well as through extensive work by the investigators. Dr. Ferrell will coordinate this process. Each faculty member will be sent a copy of the current curriculum. They will be asked to provide input as to the necessary revisions for converting the curriculum for oncology focus. This may include editing content, deletion of existing information and addition of materials. The announcements of the courses will be sent during month 3 and selection of participants for the first course will occur by month 8. The first course will be held in month 11. Post course evaluations will occur for each course at 6, 12, and 24 months post course. This system will continue for each of the 4 courses (except for course 4 which will include up to 12 month evaluation). Following each course, the faculty will be sent a summary of the course evaluations with recommended changes and they will be asked to provide continued input.

### **8. Innovation**

This project builds on the extremely successful implementation of the ELNEC program for undergraduate curriculum. There is no national effort to implement end-of-life education in oncology and there is an enormous need for improved care in oncology. The enthusiasm for this course is reflected in support letters from ONS and by letters provided by nine ONS chapters (Appendix I).

The American Association of Colleges of Nursing (AACN) as stated previously has been a partner with COH in the ELNEC project since its inception. The AACN has offered a strong link to the nation's nursing schools and they have worked closely with the COH investigators in the design and implementation of all ELNEC training. In the proposed project, the AACN will continue as a collaborator working with COH and the ONS. AACN will continue to maintain the ELNEC website (<http://www.aacn.nche.edu/ELNEC/index.htm>) and to publish on a quarterly basis the ELNEC newsletter which is distributed electronically to all ELNEC trained educators on a quarterly basis. We believe that it will be beneficial to have all ONE-EOLC trained oncology educators linked to the larger ELNEC project and to include them in the communications via the website and newsletter. This will provide them an opportunity to become a part of the larger project and to interact with educators from other areas such as nursing schools as role models who have implemented ELNEC training across a variety of settings. A special section for oncology nurses will be created on the ELNEC website with

updated information posted here as well as a special section of the ELNEC newsletter (see Appendix H for examples of the newsletter and the website).

#### **9. Plans to disseminate results.**

Dissemination of this education project will be facilitated significantly by the collaboration with the ONS. As the professional organization for oncology nurses, ONS offers the link to all ONS chapters through their ongoing correspondence, meetings, websites, and other communications. The investigators will work closely to see that information regarding the courses during their implementation is made prominent through these ONS channels. Information will also be disseminated through the ELNEC newsletter to be sent by email to all participants every 3 months following their course attendance and through the ELNEC website. The AACN has committed to maintaining the ELNEC website for a minimum of five additional years (until 2007) as reinforcement of all ELNEC participants.

Each of the two chapter members who attend a conference receive the complete teaching materials including the syllabus as well as a CD copy with the complete materials including all lecture outlines, handout materials, PowerPoint slides, references, etc. These team members are designated as "ONE-EOLC trainers" as they will have participated in the complete curriculum and training sessions. The chapters will then be provided with the current ELNEC project criteria for certifying others as trainers in the curriculum. Nurses who attend education in the complete nine modules will be eligible to also be certified as trainers so that they can conduct this training in their own clinical settings. The investigators have designed the syllabus such that owners of any copyrighted materials have provided release for the investigators such that educators have permission to duplicate the syllabus for their training purposes and do not have to seek separate copyright permission. The investigators previously have and will for this course produce all of the training materials on CD for easy dissemination to others. ONS chapter members or others who are trained through the project will be able to duplicate the training materials from their training course or they may purchase all of the training materials from the COH investigators project office. The CD also will be distributed to all ONS chapters at the conclusion of the project as described in the dissemination efforts. The cost of the CD format is anticipated at \$35 which would include the CD and case, production using an outside professional studio, and accompanying written materials as well as postage, packaging, and handling.

#### **Dissemination**

At the conclusion of the project, a copy of the entire project syllabus on CD will be sent to all ONS chapters. This will provide an updated version for the 120 chapters who have attended the training. For those chapters who have not attended the ONE-EOLC training, a letter will be sent to the chapter president explaining the project and providing them with the CD and contact information if they require further assistance from the COH staff. Additionally, the ELNEC website includes a listing of all individuals trained in the ELNEC curriculum and a similar page will be created on the internet in the ONE-EOLC section of the ELNEC website so that chapters can identify others who have been previously trained and network with chapters who have already implemented the ONE-EOLC project.

The investigators will be disseminating findings of the courses in several ways. Publications will be prepared for journals targeting oncology education and practice. We anticipate presentations at several local, state and national meetings. Previous educational programs by the COH investigators and the current collaboration with COH and AACN in the ELNEC undergraduate version have resulted in numerous peer reviewed publications and presentations.

Participants attending the courses will be strongly encouraged to present the results of their own programs in local, regional and national nursing meetings. The annual meeting of the ONS is expected to be an excellent venue for such presentations. The curriculum will be revised following the fourth course with the final version disseminated on CD to all ONS chapters at the conclusion of this project.

### **Summary**

In summary, the investigators have developed the ONE-EOLC as a leading national effort to improve end of life content within oncology programs. The training program will target Oncology Nursing Society chapters directly reaching 57% of the chapters in the nation, with final dissemination to 100% of the chapters. This project has been developed to build on the experience and success of the ELNEC undergraduate project. A very strong collaboration with ONS, AACN and COH, strong support by ONS chapters and the evaluation plan create what is believed will be a very successful project that will impact cancer patient care at the end of life.

### **10. Consultants**

Patrick Coyne, RN, MS, CS. Mr. Coyne's expertise has been described prior in the qualifications of faculty section, and his biosketch is included. He is a consultant for the ELNEC project, a faculty member and an active ONS member. As an expert oncology nurse clinician involved daily in palliative cancer care, he will work closely with the investigators to guide the revision of the curriculum to be oncology specific and to insure that the content reflects the state of the art of cancer palliative care.

Gwen Uman, RN, PhD is the founding partner of a research consulting firm and is the biostatistician for the ELNEC project. She has worked with the COH/AACN since the inception of ELNEC and has conducted all evaluations.

### **E. Human Subjects**

IRB approval has been reviewed by the Director of Research Subjects Protection at the City of Hope and granted exemption status. All data collected from training course participants is anonymous and treated as confidential. A copy of the IRB approval/exemption is included as page 71.

### **F. Vertebrate Animals**

Not applicable

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