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**PI Name:** GRANT, MARCIA L.

**PI Email:** [mgrant@coh.org](mailto:mgrant@coh.org)

**PI Title:** PROFESSOR

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### **Abstract**

The primary aim of this proposal is to improve end-of-life (EOL) care for patients in cancer centers. In 2000 about 552,200 Americans are expected to die of cancer (1 in every 4 deaths). While national initiatives are providing evidence of the support patients and families need to deal with symptoms, decisions and burdens of dying, dissemination through professional education is minimal. The primary aim will be achieved through 4 annual workshops for 2 representatives each from 75 cancer treatment centers (600 total participants). The project builds on the investigators' previous experience with similar national workshops on pain management, palliative care education for home care staff, and a nursing EOL curriculum being developed with the American Association of Colleges of Nursing and supported by the Robert Wood Johnson Foundation. Specific aims to be accomplished are to: (1) Adapt the existing EOL curriculum to focus on patients with cancer and address an interdisciplinary professional audience in cancer centers. (Nurses, social workers and physicians in tier 1, and clergy, pharmacists, psychologists, rehabilitation professionals and unlicensed personnel in tier 2), (2) Implement the curriculum in national workshops to competitively selected staff from NCI-designated cancer centers, and members of the Association of Community Cancer Centers. (Two people from each institute with at least one from tier 1), (3) Develop a participants-network to share experiences in dissemination, (4) Evaluate the impact of the curriculum on participants' and cancer center staffs' knowledge and attitudes about EOL care and the implementation of individual goals for improved EOL care, (5) Evaluate EOL care at 3 levels - the participant, the interdisciplinary cancer team, and the institution level - for the ability to change and sustain improvements in EOL care, (6) Describe successes and issues related to dissemination in terms of the characteristics of individual participants, interdisciplinary teams, and institutions, (7) Refine the curriculum for broad dissemination to cancer centers to improve EOL care for cancer patients nationwide.

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OFFICE OF SPONSORED PROJECTS  
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## A. Specific Aims

The primary aim of this training proposal is to improve end-of-life (EOL) care for patients being cared for in cancer centers. In the year 2000 about 552,200 Americans are expected to die of cancer--more than 1,500 people a day (1). This represents 1 in every 4 deaths in the United States. National initiatives are providing increased evidence of the support patients and families need to deal with symptoms, decisions and burdens associated with dying. However, the dissemination of this evidence through education of health care professionals is minimal (2). The primary aim of this proposal will be achieved through four annual workshops for two representatives each cancer treatment centers. Additional dissemination methods and an extensive evaluation will provide a basis for the continuing education of health care professionals beyond the project period.

The project builds on the investigators' previous experience with similar national workshops on pain management, palliative care education for home care nursing staff, and a nursing EOL curriculum being developed with the American Association of Colleges of Nursing, the End of Life Nursing Education Consortium (ELNEC). This curriculum parallels the EPEC (Education for Physicians on End-of-Life Care) developed within the American Medical Association Institute for Ethics, and supported by the Robert Wood Johnson Foundation.

Specific aims to be accomplished are to:

1. Adapt the existing EOL curriculum to focus on patients with cancer and address an interdisciplinary professional audience in cancer centers.

Professional caregivers will include nurses, social workers and physicians as a first tier, and clergy, pharmacists, psychologists, rehabilitation professionals and unlicensed personnel as a second tier.

2. Implement the curriculum in national workshops to competitively selected staff from National Cancer Institute-designated clinical and comprehensive cancer centers, and community cancer centers as identified through the Association of Community Cancer Centers (ACCC).

Two representatives from each institute will be selected with a minimum of one from the first tier of professional caregivers.

3. Develop a network of course participants to share experiences in dissemination of the curriculum to the staff of participating cancer centers.

4. Evaluate the impact of the curriculum on participants' and cancer center staffs' knowledge and attitudes about EOL care and the implementation of individual goals for improved EOL care in respective cancer centers.

5. Evaluate EOL care at the participant level, the interdisciplinary cancer team level, and the institution level for the ability to change and sustain improvements in EOL care.

6. Describe successes and issues related to dissemination of EOL education in cancer centers in terms of the characteristics of individual course participants, interdisciplinary teams, and institutions.

7. Refine the curriculum for broad dissemination to cancer centers to improve EOL care for cancer patients nationwide.

The evidence available on the need for improved EOL care is identified in the following background and literature search.

## **B. Background and Significance**

### **1. Need for improved End of Life care**

In 1997 the Institute of Medicine (IOM) issued a formal report addressing the status of the End of life (EOL) care in the United States <sup>(2)</sup>. Specifically noted was the need for attention to EOL care due to epidemiological and societal trends which have resulted in extended life expectancy, a more mobile society with subsequent loss of the extended family, and a much anticipated aging of the “baby boomer” generation in the next two decades. The IOM report attempted to define what constitutes good care at the end of life, as well as encouraged a wider societal commitment to caring well for people as they died. Specifically, the report stressed the following:

- 1) Too many dying people suffer from pain or other symptoms that could be prevented or alleviated with our existing knowledge and therapy.
- 2) Significant organizational, economic and educational barriers to good EOL care can be identified and with varying degrees of success, remedied.
- 3) Important deficiencies in knowledge regarding needs of patients at EOL exist and warrant further attention from researchers in biomedical, clinical and social sciences
- 4) Health care provider accountability for quality EOL care will be essential: therefore, development of better tools of assessment of outcomes important to patients and families are warranted.

In attempting to define the basic elements of a decent or good death, the IOM report stated that good death is "one that is free from affordable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards." The report emphasized that care for those approaching the EOL should become a very integral and important part of routine health care. Furthermore, it was recognized that the health-care community has a unique responsibility for educating itself and others involved in the care of patients approaching the end of life about the identification, management, and discussion of the EOL care issues <sup>(2)</sup>.

Numerous studies have demonstrated that too many patients needlessly suffer from both pain and other symptoms of physical distress for which current treatments exist <sup>(3-10)</sup>. While physicians, nurses, and other health-care professionals are most often trained to recognize symptoms in order to identify and diagnose diseases, the identification and treatment of symptoms, which are manifestations of terminal disease processes, receives less emphasis <sup>(11-16)</sup>. In addition to the alleviation of pain and suffering of the dying, appropriate attention to spiritual and psychological needs with a sensitivity towards cultural differences is warranted <sup>(17-24)</sup>. In addition to the major focus on the quality of dying for the patient, there is significant evidence that family caregivers participating in end of life care are subject to significant psychological, physical, spiritual and financial stresses as well <sup>(25-27)</sup>. Several reports have demonstrated that the gradual diminishment in the patient's ability to participate in routine activities in daily living as end of life approaches results in a subsequent increased burden for family caregivers. Factors that have been demonstrated to adversely affect the overall quality of life for family caregivers have included patient's having metastatic disease, worsening patient prognosis, increased length of illness, as well as increased patient distress and discomfort <sup>(28-37)</sup>. Unfortunately, some of these factors are often part of the unavoidable progression of terminal disease.

Poor communication among and between medical staff, patients, and families regarding end of life care has also been well-documented. The SUPPORT study was perhaps the widest ranging study to systematically examine problems in communication within end of life care <sup>(38)</sup>. While this study focused mostly on severely ill patients with anticipated poor outcomes being treated in acute care settings, many of the lessons are applicable to EOL care for all patients. Specifically, the SUPPORT study demonstrated tremendous difficulty in influencing long-standing medical practice patterns and social influences regarding terminal care. The study documented that

practice patterns among physicians and social expectations can be extremely strong influences in shaping an individual patient's course of care<sup>(38-42)</sup>. Widespread system level changes were identified as more likely to achieve improvement in EOL care rather than individual interventions in individual cases. Such broad action is likely to require sweeping changes in understanding of EOL issues amongst all parties who are most integrally involved in the care of these patients<sup>(43-50)</sup>.

In addition to addressing the needs of all patients and their families as end of life approaches, it is well documented that there is a significant cost to society that is brought on by aggressive and highly technical medical interventions that can prolong life. Circumstances involving the use of technical advances in medicine to prolong life as death approaches are certainly multifactorial and can be immensely complex. Communication among health-care providers, patients, and families certainly plays an important role. Different expectations of the health-care system and modern medicine amongst any of the parties can complicate matters regarding a consensus of optimal treatment for an individual patient. Accuracy in predicting survival time for patients afflicted with advanced malignancy is notoriously inaccurate until the very latest stages of disease when patients are bedridden and highly dependent<sup>(42)</sup>. This often complicates the ability for health care professionals to assist patients and families in making treatment decisions that affect end of life care. Furthermore, tremendous regional and physician to physician variance can exist with the decision to encourage continued aggressive and often costly therapy<sup>(51,56)</sup>. While two treatments may have discernable but modest differences in efficacy (i.e. a 6 week survival advantage), substantial differences in cost may exist. Families are called upon to make decisions regarding their treatment plans amidst myriad differences in education, culture, and family support<sup>(25-27)</sup>.

The important role culture plays in EOL care can further complicate the situation. Until recently, malignancies were most often identified very late, often only when tumors were physically large or in a critical location. Unsightly cancers with accompanying disabling pain, unsightly appearance, and disturbing odors and suffering might attribute to the hushed silence regarding malignancies within a family. While earlier diagnosis and better treatment options as well as public media attention to cancer has lead to a more open acceptance of cancer in some cultural groups, this is not necessarily the experience of more recent immigrants to our society<sup>(17, 23, 62)</sup>. Certain cultural groups are particularly reluctant to discuss malignancies affecting female reproductive organs. The expectations of hospitals and medical professionals within an increasingly culturally diverse population can be extremely varied. Addressing the needs of individuals with an ever diversifying array of cultural backgrounds in an effective, meaningful fashion is a tremendous challenge. Trying to bring about effectual change in EOL care through education of physicians, nurses, social workers, clergy, and other allied medical staff remains an immense challenge.

## **2. 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, \$32000 is spent in the last year of life for cancer patients<sup>(63)</sup>. Among women aged 35 to 74, cancer remains the leading cause of death. While recent data has begun to demonstrate a decline in the mortality rate attributable to heart disease, the overall mortality rate for the majority of adult onset cancers have remained somewhat steady during the past sixty years. While people are living longer prior to diagnosis and living longer after diagnosis secondary to earlier diagnosis, better prevention, and treatments improving survival time, actual disease specific mortality rate 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 rate. 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. The majority of lung cancer patients present with later stage disease.

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 these patients is often interdisciplinary in nature, often involving the team of physicians, nurses, social workers, and other health professionals such as psychologists, physical therapists, pharmacists, occupational therapists, and clergy<sup>(3, 9, 63)</sup>. The nature of their disease can often result in a wide variety of treatment modalities such as surgery, radiation therapy, and chemotherapy<sup>(64)</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>(65)</sup>. Illnesses can be prolonged and requirements for re-treatment can be multiple. Identifying points of futility in further treatment can be extremely difficult for both the health professionals caring for these patients as well as the patients themselves and their families<sup>(66)</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>(63)</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, with a gradual industrialization of society, 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 homes and into institutions<sup>(2)</sup>. By 1949, national statistics revealed that 49.5 percent of deaths occurred into institutions, with nearly 40 percent occurring 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 the 60 percent of those occurring 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 individual 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 an inpatient wards<sup>(2)</sup>.

Hospice care, however, is certainly not without problems. When Medicare coverage was extended to cover hospice care, certain qualifying criteria certainly limit wider acceptance. The hospice enrollment criteria of a “six month” prognosis is extremely difficult to pinpoint in individual patient circumstances<sup>(63)</sup>. Furthermore, 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 families, physicians, are more reluctant to withhold curative options, even when faced with equally bleak prognoses as an older population<sup>(39-40)</sup>. Furthermore, 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 to a mean of 51 days and a median of 25 days in 1998 down from a mean of 90 days and a median of 36 days in 1990<sup>(67)</sup>. The need to effectively gap this coverage and provide meaningful end of life care for all cancer patients, regardless of their willingness to forego “curative” therapies and well before they are within their final days is paramount. 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 end of life care<sup>(68, 69)</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 end-of life issues needs to be achieved among health care providers. This is only likely to be achieved through studies which focus on quality of life issues in cancer care rather than survival endpoints, and widespread education of the healthcare professionals caring for cancer patients, as well as the patients themselves.

### **3. Educational Programs for End of Life Care**

Since the IOM report on improving care at the end of life was issued in 1997, and with the gradual expansion in acceptance of the field of palliative medicine, there have been increasing reports about the slow expansion in educational efforts in the end of life care<sup>(70-80)</sup>. The IOM report documented a wide array of deficiencies in training of health-care professionals in end of life care. Specifically they noted medical training curricula in which the topics of death and care for the dying were most conspicuous by their absence. Additionally, numerous educational materials, including medical and nursing textbooks, have been woefully inadequate in this topic, which eventually touches all patients. Several studies have clearly documented a tremendous lack of attention to EOL issues in standard medical and nursing textbooks<sup>(81, 82, 83)</sup>. Additional studies among graduating medical students, and surveys of Deans of medical schools have demonstrated a prior lack of a significant commitment to education in end of life care<sup>(84-86)</sup>. 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>(87)</sup>. In 1998 the AAMC survey of graduating medical students suggested that 66 percent felt their training was inadequate in the area of pain management. Among graduate medical education, a survey by Hill in 1988 demonstrated that only 26 percent of residency programs in the United States offered a standard course in end of life care. Additional survey of 1400 internal medicine residents reported in 1997 found that only 32 percent felt they had adequate training in talking to patients request assistance in dying<sup>(89)</sup>. Sixty-two percent said they had adequate training and telling patients that they are dying. Surveys by Ferrell have further demonstrated deficiencies in nursing education regarding EOL care<sup>(82, 90-93)</sup>.

The recently convened National Consensus Conference on Medical Education for Care Near End of Life has resulted in several reports recommending changes in our medical schools and residency training programs<sup>(94)</sup>. Nevertheless, a significant time gap remains between when these physicians will assume the majority of care for Americans dying of terminal disease and the needs of patients. Furthermore, there are little data to suggest that those currently receiving training in medical schools will eventually be the “hands on” physicians caring for the patients with terminal malignancies. The vast majority of physicians will not pursue a career focused on cancer patient care, though nearly all physicians will have some contact with cancer patients if involved in a clinical specialty. The need remains to train the physicians who are currently caring for the vast majority of patients with advanced malignancies.

ELNEC is a program developed by the COH investigators in collaboration with the American Association of Colleges of Nursing (AACN) that has sought to enhance understanding among future nurses in caring for patients in the last stages of life. The proposed program is unique in two factors. First, it seeks to adapt the ELNEC curriculum in order to reach an interdisciplinary audience. Secondly, it addresses an audience focused on caring for patients with cancer.

The IOM report specifically called for improvements in education for not only physicians and nurses, but social workers and all other health care workers involved in the care of dying patients<sup>(2)</sup>. Previous successful educational courses offered to a interdisciplinary audience have been demonstrated in Canada, where McMaster University has more than a decade of success in managing a training course in palliative care offered to a interdisciplinary audience<sup>(95)</sup>. This program has expanded courses from once a year to twice a year while

maintaining a consistent balance of physicians, nurses, social workers, and allied health professionals year after year. The interdisciplinary nature of this course has been cited as a persistent highlight among course participants who gain from the varied strengths and understandings of professionals from outside their field. Interdisciplinary post graduate training programs in palliative education have also modeled to course participants the strengths and knowledge that multiple disciplines can add to quality patient care. The need to focus such an interdisciplinary EOL care educational program to an audience delivering a significant portion of cancer care in this country in a unique opportunity to affect the quality of dying among cancer patients as well as develop a program of dissemination that will eventually reach even greater numbers of cancer patients.

The content for the proposed training program is focused on priority clinical problems established through recent publications. Topics include pain<sup>(103, 106)</sup>, symptom management<sup>(14, 100, 102)</sup>, cultural considerations<sup>(17, 105)</sup>, ethical/legal issues<sup>(90-97)</sup>, bereavement<sup>(28, 98, 104)</sup>, quality of life issues<sup>(2, 48, 92)</sup> care at the time of death<sup>(30, 66)</sup>, and communication<sup>(99, 101)</sup>. The investigators have renewed previous efforts in medical and nursing education to identify successful strategies for teaching palliative care<sup>(107-120)</sup>.

Currently in this country, the complexities of medical care have lead to a broader acceptance of “centers of excellence” in medical care. The progressive acceptance of quality assurance in medicine has additionally demanded increasing accountability among health care delivery systems for outcome data. The combination of these two factors is increasingly resulting in centers of concentrated or specialized care. These centers of excellence are demonstrated by the expansion of National Cancer Institute designated clinical and comprehensive cancer centers. These centers are anticipated to deliver the highest level of cancer care in their respective communities, undergo rigorous review from the National Cancer Institute to receive this designation, and are anticipated to be leaders in all areas of cancer care. Our approach to focus our initial training in end of life care to cancer centers is in keeping with the mission of the NCI-designated clinical and comprehensive cancer centers to be leaders in all aspects of cancer care. Similarly, the Association of Community Cancer Centers (ACCC) is an ever-expanding society representing approximately 650 regional community cancer centers that focus the majority of their care on cancer treatment, and are representative of the continued spread of specialized medical facilities not only within major metropolitan areas, but large and middle size communities as well. Current estimates from the ACCC are that these regional cancer treatment facilities may be responsible for the treatment up as much as 40% of cancer patients in this country. The need to include these centers in our initial training efforts is paramount to effectively expand end of life education.

The combination of a growing national awareness of the importance of EOL care, significant evidence of a lack of educational background in current practitioners, and the growing concentration of cancer care into regional and nationally designated cancer centers offers a unique opportunity to significantly impact the quality of care for terminally ill cancer patients. The educational training program we have proposed will reach NCI-designated clinical and comprehensive cancer centers as well as ACCC regional and community cancer centers. We feel that this targeted audience of health professionals working in these two environments offers the best mode to bring about immediate impact in EOL care for cancer patients in this country, and effectively disseminate this knowledge to broader aspects of the cancer care community.

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

This proposal builds on two current End of Life (EOL) Education projects conducted by the COH investigators. The first, 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>(92)</sup> This program has been extended for the time period of 1998-2002 through a training grant funded by NCI 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  $X = 9.3$  and for the course materials was  $X = 9.4$  (on a scale of 0 = poor to 10 = excellent). The HOPE curriculum will be disseminated through a national conference of home care agencies to be held in March, 2001. Outlines of the HOPE curriculum are included in Appendix C.

The second project, the End-of-Life Nursing Education Consortium (ELNEC) is a comprehensive national effort to improve EOL care by nurses. This 3 ½ year effort, which began February, 2000, entails the partnership of American Association of Colleges of Nursing (AACN) and the City of Hope (COH) Cancer Center 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. The project, funded by the Robert Wood Johnson Foundation, is developing a core training curriculum to develop EOL expertise in faculty in undergraduate nursing programs, continuing education programs, and through the National Council of State Boards of Nursing, Inc. Based on the AACN *Peaceful Death* document, 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 quality of life at the EOL. Outlines of the ELNEC program are included in Appendix C. The first training program is slated for January, 2001 in Pasadena, CA.

In addition to these two critical EOL education projects, the COH investigators have an extensive record of training and research in areas of pain, quality of life (QOL) and EOL care. Following is a brief summary of their related experience:

(1) 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>(121-123)</sup> 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>(124)</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. This study was published in *Cancer*. 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>(125)</sup>

(2) 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 City of Hope. 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 more than 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>(126)</sup>

(3) 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 City of Hope (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>(127)</sup> The program has been replicated in more than 80 institutions across the country.

(4) 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 Survey Related to Pain (K&A), 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>(129)</sup>

(5) Interest in evaluating the improvement of institutional resources for improved cancer pain management was the impetus for a study examining readmissions 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 readmissions 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 readmissions 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 readmitted for uncontrolled pain decreased from 8.6% (255 patients) of the unscheduled readmitted population in 1989-1990 to 103 (6.3%) in 1993-1994. With 152 fewer readmissions, 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>(130)</sup> This study provided experience in assessing institutional outcomes of clinical practice change through education.

(6) 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 (COHPPRC) to include palliative care resources. Participants of this proposed project will have access to the COHPPRC 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>(131)</sup> The PRC became available on the Web effective January 1, 1998. More than 300 materials are listed and more than 200 are available on the website which is updated monthly. (<http://prc.coh.org>).

(7) 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>(132-135)</sup>

(8) Dr. Grant's study currently funded by the National Cancer Institute is titled "Improving Clinical Practice in Cancer Pain Management." The study provided three-day courses on Improving Clinical Practice in Cancer Pain Management 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 knowledge and attitude (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-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>(136-139)</sup>

(9) 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 includes 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 will be held in October, 2000 and this course has been 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 first program rated the overall course effectiveness at  $X = 4.84$  on a scale of 0 = low to 5 = high.

(10) 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>(82)</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>(140)</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>(90, 93)</sup>

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 pain management,

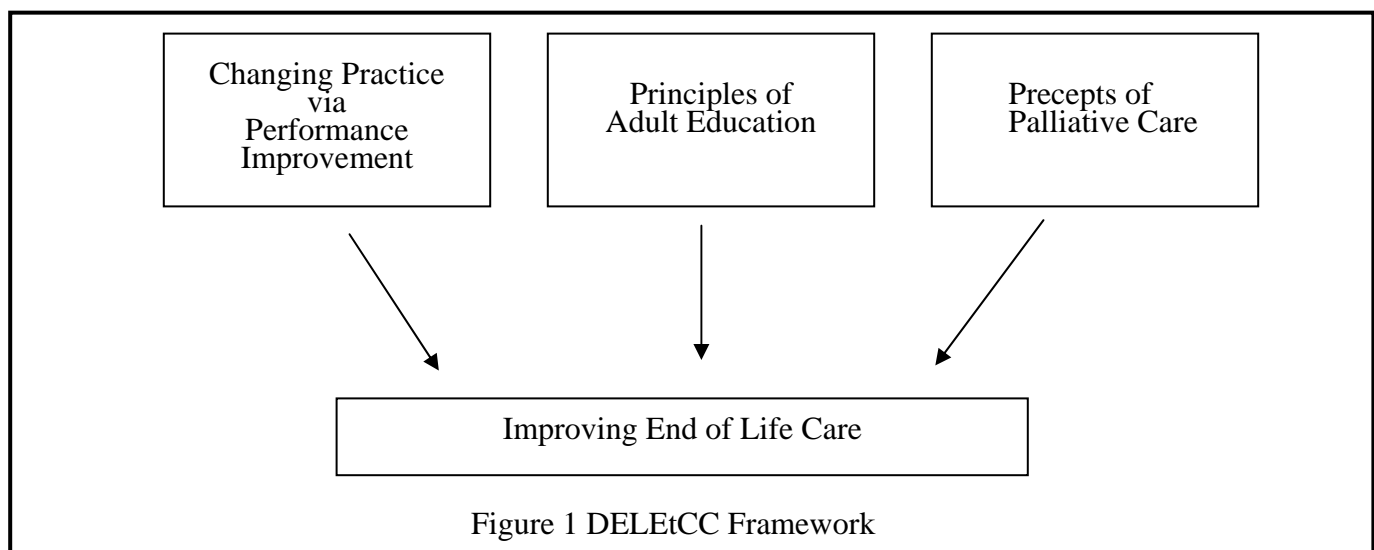
knowledge and attitudes regarding pain, institutional barriers related to changing practice as well as pain and quality of life issues. Drs. Grant and Ferrell have worked together for 11 years and have benefited from these and numerous other experiences in conducting national oncology training programs. 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. The proposed collaboration with multidisciplinary colleagues form COH and with a national advisory board and faculty compliment this record of education and research. Current projects have provided initial efforts in improving EOL care education, but have only begun to meet the needs of the approximately 4 million RNs/LPN's plus the various members of the interdisciplinary health care team. For patients with cancer, professional staff in cancer centers need access to this education and should be the leaders in their communities for further dissemination of the education.

## D. Research Design and Methods

### 1. Framework

The need for this training program is based on findings of a major study on improving end-of-life care conducted by the Institute of Medicine (IOM 1997). This study assessed the state of knowledge about important aspects of care for patients with life threatening medical problems; evaluated methods for measuring outcomes; identified factors that impede or promote high quality care for patients approaching death and proposed steps to be taken to improve end of life care. One of the recommendations of this study was that changes in continuing education were needed to ensure that practitioners have the relevant attitudes, knowledge and skills to care for dying patients (2). All health professionals dealing directly with patients and families need current information on how to give compassionate and competent care for seriously ill and dying patients. For clinical cancer settings, continuing education for professional staff should provide the knowledge and skills to change practice in end of life care.

The framework selected for meeting this educational need has three components: changes in practice, principles of adult education and selection of the educational content for EOL care. Each of these components provides direction in the development and implementation of this project. (Figure 1)



Changing Practice Via Performance Improvement Changing care in clinical settings is a major challenge. Our previous efforts in conducting courses and workshops to educate professionals to change pain management practices have identified several approaches that we feel are essential (128, 129, 138), Commitment by the participants and the institutional are needed. For participants, several activities are have assisted in this commitment. Participants were required to submit precourse data, describing their institution's program in pain

management, submit completed pain knowledge and attitude surveys for themselves and a group a staff, complete and submit chart audits on pain management, and identify written goals for changing pain management practice in their individual institutions. Continued commitment of participants following course completion was fostered by follow up evaluations of goal achievement at periodic intervals, and completion of the pain knowledge and attitude surveys by themselves and a group of staff approximately 12 months following completion of the class. Institutional commitment was obtained by requiring letters of support from the participant's administrator, chief of staff, and the nursing executive. For the proposed project these same methods will be applied and related to EOL care for cancer patients.

To further assist participants in changing clinical EOL care, a performance improvement (PI) approach will be used. PI is used in the health care setting as a strategy for evaluating, changing, and improving systems of care. This approach is derived from the work of W. Edwards Demming, a leader in transforming organizations (144). PI is advocated by the Joint Commission on Accreditation of Health Care Organizations, and will be familiar to the administrators at participants' institutions. PI provides a mechanism for improving EOL care that is advantageous for patients as well as the institution.

PI involves a cyclic approach to improving clinical practice by assessing the problem, planning an approach, implementing the approach, and reassessing the problem. The PI aspect of the framework directs the need to assess knowledge and attitudes on EOL care for course participants and the professional staff at their participating institutions, plan activities to improve care, implement the approaches and evaluate the impact of the change on the knowledge and attitudes on EOL care and the outcomes to patients. This assessment and reassessment can include changes in the care patients receive. The PI approach will be initiated in the course content on Institutional Change and be referred to throughout the course to assist participants in identifying and refining their post course goals. The PI approach will be used in participant follow up to demonstrate goal achievement in the participants' institutions.

Principles of Adult Education The education component of the framework will provide guidance to the selection of course content and methods, and will also be used as a course topic so that participants can apply these principles as they implement education goals in their own institutions. Assumptions about adult learning are based largely on the works of Knowles (145). 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. The survey on knowledge and attitudes of EOL care that participants complete prior to the course will provide faculty with valuable information about the audience. 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. It is anticipated that participants will implement educational activities at their own institutions in order to change EOL care. Therefore, participants will be provided with multiple learning resources including lecture notes, slides, and other educational tools. Course content will also include teaching participants the principles of adult education so that they can apply them as a foundation for facilitating, planning, and developing educational projects at their specific institutions.

Precepts of Palliative Care The third component of this framework, the Precepts of Palliative Care, provides an approach to the selection of content for EOL care. These precepts will be used to identify, revise, and refine the content in EOL care appropriate for the course. The Precepts of Palliative Care were identified by the Last Acts Palliative Care Task Force and published in December 1997 (146). 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. Further definitions of each of these precepts are found in Table 1. These precepts will be used to evaluate the content in the DELEtCC curriculum.

In summary, the framework provides directions for change (PI), guidance for teaching (adult learning principles) and an approach for selection of content (Precepts of Palliative Care).

**Table 1**  
**Precepts of Palliative Care**

<b>Precept</b>	<b>Description</b>
<b>Respecting Patient Goals, Preferences and Choices</b>	<p><b>Palliative Care</b></p> <ul style="list-style-type: none"> <li>◆ Is an approach to care that is foremost patient-centered and addresses patients needs within the context of family and community</li> <li>◆ Recognizes that the family constellation is defined by the patient and encourages family involvement in planning and providing care to the extent the patient desires.</li> <li>◆ Identifies and honors the preferences of the patient and family through careful attention to their values, goals and priorities, as well as their cultural and spiritual perspectives.</li> <li>◆ Assists patients in establishing goals of care by facilitating their diagnosis and prognosis, clarifying priorities, promoting informed choices and providing an opportunity for negotiating a care plan with providers.</li> <li>◆ Strives to meet patients’ preferences about care settings, living situations and services, recognizing the uniqueness of these preferences and the barriers to accomplishing them.</li> <li>◆ Encourages advance care planning, including advance directives, through ongoing dialogue among providers, patients and family.</li> <li>◆ Recognizes the potential for conflict among patient, family, providers and payors, and develops processes to work toward resolution.</li> </ul>
<b>Comprehensive Caring</b>	<p><b>Palliative Care</b></p> <ul style="list-style-type: none"> <li>◆ Appreciate that dying, while a normal process, is a critical period in the life of the patient and family, and responds aggressively to the associated human suffering while acknowledging the potential for personal growth.</li> <li>◆ Places a high priority on physical comfort and functional capacity, including, but not limited to: expert management of pain and other symptoms, diagnosis and treatment of psychological distress and assistance in remaining as independent as possible or desired.</li> <li>◆ Provides physical, psychological, social and spiritual support to help the patient and family adapt to the anticipated decline associated with advanced, progressive, incurable disease.</li> <li>◆ Alleviates isolation through a commitment to non-abandonment, ongoing communication and sustaining relationships.</li> <li>◆ Assists with issues of life review, life completion and life closure.</li> <li>◆ Extends support beyond the lifespan of the patient to assist the family in their bereavement.</li> </ul>
<b>Utilizing the Strength of Interdisciplinary Resources</b>	<p><b>Palliative Care</b></p> <ul style="list-style-type: none"> <li>◆ Requires an interdisciplinary approach drawing on the expertise of, among others, physicians, nurses, psychologists, pharmacists, pastoral caregivers, social workers, ancillary staff, volunteers and family members to address the multidisciplinary aspects of care.</li> </ul>

Precept	Description
	<ul style="list-style-type: none"> <li>◆ Includes a clearly identified, accessible and accountable individual or team responsible for coordinating care to assure that changing needs and goals are met and to facilitate communication and continuity of care.</li> <li>◆ Incorporates the full array of inter-institutional and community resources (hospitals, home care, hospice, long-term care, adult day services) and promotes a seamless transition between institutions/settings and services.</li> <li>◆ Requires knowledgeable, skilled and experienced clinicians, who are provided the opportunity for ongoing education, professional support and development.</li> </ul>
<b>Acknowledging and Addressing Caregiver Concerns</b>	<b>Palliative Care</b> <ul style="list-style-type: none"> <li>◆ Appreciates the substantial physical, emotional and economic demands placed on families caring for someone at home, as they attempt to fulfill caregiving responsibilities and meet their own personal needs.</li> <li>◆ Provides concrete supportive services to caregivers such as respite, round-the-clock availability of expert advice and support by telephone, grief counseling, personal care assistance and referral to community resources.</li> <li>◆ Anticipates that some family caregivers may be at high risk for fatigue, physical illness and emotional distress, and considers the special needs of these caregivers in planning and delivering services.</li> <li>◆ Recognizes and addresses the economic costs of caregiving, including loss of income and non-reimbursable expenses.</li> </ul>
<b>Building Systems and Mechanisms of Support</b>	<b>Palliative Care</b> <ul style="list-style-type: none"> <li>◆ Requires an environment that supports innovation, research, education and dissemination of best practices and models of care.</li> <li>◆ Needs an infrastructure that promotes the philosophy and practice of palliative care.</li> <li>◆ Relies on the formulation of responsible policies and regulations by institutions and by state and federal governments.</li> <li>◆ Promotes equitable and timely access to the full array of interdisciplinary services necessary to meet the multidimensional needs of patients and caregivers.</li> <li>◆ Demands ongoing evaluation, including the development of research-based standards, guidelines and outcome measures.</li> <li>◆ Assures that mechanisms are in place at all levels (e.g., systems, direct care services) to guarantee accountability in provision of care.</li> <li>◆ Requires appropriate financing, including the development of new methods of reimbursement within the context of a changing health care financing system.</li> </ul>

## 2. Content and Scope of Educational Activities

The objectives for this course on EOL care for cancer centers are found in Appendix A. These objectives are derived from the competencies identified for professional preparation for end of life care as defined in the Institute of Medicine report on end-of-life care (2). These competencies include scientific and clinical knowledge and skills, interpersonal skills and attitudes, ethical and professional principles and organizational skills. This content and the objectives address the major opportunities for improving end of life care for patients in cancer centers. Principles of institutional change and adult education are included to assist participants in carrying out individual goals to improve EOL care at their respective institutions.

The proposed agenda for the course is included in Appendix B. The agenda provides for a three-day course and is adapted from the nursing curriculum on EOL care. This agenda will be adapted to focus on cancer patients in

cancer centers and the interdisciplinary group defined as physicians, nurses, social workers, clergy, psychologists, pharmacists, rehabilitation professionals and unlicensed personal.

The course materials are divided into nine modules on EOL care and 3 modules on organizing principles (Appendix C). The EOL care modules currently focus on the following areas. 1. Introduction to end-of-life care, 2. Pain management, 3. Symptom management, 4. Cultural considerations in end-of life care, 5. Ethical/legal issues, 6. Communications, 7. Loss, grief and bereavement, 8. Preparation and care for the time of death, 9. Achieving quality of life in end of life care. Each of these modules will be reviewed and revised by the interdisciplinary team at City of Hope (COH) who serve as co-investigators of the project. The Precepts of Palliative Care will be used as the source for identification of appropriate content (Table 1). Universal themes that are to be found across all modules include cultural issues, individuals at risk, the patient advocate role, family centered care, cost issues and interdisciplinary care. Modules will be developed in parallel fashion to include objectives, a brief outline, detailed faculty outline, case studies, test questions, a reference list, a resource list, handouts and teaching resources, permissions, and slide content. Revised modules will be sent to the appropriate faculty member, along with the Module Evaluation Form (Appendix J). An example of a complete module for the ELNEC project focusing on pain management is found in Appendix D.

Course content will be presented over a 3-day period and repeated 3 times for a total of four annual courses. Multiple activities will be planned to promote discussion and networking. Day One of the course will begin with background information and the framework and overview. A review of course participants' results of their pre-course evaluations will be used to begin introductions of all participants and assist them to focus on goal setting. Module One will introduce EOL care, and discussion groups will focus on the case study. Other content for Day One includes Pain Management and Symptom Management with each followed by a discussion group with assessment skills and case studies discussed. Faculty will divide their presentation time between content specific to the topic plus suggestions and examples on how to disseminate this information and implement it into the care patients receive at the various participants' institutions. Practical application to cancer centers will be a priority. Universal themes across all modules will include cultural incentives, individuals at risk, the patient advocate role, family-centered care, cost issues and interdisciplinary care approaches. Cost will be addressed by including financial information available on various interventions (e.g. cost of specific pain medications). Participants will be encouraged to use a cost analysis at their own institution depending on the availability of resources to conduct such an analysis. While cost is certainly a measure of outcome and impact at the institution level, it is too far removed from the course content and implementation to be an evaluation component required by all participating institutions. An evaluation of the day is included and revisions to goals begun.

Day Two begins with a panel of past participants in EOL training courses, who will be selected by the PI from ELNEC participants the first year, and then participants from the previous year for each of the next 3 DELEtCC courses. Panel members will share successes and challenges, and how they managed the challenges. The next four modules will be discussed: cultural considerations, legal/ethical issues, communication, and grief, loss and bereavement. An evaluation of the day and another revision of participants' goals are carried out at the end of the day.

Day Three begins with a session to refine goals, and a presentation of the Cancer Center Perspective. EOL care modules include preparation for death and quality of life at the end of life. Following completion of the nine modules there will be sessions on quality improvement strategies that can be used at various institutions and a review of educational principles to be used during staff education sessions. Participants commit to their goals through sharing them with each other.

Immediate post-course evaluation includes a knowledge and attitude survey and a course evaluation. For all three days, networking will be encouraged in a variety of ways. Lunchtime seating will be by discipline one

day, by geographic area another day, and by size and characteristics of institutions the third day. With permission from each participant, a list of names, addresses, phones, faxes, and e-mails will be assembled and distributed. Another approach to encourage this networking will be to ask participants to bring simple poster exhibits or handouts of current programs for improving any aspect of end of life care in their institution. These posters will be available in the mornings, during breaks, and during lunch. Participants will be encouraged to meet each other and look over the posters and handouts to share current efforts on end of life care at each institution.

A strength of the project is the faculty and members of the Advisory Committee all of whom are recognized as national experts in their field. Letters of support from the Advisory Committee members are found in the section on Consultants. Letters of support and biosketches of all faculty are found in Appendix G.

Multiple methods for reinforcing the program content are planned. First, all course lectures will be video taped and each participant will receive a copy on video of all lectures so that they can be used in their settings. It is anticipated that each participant will involve several colleagues in their educational activities when they return to their institution. Thus, the videos may be used to prepare other trainers in their settings or for use in actually training staff. A second method of reinforcement is that the investigators will create and mail a newsletter to all participants on a quarterly basis for one year following their participation. The purpose of this newsletter is to reinforce their efforts, share the ongoing experiences of the participants with others, and keep participants aware of new resources. Various participants will be interviewed for the newsletter. Regular columns about new resources available on EOL care and ongoing tips for effective teaching will be included.

Other methods of reinforcement for the project are based on computer and Internet access. City of Hope investigators launched a website for the Pain and Palliative Care Resource Center (PRC) in January 1, 1998, which has been very well received. The PRC is a national clearinghouse of pain and palliative care information, which has been described in the Section C on Previous Research by the Investigators. Website address for the PRC is <http://prc.coh.org>. A demonstration session for the PRC will be part of the course agenda and the website will be used as a means of rapid transmission of new information to reinforce the course. The PRC currently has more than 300 materials, of which more than 200 are directly available on the website, and links with other sites and identifies those materials directly on the web.

### **3. Specific Population to be Educated and Their Availability**

Mailings will include marketing materials to NCI-designated cancer centers and community cancer centers. These centers are located throughout the United States. Currently, there are 50 clinical and comprehensive cancer centers funded through the NCI Center mechanism. The mailing list for community cancer centers will be obtained from the Association of Community Cancer Centers (ACCC). This organization was founded in 1974 and is a national interdisciplinary organization that focuses on defining quality care for patients with cancer and continually improving oncology care. Membership is by organization, with 603 members in March, 2000 (Ref). ACCC estimates that their organization sees approximately 40% of all new cancer patients. Membership includes all members of the cancer care team: physicians, program administrators, nurses, social workers, and data managers. We have used their mailing list in previous pain management courses, and found them both eager to attend, and successful in implementing goals for changing care of patients. Their journal, Oncology Issues, published 6 times per year, as well as their annual meeting will provide avenues for disseminating results of this project.

A total of 150 participants from 75 institutions will be selected for each three-day course. Participants from NCI-designated cancer centers will be given priority each course, with additional sites coming from the ACCC membership. The availability of the audience can be assured from our past records of course applicants. For our previous pain courses which focused on clinical settings, a total of 244 applications were received, for a total of 144 positions (44 in year 01, 58 in year 02, and 42 in year 03. The project budget had provided for only

40 positions per year. Additional resources were needed for additional participants). In the project on Patient and Community Education in Pain Management, first year applications equaled 180 from 40 states. Because only 50 positions were available, supplemental funding was sought, and 148 applicants were accepted. Equal or increased enthusiasm is expected for the DELEtCC, since our first ELNEC course received 429 applications, from which 100 participants will be selected. All courses have been consistently filled to capacity. We have raised the ceiling for attendees to 150 because two attendees will be present from each institution. We feel this is the maximum we can accommodate and still implement the principles of adult education, and provide follow up evaluations from 75 institutions per course.

The applicants may be nurses, physicians, social workers as tier 1 and pharmacists, psychologists, rehabilitation specialists, clergy and unlicensed personnel as tier 2. Each institution can apply with one or two members from tier one, and a maximum of one member from Tier 2. The rationale for this selection process is to provide access for personnel involved in the leadership role of the institution and who may be influential in producing changes in patient care. Our previous experience with pain management education has demonstrated the value of two people from one institution<sup>(129)</sup>. The application form will include information on the experience of the applicants in caring for patients with cancer and their participation in the institution's PI process.

#### **4. Procedures for Recruitment of Participants**

A total of 600 participants, representing 300 institutions (150 participants from 75 institutions for each of four courses), will be competitively selected from submitted applications. Prior to each course, announcements will be mailed using lists obtained from the National Cancer Institute (NCI) and the ACCC. Announcements will also be made regarding the application process in various journals (Oncology Nursing Forum, Oncology Issues, Cancer Nursing, Cancer Practice, Cancer, Journal of Clinical Oncology, Journal of Pain and Symptom Management, and the Journal of Palliative Care). The application will include information on both applicants as well as the institution. The packet will also require letters of support from the cancer center medical director, the nursing administrator, and the institution's administrator (or a comparable position). These letters will assist with institutional commitment which is needed if successful changes to clinical care are to be made. The letter will also identify who to contact for evaluation at 6, 12, and 18 months. Institutional commitment has been effective in assisting participants in our previous courses – the Mayday funded Institutional Commitment to Pain Management, and our NCI funded faculty educator courses on pain management, and our courses on pain management for clinical institutions. This commitment has enabled the participants to implement their goals to improve care in their institutions. The application packet also identifies the participants' role in providing pre-course data. These requirements have been effective in our other courses to identify participants who will be active, committed, and effective in changing clinical practice in their own settings. Applications will be reviewed by the investigators using the Application Evaluation Checklist (Appendix J). These review criteria will provide priority for participants in NCI-designated cancer centers, geographic distribution, access to minority population, and representation from each of the multidisciplinary professionals identified in Tiers 1 and 2.

Plans have also been developed to recruit and train ethnic minority participants or those who work in minority institutions. A minimum of 30% of the participant spots will be reserved for minority participants or those from minority serving institutions. The application form in Appendix I includes data for these decisions. Additionally, the investigators will promote the application by individuals representing minority-serving institutions through the marketing efforts of the course including mailing to minority professional organizations (such as the African American Nurses and Hispanic Nurses Associations), hospitals and agencies in predominant minority settings, and announcements to other groups such as previous participants in the Oncology Nursing Society (ONS) education courses and the multicultural special interest group of ONS. All participants will be encouraged to develop goals which target minority populations through several means including the program session on cultural considerations, asking all speakers for all sessions to address cultural

issues, and reinforcements with special content on this topic through the PRC Website and the reinforcement newsletters.

Prior to attending the course, selected participants will be required to complete and submit the pre-course evaluation materials as described in the evaluation section below. A candidate's failure to complete pre-assessment materials will result in his/her replacement by an alternate. Participants will be required to bring three institutional goals with them.

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

The project is designed to improve the care of patients with cancer at the EOL. It is intended to help decrease the morbidity associated with unrelieved pain and other symptoms, to improve patient/family communication, and to improve the quality of care at the actual time of death. Participants will be drawn from the interdisciplinary teams involved in the care of cancer patients, and include physicians, nurses, social workers, pharmacists, psychologists, rehabilitation professionals and unlicensed personnel. The challenges involved in EOL care include dealing with uncomfortable and emotionally challenging needs of patients and families. This innovative program focuses on personnel in cancer centers, whose position in their communities include modeling the best care available for patients. A total of 600 participants from 300 cancer centers will participate in one of four courses. The targeted cancer centers, 50 NCI designated clinical and comprehensive cancer centers, and the 650 institutions that are members of ACCC, provide care to a substantial number of cancer patients, with the 650 seeing approximately 40% of all new cancer patients. Combined with the NCI cancer centers, our training could reach institutions which provide care to over 50% of all cancer patients. Additional broad dissemination methods will be used to provide for nationwide distribution to other settings.

Course content will include the framework (PI) for changing clinical practice and using adult education principles. Course content will be shaped by the Precepts of Palliative Care, where patient and family needs are easily evident.

A strong evaluation plan and opportunities for dissemination following completion of the project further strengthen the potential benefits to cancer patients. Each institution will be implementing goals at their institution once they have completed the course. Their leadership in their communities for EOL care will benefit theirs as well as other institutions caring for cancer patients.

## **6. Methods of Evaluation**

To evaluate dissemination of EOL education to cancer centers, an extensive evaluation plan has been developed based on the experience of the investigators in educational programs as well as from their research. Data used for evaluation are derived from pre course materials starting with the participants' applications and continuing through the 18 months following each course (except for the 4<sup>th</sup> course, when follow up ends at 12 months). A number of evaluation tools have been created specifically for the DELEtCC project. Some of the evaluation tools have been used in other courses. All tools will be pilot tested while the curriculum revisions are occurring (month 5). The evaluation includes the process, outcome and impact of the program. In addition, the focus of the evaluation is on the participant, the nature of the team from each institution, the institution, and the EOL curriculum content. Table 2 identifies the evaluation plan by type and target of the evaluation. Each tool is described next. Table 3 identifies the time evaluation is conducted for each course.

**Table 2  
Evaluation Plan**

	<b>Process*</b>	<b>Outcome**</b>	<b>Impact***</b>
<b>Curriculum Content</b>	Module Evaluation Form		
	Course Evaluations	Administrative Interviews	Website Activity PRRMC I Requests
<b>Individual</b>	K&A Survey	K&A Survey	K&A Survey
	Agency Application		
	Pre Course Goals	Post Course Goals	Goal follow-up
	Letters of Support	Administrative Interview	Administrative Interview
			Participant Goal Achievement Interview
<b>Team from Each Individual Institution</b>	Agency Application	Post Course Goals	K&A Survey
	K&A Survey	Agency Application	K&A
	Chart Audits		Chart Audits
		Administrative Interview	Administrative Interview
	Case Study Analysis Discussion		Case Study Analysis Discussion
	Pre Course Goals	Post Course Goals	Goal Follow-up
	Organization Assessment		Organization Assessment
			Participant Goal Achievement Interview

\*Process = Pre or during course;\*\* Outcome = Immediately post course;\*\*\*Impact = 6, 12, and 18 months after course

Agency Application: (Appendix I) This tool provides descriptive data about the agency and an assessment of interest and current status of end of life care. It is modified from our HOPE project. It is completed by a Cancer Center administrator in collaboration with the two institution applicants. The application provides data on the discipline of the applicant, experience of the participants, and characteristics of the institution. Three letters of support are included in the application from the Director of Nursing/Patient Care Services, Chief of Staff/Medical Director, and an Institution Administration representative. These letters of support are used to capture commitment and support from the institution and will be used as a baseline of enthusiasm for institutional change. Data will be used for individual and team process and for institution outcome evaluation. It will be used to characterize participants and institutions and allow for comparison (type of discipline involved, large vs. small institutions, etc.).

Module Evaluation Form (Appendix J). This form is used by the investigators and by the Faculty in evaluating the adapted modules prior to course implementation. It provides for expert content review. The form provides for an accounting of all the required components of the module (case studies, resource list, etc). Data are used to evaluate the curriculum content for process.

Application Evaluation Checklist: This checklist is used by the City of Hope team of coinvestigators to evaluate the applications received. It addresses geographic location, ethnicity of the cancer population, leadership experience of the applicants, and several other aspects. It is used to screen those not eligible and provide data for prioritizing applications for invitation to the course. We are currently using a parallel form for processing ELNEC applications.

DELEtCC Knowledge and Attitude (K&A) Survey: This survey will be adapted from the ELNEC curriculum to reflect interdisciplinary care and cancer patients. We are unable to include the current ELNEC knowledge survey tool as reliability and validity of the instrument are being developed within the ELNEC project, and distributing it would jeopardize the validity of the instrument. In place of this as example only is the HOPE survey (Appendix J). This survey was developed to describe EOL knowledge and attitudes of nurses in home care agencies. The process of test construction resulted in a 24-question survey. Mean score pre education was 84.6%. Post course mean score increased to 89.0 % ( $p < 0.0001$ ). Test construction principles will be used to refine the questions from each ELNEC module to focus on cancer centers and the interdisciplinary team. K&A survey results will be used as process, outcome, and impact data for individual course participants and for a minimum sample of 20 staff from each institution for process (pre course) data and at 6, 12, and 18 months for course impact. Long term follow-up at 18 months will indicate changes that have occurred, and whether or not those changes have persisted.

Chart Audit Tool (Appendix J). This tool is used to capture information that has been documented about EOL care issues. Data include EOL care information expected in the medical record from one chart per time period (pre 6, 12, and 18 months). Selection criteria for the charts will be the same as that as used in the SUPPORT survey. Data are used to evaluate the institution for process and impact.

Case Study Analysis Discussion Form: (Appendix J) This form has been designed for use before and after the course implementation as a means of having the agency apply EOL care principles to an actual patient cared for by their agency. It will be completed by the staff of the cancer center as a group with the institution's course participants as leaders. Further pre course case study staff will select a patient who recently received EOL care by the agency and will use the form to analyze agency strengths and weaknesses. The post course case study will be a recent terminally ill patient at 6, 12 and 18 months post course. Data will be used for institutional assessment for process and impact evaluation.

Organizational Assessment Tool (Appendix J). This tool is a self-rating instrument for providing organizations with information about supportive structures for EOL care. It was designed by the Supportive Care of the Dying, and is filled out during a group meeting. The meeting will be lead by the course participants. Data are used to evaluate institutions for process and impact and will be carried out pre course and at 12 months.

Course Evaluation (Appendix J). This evaluation form has been used extensively by the COH Education Department. It provides evaluation from the participants on the actual course for each day. Data are used to revise subsequent courses and in determining the content most valuable to the participants. Data are used to evaluate curriculum content for process.

Final Goal Form (Appendix J) The investigators have learned the value of training programs which are based on the establishment of individual goals submitted and committed to by participants. The use of participants' goals pre course and evaluation of the goals following the course is consistent with adult learning principles. Participants will be asked to work as an institutional team of two to establish goals prior to coming to the course. During the three day course, goals will be refined and revised as ideas from discussion and networking lead to more specific ideas and strategies for implementation. Participants will be asked to include the target audience in the goal (which health professionals at the institution), method of education if applicable, and connection with the institution's quality improvement program.

Administrative Interview (Appendix J). This tool will be completed via phone interviews to one of the designated administrator (Director of Nursing/Patient Care Services, Chief of Staff/Medical Director, or an Institution Administration representative). The selection of the administrator to contact will be made by each agency with arrangements for the phone interview made by the investigator. Questions focus on whether or not the administrator perceives the course content and local implementation appropriate. Information will also include the leadership skills and change agent abilities of the course participants and their fit with the agency. Questions also provide data on institutional changes that may affect EOL care. Data are used to evaluate the individual and the institution for outcome and impact, and the curriculum content for outcome.

Goal Evaluation Tool (Appendix J). This tool will be used by the investigators at 6, 12 and 18 months post course to evaluate goal achievement by participants; Data from this tool will identify which goals are implemented most commonly across institutions, and which goals meet the most resistance to implement. Data will be used for individual, team, and institutional assessment for process, outcome and impact.

Participant Goal Achievement Interview (Appendix J). At 6, 12 and 18 months post course, participants will be interviewed by telephone to determine the institutional successes and barriers encountered when trying to implement goals. Comparison of responses by each team member will be used to identify any differences in perceptions within an institution. Results will be used to alert future course participants to commonly-encountered obstacles, and approaches and activities that were successful. Data will be used for individual, team and institutional assessment for impact.

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

Instrument	Pre-Course	Course Day 1	Course Day 2	Course Day 3	Immediate Post-Course	6 Months	12 Months	18 Months
Agency application	X					X	X	
Letters of Support	X							
Participants K&A	X				X		X	X
Institutional staff K&A	X						X	X
Pre-course goals	X							
Chart Audits	X					X	X	X
Case Study Analysis	X					X	X	X
Institution Asses.	X						X	
Daily course evaluation		X	X	X				
Post-course goals					X			
Administrative Interview					X	X	X	X
Faculty Debriefing					X			
Goal evaluation tool						X	X	X
Participant Goal Achievement Interview						X	X	X

Data from all forms will be coded, entered and analyzed at the COH. Each institution will receive a report of their own agency data and results from the total group. Table 4 organizes evaluation instruments by aim.

**Table 4**  
**Evaluation by Aim**

<b>Aims</b>	<b>Instruments</b>
1. Adapt the existing EOL curriculum to focus on patients with cancer and address an interdisciplinary professional audience.	Precepts of Palliative Care Module evaluation tool
2. Implement the curriculum in national workshops to competitively selected staff from National Cancer Institute-designated clinical and comprehensive cancer centers, and community cancer centers as identified through the Association of Community Cancer Centers (ACCC).	Agency application Course evaluation Faculty debriefing
3. Develop a network of course participants to share experiences in dissemination of the curriculum to the staff of participating cancer centers.	Newsletter articles Newsletter responses Website stats
4. Evaluate the impact of the curriculum on participants' and cancer center staffs' knowledge and attitudes about EOL care and the implementation of individual goals for improved EOL care in respective cancer centers.	K&A survey Case study analysis Institution assessment Goal evaluation tool
5. Evaluate EOL care at the participant level, the inter-disciplinary cancer team level, and the institution level for the ability to change and sustain improvements in EOL care.	See Table 2
6. Document and describe issues related to dissemination of EOL education in cancer centers.	Participant goal achievement interview
7. Refine the curriculum for broad dissemination to cancer centers to improve EOL care for cancer patients nationwide.	Course evaluations Website stats

## **7. Timeline**

The first five months of the project will be used to adapt the ELNEC curriculum to focus on the interdisciplinary team and cancer patients. Pilot testing of all evaluation tools will occur. The Advisory Committee will meet to review the curriculum, the evaluation tools, and critique the recruitment materials. This committee will also review the plan for inclusion of minorities. Announcements and advertisements will occur and selection of participants for the first course will occur by the 8<sup>th</sup> month. The first course will be held in the 10<sup>th</sup> month of the first year, with evaluation of pre course materials being used to provide feedback to participants at the start of the course. Post course evaluations will provide initial outcome data, and 6,12, and 18 month data will provide information on the impact of the course on participants, the team attending, the institution and the curriculum. This pattern will occur for each of the four courses, except the last course which will have follow up only until the 12 month period. Each year the Advisory Committee will meet to review course evaluations and recommended changes where needed, advise on dissemination methods, and assist in interpreting data from the goal achievement follow up, the knowledge and attitude survey results, and the institutional descriptions. This committee will also advise the investigators on publication and presentation recommendations. A detailed summary of the Timeline is found in Appendix E.

## **8. Innovation**

This project builds on the investigators background in national courses in pain management. It is innovative in that it focuses on EOL care and targets cancer centers as models for this care and focuses on the interdisciplinary team. It will be the first national effort to our knowledge to improve end of life care in the nation's cancer centers.

## **9. Plans to Disseminate Results**

Dissemination of this educational endeavor will begin with the completion of the first training program. Because this project is based on the content and methods used in the ELNEC program, the time line for this project allows for rapid implementation rather than delay by a lengthy period of development.

The investigators will analyze the pre and post course evaluation data and determine what areas of significant change occur. Results of this evaluation will be used to a) identify materials and approaches to improved EOL care that appear to have a major impact and b) identify teaching methods that appear to be associated with positive changes. These results will be disseminated in several ways. Publications will be prepared for submission to interdisciplinary journals; results will be incorporated into presentations that the investigators carry out at local, state, and national meetings. Previous educational efforts by the City of Hope investigators have resulted in numerous peer reviewed publications and presentation.

Participants who successfully carry out their institutional goals will be encouraged to prepare their results for presentation and publication. The annual meeting of the ACCC is expected to be an excellent program for these presentations, and ACCC has encouraged us to promote this vehicle for dissemination. Continued dissemination of the positive aspects of this program will occur in the courses taught by the investigators and faculty that are a part of this project. The long term follow up after completion of the project is appreciated by the investigators and will be pursued. All course materials will be submitted to Pain Resource Center at the City of Hope for distribution to others.

In summary, the investigators have planned to implement four courses for 2 participants from each of 75 cancer centers, for a total of 300 institutions and 600 participants. Dissemination will occur not only in the cancer centers participating, but in the communities in which the centers are located, as expertise in EOL care is demonstrated and shared. The strong team of investigators, Advisory Committee members, and faculty provide a foundation for successful implementation of this program in cancer centers for improving EOL care for cancer patients nationwide.

## **E. Human Subjects**

IRB approval has been reviewed by the Director of Research Subjects Protection at the City of Hope and granted exemption status. Processing of human consent will vary according to the policies and procedures of the participating institutions in their gathering data and implementation of training in their institutions

## **F. Vertebrate Animals**

Not applicable

## G. Literature

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