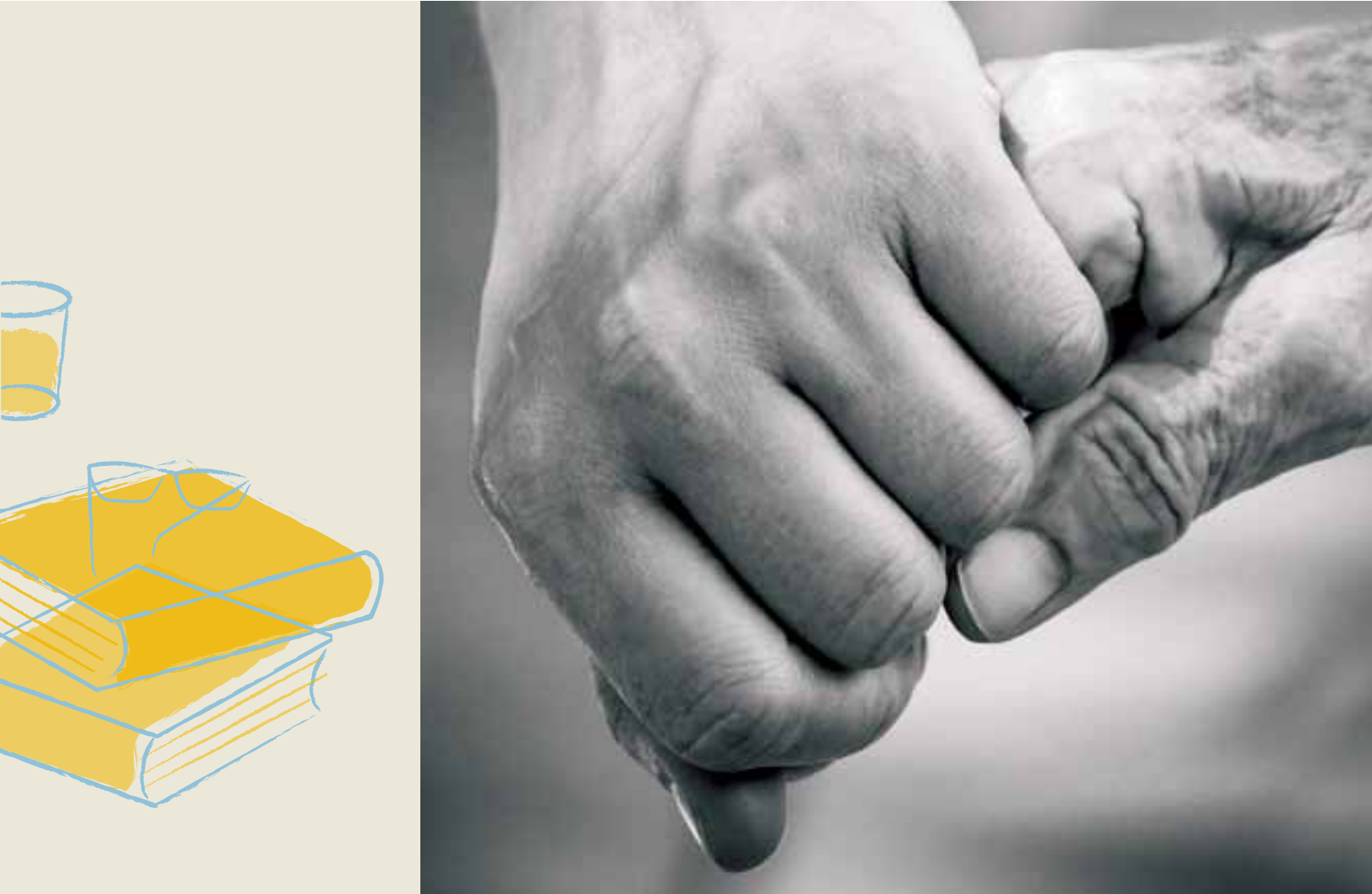


End-of-Life Nursing Education Consortium (ELNEC)

History, Statewide Effort and Recommendations for the Future

Advancing Palliative Nursing Care



A partnership between City of Hope and the American Association of Colleges of Nursing

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Acknowledgements: ELNEC is a national educational program administered by the City of Hope and the American Association of Colleges of Nursing and designed to enhance palliative care in nursing. ELNEC was originally funded by a grant from The Robert Wood Johnson Foundation in 2000. Since 2003, the project has received additional key support from these supporters: Aetna Foundation, Archstone Foundation, Bristol Myers Squibb Foundation, California HealthCare Foundation, the Department of Veterans Affairs, National Cancer Institute, Oncology Nursing Foundation, and the Open Society Foundations.

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Executive Summary

Nurses spend more time than any other healthcare professional at the bedside, in the community, and in clinics caring for patients and families who face end-of-life issues. Nurses assist patients in navigating the healthcare system and provide counsel in their many decisions.

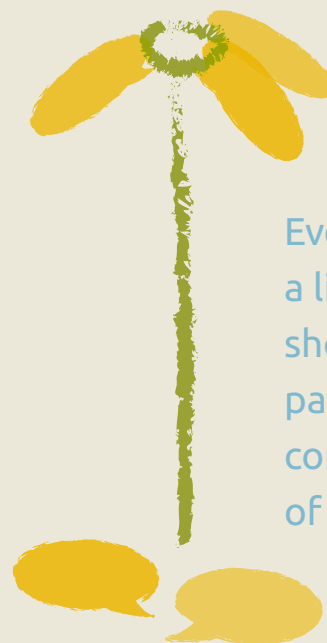
Working with patients and families to prevent and/or relieve end-of-life suffering requires thoughtfulness, time, and organization. It also takes a team effort. Nurses play a significant role in facilitating effective collaboration among physicians, psychologists, social workers, chaplains, pharmacists, nutritionists, and other care providers to ensure goals of care are met in a wide variety of clinical settings. Although patients may be diagnosed in a clinic, many will have frequent admissions to an acute care setting for evaluation, tests, and treatment. Many will be discharged to home care or to long-term care facilities. To make this care as seamless as possible, nurses in each of these clinical settings need to understand palliative care and gain experience in caring for those at the conclusion of their lives.

Patients also must be educated on care options so they can make informed decisions according to their individual wishes. Ideally, every patient with chronic, life-limiting illness would receive a palliative care consult at the time of diagnosis.

Palliative care is both a “philosophy of care and an organized highly structural system for delivering care”.¹ It attends to the body, and offers assessment and management of psychological, emotional, social, and spiritual needs. Palliative care can be provided concurrent with life-prolonging treatment. It expands

traditional disease-model medical treatments to embrace quality of life for patients and family members, support decision-making, and open up opportunities for personal growth.

Though nurses are key to providing palliative care, they cannot do so if they have not been trained. In 2000, nursing researchers from City of Hope and colleagues at the American Association of Colleges of Nursing (AACN) partnered to develop a new curriculum—End-of-Life Nursing Education Consortium (ELNEC)—to meet the needs of these professionals. This historic step came after years of data collection from Schools of Nursing faculty, clinicians, continuing education providers, and staff development educators. Since ELNEC’s inception, seven separate curricula have been developed and widely presented throughout the United States and in six continents. The result: ELNEC is implementing a comprehensive global effort to improve end-of-life care by nurses.



Every patient with a life-limiting illness should receive a palliative care consult at the time of diagnosis.

In the late 1990s, two major events occurred on two different coasts in the United States with the aim of improving end-of-life care for all Americans. In 1997, nursing researchers at the City of Hope in Duarte, California, outside Los Angeles, began to collect data showing that nurses had little knowledge about how to care for people with life-threatening illness and their families.²⁻⁵

ELNEC: A History of Need and Collaboration

“Strengthening Nursing Education to Improve End-of-Life Care”—was supported by The Robert Wood Johnson Foundation (RWJF). The City of Hope research identified major deficits in nursing education, including that less than 2% of content in nursing textbooks was related to end-of-life and that nursing faculty had extremely limited knowledge in teaching such care, barriers which would prevent good palliative care.

Also in 1997, the American Association of Colleges of Nursing (AACN) in Washington, D.C., convened a workgroup, again supported by RWJF, to develop competencies in end-of-life care for baccalaureate nursing students. Out of this workgroup came *“A Peaceful Death: Recommended Competencies and Curriculum Guidelines for End-of-Life Care”*.⁶

As a result of this confluence of events, and growing nationwide interest, the ELNEC project was launched in February 2000, with funding from RWJF. The City of Hope and AACN began collaborating with palliative care nursing experts to craft a national education program for registered nurses. National experts in palliative care were selected to assist.

ELNEC-Core, the initial curriculum, was written by nurses for nurses to address the needs of patients across the lifespan—from neonates to geriatrics (Chart 1).



After the first year of ELNEC-Core, nursing faculty added 10+ hours of end-of-life care education into their curricula.

Chart 1. ELNEC-Core's Nine Original Modules

<p>1 NURSING CARE AT END OF LIFE</p> <p>Definitions and principles of hospice and palliative care within a quality-of-life framework. An overview of the need to improve palliative care and the nurse's role as a member of an interdisciplinary team.</p>	<p>2 PAIN MANAGEMENT</p> <p>Basic principles of pain assessment and management specific to caring for patients at the end of life.</p>	<p>3 SYMPTOM MANAGEMENT</p> <p>Other symptoms common in advanced disease such as dyspnea, cough, fatigue, depression, and the nurse's role in managing symptoms.</p>
<p>4 ETHICAL/LEGAL ISSUES</p> <p>Ethical issues and legal concerns specific to end-of-life care, plus resources to address these in practice.</p>	<p>5 CULTURAL/SPIRITUAL CONSIDERATIONS</p> <p>Dimensions and assessment of culture and spirituality that influence communications and the ability to provide competent care.</p>	<p>6 COMMUNICATION</p> <p>The importance and complexities of good communications with patients and families at this critical time, along with suggestions for care, experiential learning resources and case studies.</p>
<p>7 GRIEF/LOSS/BEREAVEMENT</p> <p>Challenging aspects of grief, loss, and bereavement for patients and families, as well as the health care professionals and importance of self-care.</p>	<p>8 ACHIEVING QUALITY CARE</p> <p>The role of nurses in achieving quality care for patients and their families, in view of limitations in existing systems and opportunities for institutional change.</p>	<p>9 CARE AT THE TIME OF DEATH</p> <p>Preparation necessary to provide the best care at the actual time of death.</p>

ELNEC-Core's Common Themes

- The family is the unit of care.
- Nurses play an important role as patient and family advocates.
- Culture plays a vital role in influencing the use and selection of palliative care.
- There is a critical need for attention to special populations, such as ethnic minorities, the poor, and the uninsured.
- End-of-life issues impact all systems of care across all settings.
- Financial issues may influence the use and/or selection of palliative care.
- Palliative care is not confined to cancer or AIDS, but is essential across all life-threatening illnesses and sudden death.
- Interdisciplinary care is essential for quality care at the end of life.

Train-the-Trainer: Positive Response

The original ELNEC course (ELNEC-Core)—a three-day train-the-trainer program—offered lectures by nationally renowned faculty, role playing, small group and case study discussions, and networking opportunities. A stringent application process assured that each ELNEC participant shared the goal of disseminating and implementing the curriculum within their academic setting by documenting the support of their School of Nursing Dean.

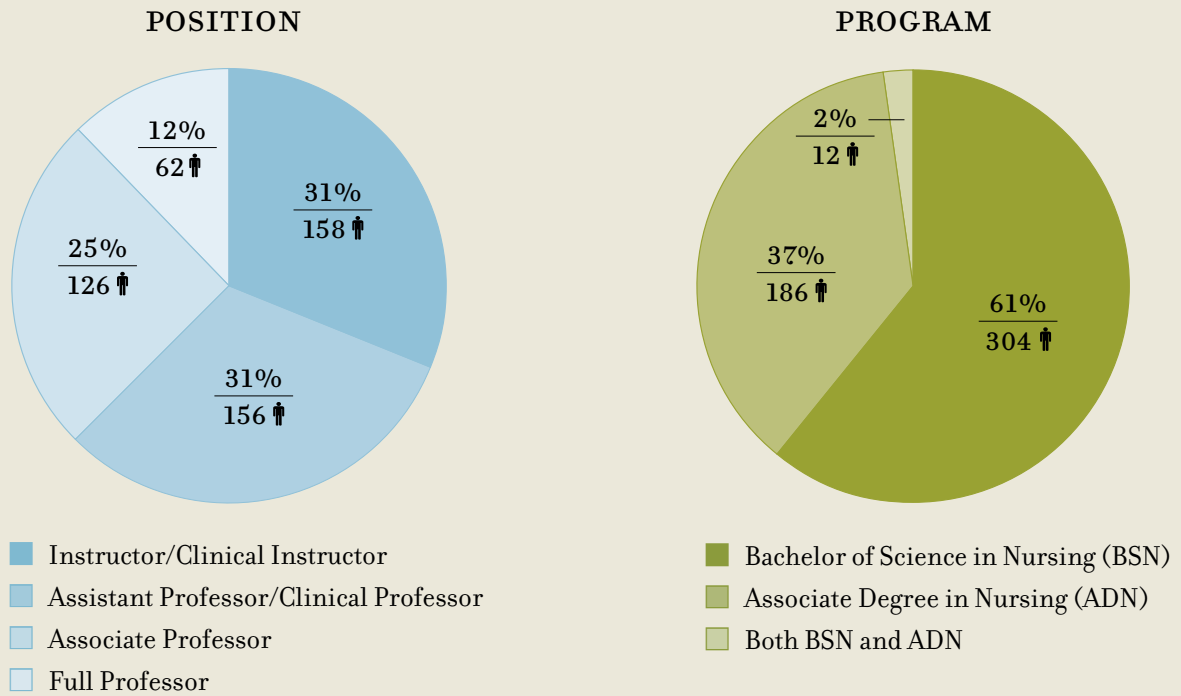
Demonstration funding was provided by RWJF and ELNEC-Core entered a pilot phase with eight train-the-trainer courses—five that targeted undergraduate nursing faculty and three directed to continuing education (CE) providers and staff development (SD) educators. A total of 546 nursing faculty and 261 CE providers and SD educators attended one of these courses between 2001 and 2004, with participants from all 50 states, District of Columbia, Puerto Rico, and the Virgin Islands.

Six- and 12-month evaluation data were collected by mail and E-mail, with a 92% (502) response rate for undergraduate faculty (Chart 2) and 87% (227) rate for CE and SD attendees (Chart 3). The 502 faculty members in the 12-month update represented 461 undergraduate nursing programs— one-third of the nation's total.⁷

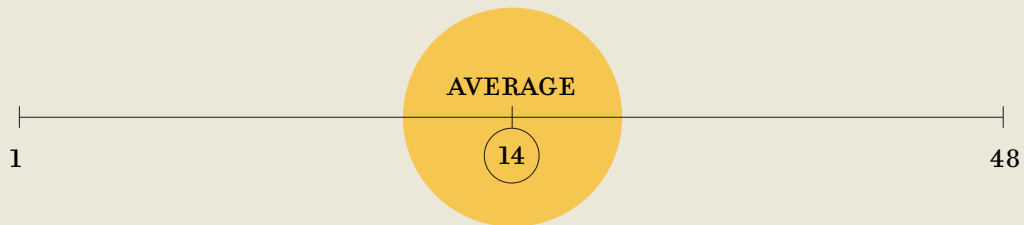


ELNEC trainers have educated 400,000 nurses and healthcare providers nationwide.

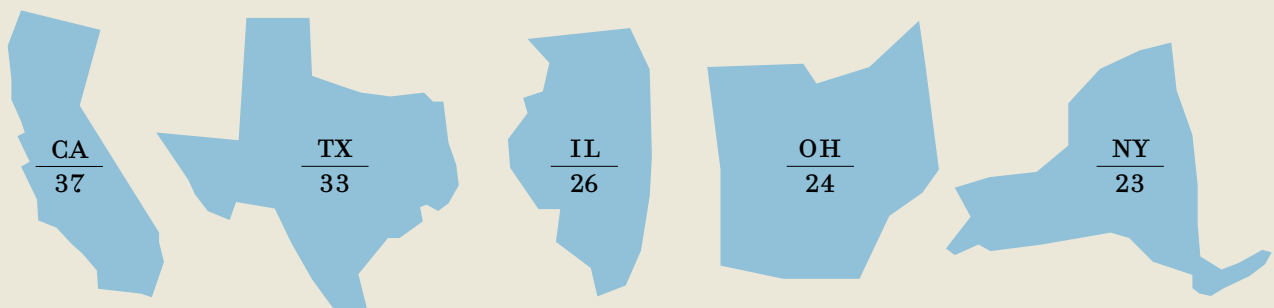
Chart 2. **Demographics of Undergraduate Faculty** (total number of participants: 502 ♀)



YEARS IN NURSING EDUCATION



STATES WITH GREATEST PARTICIPATION AND FREQUENCY*



*Numbers refer to frequency

Twelve-month post-course data showed these ELNEC trainers were able to add more than 10 hours of instruction in end-of-life care to baccalaureate curriculum (pre-course = 18.59 hours, post-course = 28.72 hours). The City of Hope investigators were impressed with the data, given all the other commitments and subjects that needed to be covered in nursing education programs. More than 19,000 students received end-of-life care content in each module, with an average of 50 students per program.⁷ This development took place within 12 months or less from participation in the demonstration ELNEC-Core course.

In the same first 12 months, 107 (49.3%) of CE and SD participants taught ELNEC-Core outside of their institution within the first year. Pre-ELNEC training, CE providers and SD educators offered 34.83 activities/482.09 attendees (mean), compared to 35.86 activities/654.30 attendees (mean) 12-months post-course.⁸ This achievement came despite these educators' many responsibilities, such as quality improvement, staff orientation, internship supervision, competency labs, and other staff training.

ELNEC'S First Decade of Achievement

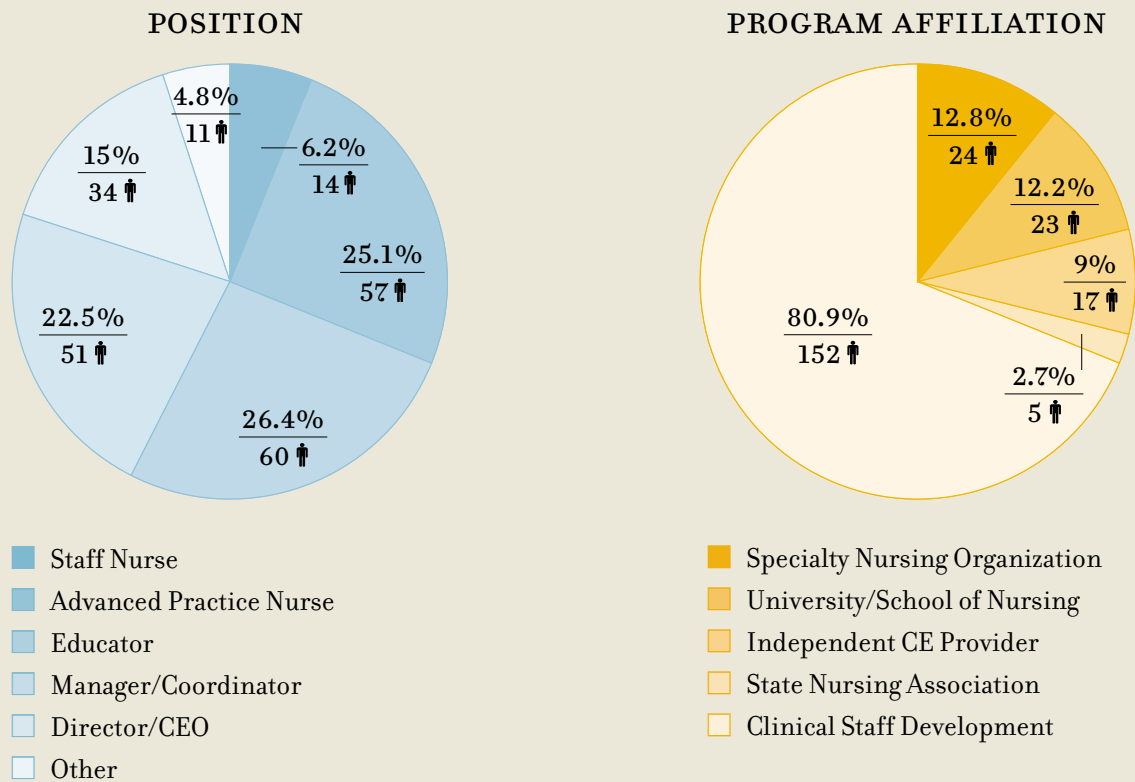
Since January 2001, more than 14,000 nurses have attended a national train-the-trainer course. Estimates are these trainers have returned to their universities, hospitals, hospices, and other organizations to train more than 400,000 nurses and team members, using the ELNEC curriculum.

The National ELNEC Project continues to stay in touch with these trainers, producing an electronic quarterly newsletter, *ELNEC Connections*, with information about future courses and activities across the country. The ELNEC Web site (www.aacn.nche.edu/ELNEC) also has a trainer directory to encourage networking. ELNEC curricula are updated annually to reflect new data and evidence-based practices for palliative care and are available at minimal cost to trainers. ■

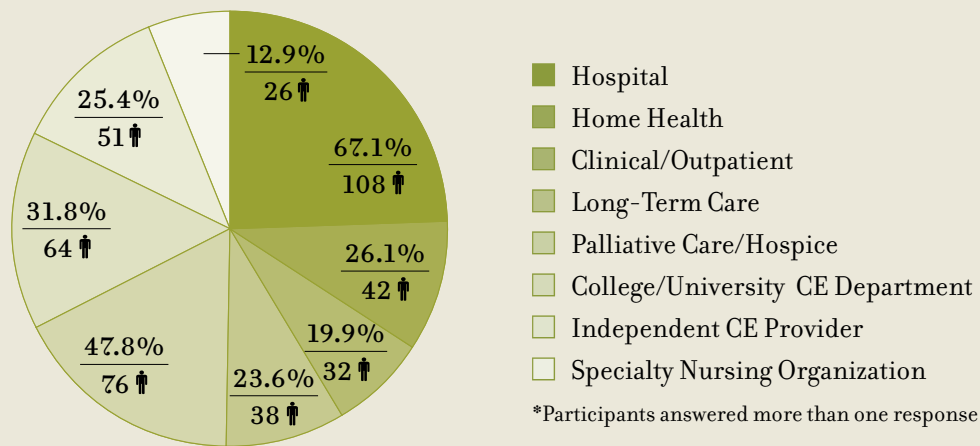


Since 2001, 14,000+ nurses have attended a national ELNEC train-the-trainer course.

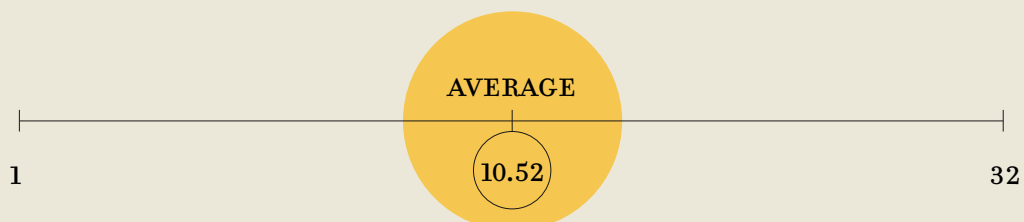
Chart 3. **Demographics of CE Providers and SD Educators** (total number of participants: 227 🧑)



PRIMARY SETTING FOR ELNEC*



YEARS IN NURSING EDUCATION



ELNEC-Core was designed to meet specific needs of Americans experiencing end-of-life issues. It quickly became apparent that certain specialty populations, age groups, and clinical settings had unique needs that one generic curriculum could not meet.

Growth of Other ELNEC Curricula

Just eight months after the first ELNEC-Core course in January 2001, the idea for **ELNEC-Pediatric Palliative Care (ELNEC-PPC)** was launched. Its goal: to aid children facing life-threatening illness and their families. In June 2002, the ELNEC-PPC curriculum entered a pilot phase, with 20 pediatric palliative care experts on the advisory board. Since 2003, more than 1,700 nurses and interdisciplinary team members have attended a national ELNEC-PPC course. In 2009, the curriculum was updated to include enhanced perinatal and neonatal content.

In 2002, ELNEC obtained funding from the National Cancer Institute (NCI) to develop a curriculum for graduate nursing faculty entitled **ELNEC-Graduate**. Between 2003-2006, four NCI-funded ELNEC-Graduate train-the-trainer courses took place, with 400 graduate nursing faculty in attendance, from every state in the United States and 285 out of 438 (65%) graduate nursing programs.⁹⁻¹⁰

Nurses are the primary caregivers for patients and families facing end-of-life issues.

In 2003, the ELNEC project received a four-year grant from the NCI to develop and teach a curriculum specific to oncology nurses. This national **ELNEC-Oncology** train-the-trainer course, conducted in collaboration with the Oncology Nursing Society (ONS), drew 264 oncology nurses, representing 141 out of 222 (64%) ONS chapters. Oncology nurses were trained to disseminate palliative care education through their local ONS chapter with the intent of improving care of cancer patients and their families. Although both ELNEC-Graduate and ELNEC-Oncology have concluded, oncology and graduate nursing educators can now attend ELNEC-Core courses that include specific case studies and enhanced supplemental teaching materials on pain and symptom management.

In 2005, the California HealthCare Foundation provided funding for development of the ELNEC-Geriatric curriculum and two train-the-trainer courses. **ELNEC-Geriatric** debuted in 2006, with a focus on geriatric nurses who work in long-term care and skilled nursing facilities, as well as hospices. The curriculum provides

modules specific to unlicensed personnel that work with geriatric patients and their families, such as certified nursing assistants (CNAs). This addition has been particularly successful, with CNAs frequently the ones who spend the most time with older adults in long-term care and skilled nursing facilities. Undergraduate and graduate nursing faculty also have found ELNEC-Geriatric invaluable in lectures regarding care of the older adult.

Subsequent funding by the Archstone Foundation for three ELNEC-Geriatric courses (2008-2010) enabled California nurses to attend with free registration. Currently, over 785 geriatric nurses have attended a national ELNEC-Geriatric train-the-trainer course. Nurses reported that within 6-12 months following course participation, an opportunity to implement changes within their respective care environment occurred. Examples include:

- Developing algorithms for pain management;
- Inclusion of bereavement services for those in long-term care settings;
- Partnering of nursing homes and community hospices;
- Conducting chart audits of patients who could have benefitted from palliative care; and
- Providing education session for administrators.



1,020 critical care nurses from California have attended an ELNEC-Critical Care train-the-trainer course in the past 5 years.

Also in 2006, **ELNEC-Critical Care** debuted, adapted from ELNEC-Core. Its audience: nurses in intensive care, coronary care, burn, dialysis units, emergency departments, and other clinical areas that encompass critical care. National ELNEC-Critical Care courses were also funded by the Archstone Foundation and offered to California nurses in January 2007, April 2008, January 2009, and October 2010. Over the past five years, 1,020 critical care nurses have attended one of 11 national ELNEC-Critical Care train-the-trainer courses.

In 2010, the Department of Veterans Affairs (VA) funded four **ELNEC-For-Veterans** courses to provide ELNEC training to nurses caring for Veterans with life-threatening illnesses. More than 54,000 American Veterans, mostly from WW II and Korea, die each month. However, fewer than 4% of Veterans die in VA facilities, making such education equally essential for hospice community partners and staff at other non-VA facilities. More than 500 nurses and team members have been trained at an ELNEC-For-Veterans course.

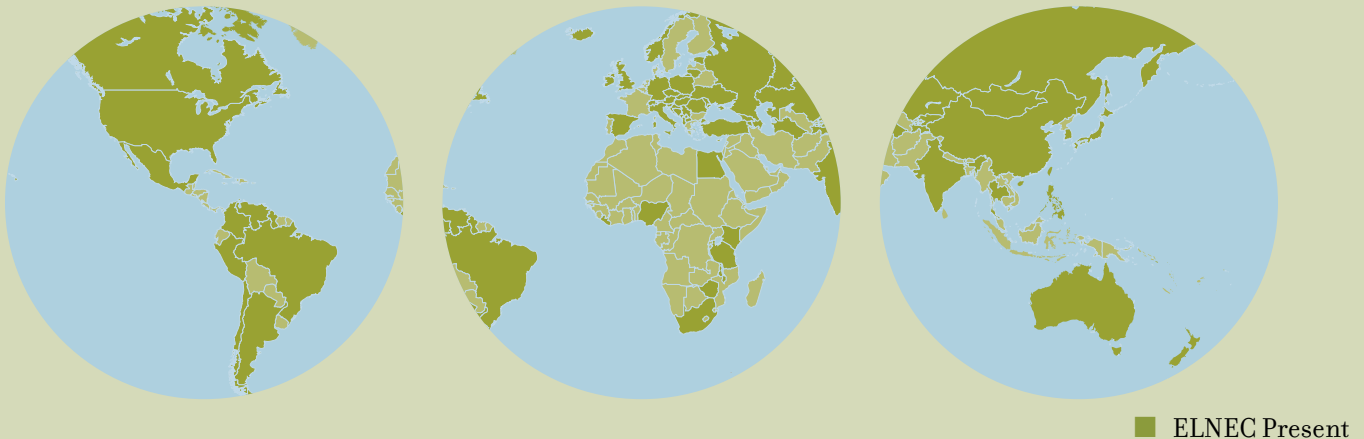
The statewide training efforts have been presented at national and state nursing conferences and meetings. In addition, two peer-reviewed articles appeared in the *Journal of Palliative Medicine and Critical Care Nursing*. Funding from the Archstone Foundation resulted in the State of California having the most trained ELNEC nurses in the nation who are providing bedside care and making system changes in hospitals and long-term care settings.

ELNEC's initial focus in 2001 was on improving end-of-life care in the United States. Since then, many ELNEC trainers have traveled internationally and provided education to healthcare providers throughout the world through **ELNEC-International**. This global course reflects cultural differences and the varied availability of medications from country-to-country. ELNEC trainers and faculty have now traveled to six of the seven continents, representing 70 countries (Chart 4), and trained more than 2,000 nurses and healthcare providers. ELNEC curriculum has been translated and adapted to increase its relevance to other cultures. Funding for ELNEC-International was generously provided by the Open Society Foundations, Oncology Nursing Foundation, and the Bristol-Myers Squibb Foundation. ■

Palliative care tends to the body and to the patient's psychological, emotional, social, and spiritual needs.

Chart 4. ELNEC's International Presence

(includes train-the-trainer courses and speaker participation in or invitation to conference on behalf of ELNEC)



Growth of ELNEC Curricula

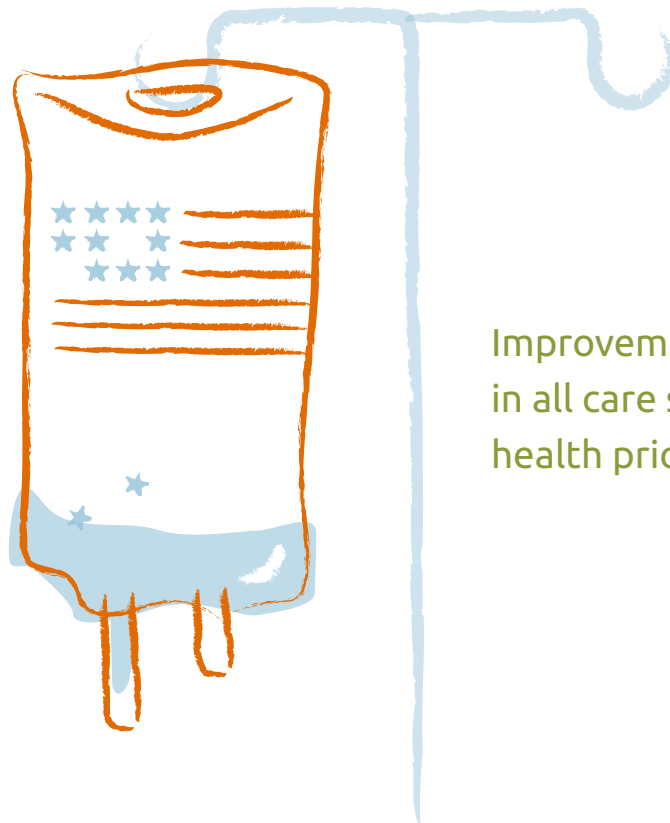
CURRICULUM	DATES	FUNDING	FOCUS
ELNEC-Core	2001–2012	Robert Wood Johnson Foundation (initial); Archstone Foundation	Undergraduate and graduate nursing faculty; CE providers; SD educators; hospice, medical/surgical, and home care nurses
ELNEC-Pediatric Palliative Care	2003–2012	Partial funding from Aetna Foundation	Nurses in pediatric settings, such as acute care, hospice, and home care. In 2009, materials added on perinatal and neonatal end-of-life issues
ELNEC-Graduate	2003–2006	National Cancer Institute	Graduate nursing faculty teaching advanced practice nurses (i.e. nurse practitioners, clinical nurse specialists), future administrators, and researchers
ELNEC-Oncology	2003–2006	National Cancer Institute	Nurses in oncology settings (i.e. acute care, bone marrow transplant units, clinics) and nursing faculty teaching oncology courses
ELNEC-Critical Care	2006–2012	Archstone Foundation	Nurses in critical care areas (i.e. intensive care, coronary care units, emergency departments)
ELNEC-Geriatric	2006–2012	California HealthCare and Archstone Foundations	Nurses in long-term care and skilled nursing facilities, nursing faculty, and nurses in medical-surgical settings. Four modules developed for CNAs
ELNEC-International	2007–2012	Open Society Foundations	International presentations
ELNEC-For-Veterans	2010–2012	US Department of Veterans Affairs (VA)	Nurses working with Veterans in VA facilities, and nurses and other personnel who care for Veterans in non-VA facilities, hospices, home care

Founded in 1985, the Archstone Foundation (www.archstone.org) is a private grant-making organization with a mission to contribute towards preparing society for an aging population and a long history of supporting end-of-life issues. In 2005, the Archstone Foundation awarded funding for three ELNEC-Core trainings for nurses working in California. ELNEC-Core complemented the Foundation's priorities, which include increasing education of nurses, physicians, and social workers in palliative care; expanding palliative care services in acute care facilities and long-term care settings; and addressing spirituality at the end of life.¹¹

Impact of Archstone Foundation Funding

A total of 343 nurses representing 34 of California's 58 counties (58.6%) participated in the courses in October 2005, February 2006, and March 2007 (Chart 5). The participants—educators, managers, or directors—were chosen for their ability to change education and/or nursing practice in their institutions.

At 6- and 12-month follow-up, 86% of the trainers reported implementation and dissemination of ELNEC-Core throughout their institutions and communities (Chart 6).



Improvement of palliative care in all care settings is a national health priority.

Chart 5. Participants by California Counties (total number of participants: 343 📈)

COUNTY	📈	%	COUNTY	📈	%	COUNTY	📈	%	CA
Alameda	12	3.5	Nevada	7	2.0	Santa Clara	5	1.5	North 28% 96 📈
Contra Costa	11	3.2	Orange	27	7.9	Santa Cruz	3	0.9	
El Dorado	2	0.6	Placer	2	0.6	Shasta	1	0.3	
Fresno	4	1.2	Plumas	2	0.6	Solano	9	2.6	
Humboldt	1	0.3	Riverside	22	6.4	Sonoma	6	1.7	
Kern	5	1.5	Sacramento	10	2.9	Stanislaus	3	0.9	
Kings	2	0.6	San Bernardino	16	4.7	Tulare	1	0.3	
Los Angeles	135	39.4	San Diego	28	8.2	Tuolumne	1	0.3	
Madera	1	0.3	San Francisco	5	1.5	Ventura	2	0.6	
Marin	1	0.3	San Luis Obispo	2	0.6	Yolo	1	0.3	
Merced	1	0.3	San Mateo	2	0.6				South 72% 247 📈
Monterey	3	0.9	Santa Barbara	10	2.9				

Chart 6. Implementation and Dissemination of ELNEC-Core

IMPROVEMENT	EXAMPLES FROM TRAINERS
Increased Education	<ul style="list-style-type: none"> • Used ELNEC-Core curriculum in new employee orientation. • Taught one ELNEC module per month and invited community hospice nurses, social workers, home health workers and aides. • Trained all staff, including unit secretaries and nursing assistants. • Partnered with the pharmacist to provide end-of-life education related to pain and symptom management. • Used ELNEC for an online ethics course. • Used ELNEC pain module in yearly competency training.
Changing Systems of Care	<ul style="list-style-type: none"> • Started a palliative care program. • Changed a protocol in assessing and managing pain. • Revised patient admission sheet to include information regarding spiritual needs and preferences for patients at end of life. • Developed policies and procedures on post-mortem care, parent’s conference guidelines, and palliative pain sedation guidelines. • Revised pain documentation on the nursing flow sheets. • Developed physician order form for comfort/palliative care. • Initiated a research proposal to develop a comfort care model. • Formalized a pain management consultative service. • Instituted daily interdisciplinary rounds to encourage palliative care. • Developed a palliative care/bereavement program. • Developed hospital specific guidelines and order sets to improve palliative care.
Community and International Endeavors	<ul style="list-style-type: none"> • Reviewed palliative care cases with 2nd and 3rd year medical residents. • Used ELNEC to assist in developing guidelines for pediatric palliative care pilot waiver. • Spoke to chaplain students regarding end-of-life and palliative care quarterly. • Presented ELNEC Pain Management module at Philippine General Hospital and the College of St. Besilde (Manila).

Funding for ELNEC-Critical Care

Improvement of palliative care in critical care settings has been identified as a national health priority by the Institute of Medicine.¹² No other healthcare environment engenders more anxiety and a sense of helplessness and hopelessness than intensive care units (ICU), emergency departments, and other critical care settings. Many times patients are brought into these settings without advanced directives and little, if any, prior discussion about their care goals. Often patients and their families do not understand their original diagnosis and treatment. Frequently, this lack of knowledge and cultural sensitivities are not assessed, due to the nature of emergency treatments and medical instability. The family practice physician, who has known and cared for the patient perhaps for decades, is suddenly a minor player, as surgeons, intensivists, and other specialty doctors and nurses begin to provide the majority of care to the patient.

ELNEC-Critical Care teaches nurses how to care for patients in these settings and how to change institutional systems to improve care. The nurse must be the advocate for the patient and family, the constant in a sea of numerous caregivers. To help meet this need, the Archstone Foundation funded four ELNEC-Critical Care courses for California-based nurses in January 2007, April 2008, January 2009, and October 2010. A total of 372 California nurses and team members attended, plus 65 nurses from other states.

In 6- and 12-month post-course updates, slightly more than 94% of the critical care trainers reported implementation and dissemination of ELNEC-Critical Care throughout their institutions and communities (Chart 7).



By 2020, an estimated 40% of all deaths in the U.S. will occur in nursing homes.

Chart 7. Implementation and Dissemination of ELNEC-Critical Care

ACTIVITY	EXAMPLES FROM TRAINERS	
<p>Changing Systems in the Delivery of Care</p>	<ul style="list-style-type: none"> • Participated on institution’s palliative care committee. • Worked with interdisciplinary team to build ICU grief program. • Formed Professional Ethics Advocacy, Compassion and Enrichment Committee to document a need for improved palliative care training, determine topics of interest, and offer education and support to ICU nurses at three hospitals. 	<ul style="list-style-type: none"> • Refined process for identifying patients on End-of-Life Care Pathway. • Planned and facilitated two memorial services for ICU nurses to honor and remember patients the team cared for. • Formed a “committee for the quality of life” with physicians, nurses, social workers, clergy, and nutritionist to address symptom management, family meetings, and ventilator withdrawal.
<p>Communicating to Improve Care</p>	<ul style="list-style-type: none"> • Submitted a proposal to the American Cancer Society to assess nurse-driven palliative care consultation team. • Invited nurses from other local hospitals to attend monthly ELNEC presentations. 	<ul style="list-style-type: none"> • Collaborated with community hospices to establish a multidisciplinary advisory board for end-of-life care.
<p>Providing Resources and Knowledge to Advance Care</p>	<ul style="list-style-type: none"> • Modified critical care course to include palliative care discussions and content within sepsis, lung cancer, and pulmonary disorders lecture and coursework. • Integrated end-of-life care and palliative services into fundamental-level courses for new nurses. • Coordinated more time in Regional Critical Care Program to teach pain and symptom management at the end of life. 	<ul style="list-style-type: none"> • Completed a pain management simulation critical events training for oncology nurses. • Completed four, two-day Pain Management Resource classes in 2008 and three more in 2009. • Used ELNEC case studies to teach and open communication about palliative care. • Used ELNEC to help 20 critical care staff preparing to take the Hospice and Palliative Care certification exam.
<p>Adding to the Science of Palliative Care</p>	<ul style="list-style-type: none"> • Completed Masters of Science in Nursing with thesis, Barriers to Providing End-of-Life Care for Terminally Ill Patients in the CCU. Hypothesis: Education using ELNEC materials will diminish barriers for critical care nurses. In before-and-after survey, 24 CCU nurses supported the hypothesis. 	<ul style="list-style-type: none"> • Completed a book, Empty Hands: A Nurse’s Perspective on Hospital-Based End-of-Life Care, which explores such barriers to providing end-of-life care as a lack of education, inexperience, and cultural issues. Content based in part on ELNEC classes.
<p>Caring for Caregivers</p>	<ul style="list-style-type: none"> • Began journaling to enhance self reflection and growth related to terminally ill patients and family, improving ability to address their emotional, psychological, social, and spiritual concerns on a much deeper level. 	<ul style="list-style-type: none"> • Presented ELNEC “Loss, Grief, and Bereavement” and self-care materials to ICU staff.

Response to a Growing Need

By 2020, an estimated 40% of all deaths in the U.S. will occur in nursing homes.¹³ In preparation for this tremendous surge, the Archstone Foundation committed to fund three ELNEC-Geriatric courses to support geriatric nurses who work in long-term care facilities, skilled nursing facilities, and hospices. A total of 314 California nurses plus 23 nurses from other states attended the courses in May 2008 and 2009 and April 2010.

From its birthplace in California, ELNEC-Geriatric has served as a template for three other states endeavoring to promote excellent palliative care for the geriatric population: Pennsylvania, Virginia, and Arizona. ELNEC-Geriatric trainers in each of these states secured philanthropic funding to provide courses. In Pennsylvania, a course hosted by the University of Pennsylvania, School of Nursing emphasized the training of nursing faculty. In Virginia, the Virginia Geriatric Education Center, the Virginia Association for Nonprofit Homes for the Aging, and the Virginia Initiative for Palliative Care collaborated to offer two courses. And in Arizona, two organizations—the Arizona Department of Health Services and the Arizona Health Care Association and Aging Services—sponsored ELNEC-Geriatric.

More than 91% of the ELNEC-Geriatric trainers from these three courses have implemented and disseminated the program in an effort to improve care of the older adult (Chart 8).

By expanding nurse education and training, ELNEC-Geriatric already has had an impact on the way older adults in California die. However, there is much more work to be done, as the number of older adults nationwide continues to increase. Many live alone, without family or friends to care for them. An influx of older Vietnam Veterans brings unique treatment challenges, such as post-traumatic stress disorder and other problems associated with military service. Medicare reimbursement issues cause further angst as patients and families seek good medical attention at the end of life. Adding to the confusion are inadequate conversations between the healthcare team and family members about desires and expectations for end-of-life care. These issues and more will impact the way older adults are cared for—and nurses are on the forefront, making training imperative.

Every patient with a life-limiting illness should receive a palliative care consult at the time of diagnosis.

Chart 8. Implementation and Dissemination of ELNEC-Geriatric

ACTIVITY	EXAMPLES FROM TRAINERS	
Education	<ul style="list-style-type: none"> • Coached medical students as guest instructor on how to break bad news utilizing ELNEC materials and Fast Facts. • Incorporated ELNEC modules into employee orientation, so new staff are aware of our commitment to excellent palliative care. • Used ELNEC and other resources to develop a presentation on end-of-life program as a “best practice” example for California Association of Health Care Facilities. • Used ELNEC to introduce student nurses to hospice concepts. <ul style="list-style-type: none"> • Used ELNEC-Geriatric to train volunteers. • Used ELNEC in long-term care education project to teach CNAs in skilled nursing facilities about pain, delirium, end-of-life care. • Rotated monthly in-service topics using ELNEC-Geriatrics for the PM/Night shift staff. • Trained CNAs in the pain module, empowering them to report pain levels. • Established undergraduate and graduate courses on palliative care using ELNEC and/or embedded its curriculum into existing courses. 	
Changing Systems of Care	<ul style="list-style-type: none"> • Evaluated a prognostic tool, the Flacker Mortality Scale, to help identify residents closer to end of life and provide opportunities to discuss palliative care wishes and offer needed support. • Discussed palliative care with physicians and provided education about palliative care team. <ul style="list-style-type: none"> • Developed a post-death survey tool to rate family satisfaction with staff in addressing patients’ end-of-life pain, symptom control, and quality of life. Received more than 95% positive approval with interventions. • Updated orientation/reorientation materials to reflect ELNEC information. 	
Staff Development	<ul style="list-style-type: none"> • Used ELNEC self-care and loss and grief materials to create the first staff retreat on self-care and caregiver fatigue, now an annual event. • Involved in a mentoring/education program in long-term care facilities also supported by the Archstone Foundation. <ul style="list-style-type: none"> • Took leadership responsibility on end-of-life committee and presented ELNEC-Geriatric modules to attendees. 	
Community Outreach	<ul style="list-style-type: none"> • Assessed Alzheimer’s Association service area in Los Angeles for long-term care facilities to determine needs for end-of-life education. • Held memorial services every 6 months for family and staff. <ul style="list-style-type: none"> • Provided ELNEC-Geriatric training from hospice staff to long-term care and skilled-nursing colleagues. • Provided in-services to community about Physician Orders for Life-Sustaining Treatment (POLST) paradigm. 	

Chart 9. How Archstone-Funded Trainers Have Implemented ELNEC

INSTITUTION	EXAMPLES FROM TRAINERS	
<p>Loma Linda University (LLU) <i>Loma Linda, CA</i></p>	<ul style="list-style-type: none"> • Provided three ELNEC courses: two focused on Oncology and Medical ICUs, third open to all LLU Hospital employees. Each filled at 35 participants per course. • Collaborated with Staff Development Educators, Coordinator of Bereavement Program, and Pediatric Internship Faculty to provide a course including pediatric nurses. 	<ul style="list-style-type: none"> • Coordinated an ICU Committee of physicians and nurses to improve palliative care. Used “Get To Know Me” posters to enhance staff and patient/family communication and distributed pamphlets to assist families in making informed decisions. • Dedicated two designated palliative care rooms at LLU on September 19, 2006.
<p>Long Beach Memorial Medical Center <i>Long Beach, CA</i></p>	<ul style="list-style-type: none"> • Provided two palliative care classes to ICU nurses and medical residents. • Developed an education letter on pain management for RNs. 	<ul style="list-style-type: none"> • Provided at least five family/patient conferences per week. • Provided a six-hour Palliative Care Conference for about 250 attendees.
<p>Palomar Pomerado Health (PPH) <i>Escondido, CA</i></p>	<ul style="list-style-type: none"> • Collaborated in creating a palliative care program, led by a dedicated Palliative Care Clinical Nurse Specialist on staff. 	<ul style="list-style-type: none"> • Completed Palliative Care Resource Binder for every in-patient unit within PPH system, listing all in-house, in-system, and community resources for patients, families, and providers.
<p>Ramona VNA and Hospice <i>Hemet, CA</i></p>	<ul style="list-style-type: none"> • Within six months of ELNEC training, presented three seminars in Palm Springs, San Diego, and Irvine, California. 	<ul style="list-style-type: none"> • Presented three ELNEC modules, twice a month through all nine modules. Ongoing effort repeated every three months. • Incorporated ELNEC modules into nursing orientation.
<p>Bakersfield College <i>Bakersfield, CA</i></p>	<ul style="list-style-type: none"> • Incorporated ELNEC into didactic presentations for nursing students’ fundamentals classes (includes distance learning). 	<ul style="list-style-type: none"> • Promoted inclusion of ELNEC into Philosophy Department courses that deal with the ethics of illness and death.
<p>UCLA Medical Center <i>Los Angeles, CA</i></p>	<ul style="list-style-type: none"> • Provided an ELNEC-based course for 60-65 nurses on L.A. and Santa Monica campuses. Because of its success, plans were made to offer this course twice a year. 	<ul style="list-style-type: none"> • Collaborated with pediatric faculty to provide ELNEC-Pediatric.
<p>Kaiser Permanente <i>Redwood City, CA</i></p>	<ul style="list-style-type: none"> • Presented a four-hour class to 40 RNs on pain and symptom management in hospice and end-of-life care. • Assisted 12 nurses in learning how to recognize patients who could benefit from a palliative care consult. 	<ul style="list-style-type: none"> • Worked with 12 nurse case managers and three social workers on “how to have difficult conversations” related to care and how to improve advance care planning for home care patients who are frail and elderly with multiple co-morbidities. • Distributed three different “Fast Facts” on a medical unit each week on caring for patients with chronic, end-stage disease.
<p>UCSF Medical Center <i>San Francisco, CA</i></p>	<ul style="list-style-type: none"> • Facilitated an ELNEC course at UCSF Medical Center, in which two palliative care physicians assisted in case study discussions. 	

ELNEC's Global Influence

Throughout ELNEC's history, many lessons have been learned and challenges overcome. ELNEC has impacted the healthcare community not only in California but across the nation and the world. Its benefits include:

- More opportunities for **nurse training in palliative care** and opportunities for nurses to envision their role in improving this care in their institutions. ELNEC nurses are more secure and empowered to provide, lead, and direct compassionate care—not just physical care, but psychological, social, and spiritual—for patients and their families in the case of life-threatening illnesses, injuries, and sudden death.
- More opportunities to **reinforce the family as the unit of care**. For many families, end of life is a time of great angst—psychologically, physically, and financially. Through ELNEC courses, nurses gain understanding in how to listen to families and orchestrate their care, honor their goals of care, and work closely with the interdisciplinary team. The end result: families in turn can better care for their loved ones.
- More opportunities to **improve practice and to update and change systems of care**. ELNEC trainers have been busy changing rules about ICU visitation, developing pain management algorithms, beginning bereavement services for long-term care patients, developing partnerships between nursing homes and hospices, embedding ELNEC content into nursing curricula, educating administrators about the value of palliative care programs, and promoting self-care strategies to providers who do this work daily. ■

The participants were chosen for their ability to change education and/or nursing practice in their institutions.

ELNEC Dissemination Activities

Since the first ELNEC course in 2001, disseminating the curriculum has been a top priority. The primary means have been national ELNEC train-the-trainer courses—and the return of these trainers to their institutions to instruct others. This process has been extremely successful, as reported in 6- and 12-month post-course updates. In just the first six months of 2011, 110 ELNEC regional courses had been registered in 32 states plus the District of Columbia.

Chart 10. Additional ELNEC Dissemination

METHOD	ACTIVITIES	
<p>ELNEC Web site: <i>www.aacn.nche.edu/ELNEC</i></p>	<ul style="list-style-type: none"> • Resources for upcoming regional, national, and international courses. • Tools to assist trainers in holding courses in their own institutions. • Trainers who've done international coursework, building resources in other countries for future trainers. 	<ul style="list-style-type: none"> • ELNEC Award Winners and their outstanding work in implementing and disseminating ELNEC. • Links to articles by ELNEC faculty and staff, along with other articles related to end-of-life care. • Listing of trainers by states.
<p>ELNEC Connections, quarterly electronic newsletter <i>www.aacn.nche.edu/ELNEC/EOLArticles.htm</i></p>	<ul style="list-style-type: none"> • Future national and international ELNEC train-the-trainer courses. • Updates on national and international ELNEC courses in the last three months. • Honors received by ELNEC trainers. 	<ul style="list-style-type: none"> • State and/or national palliative care initiatives. • Projects that enhance palliative care. • Updates from the National ELNEC Project Office.
<p>Hospice Education Network (HEN) <i>www.hospiceonline.com</i></p>	<ul style="list-style-type: none"> • ELNEC partnered with HEN in 2008 to offer the hospice industry, hospitals, schools of nursing, and other interested individuals or groups online subscription access to ELNEC-Core courses by national ELNEC faculty. Today, ELNEC-PPC, ELNEC-Geriatric, and ELNEC-For-Veterans are also part of HEN. 	
<p>Speaking Engagements <i>www.aacn.nche.edu/ELNEC/pdf/IntlTrainers.pdf</i></p>	<ul style="list-style-type: none"> • The National ELNEC Project Team and ELNEC faculty receive frequent requests to speak. Presentations include the Oncology Nursing Society Congress, National Hospice and Palliative Care Organization's Annual Meeting, AAHPM/HPNA Annual Assembly, MD Anderson Cancer Center, Sigma Theta Tau International Conference, and International Society of Nurses in Cancer Care Conference. ELNEC faculty is scheduled to speak in Japan (Tokyo and Osaka), Seoul, Korea, and Nairobi, Kenya. 	

Next Steps and Recommendations

Next Steps for ELNEC

Palliative care services are rapidly growing nationwide. According to recent data, the number of such programs in U.S. hospitals with 50 or more beds has increased from 658 (24.5%) to 1,486 (58.5%)—a 126% increase from 2000 to 2008.¹⁴ The orchestration of end-of-life care will only become more time-consuming and complicated with such issues as an aging population, co-morbidities, healthcare reimbursement, lack of advance care planning, and un/underinsured patients.

Nurses must be on the forefront, taking on leadership roles in new palliative care programs and dedicating more staff nurses to the task. All of this requires a timely, urgent response from the ELNEC Project Team. The following steps are already underway to educate nurses in providing excellent palliative care:

- 1 Offer ELNEC courses at national conferences/meetings.** This strategy enables the team and faculty to train larger number of participants at one location and gives nurses from various clinical settings the chance to network with others doing this work.
- 2 Focus on palliative care in ICUs.** ELNEC staff is working closely with the VA to provide two ELNEC-For-Veterans courses in 2012 with a concentration on the intensive care environment.
- 3 Continue to support palliative care in public hospitals.** Sixteen California public hospitals received funding from the California HealthCare Foundation in March 2011 to begin palliative care programs. The ELNEC project team has monitored developments and provided counsel, and will continue to assist in building nurse leadership and mentorship skills and palliative care training, using a tailored ELNEC curriculum.
- 4 Offer alternative training modalities of ELNEC.** Continue to expand web-based training available via the Hospice Education Network. Archstone Foundation is supporting access for California's 16 public hospitals to online ELNEC courses.
- 5 Continue technical assistance and support for ELNEC trainers worldwide.**
- 6 Expand international trainings.** A cadre of faculty is being developed to respond to international opportunities. ELNEC has already reached out to colleagues from Eastern Europe, Kenya, Tanzania, Tajikistan, Japan, Taiwan, Philippines, and more.

End-of-life care will only become more time-consuming and complicated as society ages.

Recommendations for Foundations, Health Care Systems, Hospitals, Hospices, and Nursing Homes

The education of nurses is a central component in providing excellent palliative care. Nurses advocate for patients and assist them in verbalizing their care goals; clarify treatment and medications; collaborate with the interdisciplinary team; and endeavor to provide impeccable physical, psychological, social, and spiritual care so patients can experience a “good death.” Education empowers nurses not only to learn concepts, but to see how care can be improved and how systems within their own organizations may inhibit or promote best-practices palliative care. Nurses must be central members on palliative care teams and hold key administrative positions within their institutions so they can advocate for changes to improve care of the dying.

The commitment of the Archstone Foundation and California HealthCare Foundation to improve care for all Californians experiencing end-of-life issues, along with the shared belief that nurses can make a difference in improving palliative care, have had a positive impact that serves as a template for other states. The success of ELNEC courses in California can be replicated elsewhere. For this effort to be effective, organizations are strongly urged to adopt mission statements supporting excellent palliative care and that all states commit themselves to improving palliative care.

Health care systems must work together to develop a vision of seamless transitional care for the sickest of the sick. Nurses must be trained across all health

care settings. For example, when a patient leaves the acute care setting for home care, both facilities need to have nurses trained in palliative care. If this patient is then transferred to a nursing home, its nurses must be knowledgeable so the care is smooth and coordinated. When the patient goes to the clinic, nurses there must understand palliative care as well. This process involves working with patients and their families long before death to orchestrate good and meaningful days for them. Impeccable attention to pain and other disturbing symptoms, including existential suffering, must be addressed.

Nurses have the extraordinary opportunity to be educated in this important role, to communicate clearly with those in need, to practice with integrity, and to care for the human spirit with great dignity.



A shared belief that nurses can make a difference has had a positive impact in improving palliative care.

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Appendix—Publications of ELNEC Outcome Data

The following publications include outcomes data from the follow up evaluation of ELNEC courses.

Coyne, P., Paice, J.A., Ferrell, B.R., Malloy, P., Virani, R., & Fennimore, L.A. (2007). Oncology End-of-Life Nursing Education Consortium training program: Improving palliative care in cancer. *Oncology Nursing Forum*, 34(4), 801-807.

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